

**A QUALITATIVE STUDY EXAMINING PARENTAL
EXPERIENCES AND ASPIRATIONS REGARDING
PARTICIPATION IN DECISION-MAKING IN TWO
NEONATAL INTENSIVE CARE UNITS**

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ABSTRACT

Background: Parents of babies hospitalised in neonatal intensive care units in the United Kingdom are faced with multiple decisions regarding their baby's care throughout their neonatal journey. There are disparities in care across the 23 neonatal networks in the UK, with parental participation in decision-making being an area in which significant improvements in practice could be made.

Aim: To establish parents' experiences of participating in clinical decision-making whilst eliciting the aspirations of parents to participate in clinical decision-making.

Objectives: The objectives of this study were to

- Establish parental understanding about their baby's admission to NICU
- Identify parents' perceptions of their level of involvement in decision-making about their baby's management
- Decipher if parents felt listened to by healthcare professionals
- Determine how comfortable parents were with questioning and challenging the care provided to their babies
- Ascertain how parents felt about decisions that they had made, if any
- Identify learning for professionals to improve care further.

Design and Sample: A qualitative study was undertaken to gain insight into parental needs in two neonatal intensive care units. This study was informed by an organised consultation with a local parent support group to discuss parental experiences. This, combined with knowledge of health professionals, guided the development of a survey. This self-completed cross-sectional survey was administered to eligible parents 1-3 weeks after admission (n=21). It was structured on a five-point Likert scale with additional free-text spaces for comments. The results from the survey informed individual focussed interviews with a sub-group of the survey sample (n=5). This qualitative component was designed to enhance the survey findings through exploration of parents' personal experiences and reflections on the outcomes of the survey. A single group interview was conducted with five parents attending the local parent support group after expressing interest in sharing their experiences.

Data Analysis: Survey data was analysed using descriptive statistics. Survey comments were then analysed using thematic analysis. Interview data was subjected to framework analysis, with the initial frame set by survey findings.

Outcomes: This was the first study in the world to study the whole of decision-making in NICU whether parental participation was allowed or not. Staff-parent communication and relationship-building require considerable attention first before the issue of participation in decision-making can be addressed effectively. The use of transactional analysis as a means of understanding the dynamics and potential for change in relationships in NICU was a further novel aspect to the study. The application of Van Manen's explanation of categories of decisions led to a new way of understanding and decoding parental acceptance of exclusion from decision-making.

CHAPTER 1: INTRODUCTION

For hundreds of years health care professionals have been faced with the daunting situations of saving a mother's life during childbirth and then saving a baby's life after delivery. During this time, the limits of medical technology did not allow many premature or sick babies to survive. However, as technology and treatments have advanced it is now possible to save increasingly more babies' lives. Neonatal mortality rates have fallen by 47% from 5.9 deaths per 1000 live births in 1983, to 2.8 deaths per 1000 live births in 2016 (Office for National Statistics, 2018). This improvement in survival is achieved at a price, though, since extremely preterm babies may survive with significant chances of severe physical or cognitive deficits. Consequently, difficult clinical decisions must be made in the neonatal intensive care unit (NICU) (Nuffield Council on Bioethics, 2006).

Usually, when parents realise that they are expecting a baby it is a time of great excitement and anticipation. This is not to say that parents do not worry throughout the pregnancy. A common worry that mothers have during pregnancy is whether there is something wrong with the baby, although it has been found that this worry becomes less significant during the third trimester of pregnancy (Penacoba-Puente et al, 2011). However, it is only when an abnormality is discovered on an antenatal scan, when labour starts prematurely, or when a problem arises soon after birth that the true reality of an event begins to be contemplated.

When a baby is admitted to NICU parents are faced with many challenges. The environment is unfamiliar and frightening and their expectations of parenthood are immediately challenged (Cleveland, 2008). There are many decisions to be made whilst a baby is in the NICU. These decisions incorporate aspects of care such as the provision of mothers own or donor breast milk, administration of a blood transfusion, whether to enrol a baby into a clinical trial, prescription and administration of various medications, or withholding or withdrawing intensive care treatments. During their baby's stay in NICU the amount and complexity of decisions that a parent will face will vary between families. All parents are individuals, will have different needs and will make decisions in different ways. There is a significant number of studies exploring the antenatal period when women are in pre-term labour at the limits of viability or when

end of life decisions need to be made regarding an extremely sick baby in the NICU (Gallagher et al, 2014., Boss et al, 2015., Kavanaugh et al, 2009). Although these are complex and distressing ethical decisions for parents to be involved in, healthcare providers need to be better informed about how they can improve the quality and effectiveness of decision-making for all parents who have a baby in NICU, regardless of the complexities of the decision.

As the focus of patient participation in their own care within the NHS changes so does the scope of parental participation in NICU.

Study aim

The aim of this research study was to establish parent's experiences of participating in decision-making whilst eliciting the aspirations of parents to participate in decision-making.

Study objectives

The objectives of this study were to

- Establish parental understanding about their baby's admission to NICU
- Identify the parental perception of their level of involvement in decision-making about their baby's management
- Decipher if parents felt they were being listened to by healthcare professionals
- Determine how comfortable parents were with questioning and challenging the care provided to their babies
- Ascertain how parents felt about decisions that they had made, if any
- Identify learning for professionals to improve care further

THE PROBLEM

A gap in the evidence base clearly identified inequality in care provision across the 21 operational delivery networks (ODN) in the United Kingdom (UK). This inequality was demonstrated through the summarisation of the findings in the Bliss Neonatal Survey (Howell and Graham, 2011) and the Bliss Baby Report: Hanging in the Balance (Burger, 2015). When questioned, parents have been found to contrast care between different hospitals and different staff (Redshaw and Hamilton, 2006). More specifically, there was little evidence about practices relating to parental participation in the medical

or surgical management of their baby in the NICU. The Department of Health (DH) (DH, 2009), Howell and Graham (2011) and the National Institute for Health and Care Excellence (NICE, 2010) have highlighted disparities in care across the 21 ODNs in the UK, with parental participation in decision-making being an area in which significant improvements in practice could be made.

Alongside the identified gap in the evidence base, a personal reflection on situations witnessed in clinical practice also motivated the development of this study.

REFLEXIVITY

I have particular insight into this area of research as an Advanced Neonatal Nurse Practitioner (ANNP) who has worked for seven years in this role. As an ANNP I am a nurse who has undergone highly specialised advanced training at MSc level. This enables me to work as part of a team of doctors in the NICU. It was not only academic reasons that led to the development of this study. During my time as a nurse in neonatology I have seen many parents being faced with decisions of varying degrees of difficulty. Some parents have relinquished their decision-making responsibilities altogether, placing complete trust in the doctors and nurses. Other parents have wanted to be fully involved in all decisions regarding their baby's management, sometimes with opposing ideas to those of the doctors. Observing the parental attempts to achieve a level of participation that was right for them whilst also observing and understanding the strain upon the neonatal unit with poor staffing levels, inexperienced, and at times overworked, nurses and doctors, it was clear that the parental experience and their subsequent desires needed to be unearthed.

There are both benefits and disadvantages to having such an involvement and commitment to neonatal services. One clear benefit is my thorough understanding of the practicalities of the neonatal system alongside spoken terminology allowing me to easily understand what parents are trying to explain whilst assisting them if they are confused or unsure. Although this is important it is obviously vital to ensure that parents are not being led to an explanation or conclusion that was not intended by them. Due to my commitment to, and passion for, neonatal care, the development and improvement of neonatal services is an area of importance to me. Over the last 14

years I have refined my skills in dealing with parents in stressful situations and delivering bad news.

The obvious disadvantage is the likelihood of having pre-conceived ideas about the information that parents may provide. I was also concerned about parents seeing me working on the neonatal unit as an ANNP and then talking to them as a researcher and asking them to disclose their experiences. I felt that this would have an impact on the information they provided and decided not to undertake the study in the neonatal unit in which I worked clinically.

I am also a mother of four young boys, which gives me personal experience of being a parent. Although none of my children were admitted to a neonatal unit, I have had some experience of my first child needing phototherapy as a new-born, my third child needing admission to hospital at nine weeks of age because he required five days of intravenous (IV) antibiotics and a lumbar puncture, and my fourth child being of low birth weight and subsequently having low blood sugars, requiring phototherapy and receiving five days of IV antibiotics. These experiences would inevitably have influenced my perceptions of events that informants portray.

In an attempt to balance my own perceptions, a PPI event was undertaken prior to the complete development of the parental survey. This event was held at a local parent support group specifically for parents who have had a baby in NICU. This event will be discussed further in chapter four.

Inexperienced nurses

As a highly experienced and educated ANNP I have spent many years observing changes in practices in NICU. Nurses, both experienced and inexperienced, are leaving the neonatal unit in which I work to go to work in a neonatal unit elsewhere. They often leave to work either in a lower level unit or to work closer to home. There are times when they take up employment in a completely different speciality altogether. New nurses are frequently employed to work in the neonatal unit, often with minimal neonatal experience or none at all. Due to poor staffing levels, these newly employed nurses often have little time to gain basic neonatal knowledge and experience. They are quickly required to work in the intensive care environment caring for especially sick

new-born and premature babies under the supervision of a more experienced nurse, who themselves will have a sick baby to care for.

There is no direct requirement from the Nursing and Midwifery Council (NMC) for children's nursing students to have any neonatal education (NMC, 2010). They focus upon complexities of family relationships during their training, however it is unlikely that they could support and advise on decisions of which they have had little or no experience. McEwan et al (2014) interviewed three newly qualified children's nurses regarding their experiences of working in a neonatal unit. The identified population of ten newly qualified child branch nurses working within three neonatal units in Scotland significantly limited the overall recruitment number. Recruitment packs were sent to all ten nurses with three being successfully recruited. It may have been beneficial, with such a small sample, to have extended recruitment to several other NHS trusts allowing a wider opinion. He found that these inexperienced nurses were significantly concerned with their abilities to support and assist mothers to breastfeed, finding the whole situation daunting. They were anxious about how little educational preparation they had for the role in general. Although they did not discuss the issue of managing babies in intensive care specifically, it could be suggested that as they felt generally under-prepared educationally, and as a task such as breastfeeding was concerning for them, they would certainly not be adequately prepared to support and advise parents who have decisions to make for their baby in NICU.

Occupational burnout

Due to the limited number of nurses with acceptable neonatal knowledge and experience, I have witnessed particular nurses repeatedly caring for the sickest babies. This in turn increases the nurse's risk of occupational burnout. Zarei et al (2016) identify occupational burnout as physical, emotional or psychological exhaustion from being repeatedly exposed to demanding and stressful situations. Eventually, there is a double response to burnout. First, it can cause psychological changes in the nurse ultimately leading to time off or leaving to work elsewhere. Second, it can reduce the quality of the care the nurse provides, leading to delayed provision of treatments and diagnostics and ultimately parental disappointment (Zarei et al, 2016). Halbesleben et al (2008) hypothesised that occupational burnout for nurses will result in a reduction in their efforts to provide the highest quality of care and less cognitive vigilance, ultimately

leading to an increased number of errors, and perceptions of a less safe environment. Unfortunately, they did not report any results discussing a reduction in quality of care; however, they confirmed their hypothesis of nurses perceiving a less safe environment with a finding of a decreased patient safety grade with higher burnout levels.

Inadequate staffing levels

Neonatal units are considerably understaffed with a shortage of both nurses and doctors (Bliss, 2015b). I have frequently witnessed in practice the use of locum doctors and 'borrowing' of midwives and children's nurses from other wards in desperation to improve staffing numbers on a shift. Locum doctors frequently have minimal neonatal experience from a short placement during their medical training, and midwives and children's nurses employed on the paediatric ward may not have had any neonatal experience since their clinical training. They are not as familiar with the layout and functioning of the neonatal unit, nor the clinical guidelines or practices. There have been many occurrences where locum doctors have cancelled their shift with very little notice and sometimes have simply not arrived for duty, or there are no nurses or midwives available to assist from other wards. This then leaves the neonatal unit in a precarious position, increasing the workload for the medical and nursing staff resulting in unacceptable patient to staff ratios. Obviously, this impacts on the amount of time a nurse or doctor can spend with each family, again compromising care provision.

My observation of unacceptable staffing levels, lack of specialised neonatal experience and education, and limited time led me to question the extent and effectiveness of parental participation in decision-making in NICU. Ultimately, whether it is unacceptable staffing levels, inexperienced staff caring for babies and their families, or simply a lack of time dedicated to families, these situations may result in undesirable care for parents of babies in NICU. This, in combination with the limited evidence suggesting that improvements in parental participation should be made, made clearer the need to understand parental experiences and desires regarding their participation in decision-making. Lachman et al (2014) support this through expression that family-centred care is the major basis for all quality improvements in neonatal care. Parents have many expectations of the care that they and their baby will receive during their time in the NICU including safety, reliability, consistency and technical skill. Ultimately parents need to be included in decision-making for their baby (Lyndon et al, 2014).

CONTEXT OF THE STUDY

The development of neonatal networks

In 2001, the DH called for an expert commissioning panel to review the provision of neonatal services (DH, 2009). This review resulted in the recommendation that neonatal units be split into networks across the country. Before the development of networks, babies needing to be transferred to a higher level neonatal unit for more specialist care could travel the whole length of the country if that was where a cot was available. This in turn led to stressful long-distance journeys for babies and sometimes significant periods of separation of mother and baby.

In 2003, neonatal services were divided into 23 managed clinical networks. A managed clinical network is defined as a group of organisations and professionals linked together to allow high-quality, clinically effective services to be delivered (Marlow and Gill, 2007). There are many drivers which will encourage establishment of a managed clinical network including inequalities in healthcare provision, the realisation of the need for staff with specialist clinical skills to practice and maintain such skills, and difficulties in nursing recruitment especially within intensive care areas which in turn requires continuous rehiring and retraining of staff which can be an expensive process (Marlow and Gill, 2007). The division of neonatal units into networks was a complex process. In the two years between the review of neonatal services and division into networks several specific elements were recommended for consideration for development by the DH. These were the functionality and financial implications of the managed clinical networks, neonatal unit capacity, neonatal unit staffing, neonatal transport and services, and parental needs (Redshaw and Hamilton, 2006).

Despite the managed clinical networks working successfully and allowing some significant and maintained improvements in care, the NHS Commissioning Board (2012) felt that healthcare in certain areas could continue to be improved through the development and application of operational delivery networks (ODN). Neonatal intensive care was one of the specified areas to benefit from this. The neonatal networks in the UK were then condensed further into 18 ODNs. Within the North West three ODNs were created: Cheshire and Merseyside, Greater Manchester, and Lancashire and South Cumbria (British Association of Perinatal Medicine (BAPM), 2015). This study was undertaken in the Greater Manchester Neonatal Network

consisting of eight neonatal units within the Greater Manchester region. These neonatal units were located in Bolton, Oldham, North Manchester, Wythenshawe, Tameside, Stepping Hill, Central Manchester and Wigan, though repeated restructuring of the National Health Service (NHS) makes such arrangements somewhat given to change. These ODNs were developed to co-ordinate patient pathways across neonatal units throughout a wide area allowing babies and their families to have access to specialist resources and expertise (NHS Commissioning Board, 2012). It was identified that an ODN will 'enable the development of consistent provider guidance and improved service standards, ensuring a consistent patient and family experience' (NHS Commissioning Board, 2012, p11).

Neonatal units offer care at up to three levels. Bliss (2015a) explains the three levels of care offered across neonatal units within the NHS. At level one, the Special Care Baby Unit (SCBU) provides the most basic care such as continuous monitoring of vital signs, phototherapy treatment, feeding through a nasogastric (NG) tube or simple recuperation. At level two, Local Neonatal Units (LNU) provide care for babies born after 28 weeks gestation which require more complex care. They may provide some short-term intensive care treatments, usually up to 48 hours of age, and the babies there may require continuous positive airway pressure (CPAP) support with or without the need for supplemental oxygen. At level three, Neonatal Intensive Care Units (NICU) provide care for babies of all gestational ages requiring intensive care management. Level 3 units will offer all intensive care treatments, but only tertiary neonatal units will offer surgical management.

All units can provide a basic level of care meeting the local care requirements. However, a baby may need to be transferred within the network for more specialist intensive care treatment or surgical care. Occasionally there are situations where a pregnant mother or baby may need to be transferred outside the network such as in threatened premature labour or lack of capacity within local neonatal units. The neonatal units that participated in this study were both level three units, and one, being a tertiary unit, also offered surgical care.

Major service reconfiguration

In Greater Manchester, the 'Making it Better' (MiB) programme was completed in 2012 (Office for Public Management, 2014). This programme was a local reconfiguration of maternity, neonatal and children's services within Greater Manchester to allow improved safety and sustainability of services (Dowler et al., 2012). During this time, four hospitals in the region closed their inpatient maternity services leaving eight consultant obstetric units (Davies and Rawlinson, 2012). Neonatal care was now to be provided in three state-of-the-art centres of excellence in St Mary's Hospital in Central Manchester, the Royal Bolton Hospital and the Royal Oldham Hospital (McKay, 2010). It was felt by policy-makers that there were too many hospitals within one area, and by reducing the number of hospitals (and, therefore, intensifying demand in a smaller number of institutions), health care professionals would gain from more consistent and intensive experience of specialist care and become better-equipped to provide safer, more expert clinical care.

The key drivers for implementation of MiB were lack of training exposure, the use of locums to fill gaps in rotas and the inability of hospital units to meet the required standards for patient care (Office for Public Management, 2014). It was thought that the nursing workforce would be expanded in order to meet BAPM requirements, providing one-to-one care where appropriate, and that new and current staff would be further trained and educated (McKay, 2010). There were mixed opinions from nurses and midwives directly affected by such a significant change. As maternity services closed, staff were relocated to other hospitals, some leaving friends and colleagues behind. Many staff chose to retire rather than to deal with the upheaval, and others simply left the area (Davies and Rawlinson, 2012).

Through the closure of smaller neonatal units and the development of larger, more specialised units it is undeniable that families are now privileged by a service supplied by healthcare professionals that have increased exposure to everyday cases but who are also increasingly exposed to the more complex and challenging ones. Despite this, it is understandable that parents would, in turn, expect the healthcare professionals to be skilled and competent in dealing with these situations. Dowler et al (2012) express the concept of 'pay more get more'. They consider the fact that ultimately MiB was about care quality not cost savings, and overall the reconfigured services would 'cost

more, not less' (Dowler et al, 2012). Despite this, neonatal services currently have significant problems with lack of funding and resources, poor staffing and lack of neonatal-specific training for staff (Bliss, 2015b) which will inevitably have a significant impact on the care of the neonate and their families.

Variation and state of services

Each neonatal network is managed at a local level, leaving variability between budgets, stakeholder representation, pathways, guidelines and clinical audit programmes. Due to these inconsistencies in care, parental satisfaction levels also vary between neonatal units (Howell and Graham, 2011). In 2007, the National Audit Office (NAO) reported '*Caring for vulnerable babies: the reorganisation of neonatal services in England*' highlighting that '*parents are mostly very happy with the specialist care and expertise their babies receive, but they also have needs which are currently not always met*' (NAO, 2007, p9). The areas in which parents had made consistent suggestions for improvement were breastfeeding support, information about their baby's care, car parking and accommodation, and communication with the medical team (NAO, 2007). This is discussed further in chapter two.

Over the last 20 years, due to improving health expertise, pharmacological and technological advances, neonatal care has become an innovative and leading-edge area of medicine. Historically, with the introduction of antenatal steroids and exogenous surfactant, and more recently with the development of the use of therapeutic hypothermia in babies diagnosed with hypoxic ischaemic encephalopathy (HIE), survival rates of extreme preterm babies and term babies in specific situations have increased. It was clear that the demand for neonatal services was increasing (NAO, 2007). The birth rates had been noted to increase by 3.7 percent from 2005 to 2006 and had increased by 20% since 2001. One in ten babies were admitted to all levels of neonatal unit (an increase from 2005-06). The trend in babies being born at low birth weight was increasing in the UK and other developed countries. The number of women over 40 years of age, non-UK born mothers, and mothers using assisted conception giving birth has all increased. Survival rates for preterm or low birth weight babies has improved dramatically and infant mortality as a whole has reduced. At the time of the NAO report, neonatal services were faced with the problems of increased demand for services whilst in the knowledge of the disparities between networks which

potentially left parents and babies experiencing inequalities in care. This increasing demand and pressure on neonatal services continues unchanged.

The first assessment of five years examining the state of neonatal services resulted in the publication of the report 'Hanging in the Balance' (Bliss, 2015b). This report demonstrated, as the title suggests, that neonatal services are hanging in the balance and are attempting to function on limited resources. There are many findings in this report that are likely to impact on parental participation in decision-making in NICU whilst supporting my observations from clinical practice. Overall it was found that 64% of neonatal units do not have enough nurses to meet national standards, with 65% of the current neonatal nurses not having a specialist neonatal qualification. Seventy percent of neonatal units are caring for more babies than is considered safe and nearly a third of neonatal units do not have access to psychological support for parents (Bliss, 2015b). Clearly, having a significant lack of nurses and doctors alongside a lack of specialist neonatal skills in the staff currently caring for babies will exert an impact on if, when and how parents participate in the decision-making for their own baby.

Although the reviews examining the impact of both the complete reorganisation of neonatal services into managed clinical networks and then further into ODNs, and the implementation of the MiB programme, show that positive improvements have been made, it was clear from the Bliss (2015b) report that further significant improvements in neonatal care are required. The first recommendation from the report is to address the implementation of national standards. Bliss (2015b) recommends that the government and NHS England recommit to neonatal services and outline a timetable of how national standards will be met.

Introduction of standards

Prior to, and immediately after, the reorganisation of neonatal services there was very little guidance as to how neonatal units can improve and monitor their services. In 2009 the DH launched a toolkit for high quality neonatal services. This toolkit was developed with the aim of providing tangible improvements in neonatal care but also in response to the recommendations made by the NAO report (2007). The toolkit was the beginning of new recommendations specifically highlighting the need for improvement of the family experience.

Following this, in 2010, NICE published the specialist neonatal care quality standard. The Health and Social Care Act (DH, 2012a) highlights the NICE quality standards as standards to aspire to in care but that are achievable. This quality care standard is a set of nine prioritised statements to guide improvements in care (NICE, 2010). Quality statement five relates to encouraging parental involvement in care. Quality statement five states *'Parents of babies receiving specialist neonatal care are encouraged and supported to be involved in planning and providing care for their baby, and regular communication with clinical staff occurs throughout the care pathway'*. NICE also recommend quality measures to allow monitoring of achievement of each quality statement. The initial quality measure for quality statement five is *'Evidence of local arrangements to involve parents in decision-making processes'* (NICE, 2010).

Following the publication of the national parent survey (Howell and Graham, 2011), Bliss produced the Bliss Baby Charter Standards in 2011. This charter was devised to support and direct neonatal staff to involve parents actively as partners in their baby's care (Bliss, 2011). Charter principle two recommends that decisions should be made in the baby's best interests, with parents being actively involved. The decisions should be informed by parents who have been supported through the decision-making process and actively encouraged to participate. To allow effective assessment of how well each neonatal unit is performing when practicing the Bliss Charter principles, an audit tool is available. It allows for self-assessment and action plans to be formulated achieving compliance with the principles (Bliss, 2011). These pertinent documents will be discussed in more detail in chapter two.

Efforts to redress the balance

It is not only guidance through statements and principles that are available for neonatal service improvement and monitoring. The Bliss Family Friendly Accreditation Scheme (BFFAS) was developed to encourage neonatal units across the UK to become committed to continuous improvement and development (Bliss, 2015a). The scheme identifies ten categories, in which category E addresses empowered decision-making and category J focusses on service improvement and parental involvement. There are currently only three neonatal units throughout the UK that have full Bliss Family Friendly Accreditation; Southampton, Portsmouth and Frimley Park (Bliss, 2017).

Other organisations within the NHS participated in the pursuit of developing family-centred care as well as many other areas within the field of neonatology. In 2006 a National Neonatal Audit Programme (NNAP) was initiated by the Healthcare Quality Improvement Partnership (HQIP) in an attempt to monitor and improve care given to babies who are admitted to neonatal units (Royal College of Paediatrics and Child Health (RCPCH), 2015a). This audit programme was funded by NHS England and the Welsh government and continues to run presently. The main aims of the audit are to make sure that babies receive consistent, high quality care across England and Wales and to identify areas for improvement. Ten areas are currently audited: the baby's temperature on admission to the neonatal unit, the provision of maternal antenatal steroids, the provision of screening for retinopathy of prematurity (ROP), whether the babies are receiving their mother's milk at discharge, neonatal unit transfers, clinical follow-up at two years of age, recording of blood and cerebrospinal fluid (CSF) cultures, disturbance of neurological function (encephalopathy), data management, and the area most pertinent to this study: consultation with parents (RCPCH, 2015b). Examination of the NNAP 2014 data showed that there had been an increase from 84% in 2011 to 89% of timely consultation with parents after admission of their baby to a neonatal unit (RCPCH, 2015). Despite this, these figures also show that one in ten parents are still left without a recorded, timely consultation. The NNAP also recognises that a single question cannot capture this area of parental involvement accurately, so it advise further consideration to enable more useful information to be obtained in the future (RCPCH, 2015).

Bliss, a UK-based charity aiming to improve care for premature or sick babies and their families, carried out the first national parent survey across 19 neonatal networks exploring parent's experiences (Howell and Graham, 2011). The survey examined a range of areas, including admission, staff, support and transfers to other units, but the most applicable to this study was parental involvement. This survey reinforced the likelihood of suspicions of disparities in care between neonatal units. It identified that 55% of parents reported that doctors and nurses 'always' included them in discussions about their baby's management. The remaining parents concluded that this happened only 'sometimes' or "not at all". Overall, Bliss highlighted that parental involvement in care was an aspect of care in which considerable improvements should be made. It recommended that neonatal units should explore areas in which other units had

performed well in order to understand what improvements could be made and what initiatives could be introduced to improve parental experience. This survey will also be discussed in more detail in chapter 2.

Long-term issues

These documents clearly demonstrate that there is a requirement for parents to become more actively involved in decision-making regarding their baby's clinical management in NICU. Families all have individual desires and needs during their baby's stay in NICU, and care needs to be amended accordingly. However, there is a strong need to standardise the quality of care which all families receive. To achieve this, ways in which parents can be empowered to be involved more appropriately and actively in decision-making and the care of their baby from an early stage need to be determined. This can only be done by establishing what they are already experiencing and consequently their desires.

Although it seems obvious that improving and equalising quality of care alongside parental satisfaction are important reasons for undertaking further research in this field, it is vital to consider long-term outcomes for babies and their families.

Postnatal depression

It is well-documented that mothers of babies admitted to NICU are at higher risk of postnatal depression (Carter et al, 2005, Vigod et al, 2010, Tahirkheli et al, 2014). These sources show that parents of both pre-term and sick term babies not only have higher depression scores, but the severity of depression is inversely proportional to decreasing gestational age and birth weight. An independent report funded by the Personal Social Services Research Unit (PSSRU) has identified that perinatal depression, psychosis and anxiety combined cost the health service an average of £8.1 billion per one-year cohorts of births (Bauer et al, 2014). Alongside the financial implications are the significant adverse effects for the mother as well as compromising normal emotional, cognitive and sometimes physical development of the baby (Bauer et al, 2014). The ability of parents to make a rational decision in a stressful situation has already been questioned (Nuffield Council on Bioethics, 2006); therefore, a mother with postnatal depression may find it even more difficult to cope with these situations. Ross-Davie et al (2014) draw attention to the association between mothers with

postnatal depression and a less secure attachment between her and her baby. This in turn can have negative impacts on the baby's developmental outcomes later in life (Ross-Davie et al, 2014). To help reduce this risk the authors suggest improvement of services for mothers with and without postnatal depression to support beneficial parent-infant interactions and also making services more suited to partners and fathers allowing mothers to be supported. Through an improved service allowing supportive parental participation in decision-making there is the potential for parental satisfaction to be improved, therefore stress reduced, and an improved willingness to bond with the baby. Through improved bonding, long-term developmental effects for the baby could be reduced.

Relationship strain

There is limited evidence that the relationship between the mother and the father is put under significant strain whilst they have a baby in NICU, sometimes resulting in relationship breakdown. The evidence is largely restricted to Canada and the United States (US). Manning (2012) has identified that the strain on parents of a baby in NICU is comparable to that of parents of children with cancer or chronic illness. One factor that is unique to NICU, however, is that the baby may never have left the hospital which may lead to parental feelings of the baby not yet being their own (Manning, 2012). Cleveland (2008) suggests that whilst parenting issues are unresolved, and relationships are under strain the ongoing issues from this can persist after discharge. This can then lead to increased stress and depressive symptoms which in turn affect every-day family dynamics.

With the correct supportive care through unlimited parental presence in NICU, parental participation in ward rounds, and overall involvement in their baby's care, Manning (2012) hypothesises that negative psychological effects can be decreased, parental confidence can be increased, and overall relationship strain and breakdown can be reduced.

Child abuse

There are many factors that put a child at risk of abuse. It is usually not one factor alone but multiple factors from different sources. Queensland Government (2011) highlighted several risk factors that clearly identify babies that have been on NICU as

high-risk infants. They identify parental risk factors as isolation, poor self-esteem and confidence, and depression. Child risk factors are identified as being premature and of low birth weight, with overall poor attachment to the baby contributing to the risk of abuse (Queensland Government, 2011). Babies and children living at home with a disability are at higher risk of child abuse from their parents (National Society for the Prevention of Cruelty to Children (NSPCC), 2014). A proportion of babies discharged from the NICU will go on to develop a disability later. Currently around 1 in 20 children under the age of 16 have some form of disability in the UK (Disabled Living Foundation (DLF), 2016). Due to the increasing numbers of extremely preterm babies who survive, the rate of disability is probably increasing.

Through implementation of protective factors such as a healthy spousal relationship and a healthy bond with their baby, the overall risk of abuse may be reduced (Queensland Government, 2011). With this in mind, the potential of this research is to more closely harmonise parental participation with their expectations and desires which could lead to future research examining the overall impact on parental psychological impacts.

These desired long-term outcomes could not be established in this study, but they guided the objectives, and the study was designed to move towards at least informing further work to achieve these outcomes. Effective measurement of these suggested outcomes relied first upon establishing how to improve the extent and quality of parental participation in decision-making across the networks for parents and their babies.

DECISION-MAKING

Historically, decision-making was felt to be a rational process until the concept of bounded rationality was declared, in which emotion was felt to play an important role (Simon, 1967). In order to explore the concept of parental decision-making in NICU, it is essential first to form an understanding of the process of how people make decisions. Umass Dartmouth (2017, p1) defines decision-making as 'the process of making choices by identifying a decision, gathering information, and assessing alternative resolutions' whereas Aliev and Zeinalova (2014) identify decision-making as 'making a choice amongst appropriate alternatives' (p.16). Despite these definitions, it

becomes clear when exploring the process of decision-making that creating a definition may not be so straightforward. The neural processes of decision-making are still not fully understood; therefore, this continues to be a widely researched area (Holdgraf, 2015).

Decision theories

Decision theories have been developed as a process to allow understanding of how people who are capable of deliberation and action make decisions and the reasoning behind this activity (Steele and Stefansson, 2014). People make decisions every day, from minor issues of personal choice to major issues with potential financial, personal or even global impact. To allow a deeper understanding of the reasoning behind a person's decision or choice two main branches of decision theory may be considered: normative decision theory and descriptive decision theory.

Normative decision theory

Normative decision theory is based on a deductive approach and is concerned with how people should, or ought to, reason, make judgements and take decisions (Koehler and Harvey, 2004). Normative decision theory provides a structured approach in which following a set of rules should allow a rational decision to be made (Koehler and Harvey, 2004). This theory tends to be associated with a more mathematical approach to decision-making and is less likely to be applicable in a hospital setting when making decisions about people's health and the associated complexities and ambiguities. Resnick (2012) supports this, highlighting that due to the pressures of a natural environment, such as a hospital, a normative approach does not and, perhaps, should not apply. Normative decision theory is concerned with how people 'ought to' behave and respond to certain situations. The use of the best-interest's principle (to be considered in more depth later in the thesis) guides decision-making in healthcare, however, when combined with emotion, stress and time constraints, perceptions of what people 'ought to do' can become distorted, and this rational approach may not necessarily be applied. This is not to say that a rational decision can never be made in the healthcare setting since this is the basis of evidence-based practice, however, when considering patients, relatives or parents making decisions for others, rationality can be grossly affected by emotion, religious beliefs, cultural expectations and many other factors.

Descriptive decision theory

Descriptive decision theory is primarily inductive and is concerned with describing how people actually think when making a decision (Koehler and Harvey, 2004). In contrast to normative decision theory, descriptive decision theory recognises that people may not conform to a structured set of rules and may make decisions outside this framework of rationality. This approach operates in the 'real' world in which the cause and effect of certain situations are complex and fluid, especially if these concern psychological influences such as motivation, preferences or satisfaction (Rapoport, 1998). When considering decision making in a healthcare setting, specifically in a critical care environment, naturalistic descriptive theory becomes applicable. Lizarraga et al (2007) identify that the interpretation that underlines this naturalistic stance is concerned with the role of personal experience and competence. It explores...

“...relevant and ill-structured problems; it occurs in uncertain and dynamic environments; it proposes shifting, ill-defined, or competing goals; it generates multiple event-feedback loops; it is performed with time constraints; it involves high stakes; it allows the participation of multiple players; and, lastly, there are organisational norms and goals that must be balanced against the decision makers' personal choice” (Orasanu and Connolly, 1993).

Parents of a baby in NICU are likely to be faced with several choices during their stay. Some of these choices may be complex in nature with little time for contemplation since clinical treatment may need to be instituted almost immediately. Parents are likely to be tired, possibly juggling their visits to NICU with caring for other children and managing home life, and the mother herself may be recovering from surgery. The baby may have been transported over a long distance from the family's home town leaving parents without the support of their family. The diagnosis and prognosis may be unclear for all involved, potentially making medical advice confusing. Ultimately, all parties involved are striving to do what they think is best for the baby. Despite this there may be disagreement over the optimum choice to make resulting in the need to balance a purely medical opinion against a values-based or perhaps an emotion-fuelled parental opinion.

Klein (2016) supports this naturalistic approach but with a focus upon the positivity of the abilities of people to actually make decisions in challenging circumstances rather than focussing on the limitations of the decision makers. Klein has undertaken research since 1985 in an attempt to balance the view from the perspective of human strength and capability in times of difficult decisions. Klein (2016) is interested in how people are successful at making decisions in these difficult situations.

Influences upon decision-making

Dietrich (2010) identifies many influencing factors when making decisions. These include past experiences, individual differences (including age and socioeconomic factors) and cognitive biases. This reinforces that although several parents may be exposed to an almost identical situation, their experiences and decision-making processes are likely to differ significantly.

Sex and age

Sex and age are variables that have previously been studied in terms of their influences upon decision-making. Lizarraga et al (2007) conducted a questionnaire-based study examining the decision-making processes of 589 males and females comprising three groups; youths (first year university students), adults (from a range of professional backgrounds) and retired people. A Decision-Making Questionnaire (DMQ) was administered to explore uncertainty, time/money constraints, information and goals, consequences of the decision, motivation, self-regulation, emotions, cognition, social pressure and work pressure. Some general differences were found between men and women. Women were more concerned than men with uncertainty and doubts surrounding the decision, with emphasis being placed on the consequences of the decision whether that be for them or for others. Women were found to place more importance on their emotions. Men, however, found the analysis of information enabling them to make a decision to be an important factor, and they were conscious of the goals and purposes of the decisions. There were no differences in terms of cognition. It is difficult to interpret these results since it is possible that during the completion of the DMQ the participants were considering hypothetical decision-making scenarios and may have responded selectively in different types of decisions such as healthcare decisions as opposed to decisions about career choice or marriage.

Emotion

Resnick (2012) identifies the impact of emotion on information-processing when making a decision. Many studies have explored the impact that emotion exerts on decision-making (Lerner et al, 2015; Beresford and Sloper, 2008; Coricelli et al, 2007). It is found repeatedly that emotion affects decision-making but also that decision-making affects emotion (Zeelenberg et al, 2008). Certain decisions can be taken in an effort to decrease negative emotions (guilt and regret) or to enhance positive emotions (happiness and pride) (Lerner et al, 2015). Alongside this, emotion assists in prioritisation between different options and reduces the amount of information to be processed (Beresford and Sloper, 2008). Ultimately, it is felt that emotions are essential in the decision-making process and that they help to make the most personally appropriate decision (Zeelenberg et al, 2008).

Resnick (2012) notes that the sources from which emotion stems in healthcare are likely to relate to decisions involving life, death and well-being. He identifies that in the context of lack of knowledge, and in an attempt to preserve their own emotional well-being, patients may blindly follow the recommendations of a doctor who ultimately may not understand the true values, beliefs or desired lifestyle of the patient. Time constraints, often seen within critical and intensive care environments, can lead to different decision-making strategies, often using less information and potentially taking routes of higher risk (Resnick, 2012). Zeelenberg et al (2008) support this, declaring the impossibility of always having the time and ability to weigh up the numerous aspects required to make a rational decision.

Descriptive decision-making may be seen more commonly in this study, though others who are not under pressure to make the decision and who are removed from the intensity of the responsibility may adopt a normative position such as healthcare professionals or other family members. This may then lead to judgement of parents. A critical care environment is a prime scenario for producing the emotional, time and outcomes-related pressures that make decision-making by parents (and professionals) so difficult. Parents are likely to be in a vulnerable position, unable to understand the medical issues fully, finding themselves in an unfamiliar environment (often completely unexpectedly), presented with horrendous options, and perhaps required to state their preferred course of action. Handing responsibility for decision-making over to

professionals then may become seen as a perfectly understandable response to these circumstances.

Summary

Since 2001 recommendations have been made and action has been taken to improve neonatal services throughout the UK. Over subsequent years it has become evident that despite the changes that have been implemented, care between the 18 ODNs remains variable, leading to local and regional disparity in services. The issues of inadequate staffing, inadequate training and expertise, and lack of parental support are repeatedly being identified as major downfalls in neonatal services.

The overarching aim of this study was to identify parental experiences and desires regarding their participation in decision-making in NICU. These findings can be used to inform further studies and assist in improving and standardising care across all neonatal units within the UK, regardless of level. This, in turn, should aid doctors and nurses to meet quality care standards to provide individualised evidence-based neonatal care.

STRUCTURE OF THE THESIS

The justification for this research study, ethical considerations, the ways in which it was conducted, the results that transpired, a discussion of the most important issues that arose, and the messages from the study are organised into seven chapters. Chapter two is a synthesis of evidence from a critical review of research studies exploring the processes of parental involvement in decision-making in NICU regarding the medical or surgical management of their baby. Chapter three is a discrete discussion of the ethical considerations surrounding parental participation in decision-making in NICU. Chapter four is a detailed presentation and justification of the study design. Chapter five is a presentation of the survey findings. Chapter six is a presentation of the interview findings. Chapter seven is a discussion of the most important issues arising from the findings, explaining how they can be integrated and used in collaboration with current available evidence. Transactional analysis is applied as a means of understanding the current situation. In chapter eight the limitations of the study, its main messages and proposals for further study are presented.

CHAPTER 2: LITERATURE REVIEW

BACKGROUND

History of patient choice

To appreciate how decision-making practices in healthcare have changed it is important to understand first how these practices have evolved over time. Looking back to historical practices can aid reflection. Reflection of current practice combined with the knowledge of the challenges that were faced historically allows visions and aspirations for positive change (Lewenson, 2008).

When the NHS was first founded in 1948 the concept of 'patient choice' was present in a primitive form by allowing patients to choose their own GP, optician or dentist (NHS Choices, 2014) but this was where their choice ended. Traditionally, healthcare was hierarchical with doctors and nurses making decisions for patients that would not be questioned or challenged by parents or families.

In 1979 the document '*Patients First*' (British Medical Journal, 1979) was published. This paper identified the role of the patient as a consumer. Although to be a consumer can mean to use something, this term gives the impression that the NHS was being viewed as a business rather than a public service. The term 'patient' continued to be used, however the debate about the 'patient as a consumer' persists (Peedell, 2014; Meill and Ericson, 2012). Under Conservative doctrine, the culture of the NHS was beginning to move away from hierarchy with a greater emphasis on patient and public participation in care (McGurk et al, 2007), though this was mirrored by a general movement to reduction of funding of the NHS and greater emphasis on privatised services.

Ten years later, publication of the White Paper '*Working for Patients*' (HM Government, 1989) identified the need to give patients greater choice but delegated responsibility locally to where the patient was receiving healthcare. Between 2000 and 2008 many more changes were implemented in an attempt to improve patient choice and experience. Patients began to have a choice to receive treatment between four or five different hospitals which was then extended to the choice of any hospital, and NHS trusts were being set increasingly in competition with each other. The 'choose and

book' system was developed for patients to choose and book appointments, both electronically and by phone that suited them, and the NHS Choices website was launched, providing patients with a wealth of information to allow them to make informed decisions about their own healthcare choices (NHS Choices, 2014).

The White Paper '*Equity and Excellence: Liberating the NHS*' (DH, 2010a) was published setting out a 'bold vision' for the NHS. The White Paper discussed how the NHS would be made more accountable to patients, who would be playing a more central role in their own health care system. It stated that 'patients will be in charge of making decisions about their own care' (p4). The preliminary discussion surrounding this topic was provided in the consultation paper, *Liberating the NHS: Greater Choice and Control* (DH, 2010b). This paper explored issues such as whether the public wanted to make choices about their healthcare and if they did, what sort of people were doing so. However, maternity services, including neonatal services, were not explored in this particular paper. Following on further from this was the publication of *Liberating the NHS: No decision about me, without me* (DH, 2012b). It is clear that the NHS is constantly evolving with attempts to provide patients with adequate provision of information and subsequent freedom of choice. Despite changes in governmental parties in 2010 and 2015 the requirement for empowerment of patients in healthcare has remained a strong priority.

NHS England (2016) has committed to the principle of shared decision-making in the NHS Constitution (with one objective in the 2014-2015 NHS Mandate of 'an NHS that becomes dramatically better at involving patients and their carers and empowering them to manage and make decisions about their own care and treatment' (DH, 2014). Despite this, the choices that patients have the right to make are laid out in the 2013-2014 Choice Framework (DH, 2016). These documents clearly apply to patients making choices about their own care, and although at times carers may need to assist in making these choices, the situation of a parent making a decision for their baby could be argued to be a different situation entirely. The provision of choice within maternity services has been explored independently, but due to the limited number of babies requiring neonatal care after birth this is not an area routinely explored antenatally. Neonatal care tends to be only a brief consideration within maternity-specific documents (Paparella, 2016).

Parental choice

Since the division of neonatal units into managed clinical networks, and then ODNs, within the UK there is an increasing requirement to enhance parental empowerment through facilitation of their participation in clinical decision-making in the NICU (Howell and Graham, 2011; NAO, 2007; NICE, 2010; DH, 2009). Such an endeavour is complex and involves much more than simply asking for a parental opinion. There are certain procedures or changes in a baby's clinical management for which parental consent is required but gaining consent does not imply that parents have been involved adequately in making a particular decision. There are many different aspects to be considered when examining the evidence of whether and how parents should be involved in the clinical decision-making for their baby in NICU. There are times when parents may have to make choices that are especially difficult and could even determine whether their baby lives or dies (Nuffield Council for Bioethics, 2006). The best interests of the baby, and then the preferences of the parents, should have primacy.

It is unknown whether parents have the ability to make rational decisions under extreme stress and whether ultimately their decisions are made in the best interests of their baby. Despite this, the Nuffield Council on Bioethics (2006) recognises that making a moral decision is not done simply through detached rationality, and that emotions always have an important part to play. It highlights that decisions in NICU are often made under particularly stressful circumstances and often with limited time for reflection. Health professionals need to be conscious of the personal significance to those making the decisions and the strong feelings that may arise as a consequence. The nature of the information needed to be provided in order to make an informed decision is complex, and, as yet, it is not known how making these decisions affect parental outcomes in the long term (Allen, 2014).

There are many dimensions to parental participation in clinical decision-making such as the nature of decisions to be made, types of decision-making, parental rights and their legal standpoint, who has the final say, parental capability to make decisions, influences on decision-making, and communication and information giving. These areas will be discussed in more detail throughout the literature review. To enable positive changes in clinical practice and to facilitate the needs of parents with regard

to their participation in clinical decision-making it is vital first to establish what parents experience currently. Through this, supportive strategies can be designed and changes implemented in practice.

TYPE OF REVIEW

To enable identification of the most significant evidence in this field a critical literature review was undertaken (Grant and Booth, 2009). This type of literature review aimed to provide a well-balanced and comprehensive overview of the most important literature exploring parental involvement in decision-making in NICU whilst demonstrating extensive research and critical evaluation. Literature was examined in a critical way moving beyond mere description towards conceptual innovation thereby allowing the quality and importance of the studies selected to be highlighted, as suggested by the University of Cambridge (2017). It required extensive searching of the literature from diverse sources, with some responsiveness to inherent weaknesses and gaps in the evidence-base in order to ensure the inclusion of as much evidence as possible yet subjecting this to rigorous evaluation. Synthesis of this diverse material to result in a novel interpretation of the existing evidence base is a facet of a critical literature review.

THE REVIEW QUESTION

The review question was set as **'What is known about the process of parental participation in clinical decision-making in the NICU?'**

SEARCH STRATEGY

A PICO approach was not appropriate for this review, since no specific intervention was to be explored. A PEO approach was adopted, though this was only partly successful since there was such a paucity of research studies. In this review, the population was parents of neonates, the exposure was decision-making in NICU and the outcomes were involvement and participation (Bettany-Saltikov, 2012).

A literature search was performed using the CINAHL, Academic Search Premier, Cochrane Library, Medline (Ovid), Science Direct, Wiley Online Library, and Maternity and Infant Care databases. These databases were chosen with the knowledge that

they contained both nursing and midwifery journals and would include neonatal research articles. Keywords were set with truncation and variants (synonyms).

Table 1: Keywords and synonyms

Parent*	Neonat*	Involvement	Decision-making	Intensive Care
Father(s)	Infant(s)	Participation	Family-centred care	Neonatal Unit
Dad(s)	Newborn(s)	Assistance		NICU
Mother(s)	Baby	Sharing		
Mum(s)	Babies			
Caregiver(s)				

Originally this review was aimed to examine only studies from the UK that were published after 2009. This cut-off date was chosen based on the publication of the toolkit for high quality neonatal services (DH, 2009) which was the beginning of new recommendations specifically highlighting the need for improvement of the family experience. However, the evidence base in the UK was exceptionally minimal with most of the available evidence being undertaken in America, Canada and France. Despite this being the case, this was an acceptable step and does not weaken the review as neonatal intensive care practices are relatively common between these countries. Even widening the search to include international studies retrieved only a small number of relevant studies, so the search was widened further to include studies undertaken in the last 10 years. In keeping with a critical review, the strategy was amended to allow inclusion of these useful sources. Limits were reset to include only articles published between 2005 and present. However, due to the major change in policy in 2009 it was decided that studies discussing policy would be included only if published after 2009. Prior to this, despite reorganisation of neonatal services within the UK in 2003, it had been highlighted in a review by the NAO in 2007 that parents had needs which were not always being met including information about their baby's care and communication with the medical team. Additional limits were English language publications and research involving human babies. Once the electronic

search had been completed a manual search of reference lists from identified articles, relevant journals and subject reviews was undertaken.

Inclusion criteria

- Published report of a research study dated 2005 to present
- English language
- Focused on decision-making between parents and doctors, or parents and advanced neonatal nurse practitioners (ANNPs)
- Focused specifically upon babies in the NICU

Exclusion criteria

- Discussion or opinion articles
- Policy papers published before 2009 due to the publication of the toolkit for high quality neonatal services (DH, 2009)
- Focused specifically on communication with nurses
- Focused upon decision-making prior to admission to NICU, such as resuscitation for extremely premature babies.

Outcome of the search

The search results are summarised in Table 2. The initial step in the search process was undertaking a keyword search in the selected databases. Next, the titles, keywords and abstracts of extracted articles were tested against the exclusion criteria. If there was doubt as to whether the article was applicable (i.e. if the title did not specifically state parental participation in decision-making or the abstract information did not allow for a decision to be made) then the article was retained for further exploration. As a result, a total of 3255 potentially eligible articles were retrieved from all five of the selected databases.

After applying the inclusion criteria, a total of 22 studies remained. Duplicates were then removed, resulting in 14 remaining studies. At the end of this extensive search process a total of 14 studies were eligible with complete satisfaction of the inclusion and exclusion criteria. These studies were then included in the review and are summarised in Table 3. A total of 14 relevant studies were identified from the literature search.

Table 2: Outcome of the search

Database	Items identified	Removed by limits	Items retained
Academic Search Premier	177	167	10
CINAHL	282	280	2
Medline (Ovid)	17	14	3
Science Direct	1453	1448	5
Wiley Online Library	1326	1324	2
Duplicates removed			8
Total relevant studies			14

Table 3: Areas of evidence addressed by the reviewed studies

Ethical and end-of-life	Extremely premature babies	Neonatologists	Neonatal research	Infant feeding	Information provision
Van Manen (2014)	Kavanaugh et al (2005)	Albersheim et al (2010)	Hoehn et al (2005)	Dowling et al (2009)	Howell and Graham (2011)
Caeymaex et al (2011)		Boss et al (2009)	Jollye (2009)		
Einarsdottir (2009)		Bailey et al (2013)			
Provoost et al (2006)					
Caeymaex et al (2013)					
Brosig et al (2007)					

CRITICAL REVIEW OF THE EVIDENCE

This review begins with a focussed section identifying the main outcomes and approaches to each study. It then progresses to provide a holistic view of the relevant literature, providing an overview of the thematic findings.

Critical appraisal

All reviewed articles were processed with the PEO approach in mind. The Critical Appraisal Skills Programme (CASP) qualitative checklist was used for critical appraisal of the studies (CASP, 2013).

Themes from initial findings

Six broad, initial themes were identified from the included studies. These were end-of-life (EOL) decision-making, extremely premature babies, neonatologists, neonatal research, infant feeding and information provision.

EOL decision-making

The literature search identified six studies investigating EOL decision-making. The studies were then categorised further according to five identified study objectives. The objectives of the studies were to examine the experience and ethical concerns of parents making EOL decisions (Caeymaex et al, 2011; Einarsdottir, 2009; Van Manen, 2014); to identify factors of importance to parents in their baby's EOL care (Brosig, 2007); to establish whether the type of involvement that parents had was related to long-term grief (Caeymaex, 2013); and how frequently EOL decisions were discussed with parents and if consultation with parents was associated with the type of EOL decisions (Provoost, 2006). The six studies were undertaken in Canada, Iceland, America, France and Belgium between 2006 and 2014. The samples sizes ranged from 14 to 164.

Five of the six studies (Van Manen, 2014; Einarsdottir, 2009; and Caeymaex et al, 2011) examined the experiences of parents making EOL or ethical decisions for babies of any gestation in NICU. The studies varied in terms of the results that were produced. The studies by Van Manen and Caeymaex et al highlighted the emotional aspect for parents based mostly on their level of participation during the decision-making process, whereas Brosig et al (2007) determined what specific factors were important to parents when making EOL decisions. One study was quantitative, three studies were qualitative and two were mixed methods. Only one of the studies identified the philosophical underpinning. The remaining authors did not declare any specific approach to their study design such as pluralism or grounded theory. This does not

imply that a philosophical approach was not used, only that it may not have been declared.

Van Manen's (2014) study was undertaken using a phenomenological approach. Through the use of phenomenology, it would be expected that the data collected would be rich allowing a deep understanding of the parental experience. However, it could be argued that phenomenology requires the researcher to put aside everything they know and understand about the area being researched, which for some seems impossible. This can lead to researcher bias.

Van Manen's aim was to explore the lived experience of the parents before it had been conceptualised, abstracted or theorised. He undertook multiple interviews with 14 parents throughout their stay on NICU. Parents were recruited through their assigned doctor who was asked to identify parents whom they thought may be faced with an ethical decision. There was no identified definition of an ethical decision, therefore it is possible that there may have been eligible parents who were not recognised but may have had significant information to contribute. This is an obvious limitation to this study. In order for the researcher to increase the possibility of capturing the data he required he could have specified particular definitions for what he classed as an ethical decision. It would need to be clearly identified in a way that it was not subjective and open to interpretation.

Caeymaex et al (2011) and Einarsdottir (2009) identified retrospective samples, but Einarsdottir also included prospective groups. Caeymaex et al contacted parents whose baby had died in any one of four selected NICUs across France. Parents were contacted two years after the event and were asked to participate in an in-depth face-to-face interview. Telephone interviews were offered for those who could not attend. Fifty-three face-to-face and 80 telephone interviews were conducted with 164 individuals. The resultant themes were (1) the perceived role in the EOL decision-making process and related feelings, (2) parental description of the EOL decision-making, (3) guilt feelings and interrogations in the long-term and (4) physicians' actions and attitudes perceived as being helpful in making the decision and in coping with it afterwards. The identified aims of the study were identical to the themes obtained from parental interviews. It is suspected that Caeymaex et al found the results that they

were expecting to find. It seems that the results did not 'emerge' but were likely pre-formed, albeit subconsciously, by the researchers. Therefore, the results need to be considered with considerable caution.

Both telephone and face-to-face interview data is reported in themes 2, 3 and 4 however only face-to-face interview data is reported in theme 1. Telephone data was excluded in this theme as the researchers felt that it did not allow them to classify the parental role accurately. Despite this, the data should have been reported alongside these claims. Although it was claimed that telephone interviews were excluded only in theme 1, it is stated that guilt feelings related to the perceived role in EOL decision-making were reported only for face-to-face interviews as again, parental role could only be classified accurately in these interviews. No telephone data is available. This is a clear limitation in this study.

Einarsdottir's (2009) study was undertaken in Iceland. She examined the implications of ethical questions and their effects on the daily life of parents of babies with a birth weight of less than 1000 grams. In comparison, the studies conducted by Caeymaex et al (2011) and Van Manen (2014) included parents of babies of any weight or gestation. The gestation or reason for the EOL decision was not made apparent in any of the three studies. The nature of prematurity and extremely low birth weight (ELBW) presents different reasons for EOL decision-making by parents. Prematurity brings specific problems, while low birth weight (at whatever gestation) provokes a separate set of issues. Either set of problems (or both combined) stimulates particular ethical problems requiring difficult decisions to be made.

Einarsdottir identified both prospective and retrospective groups. Parents, family members and staff were all interviewed. The data was based on discussions with the mothers and fathers but also included particular information of interest from other research material. It is not clear throughout the paper which information has been taken from other research studies. Throughout the results there is only one reference to another author. Despite the study pertaining to EOL decisions, all of the babies of included parents survived. It is clear that the parents discussed the notion of EOL decision-making without actually having made any such decisions themselves. It must be questioned whether it is possible for parents to respond validly about how they

would behave or feel simply from imagination. Indeed, the parents stressed that had they been confronted with such decisions in reality they may have reacted differently. Vague terms such as 'only a few of the parents' and 'most parents' made appraisal of the analysis difficult. Little credence could be attributed to the results in the light of these limitations.

Extremely premature babies

Kavanaugh et al (2005) undertook a study utilising a qualitative collective case study method. The rationale for using this method was that it allowed the examination of a number of cases in one study. This study design was an appropriate choice to achieve the aim of the study which was to describe decision-making and the subsequent needs of parents, physicians and nurses. Life support decisions that were made pre-natally and post-natally for extremely premature babies were investigated, however for the purpose of this review only the post-natal results were considered. The sample size of this study was small with only 12 recruits in total: six mothers, two fathers, two neonatologists and two obstetric nurses. Again, for the purpose of this review, only the decision-making by the parents and their associated needs were reviewed. The parents were recruited into a convenience sample from two hospitals in Chicago that provided high-risk care. Mothers were identified when they came into hospital with threatened pre-term labour or if they were known to have had a discussion with the fetal medicine department. No details of failed recruitment were provided. Data was collected using four methods: audiotaped interviews, periodic assessment guides, demographic data collection forms, and a form to collect information about obstetric history, baby medical history and completion of a discussion between parents and medical staff about EOL and life support. The researcher's role and relationship to this study were not made explicit. Ethical considerations were reported superficially. There was no discussion surrounding data protection or management of parents if they became upset such as implementation of a distress protocol. It was difficult to assess how rigorous data analysis was as there was inadequate description. Overall this report lacked the information needed to make a thorough assessment of the study. It was based a small convenience sample and so the results had to be treated as being unreliable.

Neonatologists

Three of the 14 studies explored the process of decision-making by neonatologists. One study examined the attitude of neonatologists towards the authority of parents to make life and death decisions for their baby (Albersheim et al, 2010), another study examined the type of care decisions that were discussed between parents and neonatologists and how these discussions influenced the neonatologists (Bailey et al, 2013), and a third study assessed neonatology fellow training in guiding family decision-making for high risk babies (Boss et al, 2009). A fellow is a medical doctor who has completed their basic training but is undergoing a programme of extensive study, training and hands on experience in a sub speciality, such as neonatal intensive care (Anwar and Shah, 2012). The sample sizes of the studies by Albersheim et al (2010) and Boss et al (2009) were relatively similar at 121 and 101 respectively. However, Bailey et al (2013) had a significantly larger sample of 893. The three studies were undertaken across America and Canada therefore in terms of neonatology fellow training, the comparison of training with doctors in the UK is limited. All three studies utilised a qualitative approach with two also incorporating some quantitative data resulting in mixed methods studies.

A study by Albersheim et al (2010) had a clear main outcome measure which was to identify the process by which neonatologists consider restricting parental life or death decision-making when no agreement could be reached. The study design was based upon telephone interviews with open-ended questions. This design allowed the researchers to identify the neonatologists' opinions regarding parental rights, the underlying principles governing their thoughts and whether they believed that there were any limits to parental rights or parental authority in life or death decisions. Information regarding identification and recruitment of participants was limited. The term 'neonatologist' was used, but the study report failed to identify participants' level of experience accurately; asking only if they had more than ten years' experience. It is important to consider that significant differences in outlook and confidence might be found between relatively inexperienced and much more experienced neonatologists.

Data collection was barely discussed but it was clear that the interviews were audio-taped either in English or French. The language used was confusing in that a description of a 'questionnaire-based study' was included also highlighting that the

'survey tool' had been previously piloted. It may be that an interview-based survey was conducted with a highly structured interview schedule. Overall discussion of study design, data collection, data analysis and ethical considerations was limited. Due to the lack of other evidence in this field, the findings were valuable, however the authors identified that the need for future work to be undertaken to examine which types of situations stimulate neonatologists to consider excluding parents in the baby's best interests. Regardless of the situation it is reasonable to argue that the neonatologists should always be working with the baby's best interest as paramount.

The mixed methods study by Bailey et al (2013) began with a hypothesis that although parents are involved in decision-making within NICU some decisions are more heavily influenced by neonatologists than others. From this the study was devised with an aim of establishing the most common care decisions to be discussed with parents and the percentage of neonatologists that will be influenced by such discussions. Two thousand one hundred and thirty-seven neonatologists were contacted, with 2002 responding to the survey and 893 surveys completed in full. The experience of the neonatologists was categorised into less than ten years, ten to twenty years and more than twenty years which would provide a meaningful impression when interpreting the results. A simple electronic questionnaire was devised based on feedback from local neonatologists. Although the questionnaire was anonymous, it is possible that self-reported behaviour is not always a true reflection of actual behaviour in clinical practice. The results clearly identified which particular management issues, such as blood transfusion or placement of umbilical line, neonatologists felt to be important.

The third study (Boss et al, 2009), utilised a mixed method approach to evaluate the training of neonatology fellows in America. The study aimed to focus upon training in guiding family decision-making in NICU and the associated communication skills. Recruitment was undertaken via e-mail with a link to a web-based survey. One-hundred and sixty-two fellows were eligible. Of these, 101 fellows responded, resulting in a 72% response rate. The five-minute survey was devised from the literature. Results were clear with final recommendations for assessment of parent-reported outcomes of interventions used in doctor's communication training. The findings are important but further interpretation is required regarding compatibility with medical training programmes in the UK.

Neonatal research

Two of the 14 studies focussed on parents and neonatal research. Hoehn et al (2005) undertook a qualitative study analysing the unsolicited comments of parents who had either agreed or declined to take part in a research study. The aim of the study was to determine parental decisions for and against participation in a research study. A qualitative methodology was a suitable choice for this study due to the researcher's desire to interpret and illuminate parental thoughts and processes. The comments were collected through observation of 49 semi-structured interviews being undertaken for another study examining parental clinical care decisions. Thirty-four of the 49 parents interviewed gave reasons spontaneously for or against participation of their baby in a research study. It is heartening to know that the data was completely unprompted, reinforcing the likelihood that the information reflected validly what the parents felt and experienced rather than what they believed that the researcher wanted to hear. Data collection and analysis was rigorous using three independent reviewers. The results were consistent with other studies exploring parental permission, showing that personal and/or societal benefit from participating in research is likely to increase participation.

The second study was a qualitative study undertaken by Jollye (2009) in the UK. The aim of this study was comparable to that of Hoehn et al (2005), exploring the thoughts and feelings of parents when choosing or declining to enrol their baby into a study. The sample size was very small; only seven families. Semi-structured interviews were conducted two months after the baby was discharged home. Data transcription and analysis was not discussed in detail. Ultimately, the rigour of this study could not be gauged due to lack of detail regarding study design.

Infant feeding decisions

Only one study focussed specifically on feeding decisions. Dowling et al (2009) examined the factors involved in mothers' decisions to provide breastmilk for their premature babies. They also explored whether these factors differed between 'black or white' mothers. A convenience sample was used to recruit 80 mothers in total; 34 white and 46 black. The study was undertaken in America and although it describes the mothers in terms of skin colour it does not discuss country of origin, culture or any other factors which may have a more significant impact on decision-making rather than

skin colour alone. This would certainly be the case in the UK. Data was collected through secondary analysis of data from one primary study examining the psychometric properties of the newly developed Preterm Infant Feeding Survey (PIFS) and another primary study exploring the effectiveness of The Mother's Milk Education Programme (MMEP). The PIFS was developed to be used in the MMEP study therefore the primary studies were linked. Clearly, there is a challenge presented when interpreting subjective secondary data. The risk of bias being introduced as researchers interpret text that was produced in response to a different trigger is substantial. The researchers acknowledged lack of clarity as a result of race and economic factors being confused. The evidence from this study provides insights but is not to be considered robust.

Information provision

The first national survey of parent's experiences of neonatal care was carried out by the neonatal charity, Bliss, in 2010 (Howell and Graham, 2011). This survey was undertaken across 125 neonatal units within the UK, with over 9,000 parents taking part. Overall, this was a response rate of 50%. The participating neonatal units were required to send Bliss a sample of parents who had been discharged home in the three months preceding the request. The exclusion criteria were minimal with only babies that had spent less than 24 hours on the neonatal unit, parents under the age of 16 and babies that had been taken into care being excluded. Once the sample had been received by Bliss, a questionnaire was posted to the parents with up to two reminder letters if needed. There was the option of completing the questionnaire over the telephone with the help of a researcher if required.

The eight key areas that were explored in the questionnaire were admission to neonatal care, staff on the neonatal unit, parental involvement, support for parents, transfers to another unit, discharge from the unit and care and support at home. For the purpose of this review only the data regarding parental involvement was explored in more detail. As well as exploring parental involvement as a general concept, parental involvement in decision-making was questioned as a separate issue from parental involvement in providing care.

On the whole parents responded positively to their involvement in their baby's day to day care such as nappy changing, feeding, touching and comforting their baby. However, when exploring their involvement in decision-making responses were less positive. Overall only 55% of parents said that staff included them in discussions about their baby's care all the time and 37% were not always allowed to be present during the daily ward round when their baby was being discussed. It was noted that the reported percentage figures did not calculate to 100%. The study reported that 55% of parents were always included in decision-making but conversely 46% of parents reported they were only included 'sometimes' or not at all. Clearly this equates to 101%. It is likely that that these figures have been generated due to the nearest decimal place and does not affect the credibility of the results.

REVIEW OF THE EVIDENCE: PARENTAL ROLE IN DECISION-MAKING

Medical decision-making

Caeymaex et al (2011) identified three types of decision-making, medical, shared and informed parental. They identified a medical decision as a decision perceived to be made by the doctors without any direct involvement from the parents. It was found that medical decisions were largely associated with positive feelings from parents. They found relief in not having to make a decision with some feeling that they had ultimately reached the same conclusion themselves. The relief of not making a very difficult decision is understandable however parents do have a level of responsibility for their baby. Whilst parents are reassured that the doctors are making the right decisions for their baby, parents need to be self-assured that it was the right decision for them as a family.

Provoost et al (2006) identified 26/253 cases where decisions were made either without consulting parents at all or without agreement from one or both parents. There were five identified situations when this was deemed appropriate. These were in babies with severe congenital malformations, lethal chromosomal abnormalities, conditions that require pain alleviating drugs with potentially life shortening effects, resuscitative measures that were failing or deemed to be futile and severe complications such as significant chronic lung disease and sepsis. In 17 of these cases the doctors expressed that parents did not require consultation due to the obviousness of the situation. Indeed, for experienced professionals the situation may have been

obvious however for parents it may not have been so clear. Sudden realisation that their baby has died, or is going to die, without prior discussion is in no way beneficial or acceptable. Unless unavoidable, such as a failed resuscitation event, at the very least the situation should be discussed with and explained to the parents as a mark of respect. However, if the doctors were not to consult parents because the baby was deemed to have no chance of survival, similar justifications cannot be given. If death is not imminent and the baby is not suffering, time should be given for parents to be able to come to terms with the situation as well as making any necessary preparations such as contacting other family members or getting the baby blessed if that is what they desire.

There are times when doctors appear to be making recommendations to parents but instead are merely seeking acquiescence (Kavanaugh et al, 2005). Some parents may view this as shared decision-making but be that as it may, the reality of the situation is that the doctor has made the decision, conveyed it to the parents and they have agreed. That still constitutes as medical decision-making leading to the same effects in the long-term. Despite this, the doctors viewed this as parents making the decision.

Informed decision-making

Caeymaex et al (2011) used the term *informed parental* to describe decisions that were made solely by the parents after receiving a holistic explanation regarding their baby's medical situation. Queensland Health (2012) believes that informed decision-making can build trust, allowing a patient (or their surrogate decision-maker) to become a true partner in their own care. Using the term 'partner' contradicts the fact that in these situations parents are making the decision independently albeit once the doctors have provided them with the information. The term 'partner' suggests sharing the responsibility in these situations. When examining the literature on informed decision-making, it is clear that it could be confused easily with shared decision-making. Both provide parents with sufficient information to allow them to come to a decision about their baby's management. However, informed decision-making is about providing parents with this information and then allowing them to make an independent decision without undue influence from the medical and nursing team. Parents may feel oppressed by the weight of responsibility if the medical team stands back and expects a decision to be made entirely by the parent (McHaffie, 2001). Van Manen's (2014)

study discussed the notion of choice implying that parents were 'free' to make a decision. However, as the parents are making a decision for someone else (their baby), they have the added demands of responsibility and accountability.

When parents experienced informed decision-making, most described the experience as 'complex', 'neither chosen nor rational' and 'solitary' (Caeymaex et al, 2011 pg.4). They reported feeling mixed emotions and not having the ability or the desire to make rational decisions. These terms are difficult to appreciate especially when describing a decision as not 'chosen'. This does correlate with Van Manen's (2011) concept of 'the decision that was never a choice', which is discussed in further detail below. In an attempt to understand the parental comment, it could be considered that despite having a decision to make, neither choice appealed to the parent, and therefore it was never really felt as a choice. Decisions were made instinctively (not rationally) as they were not pleasant to deliberate. The frustration of making-decisions alone was expressed. Only a small minority found this type of decision-making to be a positive experience for them. In these situations, parents were completely sure that they had made the right decision in ending their baby's discomfort. Indeed, it does not seem fair to expect parents to make decisions completely alone, but one benefit is that it completely uninfluenced by doctors and therefore is made with the parents cultural, religious and moral beliefs at the forefront.

Einarsdottir (2009) did not identify specific types of decision-making however the parents in her study explicitly believed that no decision concerning withdrawal of treatment from a premature baby should be done so without involvement from the parents. Despite this clear statement it was unclear as to exactly what parents perceived as 'involvement'. Some parents felt that being involved was simply to have knowledge whereas other parents felt they should have the final say which then leads into informed parental decision-making. Three parents in Kavanaugh et al's (2005) study recognised this differentiation identifying that the felt informed but not involved. There are contradictory opinions between what doctors want to do (make a decision and then gain parental acceptance) and how parents feel a decision should be made. One mother explained how a neonatologist had told her that no parent should make an EOL decision, but it would never be done without their acceptance. The results suggest a distinct orientation away from informed parental decision-making into

medical decision-making. Removing this element of choice from parents may lead to acceptance of a decision that they are not yet ready to make, adding further to an already complex and distressing situation. Although there was a variation in the level of involvement when making decisions the majority expressed desires which would result in a parental informed decision. Many parents conveyed their belief that it was the neonatologist's job to provide them with the necessary information for them to make the ultimate decision.

Interestingly, this study contrasts with Caeymaex et al (2011). Einarsdottir found that the majority of parents expressed the desire to make an informed decision independent of the doctors whereas Caeymaex et al largely found that this type of approach to decision-making was perceived negatively by parents due to feelings of abandonment and lack of confidence that they had made the right decision for their baby. Although it is important to understand the processes of EOL decision-making for parents, it is difficult to know how valuable the data from Einarsdottir's study is in terms of contribution to an evidence base since the participants had not needed to make any EOL decisions for their babies opposed to Caeymaex et al's study where the parents were discussing EOL decisions that they had actually experienced. Despite this contrast it has been found that parents of babies born at less than 26 weeks gestation had explicitly requested an EOL decision to be made more frequently than parents of babies of a higher gestation (Provoost et al, 2006). Parents of extremely premature babies are visually aware of how small and fragile they are. It can be difficult for a parent of a more mature baby with a lethal congenital anomaly, where there may be very little physical representation, to understand that their baby cannot survive.

There is also support for informed parental decision-making in the study by Brosig et al (2007). Although approaches to decision-making were not specifically categorised as in other studies it was clearly expressed by parents that it was their decision to make with one mother stating, '*There was no-one that ever said to us 'I think you should do this or I really think you should do that, or even made us feel in any way that the decision we were making was inappropriate.'*' (p512). These parents claimed, not to feel abandoned, but supported by the doctors. One mother was upset that she had made a decision which was not supported by the doctors making her feel disrespected. The term 'abandonment' was then expressed but only when parents and doctors were

in disagreement. It then comes into question as to whether there is ever a true situation of informed parental decision-making. Is it that when doctors agree with the parental decision they agree in silence, making the parent feel like they have made an independent decision? Clearly upon disagreement the doctor makes this clear, essentially taking the decision away from the parent. It could then be questioned as to who has the baby's true best interests at heart?

Shared decision-making

Shared decision making has been advocated as the most appropriate approach to decision-making for most parents (Caeymaex et al, 2013). Despite this, the majority of available evidence supports informed parental decision-making. The Health Foundation (2012, p.5) defines shared decision-making as a 'philosophy and a process ... whereby patients and professionals work in partnership to make decisions about care when there is more than one good way forward'. Despite the Health Foundation's positive outlook on shared decision-making, often the decisions to be made in the NICU are in times of poor outlook or desperation. In neonatal care, the patients are unable to speak or make treatment decisions; therefore it is the parents that can work in partnership with the healthcare professionals to reach an agreed decision. Overall the shared decision-making approach was perceived most positively by parents allowing them to express their feelings whilst sharing the responsibilities with the doctors (Caeymaex et al, 2011).

No decision

Caeymaex et al (2011) found a third of parents from their study (n=23) felt that no decision was made prior to their baby's death. In these cases, the parents perceived the reason for this to be that their baby died spontaneously before a discussion regarding withdrawal of treatment could take place. One parent expressed that they felt it was right that he had been given a chance to survive. They seemed accepting of the situation like the baby had made his own decision, no-one was responsible.

When attempting to synthesise the results of the studies undertaken on the parental role in decision-making in the NICU although difficult there are some conclusions that can be made. The majority of studies are in agreement that informed parental decision-making is the most common approach also drawing the most positive responses from parents (Kavanaugh *et al*, 2005., Provoost et al, 2006., Brosig et al, 2005., Einarsdottir,

2009), despite this, shared decision-making is suggested as most appropriate (Caeymaex et al, 2011). Alongside this there is a theme of parents feeling abandoned when making decisions but usually when in disagreement with the doctor's decision. It is vital, therefore, that healthcare professionals dealing with parents in these situations understand the nature of each of the types of decision-making in order to apply the most appropriate for each family. It is evident across the studies that parents require some form of consultation prior to making such important, decisions although it is clear that in some resuscitative events this may not always be possible. While there is much to be learned about the processes the parental role in decision-making, the research suggests that human compassion is an essential element in allowing parents to manage their role to the greatest effect in a traumatic situation. Gillam and Sullivan (2011) suggest that rather than attempting to decipher what it is that parents need by placing them into one of these categories, healthcare professionals should attempt to have a more ethical stance in such situations. Parents should be respected in terms of their obligation to make a decision for their own baby incorporating their own values and beliefs whilst having the level of participation that they feel is manageable at that point in time (Gillam and Sullivan, 2011).

REVIEW OF THE EVIDENCE: PARENTAL RESPONSES TO INVOLVEMENT IN DECISION-MAKING

Thoughts about the future

Van Manen (2014) identified five categories of decisions that could be made by parents: the ethical decision as the decision that was never a choice, the ethical decision as looking for a way out, the ethical decision as thinking and feeling oneself through the consequences, the ethical decision as indecision, and the ethical decision as something one falls into. He identified that the parental response and thought processes may differ dependent upon which category the parents fall into. He clearly highlights the concept of an 'ethical decision' and hypothesised situations where these decisions might need to be made, such as a cranial ultrasound showing significant brain injury or the initiation, limitation or withdrawal of intensive care treatments. However, no clear definition of what constitutes an ethical decision is provided. These results cannot be generalised to all parents due to the complex and individual ways that decisions are made. Attempting to always place parents into one of these five

categories may result in more rigid and less individualised care, however could be used as a guide.

'The decision that was never a choice'

When parents are presented with treatment options there must be a potential benefit for each treatment, albeit sometimes only a small benefit, otherwise it would not be given as an option. Conversely, no treatment options may be given: only a suggestion to withdraw treatment. In these situations, Van Manen suggests that no real choice exists for the parent except to continue and let their baby have a chance of life.

One set of parents in this situation responded through avoidance of the hospital. They distanced themselves from visiting their baby as they felt pressured and hounded by the medical staff to make a decision. Contemplation of negative future impacts such as their child having severe disability was shown but was not viewed as a reason for withdrawal of treatment.

'The ethical decision as looking for a way out'

This type of decision was explained as a decision that cannot be made immediately but requires an amount of information for parents to exclude uncertainty. Although this explanation was reserved for this particular decision it could be applied to all decision-making scenarios. In an ideal situation, all decisions would be made with the luxury of time and information. As with the previous category parents were shown to respond through contemplation of the future for their baby. One set of parents described how they needed to go away from NICU for a long walk and discuss the situation between themselves. They discussed the prospect of raising a child with a severe disability and how much they were prepared to live with. Ultimately, they made an intermediary decision to base their final decision on the result of a further investigation, *'what about if we ask for a head ultrasound to confirm that she does not have a brain bleed? 'Cause if she had had a brain bleed, we were not going to go on with it.'* (p283).

'The ethical decision as thinking and feeling oneself through the consequences'

As in the first category parents expressed the feeling of being *'rushed and pushed into a decision'* (p284). When feeling this way, parents responded by refusing to make a decision. Again, the notion of needing time was expressed and going away from the NICU to think. Parents explored the outcomes for their baby contemplating what the

future may be and, as in the second category, whether they would be able to cope with a disabled child. The contemplation of the future is not only the practicalities of caring for a disabled child but, for these parents, imagining their baby in their home.

'The ethical decision as indecision'

Parents who also had other children expressed an initial indecision. As well as contemplating the future for their baby, they also have the lives of the other children to consider. It is here that responsibility a parent is explored. As well as responsibility for their baby there is also a responsibility for the lives of the other children. There is no discussion as how the decision is made in this situation however Van Manen suggests that perhaps the most responsive and responsible course of action is to endure the indecision. There is the potential, was the decision left to chance or to the doctors that parents are left with the feeling that they relinquished their responsibility as parents and the uncertainty that the right course of action did not ensue.

'The ethical decision as something one falls into'

Moving on from considering the future, parents discuss their situation after making a decision and reliving it. One mother shares the impact it has had on her life. The decision itself has left the parent responding in a negative way. Feelings of distraction, exhaustion and deliberation are expressed. Van Manen contemplates whether an ethical decision that is made without deliberation may result in these feelings. Although a parent may 'fall into' a decision through lack of time, Van Manen explores the possibility of, amidst information processing and parental contemplation of the future, a sudden arrival at a decision can be achieved unexpectedly. He drew attention to the falsity of the idea that decision-making is a rational, emotional and deliberative process based on the baby's best interests when, in reality, it seems to be more abstruse and problematic.

There were three major points that were relayed throughout more than one category. One matter of primary concern for parents was the resolution of uncertainty. For nurses and doctors assisting with this is a very difficult task as there is no guarantee as to how a baby will respond to a treatment or what the future will hold if a parent decides not to withdraw treatment. Second, many parents tried to imagine what their lives would be like raising their baby with a significant disability. This is a very personal issue and only

the parents themselves can make a decision as to whether or not this is something they can incorporate into their lives. Finally, time was something all parents desired but unfortunately may not always be available. Overall Van Manen declared that there will always be situations where parents cannot express anything other than their desires for their baby. In these situations, it is questionable as to whether what is perceived as a decision was ever a decision at all. This is supported by Caeymaex et al (2011) discovering that some parents felt that although they had verbally confirmed a particular 'decision' it was done so with a negative outlook in that they had decided something but did not wish for it to happen.

Emotional response and feelings

Several studies identified feelings of ambivalence towards their baby whilst in NICU (Caeymaex et al, 2011, Einarsdottir, 2009). Parents are entitled to feel joy after the birth of their baby regardless of the situation but understandably there will be many other feelings and emotions impeding the ability to make sense of the situation. Jollye (2009) found parents experience many emotions when their baby is admitted to NICU including shock, anxiety, guilt and fear. One father asserted that although parents are not medical experts, they are emotional experts (Einarsdottir, 2009). It could be argued whether anyone is truly an expert of their emotions especially during a time of great stress such as in NICU. There is no way of predicting one's emotional response to a situation that has never been encountered before. Regardless of the emotional response of the parents, support and understanding should be provided (Brosig et al, 2007).

Rationality

Most parents described having to make a rushed decision leading to irrationality (Caeymaex et al, 2011). It was not only a lack of time that contributed to an irrational choice but also the lack of adequate and understandable information. Some parents described difficulty in making sense of the information provided therefore leading to an inability for rational reflection. The parent's emotional state during the time of information provision can impair understanding. One mother recalls being significantly overwhelmed and crying therefore any information she was given could not be retained (Kavanaugh et al, 2005). The doctor felt they had done their job but the mother did not hear what was said. Parents are overwhelmed with concern for their baby's wellbeing

and struggle to consider anything else (Jollye, 2009). In the early stages of admission, the parental concept of reality is impaired causing a lack of understanding as to what is happening in NICU (Jollye, 2009). It may not be that parents are incapable of making the right decision for their baby only that they have specific needs that require identification and execution allowing facilitation of their decision-making process.

Some parents expressed that whilst one decision may have been made, when the definitive time arrived for the decision to be carried out, they may have changed their mind (Einarsdottir, 2009). This then reinforces the importance of parental involvement at all stages of the decision-making process which includes they very end when the decision is being carried out. Confirmation of the decision made will ensure all parties involved are in agreement and if not, provides an opportunity for further discussion.

Guilt

The awareness of *potential* guilt was expressed by one mother. She was involved in a shared decision-making process but identified that the doctors made her feel like she wasn't making the decision by herself and thereby protecting her from guilt (Caeymaex et al, 2011). The concept of potential guilt was supported by Einarsdottir (2009) who found parents anticipating these future feelings. One father argued that despite the awareness of feeling guilt, this was not an acceptable reason to not be involved in making a decision for their baby. He felt that letting the doctors decide was an easy way out.

Despite this, the same study identified that over half of the parents who were interviewed did experience feelings of guilt after their baby's death with the majority of these having made an informed parental decision. Nonetheless, guilt feelings were largely felt regardless of the type of decision made. Even years after their baby's death, some parents were still trying to rationalise the actions that had been taken, recreating reasons as to why that particular decision was the best course of action. These thoughts may in part be related to an individual parent's moral stance such as doing what they feel is best for everyone involved or simply following their conscience, possibly occurring regardless of how the situation was managed. It cannot be generalised to all parents who have made a decision resulting in their baby's death and may not necessarily occur in parents who have a strong belief that it was, for

instance, 'God's will'. This is supported by Hawthorne et al (2015) who found in their longitudinal study that having spirituality can help parents with grief and also during recovery from their baby's death allowing personal growth and maintenance of the mother's own mental health. Blossom (2015) recounts her personal experience of the death of her baby and, as an atheist, how other people tried to comfort her with religious comments. She expresses how religion was not a belief, nor a comfort, for her however it is clearly evident that she was still rationalising the reasons for her baby's death stating, 'maybe she died because of there was errors made in the care I received...maybe she died because I was unable to visit a new doctor...maybe she died because of any other reason except that it was God's will'.

Other than feeling guilt for the death of their baby, parents also expressed feelings of guilt for the lack of relationship they had with their baby during their short life, their helplessness or lack of presence at the time of their death (Caeymaex et al, 2011) and their decisions both to enrol or not to enrol their baby into a clinical trial (Jollye, 2009). It is apparent that regardless of the decision made, parents feel an element of guilt towards both the chosen decision and the alternative option. Alleviation of some of this guilt may be achieved through encouragement of bonding through skin to skin contact and involvement in the baby's day to day care.

Comfort and security

Agreement of parents and doctors over a particular decision provided feelings of comfort and security for parents (Caeymaex et al, 2011). Although parents are responsible adults capable of making many decisions in life, it seems that they gain comfort in the doctor's approval of their decisions in NICU. Clearly this is a positive response however there will be scenarios when both parents and doctors cannot come to an agreement. The baby's best interests need to remain paramount whilst supporting parents through the decision-making process.

Grief

Caeymaex et al (2013) used the previously identified types of decision-making to establish whether this has an impact on the long-term grief response of parents. Similar to other studies, the types of decision-making were identified as shared decision-making, medical decision-making, informed parental decision-making and no decision-

making. Seventy-eight individual parents of 53 children from any of four NICUs in different regions in France were interviewed two years after their baby had died. Prior to an interview, parents were assessed using a French modified version of the Texas Revised Inventory of Grief (TRIG-F) and the French version of the Hospital Anxiety and Depression Scale (HADS). They then participated in a 75-minute semi-structured interview talking about their experience and feelings about their baby's history, paying particular attention to the EOL decision-making. This study was undertaken as part of a larger study examining parental grief and opinions after the death of their baby in NICU.

The results showed that parents whose baby had died in NICU had higher grief scores, similar to scores of those who had suffered a perinatal loss. Despite this, they were functioning well and were not depressed. Factors such as parental social or demographic characteristics or any factors related directly to their baby such as diagnosis, clinical status or sex did not correlate directly to increased grief scores. However, as hypothesised, grief scores differed significantly dependent upon the level of decision-making that was experienced. It is difficult to make comparisons as the number of participants varied across the four groups. The shared decision group was the largest (n=31) and the informed parental decision group was the smallest (n=6). Despite this, the grief scores of the shared decision group were statistically significantly lower than those of the other three groups. These results correlate with findings from other studies where shared decision-making has been reported to be the most positive form of decision-making (Caeymaex et al, 2011). The highest grief scores were identified in parents who took a parental informed decision. One limitation highlighted in this study was that it was undertaken three years after the event and relied on accurate parental perception and recall. However, memories of such life-changing events may well be so ingrained as to be given to accurate recall over time, or defence mechanisms may alter them to soften the pain of recollection and guilt about decisions that were made.

Risk versus benefit

Although other studies had discussed parental contemplation of the future they had not explicitly explored how parents weigh up the risk versus benefit for their baby when making a decision. Hoehn et al (2005) and Jollye (2009) found that when considering

participation in research, parents do look at the risks and benefits, not only for their baby but also for society. Parents were aware that other families could benefit through their baby's participation in research. Hoehn et al (2005) found that societal benefit was actually quoted more frequently than personal benefit which was a secondary consideration. When attempting to generalise this to decision-making in NICU it is likely that parents will consider the risks and benefits for their baby and also the impact their decision is likely to have on themselves and their extended family. It is questionable whether they would consider the impact on society as a whole and more importantly whether they should. Due to the mechanics of the NHS parents do not have to worry about the financial implications of their decisions whereas in countries where parents have to pay for their healthcare this may be a more significant consideration.

The parental response both emotionally and purposefully is complex. The literature identified that as well as having emotional responses that are out of parental control they also have a psychological response allowing contemplation of the impact of their decision. A lack of time in combination with this uncontrollable emotional response appears to cloud their sense of understanding however there is suggestion that this could be transient and clarity may overcome this with time. Unfortunately, in some situations time is not a manipulative factor. The emotional responses of parents appear to be in the majority negative. Guilt is a commonly experienced emotion regardless of the decision made. It is suggested that a parent may feel guilt towards a decision made but also for not making an alternative decision. Grief was ultimately associated with EOL decisions and did not appear as a factor in studies discussing other types of decisions. Regardless, grief is not only associated with death and parents may experience grief simply by having a baby in NICU, grieving for the 'normal' birth and baby that they never had.

REVIEW OF THE EVIDENCE: THE IMPACT OF PROFESSIONALS' APPROACHES AND ACTIONS

Medical preparation

Boss et al (2009) undertook a web-based national survey examining neonatal-perinatal training programmes in the United States, particularly the training to guide family decision-making for critically ill babies. The survey consisted of 28 multiple choice and Likert scale questions with one open-ended question. It was emailed during the final

month of training to 140 of 162 eligible fellows with 101 completing the survey, a response rate of 72%. Nearly all (96%) reported having 'had a lot of training' regarding the medical management of an extremely premature baby, and 89% 'had a lot of training' regarding the medical management of the dying baby. Despite this, when questioned about communication training in these scenarios, 41% had no formal training of any kind, 75% had never participated in role play or a patient simulation scenario, and only 6% had attended a clinical rotation that had a primary focus upon communication skill development. Although a large proportion of fellows had led family meetings, they were rarely provided with feedback on how they had performed.

Currently in the UK doctors are required to collect feedback from patients and colleagues every five years (General Medical Council (GMC), 2016). This feedback allows doctors to reflect on how they work and identify ways in which they can improve their practice (GMC, 2016). They will also be expected to discuss this feedback at their annual appraisals. Sixty-four percent of fellows showed a lack of understanding of family needs, confusing this with parental comprehension of information. They discussed how they would assess parental comprehension through asking them to repeat the information that had been provided. Verbal repetition of information does not express understanding. Parents will need to opportunity to ask questions and may need information repeating several times. Some fellows reported that gratefulness from the family was evidence for them that they had been successful in meeting the family's needs. At a time of stress parents will appreciate communication and information provision likely expressing gratefulness. It would be wrong to perceive this as satisfaction of parental needs. Their needs are likely to be complex and will take time and attentiveness to be achieved.

Recognising parental needs

Information

Increased knowledge and experience of parental experiences of decision-making does not lead to generalisation, only acknowledgement of the complexities parents face and how each may deal with situations in different ways (Van Manen, 2011). Professionals need to develop the ability to meet the information needs of parents whilst recognising parents showing non-decision allowing reconsideration of the professional approach. Surprisingly parents expressed a desire for an expert and completely honest

explanation over a detailed one (Caeymaex et al, 2011). It seems that the depth of information is not what parents are seeking to aid their decision but a factual and easy to understand explanation providing them with clarity. The importance of the use of simple language with minimal terminology with translation and repetition if necessary was stressed. Parents found consistency of information to be reassuring. A lack of consistent information may provide parents with an impression that either the doctors cannot come to an agreement between themselves about the right course of action or that they do not have the required knowledge to guide that decision-making process. This in turn can lead to loss of trust and confusion.

There are many times when doctors will discuss the care and treatment options of a baby without the presence of a parent. This can happen during the handover period between shifts, during a multi-disciplinary meeting or 'grand ward round', or during a normal daily ward round. It is known that in some NICUs across the UK parents are not invited to attend daily ward rounds (Howell and Graham, 2011): a time when the baby's progress and clinical management will be discussed, and plans made for future investigations and treatment options. This leaves parents excluded from essential communication that may affect the development of a trusting relationship between parents and the health care professionals caring for their baby. Parental attendance on the ward round is one of the criteria towards achievement of standard 2.1 of the Baby Charter providing parents with an equal opportunity to be partners in decision-making (Bliss, 2009). It was found that the degree of involvement in ward rounds was dependent upon the level of neonatal unit with level one (SCBU) units providing the most involvement and level three (NICU) providing the least (Howell and Graham, 2011). Unfortunately, in the UK the literature does not provide reassuring evidence that parents are being provided with adequate information to aid their decision-making. Forty-six percent of parents reported that they were only included in discussions about their baby's care 'sometimes' or not at all. At best 75% of parents were always included in these discussions and at worst 35%.

Several parents recommended advice for other parents, were they ever in the same situation (Brosig et al, 2007). They advised that parents ask for as much information as possible and not to be afraid to ask for it several times. The benefit of written information was suggested by parents and doctors (Kavanaugh et al, 2005). This

would be beneficial where time was not an issue. The information could then be read in their own environment, when they felt ready and as many times as they needed. Parents advised vocalisation of thoughts and to stick to their own decision if that's what they felt was right. Parents are entitled to ask for as much information as they required although it should be being provided daily and also during scheduled one to one meetings with their named consultant. This is also consistent with vocalisation. Some parents may feel intimidated during daily ward rounds with the presence of other parents of multiple doctors, nurses and other members of the multi-disciplinary team, impairing their ability to obtain information or vocalise concerns which is where the importance of regular one to one meeting lies.

Alongside the information gained from doctor's parents have also been found to benefit from extended family support during times of decision-making (Brosig et al, 2007, Kavanaugh et al, 2005., Jollye, 2009). This was not beneficial for all parents as some families struggled to deal with the situation especially when it concerned death (Brosig et al, 2007). Even non-life or death decisions such as enrolment onto a research trial caused reluctance from extended family to offer advice (Jollye, 2009). Although extended family members often do not want to offer direct decision-making advice they are often found to support the decision made by the parents (Jollye, 2009). It is unlikely that many extended families would not support each other; it may be that they themselves need some time to process and understand what is required of them.

Trust

Parents gave clear indications of how their experience could be improved (Caeymaex et al, 2011). They discussed the need for a trusting relationship between parents and professionals, characterised by kind, non-judgemental approaches to their participation. Healthcare professionals should at the very least deliver this element of care consistently to all patients and their families. Relationships take time to develop but even after a few days this can begin to occur allowing parents to open up and being to ask questions (Jollye, 2009). Parents wish to be able to express emotions that are difficult to deal with, to be spoken to with respectful language such as always calling the baby by their name, and to be offered a frank, clear explanation of the situation. Consistency between professionals was also found to be reassuring (Caeymaex et al, 2011). It is clear that parents were not being unreasonable in their demands for how

they should be treated during such an exceptionally difficult time. They did not demand any input that should be beyond the capacity of any trained healthcare professional.

There will be situations where parents cannot agree when making a significant EOL decision (Einarsdottir, 2009). One parent may put their trust in the doctors, agreeing with the decision that they felt was appropriate whereas the other may not. Some parents feel that nature should take its course (Einarsdottir, 2009., Brosig et al, 2007). It is a lot to ask for a parent to trust a doctor that they do not know with their baby's life. Parents need to trust that doctors are providing them with honest information to enable them to understand what is best for their baby. Parents understand that honest information can mean bad news but report feelings of anger when they felt information was not honest (Brosig et al, 2007).

Time

Parents discussed the need for compassion and for more time than they are actually given to process information (Kavanaugh et al, 2005). Time for information processing is important for anyone making a decision. Unfortunately, due to the nature of NICU, time is sometimes a luxury that parents do not have when reviewing their options. Even for non-emergency decisions, such as participation in research, require an element of time for contemplation (Hoehn et al, 2005). It is not only the provision of time that parents need when attempting to make a decision. One parent in Hoehn et al's (2005) study highlighted timing of being asked about decisions as an issue stating that 'half hour before surgery is not the time to ask about a research study' (pF268).

Attitudes of medical staff

Respect

Respectful attitudes such as calling the baby by their name was taken positively by parents opposed to a casual, emotionless attitude experienced by one parent (Caeymaex et al, 2011). The mother felt that the doctor's attitude was cold and uncaring, and this made her question the decision, she contemplated whether he was telling the truth.

Application of limitations to the parental role

Albersheim et al (2010) questioned whether doctors would limit parental decision-making authority in specific situations. They provided the doctors with several scenarios ranging from uncomplicated premature birth from 23 weeks up to 26 weeks, a severe grade four intraventricular haemorrhage (IVH) at four days and four weeks of life and end-stage and severe chronic lung disease (CLD). All situations presented parents that wanted to withhold or withdraw intensive care treatments. It was clear that neonatologists were much less likely to limit parental decision-making authority for a lesser gestation baby such as 23 or 24 weeks opposed to the baby born at 26 weeks. Some doctors expressed concern that withdrawal of treatment beyond a certain point may result in survival with an increased neurological impairment. This then had an impact on their response to parental limitations in the baby with a grade four IVH at four days opposed to four weeks. Eighty-nine percent would agree to withdrawal of treatment on day four of life, but this dramatically reduced to only 11% of doctors agreeing to withdrawal of treatment at four weeks of age.

Whereas Albersheim et al (2010) explored limitation of decision-making in specific clinical scenarios Bailey et al (2013) discussed specific interventions for which doctors were influenced by the parents. They created a 'Parental Influence on Clinical Management Pyramid' that showed the interventions that inspired the least influence at the bottom and the most influenced interventions at the top. Bailey et al (2013) identified that parental influence was not only participating in a discussion but being empowered to be involved in making a decision. The least influenced interventions included placement of umbilical lines, phototherapy, ventilator strategies, the use of total parenteral nutrition (TPN) and placement of a chest drain. The most discussed was the use of steroids for chronic lung disease (CLD) and blood transfusion. It is clear that the interventions at the bottom of the pyramid, if not performed, would have a detrimental impact on the baby. Likewise, the interventions at the top are interventions that would make an improvement to a baby's clinical situation but are unlikely to cause significant deterioration. It is therefore at the doctor's discretion as to what decisions they feel are appropriate for parents to make.

It was also discovered that doctor's years of practice combined with experience of disability had a significant impact on the limitations applied to parents. Doctors who

had been practicing for ten years or less applied more limitations to parental decision-making for both scenarios of the grade four IVH compared with doctors who had been practicing for more than ten years. Conversely, doctors who had experience with disability were less likely to apply limitations for babies born at 24 weeks gestation. Surprisingly experience in neonatal follow up did not have any impact on application of limitations. It would be expected that through experience with babies in later life encountering the effects of extreme prematurity and other morbidities known from NICU that this would have an impact on how doctors deal with parental decision-making authority. Bailey et al (2013) found similar results. They found that doctors practicing ten years or less were less likely to be influenced by parents opposed to those practicing for 20 years or more. It may be thought that more experienced doctors could be set in their ways and prefer a specific way of working and conversely that less experienced doctors may be more open to influence from parents however these studies suggest differently. The lack of experience may cause more junior doctors to feel unsure and comply more rigidly with guidelines rather than having a family centred approach whereas wealth of experience allows each family to be treated individually with the knowledge that variation in practice may be beneficial for certain families.

Albersheim et al (2010) identified that a majority (55%) of doctors felt that parents should be part of a decision-making team. Less than half felt that parents should be the primary decision-maker with only a small percentage believing that the doctor should be. It is positive that only a small number of doctors believe that parents should have no say in the decision-making for their baby however these results were extrapolated from the doctor's response to 'What would you do?' for specific scenarios. Potentially their perceived role of the parent may change dependent upon the situation.

It could be anticipated that parental needs are complex and numerous however the studies identify only three: time, trust and information. As previously discussed, time is sometimes a luxury that parents are not enabled with. The evidence surrounding doctor's communication training to deal with decision-making in NICU is restricted to one study and is therefore difficult to evaluate. Several studies do suggest experience does have an impact on how parents are involved in decision-making. Parents need to be reassured that doctors can provide them with the information they need whilst treating them with respect as a parent.

REVIEW OF THE EVIDENCE: INFLUENCES UPON DECISION-MAKING

Parental responsibilities

Parent's beliefs as to what they feel they ought to do for their child will have a significant influence on how they make a decision (Van Manen, 2011). All families in NICU will have very different structures and dynamics. Although the concept of best interests of the baby are at the forefront of any decision Van Manen explores the extended complexities such as parental coping abilities and the effects on other children and family members. These are influences upon which professionals have very little, if any, control over. Spence (2000) raises an important issue regarding decision-making for a baby rather than on behalf of a child or an adult. She notes that throughout their life and relationship with the decision-maker, adults and even young children will have probably expressed their wishes, preferences, and attitudes about events in life such as to make clear to the eventual decision-maker how to uphold these in making a decision on unforeseen issues. The development of this will have involved a certain level of attachment. There is a large body of evidence supporting the importance of parent-baby bonding at birth (Parfitt et al, 2014., Cockcroft, 2012., Bancalari et al, 2016). If this bonding process were hindered in any way and attachment restricted, then the parental decision-making process might be affected through lack of enthusiasm for the baby's best interests.

Some fathers felt that mothers should have slightly more influence over the decision-making process than them especially over the care of the baby, as this can affect mothers more than them (Kavanaugh et al, 2005). This was supported by Jollye (2009) who also found that the final decision was usually made by the mother. This was not beneficial often leaving the mother feeling upset and worrying whether she had made the right decision. This could be construed as father's offloading some of the responsibility onto the mother. Although he may feel he is allowing her to choose what she desires for their baby she may be appreciative of his opinion and support during this time.

Perception of harm

Several studies identified parental perception of their baby's suffering as a significant influence on their decision-making (Caeymaex et al, 2013). Parents worried about the physical implications certain procedures or investigations, such as EEG monitoring,

may have on their baby (Hoehn et al, 2005). Conversely one mother had every confidence in her hospital experience stating 'Its top notch. You're not going to do something that's going to put them at risk.' (Hoehn et al, 2005 pF268).

Parents that were considering enrolling their babies into research studies also discussed the concept of harm. If they perceived their baby to be well and progressing they were more likely to enrol them into a study (Jollye, 2009). Some trials were perceived to hold more risk than others. Parents perceived a blood transfusion study to be riskier than a ventilation study. This was attributed to parental knowledge. It was found that the more knowledge, or even pre-conceived ideas, the parents had, the riskier they saw the decision. Although with increased knowledge parents perceive more risk they are enabled to appreciate benefits allowing them to make a more informed decision. An increased perception of risk would not be a justifiable reason to withhold information from parents.

The literature identifies that parents are influenced by each other, doctors and extended family members. It also suggests that the weight of their parental responsibilities and the perception of suffering and harm are also significant influences upon their decision-making abilities. It is questionable as to why fathers feel that mothers should take ultimate responsibility, perhaps their level of involvement is inadequate leaving them to feel they are not entitled or even equipped to make a decision. The inclusion of fathers is as important as mothers. This may be more challenging due to his extra responsibilities whilst his family are in hospital such as running the house, caring for other children, bringing provisions to the hospital and even going back to work. This is further compounded for unmarried parents who have not yet registered the birth, leaving the father without any legal parental responsibility.

CONCLUSION

The findings of this critical literature review illustrate the process of decision-making for parents in NICU. The available evidence base was minimal. Lack of detail in reporting study design, recruitment, data collection and data analysis prevented thorough appraisal of the rigour of the studies.

The parental role in decision-making is variable with current literature suggesting that the *informed parental* role, allowing parents to make the ultimate decision, is increasingly desired. Despite this there is still a requirement for medical and shared decision-making for some families. Regardless of the role parents assume it is evident that there will always be an array of emotional complexities to follow.

The majority of feelings and emotional responses experienced by parents were negative. Aside from one study identifying feelings of comfort and security when a decision is made with agreement or approval from doctors (Caeymaex et al, 2013), responses of guilt, grief and irrational choice was reported. The literature suggests several reasons for these feelings. A lack of parental knowledge and experience in NICU leading to confusion as to whether the right decision has been made alongside parents having a heightened awareness of the potential for suffering and harm for their baby. The added pressure of time and the weight of responsibility, particularly for the mother, with several studies illustrating the transfer of responsibility from the father.

The experience of doctors clearly had an influence on their response to and management of decision-making situations with increasing experience allowing greater influence from parents. Experience can only come with time however some doctors spoke of lack of formal communication training or exposure to decision-making situations. Doctors that were exposed were unsupported and lacked feedback on their practice leading to misinterpretation of parental responses. This in turn can lead to inadequate identification of parental needs and impairment of the development of a trusting relationship.

It is already known that care provided for parents and their babies in NICU cannot be prescriptive but needs to be based on an individualised and holistic basis (Royal Australasian College of Physicians, 2008). Despite this, the most recent evidence (Howell and Graham, 2011) suggests that parents still seek an element of care which is not currently being provided. While a worldwide problem, this is especially important in the UK due to the limited availability of data on parental experience of participation in decision-making in a UK NICU. It is essential to discover what parents in the UK desire and what they experience currently in order to improve practice. This can be done only through increased research with parents living in the UK, assessing their

desires and experiences of participation and how this can be amended in practice in order to improve their experience. It is clear that there is a significant need for further research to be undertaken, specifically in the UK, in order to establish how doctors and nurses in NICU can facilitate parental participation in making clinical decisions. Once there is a clear evidence base surrounding this topic, changes can be made in practice to improve long-term outcomes for these families.

CHAPTER 3: ETHICAL CONSIDERATIONS OF MEDICAL TREATMENT IN NICU

In order to support appropriate and sensitive participation in clinical decision-making in the NICU there must be consideration of the legal and ethical issues that are raised. Despite many laws stating specific practices which are, and are not acceptable, situations become more complex when values, including religious beliefs or traditions, of the parents and healthcare professionals are combined. A significant amount of the literature on ethical decision-making is based on the management of extremely premature babies or withdrawal of treatment, from term or preterm babies. However, moral guidance of some nature is needed to inform all clinical decisions in the NICU.

LEGAL AND OTHER RIGHTS

There are many basic rights by which a baby's care may be governed. For example, when applying human rights to decision-making in the NICU, Donzelli (2010) identifies a baby's right to receive care that is appropriate when ill. He claims their right to be pain-free and never to receive treatment that is felt to be futile, particularly for pre-term babies. Why pre-term babies should have more claim to this right than term babies is not argued clearly. Giubilini and Minerva (2012) agree that since there is conclusive evidence that babies can experience pain, they should have the right to be pain-free. Even with this there is a problem. A degree of pain may be unavoidable and may even be impossible to identify. The Parma Charter of the Rights of the Newborn holds that no medical procedure should be performed on a baby without prior parental consent, except in an emergency situation when the action is taken in the best interests of the baby (Bevilacqua et al, 2011). This would likely include procedures such as emergency intubation or chest drain insertion. When parental consent cannot be sought, then this reflects the case in English law pertaining to adults who are unable to provide consent to their own treatment when the proposed treatment will be life-saving. The principle of assumed consent is upheld in English courts. The Parma Charter also states that 'parental choices must be respected within the limits of feasibility and medical appropriateness'. This is an example of the common failing of such pronouncements: ambiguity. What should be considered "feasible" or "medically appropriate" is given to varying perspectives and interpretation, and this leads to the cases in which medical teams resort to applying to the courts for a ruling on what should happen to a particular child.

Parental Responsibility as a Legal Issue

Parental responsibility is defined in the Children Act 1989 as all the rights, duties, powers, responsibilities and authorities which by law a parent of a child has in relation to the child and the child's property. In the UK, a mother automatically assumes parental responsibility for her baby at the time of birth. There are several specifications for a father to have parental responsibility over their baby. A father will have parental responsibility for a baby if he is married to the mother at the time of the birth or if he marries the biological mother after the birth. Since 2003, an unmarried father who is registered on the birth certificate will have parental responsibility (though not in Scotland). Many babies are not registered before commencing treatment in NICU, with the result that some biological fathers have no legal parental responsibility. Parental responsibility gives the parents the right to consent to or refuse healthcare treatment (Medical Protection Society (MPS), 2012). Despite this, if a doctor believes that a parent's decision is not in the best interests of the baby and the issue cannot be resolved with the parents, it may be necessary for the decision to be taken to the courts (MPS, 2012).

The challenging issue with parental responsibility is that usually decisions can be made by one parent even if both parents have parental responsibility (Child Law Advice, 2015). It is not always necessary to gain consent from both parents. Despite this, if there is a major decision to be made then both parents will need to be in agreement. If they cannot agree then family mediation is the first step in resolving a dispute. There may be times when this does not work, in which case a Specific Issue Order or Prohibited Steps Order may need to be applied for through the courts (Child Law Advice, 2015). A parent can do this without parental responsibility and is effectively asking the court to make a decision on their behalf based on the best interests of the baby. This again becomes problematic due to the lack of definition as to what constitutes as a 'major' decision, and although it might be considered that potentially life-saving or life-limiting decisions would qualify, a sliding scale of impact might be seen in the range of decisions to be made, and some would argue that all clinical decisions are major.

THE ARGUMENT FROM DEONTOLOGY

Deontology is a moral theory usually associated with Immanuel Kant (1724-1804). The central issue of deontology is the Categorical Imperative which is the highest overriding principle which is based on reason and rationality, and, vitally, that is never context-dependent. Acts are seen to be morally good or bad of their own right; the means to the end being just as important as the outcome of the action. Kant suggested that moral decisions could be made by considering what the effects of an act would be if the action were to be applied universally. If the effect (overall) could be expected to be good, then pursuing that course of action would always be right and in compliance with natural moral law. This approach then leads to a complex set of rules that must always be followed, regardless of the expected consequences. Beauchamp and Childress (1994) proposed four principles that are the basis of these rules: respect for autonomy, beneficence, non-maleficence and justice.

Latterly, these principles have been encompassed in a number of approaches to ethical decision-making in clinical practice, including the 'four box' or 'four topics' method, but ultimately they all describe ethics from a deontological viewpoint. The four principles are distributed throughout four boxes, and following these principles is held to allow a comprehensive assessment of an ethical decision-making situation. The titles have been modified slightly here to become directly applicable to neonatology.

Clinical Indications

Clinical indications focus specifically on the ethical principles of beneficence and non-maleficence, or to do good and to do no harm. This is the first process involved and requires clear examination of the baby's medical problems, and consideration of the history, diagnosis and prognosis. Once established, the level of the problem should be assessed as being acute, chronic, critical, emergent or reversible. It is then vital to establish the goals of the proposed treatment or management decision and the probabilities of success. Overall the treatment or management needs to be seen to be benefitting the baby with either no or minimal harm being caused in the process. However, as will be seen later, this is really a consequentialist argument: establishing a balance of the best outcome in a specific case rather than following the rules in a similar manner in all cases.

Parent preferences

The ethical principle guiding this section is respect for autonomy. Autonomy is defined as ‘the quality or state of being independent, free and self-directing’ (Merriam-Webster, 2015). Unlike in adult medicine, respect for autonomy must be applied to the parents in neonatology. The neonate clearly does not have the capabilities for self-governance. They do not have the abilities for understanding and making voluntary decisions. When respecting a parent’s right to autonomy their capacities and perspectives must be considered. In neonatology, doctors and nurses are faced with parents, families and friends from many different religious, cultural, social and educational backgrounds which, in turn, have an impact on their views and beliefs about the management of the baby.

Ashcroft et al (2007) highlight that these autonomous decisions cannot be made without human research and healthcare providers disclosing information, ensuring understanding and fostering adequate decision-making ability. They see it as the role of the healthcare professional to support and encourage parents to make these autonomous decisions whilst at the same time allaying their fears or any other issues which may be harmful to their decision-making process.

Sundean et al (2013) provide a theoretical example of a mother of a preterm 24-week baby asserting her autonomy by insisting that the baby be breastfed. Due to prematurity and ventilatory requirements the baby cannot be put directly to the breast. The mother goes on to assert that she wants the baby to be given her colostrum. However, due to the risk of necrotising enterocolitis this is not a possibility currently. Each time the mother attempts to make an autonomous decision, due to her lack of knowledge and experience in NICU, she is being told that her decisions cannot be acted upon. As she begins to feel a loss of autonomy over her baby’s care the nurse shows her how to express her milk, label and freeze it whilst encouraging her with the knowledge that her milk will then be available when her baby is ready for enteral feeding. This situation highlights how parents can be offered alternative ways to engage with their baby, maintaining their feelings of autonomy.

There is concern within clinical practice that autonomy may not be respected through withholding important information or the non-recognition of a parent’s refusal of

medical treatment (Ashcroft et al, 2007) or more pertinent to neonatology, refusal of withdrawal of treatment or implementation of a non-escalation policy for intensive care management. If a conflict arises between parents and doctors and they cannot come to an agreement about the direction of the baby's management then the reasoning for this from a health care perspective should rest upon one or more of the other ethical principles.

Quality of Life

This section is related to all of the three principles already discussed, beneficence, non-maleficence and respect for autonomy. Firstly, consideration should be made as to the likelihood of a normal life for the baby either with or without the proposed treatment or management plan. As with many areas within ethical decision-making, this could be a particularly subjective discussion as to what constitutes as a 'normal' life. Alongside this runs the prospect of potential physical, mental and social deficits that the baby might experience dependent upon the decision that is made. Although bias should not be a feature, there is a need to be truthful as to whether there are any biases against the doctors or nurse's evaluation of the baby's quality of life and whether this evaluation exposes any conditions that would be considered undesirable in either present or future life. It could be argued that contemplation for some decisions would extend across all four of the boxes, however true reflection non-escalation of treatment plans or comfort and palliative care would take part in this process. As with most other areas of ethics in neonatal care, when contemplating the notion of quality of life for a compromised newborn it is likely that parents and doctors see future potential based on their own intuitions and ideals rather than on objective reality (Wyatt, 2007). Even knowing this is may be hard to argue. Although certain diagnoses in babies have a likely outcome, it is considered that all babies may respond differently, therefore a significantly poor prognosis may materialize into a more positive future.

Alongside overall quality of life there is disagreement over the notion of the sanctity of life. The sanctity of life is often discussed during ethical debates on topics such as abortion, euthanasia or genetic engineering, along with many others (Gushee, 2006). The sanctity of life will have a large part to play for some in these situations. There are various definitions of what the sanctity of life means and adoption of these may vary

between people. Gushee (2006) comprehensively explored the concept of the sanctity of life and devised his own working definition.

'The concept of the sanctity of life is the belief that all human beings, at any and every stage of life, in any and every state of consciousness or self-awareness, of any and every race, colour, ethnicity, level of intelligence, religion, language, gender, character, behaviour, physical ability/disability, potential, class, social status, etc., of any and every particular quality of relationship to the viewing subject, are to be perceived as persons of equal and immeasurable worth and of inviolable dignity and therefore must be treated in a manner commensurate with this moral status'. [Online resource]

There is a major limitation in this argument. Sanctity implies that something is sacred, saintly or holy, and is, therefore, intimately linked to religious belief and religion. Those without religious beliefs will find this notion impossible to justify. Not all religions hold life to be sacred in any case, and in some religions, babies do not hold the same status as adults. Gushee's definition is merely an assertion of personal belief rather than a universally-held principle or justification.

The Nuffield Council on Bioethics (2007) interpreted the definition of the sanctity of life to create several moral obligations; it is never acceptable to take a human life and people should always do their utmost to preserve the life of a baby. Despite this, these obligations caused some discussion within the Nuffield Council of Bioethics Working Party. The notion of an 'intolerable' life was considered, however views varied between members, and became difficult when attempting to define when the risks of continuing with treatment or life outweighed the benefits. Once again, while attempting to establish a firm rule, the Council returned to a consequentialist argument of assessing and balancing the positive and negative outcomes of an action rather than applying a rule universally regardless of context.

Contextual Features

This final 'box' is concerned with the ethical principles of loyalty and fairness. This is the process by which any concerns regarding influences from parents, nurses or doctors on the decision-making process should be addressed. That loyalty and fairness are essentially linked or compatible is questionable, and no rational argument

is offered to support such linkage. However, issues with financial, religious or economic influences should all be examined and discussed according to this model. It is important that, if applicable, parents are aware of how the law may affect the decisions made and whether there are any conflicts of interest from any of the decision-making parties.

The ethical principles themselves are often said to guide healthcare professionals in their partnership with patients, but it has been seen that much of the attempt to effect application of these principles has failed, turning instead to consequentialist strategies to make the decision. The four-box method, while apparently a logical and concise guide to decision-making fails to stand the tests of scrutiny.

THE ARGUMENT FROM CONSEQUENTIALISM

The ethical theory of consequentialism - sometimes referred to as utilitarianism - is often associated with Jeremy Bentham (1748-1832) and John Stuart Mill (1806-1873). The crux of this approach to moral decision-making is that to act morally is to try to bring about the best consequences. Actions are assessed by the way they bring about what is judged to be the most desirable outcome rather than by any intrinsic value. This has led to the field of applied ethics. Importantly, it also recognises the significance of minority views in contrast to the common understanding that it is concerned only with the majority preference. In any difficult ethical decision, the potential positive and negative consequences of a course of action should be weighed rationally, with due regard to the specific context of the case. In that specific case (and without setting a precedent for future cases), what is gauged to bring about the best balance of desirable rather than undesirable outcomes is the right moral decision. John Harris (1985) and Jonathan Glover (1977) have been notable in pursuing the consequentialist perspective in medical issues and particularly life-and-death decisions.

When considering any treatment decision, the concept of best interests should be a central consideration (Nuffield Council on Bioethics, 2006). In certain situations, doctors have the right to provide limited treatment that is essential to maintain life or prevent serious deterioration. This is supported in the English Law of Tort by the principle of assumed consent - that most people would wish their life to be saved even if unable to give consent at the time. Two statements were published by the Committee

on Foetus and Newborn and the Committee on Bioethics, both in the American Academy of Paediatrics, detailing two models to aid the decision-making process, ultimately based around the concept of 'best interests'. The Expertise model is based upon factual evidence regarding the baby's prognosis, ideally with no emotional involvement whereas the Negotiated model includes the values of doctors and parents providing a more moral standpoint (Guimaraes *et al*, 2012). Overall it would seem sensible to use these models jointly providing a more holistic and collaborative decision-making process.

Consideration needs to be made as to whether parents are able to make a decision under extreme stress alongside the complexity of the information provided. It is sometimes questioned whether parents can make a logical decision during these times which meets the best interests of their baby. However, a counter-argument is that parental values about their baby and their utter commitment to doing the best that they can for the baby are so deep and strong that no amount of stress would overturn these. Moreover, doctors and nurses can also be under severe stress, yet there is rarely any suggestion that they can no longer make a rational decision.

The concept of best interests in neonatology is a controversial one. It is often true that when parents are in agreement with medical decisions their decision-making capabilities are not questioned. However, when they begin to disagree with treatment options or management plans, questions arise about their rationality and capability to make decisions (Klugman, 2013). This scenario suggests that consent is deemed really to be restricted only to the right to agree with medical advice. Clearly, this is unacceptable.

Disagreement may not be only between parents and doctors. Parents themselves may not agree with each other about the decisions that are to be made. The ethical focus of shared decision-making has to be that decisions made in the best interests of the baby. Yet deciding what the best interests are is the central problem. This is rarely to be decided on factual evidence alone, but involves ethical notions of quality of life, risk, and a life worth living in addition to compounding issues of religious belief and personal values. Moreover, there is no single clear definition of what constitutes a seriously

compromised baby (Daboval *et al*, 2014) leaving the matter open to interpretation and subjective opinion.

Some might argue that survival alone is in the baby's best interests where as others will look upon the degree of a disability or essentially the baby's quality of life in the future. It is difficult to know how the best interests of a sick newborn baby can be assessed. There are many situations when, although the doctors can give some estimation of long-term outcomes, they cannot specify an exact prognosis in terms of degree of disability or complex care needs.

The calculation of best interests is not restricted to the consideration of future implications. As previously highlighted, one point that does not seem to be disputed throughout the literature is that babies should be free from pain. It is clearly in the baby's best interests to be comfortable and pain free (Spence, 2000), yet neonates' best interests may also require that they are subjected on a daily basis to painful procedures such as bloodletting, cannulation, intubation and (for some babies) physical handling. Unfortunately, despite attempts to minimally handle babies, increasing severity of illness may require closer monitoring with more procedures and handling. This conflict between competing demands is typical of the problems associated with a principles-based approach, and best interests has to be seen not as a simple universal rule to be followed but as a balancing of various interests to gauge the best overall outcome. Best interests apply to the baby's short-term and long-term interests.

THE ARGUMENT FROM HUMAN RIGHTS

Although all 'humans are born free and equal in dignity and rights' (United Nations, 1948) 'the child, by reason of his physical and mental immaturity, needs special safeguards and care' (United Nations International Children's Emergency Fund (UNICEF), 1989). This widely-supported perspective forms the main ethical assumption that prompts and guides relevant legislation.

Entitlement to human rights

There is an international convention that all live humans have certain basic rights which are enshrined in international law. These rights apply to babies however young or

premature, and English law allows for no distinction in status as a human between adults, and children from birth onwards. While the fetus right up to the moment of birth has no legal status as an individual, there are laws which regulate how a fetus can be treated. These are matters of law (and it is often suggested that the only rights that are worth having are those which can be enforced). The moral status of a fetus and of a neonate may be more complicated.

Personhood

The notion of moral personhood arose from arguments about the assumption of being human linking to essential moral status being flawed. In many aspect of human life discrimination is judged to be unacceptable, Ageism, racism, discrimination on grounds of gender or religion are all considered to be unacceptable. Philosophers point to the problem of “species-ism” - discrimination by one species of itself as essentially superior in a moral sense to other species. The counter-claim for the human race being more intelligent than other species is easy to refute. Chimpanzees come especially close to human intelligence in a way that neonates and many intellectually impaired humans fail to manage. This is the recognition and valuing of the self and the value of life. A person can have interests only if they are conscious of the existence of them (Kennedy, 1988). In moral terms, chimpanzees are more on a par with intellectually-able adults (of even very low intellectual ability) than are neonates. If human intelligence is the justification for the greater moral value of humans, then some humans must be excluded from this status and (possibly) some animals should be included.

Walker (2014, pg157) defines *potential* persons as ‘persons who do not yet exist or have no claims, interests or standing that can restricts the actions of actual persons’. It is argued that although human, a baby may not be classed as a ‘person’ until they have the ability to create aims for their future life and to appreciate their own existence (Giubilini *et al*, 2012). Rocchi (2013) completely refutes these claims and challenges this view, claiming that the whole concept could be abused, focussing on babies ‘less favoured by life’ and/or ‘belonging to socially discriminated minorities’. This would then lead onto human’s having too much control and essentially ‘playing God’ through picking and choosing who lives and dies from birth with no apparent consequence. Ultimately Rocchi (2013) claims that every potential person, regardless of definition,

should be treated as an actual one, with every baby being fully entitled to their rights as a human.

These, too, are inadequate arguments. The philosophical strategy of *reductio ad absurdum* can be applied to show this. If young children are potential persons, then so are neonates, but so, too, is the fetus and even the sperm or ovum. Given the right circumstances, all have the potential to become moral persons. This would mean every sperm should be afforded the rights of a moral person, and every ovum lost in menstruation is a lost person.

A different argument must be applied for decisions to afford treatment to neonates at the edge of survivability. Rather than a moral right to existence, applicable law provides guidance (killing an extremely premature neonate would be murder just as much as killing an adult), and the concern of humans for human babies are probably the main factors. Professional judgement of likely outcomes, parental judgement of acceptability of possible disabling consequences, the pressure on resources (should another more obviously viable baby have immediate need of medical resource, for example), and personal values of those involved in making the decision all contribute to arriving at a mutually acceptable plan of action, most likely involving compromise and responsiveness to rapidly changing status of the baby.

CONCLUSION

There are many guiding principles and models of working to aid doctors and nurses in their involvement with parents who are in a position of decision-making, but there is no definitive guidance explaining exactly how to undertake this task. This is the case from an ethical position, but relevant legal frameworks may also be more or less helpful in guiding decision-making. The lack of guidance, together with so many unknowns in terms of long-term prognosis and sometimes rapidly evolving clinical picture make such decision-making in NICU both stressful and complex. Effective communication between the concerned parties must be essential for a negotiated plan of action which, as far as can be ascertained, will promote the best interest of the baby.

CHAPTER FOUR: STUDY DESIGN

Key: Doing the study Writing chapters Dissemination

Original Plan

2014			2015								
Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept
	Introduction		Ch2 Lit Review		Ch3 Study Design		Report	1 st assess		Pub Lit review	
	Proposal & Ethics approval					Phase 1 Consultation				Data analysis	
2015			2016								
Revise 1	4 Findings		Revise Ch3			4 Findings			2 nd assess	4 Findings	
Qu design & pilot				Phase 2 Survey and analysis						Interviews	
2016			2017								
5 Discuss	6 Conc		4 Findings		Finalise thesis			Viva		Amendments	
Interviews and analysis			Final analysis		Prep for viva					Pub Findings	
2017			2018								
Pub Implications											

Final Timeline

2014			2015								
Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept
	Introduction		Ch2 Lit Review						NHS REC approval		
			Univ REC approval			Phase 1 Consultation			1 st assess	Data analysis	
2015			2016								
Qu design & pilot			Phase 2 Survey and analysis						4 & 5 Findings		
Ch3 Study Design				4 Findings			Combined survey and interviews				
2016			2017								
	Interviews and analysis									Data analysis	
Report	2 nd assess			5 Findings		Interruption of studies				5 Findings. Discussion	
2017			2018								
Final analysis			Univ REC amend		Pub Findings			Viva		Amendments	
Discussion and Conclusion			Finalise thesis		Prep for viva					Pub Findings	

Figure 1: Intended and Actual Timeline for the Study

A study timeline was created allowing clear visualisation of the processes undertaken during the development of the study. Throughout the course of the study adaptations to certain situations were required resulting in a change in study design. These

changes and the associated decisions that were made are discussed later in this chapter.

OVERVIEW OF THE STUDY

Research question

The research questions posed for this study was:

How can the frequency and extent of parental participation in clinical decision-making in the NICU be harmonised more closely with parents expressed wishes?

Research paradigm

The Ontological position

This was an exploratory, descriptive study carried out using elements of interpretivism and critical realism. The basis of an interpretive approach lies in symbolic interactionism (George Herbert Mead 1863-1931) – the notion that humans understand and make sense of the world around them by identifying signs and interpreting them. This is applied to research when the researcher takes as unavoidable that both researcher and respondent are unable to be entirely objective in their interactions, but instead, interpret questions and responses (whether printed in a questionnaire or expressed verbally in an interview). Consequently, the outcome is understanding of phenomena and experiences that is necessarily flawed because of the researcher's interpretation. For some people, this means that there can be no facts or truths, and reality is entirely a construct of the individual's position or viewpoint. I rejected this as untenable, recognising that it is the completeness of understanding achieved from each viewpoint that is responsible for variance in interpretation rather than the lack of integrity of a phenomenon itself.

Critical realism was first introduced by Roy Bhaskar in the 1970s but is currently emerging more frequently within the world of nursing research (Schiller, 2016). Critical realism provides an ontological view that there can be more than one concept of reality (but of the same reality). Humans are aware of the physical world in which they live, and, although not experiencing them directly, things that happen continuously but remotely such as a tree falling within the depths of the Amazon rainforest. The fact of the tree falling is real, and this fact is understood though not experienced directly.

Humans also experience a version of reality which is their own. The empirical domain within critical realism is directly comprised solely of human perceptions and experiences (Schiller, 2016). An example applicable to this study would be the hospital building ('real' domain), the NICU ('actual' domain) and the baby in the incubator ('empirical' domain).

Together, these positions represent the ontological position adopted in this study. The researcher could discover only a perspective on the reality of parental participation in NICU, but this reality was perceived through a variety of means and domains. The ontology of such an approach is characterised by a desire to portray phenomena and situations as accurately and faithfully as possible, accepting that there may well be truths, facts and objective reality, but realising that the closest that the researcher can approach to this is always a perspective on the phenomenon. Everyone sees the case through a different lens, yet all viewpoints can be equally valid and real for that individual. This is often referred to as multiple realities, but it might be better considered as varying perspectives on what is potentially a single reality, therefore both interpretivist and critical realist perspectives are valid.

Critical Epistemology

A critical epistemology resulted in which objectivity and accuracy were strived for, yet it was acknowledged that this could not be achieved fully. The more robust a study is, the more valid the conclusions may be – a more accurate portrayal of the topic than was available previously. The researcher remains self-critical, actively seeking out the potential to introduce unnoticed bias, reflecting upon the researcher's role in the study and their impact on the data, and reporting this as part of the findings. The researcher's interaction with the participants and the data is both a strength, as the researcher's knowledge and skill are brought to bear, and a potential weakness if these effects are not fully recognised and accounted for.

Study Design

Data collection methods may be varied as different strategies are employed to enhance validity by, for example, devising the questions to be asked with members of the population being studied, non-statistical survey to achieve an overview of key issues that need to be addressed, and detailed interviews to elicit first-hand narrative

and to test out the researcher's growing understanding. These strategies were adopted in this study.

As methodologies have emerged, grown, developed and altered over time it is arguable whether they are truly pure and uncorrupted. It is difficult to comprehend that there could only ever be one version of an experience and to rationalise how one approach to research can always be better than another. This has led me to consider and apply a more pragmatic approach to my study.

Rather than the deployment of numerous methodologies into the study I employed an integration of perspectives into a new methodological synthesis as described by Kincheloe (2001). All methodologies have their limitations and different approaches can be complementary. There were many benefits to the utilisation of several methodological perspectives when undertaking this study. Pluralism allowed me to make use of the best tools available to complete the research task. Through this I learned a variety of ways of seeing and interpreting information which in turn will help to make me a more multi-skilled and open-minded researcher. My results were not limited by overspecialisation of one particular methodology providing a one-sided approach but allowed more dimensions and consequences of a text or situation to be illuminated.

Alongside the many benefits lie clear limitations to the use of pluralism. The main issues appear to lie with the issue of lack of conformity to procedure, inhibiting the ticking off of processes which are designed to enhance rigour. Standard methods with recognised steps and processes can guide the researcher and ensure fidelity to the stated approach. However, the risk of this is that the exclusion of alternative perspectives and explanations will limit the validity of the findings. The outcome of this is questionable rigour and the possibility of superficial analysis. It has been argued that due to the amount of available information from multiple authors across many different disciplines, perhaps choosing one methodology and rigidly conforming to it leads to an over-simplified research process (Knox, 2004). However, using multiple methodologies is likely to be confusing for a student, and, for any researcher, establishing the relationship between philosophy and methods can be the most 'daunting, messy and controversial areas' of the research process (Knox, 2004 p.121).

Although challenging, I chose not to exclude the use of a pluralistic approach but to embrace the challenge as this was the most appropriate choice to achieve my research objectives.

Application of a Pluralistic Approach

The application of pluralistic approach influenced the development of research questions, choice of data collection methods and ultimately data analysis. Research questions were developed through concerns that arose from personal experiences as an ANNP working in neonatal units, through the use of a PPI event speaking to parents who had previously had a baby in NICU, and through an extensive literature review. The initial data collection method used was a Likert-style survey with an open-ended comments section. The purpose of this survey was not to gain a mass of rich data but to obtain sample demographics and aid theoretical sampling through highlighting key areas of interest or recurrent themes. Parents were then selected based on their survey responses to take part in a one-to-one interview. The interview was the second method of data collection allowing the parents' subjective experiences and interpretations of their time in NICU to be explored. This was the main source of data. The previously completed survey allowed issues raised by parents to be explored in further detail as well as exploring their deeper thoughts and feelings. Returning to the PPI group to consult on the findings was both a matter of courtesy and a means to check the interpretation of the findings, unavoidably gaining additional insights into the study problem.

The pluralistic approach was pursued into data analysis, too. All of the demographic data was obtained from the survey and allowed simple descriptive statistics to be calculated. The value of the open-ended comments section was under-rated initially but these were found to be illuminating, proving to be of considerable value in sampling and exploration of key themes during the interviews. The surveys were used to identify superficial themes which were incorporated into several concept maps which were developed as more surveys were undertaken. An emergent strategy was used when analysing the interview data. This defined the importance of never closing down to new themes emerging regardless of the number of interviews undertaken. Alongside this was the awareness that there were both collective themes shared by a number of

parents but also individual themes which may have been specific to one parent's particular experience and not necessarily experienced by any other parents.

Reflexivity

The interpretivist influence on the work was highlighted in the acceptance that there is never a single, undisputed, true telling of an experience. Each explanation represents a different perspective on the event. With this in mind, as the researcher I recognised that my own personal history and professional experiences were likely to have some bearing on the interpretation of events. Reflexivity was used throughout this study, allowing understanding of how my positioning affected the research processes. Finlay (2002) clearly suggests that a reflexive approach benefits the research process allowing appreciation of the complexities of the subject and the findings.

'Reflexivity can be defined as thoughtful, conscious, self-awareness. Reflexive analysis in research encompasses continual evaluation of subjective responses, intersubjective dynamics, and the research process itself. It involves a shift in our understanding of data collection from something objective that is accomplished through detached scrutiny of "what I know and how I know it", to recognising how we actively construct our knowledge.' (p.532)

To achieve this, I devoted time throughout the study, but particularly at times of making key decisions or coming to conclusions, to reflecting actively on my position and influence. I kept reflective notes both electronically and on paper, discussed such issues with my supervisor and colleagues (while maintaining confidentiality), and ensured that placeholders were positioned to add an account of the outcome of such reflections at points in the thesis.

SAMPLE

Target population

The target population for this research study was all parents within the UK who have a baby who has been admitted to a neonatal intensive care unit. That is, without intending to make inappropriate claims to generalisation, this was the population on which the outcomes of the study could exert an impact - even if in the longer term.

Study population

The study population for this research study, that is the population which had a real chance of being selected to participate, was mothers and fathers of babies who had been an inpatient in a level three neonatal intensive care unit between one and three weeks. The decision-making experience for both mothers and fathers is equally valid therefore it was vital that both parents had the opportunity to be recruited. The lack of studies exploring the father's experiences only strengthened the need for their participation. The decision to recruit parents between one and three weeks was made on the basis that their experience would still be very recent and their recollection of information would be accurate. It later transpired, during the discussion and interview with the parent support group, that even when many months had passed, the parental memory of their experience is still very accurate, spoken about as though it was recent.

Sample

Characteristics

Table 4: Characteristics of study population

Age	<16	16-19	20-30	31-40	>40
	0	0	11	7	0
Sex	Male		Female		
	8		10		
Employment	Employed		Unemployed		Student
	13		4		1
Religion	None	Christian	Muslim	Jewish	Other
	8	9	1	0	0
Other children	0	1	2	3	4+
	9	6	2	0	1

Number

The sample size was not established using a specific calculation but through theorising about the likely size of the study population and consideration of realistic recruitment targets for a single researcher. The sample size was achieved through consideration of admission rates within the participating NICUs. At the time of the study, the tertiary

unit's admission rates were around 1,100 a year which equates to around 20 admissions per week. The other level 3 unit had 641 admissions in 2015 which equates to 12 admissions per week. Clearly, comparison of results between the two units may be difficult with only one third of participants being recruited from the second unit, but it would be unlikely that a larger sample could be recruited in the time scale allocated. The target recruitment numbers were 100 surveys and 20 interviews. Within this 70 surveys were expected from the tertiary unit with 15 interviews, and 30 surveys from the level 3 unit with 5 interviews. At this time the tertiary unit was receiving around 1,100 admissions per year across intensive, high-dependency and special care equating to just over 20 per week. There is a possibility that the numbers may have been slightly higher than this as the unit had been running at over 100% occupancy in the few months prior to commencement of this study.

Inclusion and exclusion criteria

The aim was to include as many parents as possible in the study therefore minimising exclusion. The inclusion and exclusion criteria were as follows:

Inclusion

- Parents of babies admitted to neonatal intensive care regardless of gestation
- The carer was the legal guardian of the baby
- The baby had been an inpatient in NICU between one and three weeks.

Exclusion

- There was a negative relationship between the parents and health care professionals (e.g. court proceedings, minimal communicative relationship) – it was felt that an ongoing disagreement between parents and health care professionals may result in an unbalanced account of events.
- There had been confirmed withdrawal of intensive care treatments from the baby (not including non-escalation of intensive care treatments policies in place) so it would not be ethically appropriate to burden the parents with research at this point.

Recruitment process

Due to the researcher having no direct employment by the participating NHS trusts, the research and development (R&D) departments expressed an information governance concern, more specifically about confidentiality, regarding parents being approached directly by the researcher for recruitment purposes. Several options were considered as to how recruitment would take place. The first option was for the neonatal unit ward clerk to provide the parents with the parent information sheet and contact details of the researcher. It would then be at the parent's discretion to contact the researcher directly if they wished to participate in the study. During the patient and public involvement (PPI) event in stage 1 of the study, this option was explained to parents. The parents felt that from their experience they would have had neither the motivation nor the emotional stability to initiate such contact themselves.

The second option was for the local team to provide the parents with a parent information sheet and a 'consent to contact' form (see Appendix 1). The 'consent to contact' form allowed the parent to complete their preferred contact details and a preferred contact time which would then be returned to a designated area for the researcher to collect. During the PPI event parents agreed that this would be a more effective form of recruitment therefore it was chosen for this study. Once this form had been completed by the parent the researcher had consent to initiate contact, discuss the study in further detail and gain consent if appropriate. Both neonatal units involved in this study felt that the neonatal unit ward clerk was not the appropriate person to provide the parents with the initial information. Study packs were put together consisting of a parent information sheet (PIS) (see Appendix 2) and a consent to contact form. These were placed inside a plain A4 envelope with the participant study number written on the outside. This was clearly a less than ideal arrangement, particularly since the researcher had no permanent base or frequent presence on the unit. It emphasised an issue that had been discussed more than once during supervision: the risk of being dependent on other agencies and individuals for access to the population and recruitment.

The tertiary unit

R&D permission was granted two months and five days after a favourable opinion was granted from the Research Ethics Committee (REC). All documents requested

from the researcher by the R&D department were returned promptly, however time was taken requesting and obtaining documents and signatures from the researcher's employing trust and also from the local collaborator (LC). The LC was a consultant neonatologist. Several e-mails had to be sent and phone-calls made in order to obtain what was required for permission to be granted. This highlighted both the perceived position of the researcher as a student and a visitor to the unit, despite being a senior staff member in another unit, and the low priority assigned to the study as non-funded, non-experimental; and external to the unit staff.

The tertiary unit had an established research team consisting of three research nurses and one seconded nurse who worked part-time on the research team and part-time in clinical practice. The team members felt that they were the most appropriate people to provide the parents with the initial information. Seven other studies were taking place at the time of this research study such as PlaNet-2 and the PREVAIL trial. These included five national studies and two local (internal) studies. These studies were more clinically based. PlaNet-2 was a study designed to identify the best time to give platelet transfusions to thrombocytopenic babies. The babies were randomised through a computerised system into one of two groups, (1) transfuse when platelet count is 50 or below or (2) transfuse when platelet count is 25 or below (Stanworth et al, 2015). PREVAIL was a phase three un-blinded randomised trial examining the effectiveness and cost-effectiveness of using antimicrobial impregnated longlines (Premistars) compared with the standard longline (Premicath) for reducing bloodstream infections in neonates (Institute of Child Health, 2015). Clearly, both of these trials could be considered as being invasive for the babies involved.

The study packs were stored in the research office on the neonatal unit. This office was locked when there was no-one present. The researcher attended one meeting with all three research nurses once R&D permissions had been authorised. The study was discussed in detail. The research team was briefed of the inclusion and exclusion criteria and also given a paper copy. During this meeting, the research nurses made it clear that they had other studies which took precedence over this study, that they were especially busy, and that they were unsure as to how successful recruitment would be. One nurse felt that they did not have time at all to hand out research packs to the parents but was convinced by another that it would

not be particularly time-consuming. The research nurses assessed parents on a regular basis for eligibility. If a parent fitted the criteria, a research nurse approached them with a study pack, briefly explain the purpose of the pack then left it with them to complete and return. Once a study pack had been returned the research team would e-mail the researcher advising that a pack had been completed. It remained clear, however, that larger, well-funded, consultant-led studies were considered to be the over-riding priority. Perhaps this study was not thought to constitute “real” research, or perhaps the additional burden was not welcome (possible perfectly reasonably).

Level 3 unit

R&D permission was granted three months, three weeks and one day after a favourable opinion was granted from the REC. Again, documents requested from the researcher were sent promptly. A change in local collaborator had to be made nearly two months into the R&D process. The original local collaborator was initially slow to respond to any forms of communication and was therefore given the opportunity to step down. She refused, highlighting that she was happy to carry on with the process. Despite this communication was slow and no responses were being made to requests for documents or signatures. Ultimately the local collaborator informed the researcher she had been on long-term sick leave and had no intentions to undertake any duties until her return. A new local collaborator was therefore assigned, which was the lead research consultant, under the advice of the original local collaborator. Response to communication remained minimal despite the efforts of several research nurses and the R&D department.

An initial meeting was arranged on the neonatal unit between the researcher and the local collaborator. It was the intention of the researcher that during this meeting the local collaborator would sign the site-specific information (SSI) form which would allow R&D permissions to be granted. Despite this the local collaborator claimed she was very busy and the meeting would have to be prompt. She advised she had no intentions of signing the SSI at that time and wished to further look at the study documents and possibly suggests some changes. A further meeting was arranged, however the local collaborator cancelled due other research commitments in another city. It was then arranged for the researcher to attend a consultant meeting the following week, allowing

the opportunity to familiarise the other consultants with the study. Upon attendance, the researcher was informed by the local collaborator that the meeting had been cancelled but that she would sign the SSI form.

During this time contact was made with the Director of R&D in order to gain advice as it was felt that the non-tertiary unit might have to be withdrawn from the study. His advice was to wait one month before pursuing it further. During this time, the local collaborator signed the SSI, and R&D permissions were granted. The advice had been wise, and I spent time pondering the role of the student: how far to push for progress and compliance without alienating those who held the power to facilitate recruitment or not; and how to explain the pressure of time on my studentship in the context of pressure of work-time for the unit staff.

The non-tertiary unit also had an established research team; however, the consultant stated that their research team was not going to be involved with this study though without offering a specific reason. The local collaborator at the non-tertiary unit was also the consultant lead for the research team. She felt that the neonatal consultants would be the most appropriate people to initiate contact with the parents. The study packs were stored in the consultant office on the neonatal unit.

Once the SSI had been signed and R&D permissions granted, a further meeting was arranged to provide staff with information and awareness of the study. This meeting was undertaken on the neonatal unit in a teaching room. Documents were taken and shown to attending staff members and a poster provided which was displayed on the staff research noticeboard. The study was explained and discussed in detail with several staff members including consultants, registrars, junior doctors, nurses and student nurses. Staff questions were also answered and discussed. A site file was constructed and placed in the doctors' office along with a file containing the study packs, consent forms and surveys. During this meeting, the local collaborator decided that the registrars could also provide parents with study packs.

Selection for interview

There was no intention to polarise parental views into complete contentment and complete dissatisfaction with care since this would not relate to reality. A continuum of

views was expected, and even that some parents would be especially happy with some aspects of their experience and less satisfied with others. For this reason, a cross-section of experience was both expected and sought. The initial plan was for parents to be selected for interview based on the results of their completed survey. This would have been based on a numerical calculation (detailed on p92) but was based on the expectation of a much larger sample and the need to select a sub-sample for interview based on the limitations of time and resources. However, the folly of this was soon realised, and the invitation to be interviewed was extended to all participants. It would be better for parents to have the option rather than to be selected on a pseudo-statistical basis. This was a positive learning experience, despite the angst at the time of realisation that the strategy needed to change.

The second process was analysis of the comments written in the comments section underneath each question. Some parents simply answered the questions by ticking the Likert items and not supplying any further comments whereas others expanded in detail. Upon reading the comments expressed by the parent it was considered whether an interview would be likely to produce valuable data.

Parents were made aware that they might be contacted again after they had completed the survey to discuss their answers in further detail. Parents expressed that they were happy with this during the initial consent period.

Outcome of recruitment

Tertiary Unit

Time to recruit

It took two weeks and three days for the first participant to be recruited. Recruitment was initially very slow with a poor response rate. During the first month of recruitment 12 study packs were given to parents with only one response. The National Institute for Health Research (NIHR) has a gold standard performance indicator of the initial recruit to a study confirming consent within 70 days of R&D approval (NIHR, 2013). The first recruit to this study gave consent 69 days after R&D approval, therefore just within the gold standard guidelines. Due to the nature of this study being undertaken as part of an educational programme it was not eligible to be entered onto the NIHR Clinical Research Network Portfolio. The 70-day benchmark then became less

relevant, and no penalties would have been enforced if the target had not been met. Despite this, R&D continued to view this benchmark as a gold standard for all studies.

Recruitment issues

Although the initial target of recruiting the first participant was met, recruitment over the next three months was exceptionally poor with several barriers being met. Initially the research nurses felt that parents were not returning the packs due to their increased stress levels and their required consideration to participate in many other studies alongside this one. Once again, other in-house, consultant-led studies were prioritised to the detriment of this study. The concern was expressed that there was a problem with the initial contact phase due to only one parent returning a pack in three months despite reassurances that packs were being handing out.

Contact was made several times through e-mail and in person with a consultant neonatologist, and a suggestion made as to whether recruitment may be improved if consultants were to hand out packs on the daily ward round. This suggestion was acknowledged by the consultant and a plan made to discuss the suggestion with the other consultants who would be assisting. This suggestion was never taken any further. The consultant felt that the problem of packs being handed out but simply not returned was not something that could be improved through amendment to who handed out the initial packs.

It was then suggested by the consultant that an honorary contract was provided to the researcher to enable direct contact with the parents to gain consent, therefore eliminating the 'consent to contact' forms from the process. Again, this took time to arrange when eventually a 'student placement' contract was sent to the researcher to be signed and returned. The terms and conditions of this 'student placement' contract did not differ from those stated on the Letter of Access (LOA) obtained at the beginning of the process and therefore was not signed. At this point the R&D office was contacted to further establish the terms of the LOA and whether direct access to parents was permitted with this alone. This misunderstanding and lack of clarity was frustrating, though the need for probity in research was acknowledged. At the time of the study considerable changes had already been made to the NHS research ethics

and research governance procedures and processes, and even wider change was about to be implemented.

During this time contact was made with the research nurses requesting recruitment updates as no e-mails had been sent to state there were any further potential recruits. The research nurse advised that she was told that the consultants were now providing parents with packs, therefore indicating that they had not been having any active participation in the study. They insisted that they had been undertaking all that had been asked of them and felt that they were not required to speak to the parents once the packs had been provided to confirm agreement or declining to fill in the 'consent to contact' form. They stated again that the parents were significantly stressed and that they have other studies to consider: these being the likely reasons for the lack of recruitment. At this point they were made aware of impending educational deadlines and a face-to-face meeting was arranged.

A meeting was attended by me and one of the research nurses and we discussed the problems with recruitment. She felt that recruitment was very poor for several reasons. She expressed again that parents were very stressed and were unlikely to want to participate in a study so early on in their time on NICU (between seven and twenty-one days). She felt that due to the unit recruiting for seven studies simultaneously parents felt bombarded with studies, and she also thought that it might be unethical to ask parents on numerous occasions for their consent to participate in studies. The irony that this logic was not applied to the other seven studies was not apparently appreciated.

There were also issues regarding the research team seeming to be deciding who they felt was appropriate for the study based on their own moral values and not on the inclusion and exclusion criteria. She explained how she had identified a mother who fitted the inclusion criteria but was known to have significant mental health issues such as bipolar depression. She felt that due to this the mother should not be approached to participate in the study despite her meeting the inclusion criteria. This then raised the question as to how many other parents may have not been approached due to the personal values of the research nurses.

We discussed the need to restart recruitment and to boost numbers as soon as possible. It was felt that recruitment may be more successful if, as long as parents continued to meet the inclusion criteria, they were recruited once they had moved into the high-dependency area. The research nurse felt that the parental stress levels might have reduced by this time and that recruitment might then increase.

After the meeting had taken place I approached a nurse who leads the family-care team on the neonatal unit. She was aware of my study but asked for the protocol which I promptly emailed to her. I asked if she would like to assist with recruitment by following the parents up once a pack had been provided and they had had time to consider participation in the study. She said she would be interested in this role. The local collaborator was contacted and informed of the lack of recruitment and the action that had been taken to improve the situation. She suggested creating a notice board outside the parent's sitting room on the neonatal unit highlighting the study, as well as promoting the study through the staff newsletter. Despite interest from the family-care nurse, upon contact following our initial discussion she disclosed that she thought that it was not appropriate for her to approach parents once packs had been provided due to the number of studies in which they were being approached to participate. She advised that I discuss it further with the research team.

I devised and printed a poster (see Appendix 3) advertising the study which was put up on the neonatal unit in the breastfeeding rooms, parents' kitchen and parents' sitting room. This poster generated interest from only one parent who was not eligible to participate.

Six months into recruitment, only seven parents had consented and completed the survey and one had participated in an interview.

Level 3 unit

As with tertiary unit, the first participant gave consent within the 70-day target set by National Institute for Health Research (NIHR). Recruitment was slow initially with only two participants recruited in the first month. Various reasons for this were provided by the local collaborator such as a lack of doctors to provide packs to parents and the local collaborator having been away from the unit for several weeks. Although

recruitment was initially slow it was consistent with several 'consent to contact' forms being returned each month allowing continued recruitment.

It was noted that almost all parents that were approached returned their signed 'consent to contact' forms. The method of recruitment here was for a consultant or registrar to approach the parents with a research pack and provide them with a small amount of information about the study. The parents were then left to read the PIS and were then followed up to confirm whether or not they wished to be contacted to consider participation in the study. The following-up of parents was not explicitly communicated to the local collaborator; however, this is how they managed recruitment.

On visiting the NICU to undertake the consent process with parents it was discovered that the nurses were not aware of the study. Despite this they expressed interest and were keen to provide information on eligibility of the parents for whose baby they were responsible for providing caring. In supervision meetings I had to discuss the frustration that I felt when it seemed that every step of progress had to be retraced every time I returned to the units.

DATA COLLECTION

Patient and Public Involvement (PPI) event

PPI constitutes many things and cannot be summed up into a single definition. The phrase can be viewed in very narrow terms with many NHS trusts focussing primarily on securing and promoting involvement (House of Commons Health Committee, 2007). PPI can be used as an umbrella term for a spectrum of activity ranging from discussions with a general practitioner (GP) surrounding personal medication and treatment plans, to opinions on how services are run alongside research development, through to more complex decision-making regarding service reconfiguration and improvement (House of Commons Health Committee, 2007).

The NIHR (2014) defines PPI in research as 'an active partnership between patients and/or members of the public and researchers.' It also identifies that involvement in research is different to actively participating, allowing assistance in the development of the research process (NIHR, 2014). It is likely that although the researcher will have a

wealth of professional experience in the research area, they may not have direct personal experience. It then becomes useful in the research development process to involve people who have had actual personal experience and an understanding of what it is like to live with a particular medical condition or having experienced a specific situation (NIHR, 2014), such as being a parent of a baby in NICU. Through this, the research then becomes directly relevant to the people being studied.

In 1996 a national advisory group known as INVOLVE was set up within the UK. INVOLVE is part of, and funded by, the NIHR and is currently one of a limited number of government funded programmes throughout the world (NIHR, 2015a). Overall, the aim of INVOLVE is to 'bring together expertise, insight and experience...advancing PPI as an essential part of the process by which research is identified, prioritised, designed, conducted and disseminated' (NIHR, 2015a). INVOLVE has established six values with collaborating principles that should be used to guide PPI (NIHR, 2015b). These principles were developed following a literature review undertaken in 2013 and were intended to be used by researchers, organisations and any others involved in PPI in research. Although the six values are currently set out in the document it is identified that over time these values should evolve and develop.

The six values are: (1) respect, (2) support, (3) transparency, (4) responsiveness, (5) fairness of opportunity and (6) accountability (NIHR, 2015b). Throughout the PPI process of this study these six principles were applied. This will become evident throughout discussion of the PPI process.

In order to inform the development of the survey and advise on the recruitment process the researcher attended a parent support group for parents who have had a baby in NICU around the wider geographical area of the research study. The NIHR's (2015b) first value of respect is met through involvement of the public in the ideas stage of the research process discussing recruitment and research questions. The group was identified through the Bliss parenting group's page on the website. The group coordinator was contacted and authorised a visit to the group. Parents were prepared for the researcher's attendance and were advised of the visit date.

Throughout the process of planning the PPI approach for this study support was provided by my academic supervisor. Through this, the second value of support was met. The support gained through my academic supervisor was practical whilst organisational support was gained from the Bliss charity through their interest in my study, their understanding of the study's importance and also through support to set up and conduct the actual PPI event itself. This clearly demonstrates the Bliss charity's support not only of me but also of PPI in research as a whole.

Upon arrival at the arranged PPI event I introduced myself and advised the mothers of who I was, my background and my research intentions. I provided them with a sample of a survey I had developed and asked for their opinions and constructive advice. Whilst examining the survey we discussed their time as parents in NICU and how this research might contribute to neonatal care. This in turn allowed principle three of transparency to be met. I was open and honest about the value to me of their involvement in the design stage of the research process. I made it clear that their role was purely advisory, and I would then require no more of their time.

The main issue that the mothers wished to discuss was information-giving. They discussed parental attendance on ward rounds in length. They explained that they were especially conscious of other parents in the NICU also having sick babies, sometimes feeling that the other babies were sicker than theirs. In these cases, they felt they wanted to be updated quickly so that the doctors could move on and deal with the babies that they felt needed them more. One mother described the doctors as her 'heroes' and saw them as 'life-saving'. The parents that had been in a tertiary NICU explained that they were not allowed to be present on the ward round even for their baby. They said they were told it was because they were in a teaching hospital and the junior doctors might discuss potential outcomes that would scare them. They explained how they would wait, sometimes for an hour, to go to see their baby. They would look through the glass in the door and see the doctors talking about their baby but without knowing what they were saying. They were also given the reason of confidentiality for other babies and parents, however when I asked if this was an issue for them they all agreed that if they got to spend that extra time with their babies they would not mind other parents hearing information.

One mother discussed her experience of a time when doctors were looking at and discussing an X-ray of her baby. She remembered how they were all crowded around a screen looking at the image, but they did not include her in the conversation. Several parents talked about sometimes 'straining to hear' what was being said to try to gather pieces of information. They said they usually asked the nurse to clarify what had been said once the ward round was finished. They discussed, specifically about consultants that some days they would not even say 'hello' or make eye contact, making the parents feel excluded from discussions and feeling that they could not contribute. A few parents discussed how they would sit and think of questions they wanted to ask or things they wanted to say, but because they had not been brought into the discussion they just sat quietly. One mother said she didn't feel important enough to comment on their baby's management. She said that she always felt that her questions were 'stupid' but in hindsight she felt that they were good questions.

I showed all of the parents my sample survey. No negative comments were received. The parents felt that this survey was worthwhile completing and said they would have done so having been given the opportunity. They felt that all of the questions were appropriate, and they had nothing to add in terms of changing or adding new questions. This was still commensurate with value four of responsiveness. Although the parents did not provide any areas for development of the survey they affirmed the value of it as it was, and this was not the only matter to be discussed and improved.

Once parents had finished discussing the survey we moved on to discuss recruitment strategies. I informed them that I had been provided with two options from the R&D departments of the participating trusts. I asked which they would prefer in terms of being given the telephone number of the researcher to contact if they wished to participate in the study or being given a 'consent to contact' form to sign to allow the researcher to contact them. They were all in agreement that if they were given the responsibility to make first contact with the researcher that this would not be done. They highlighted that they were in no place emotionally to contemplate initiation of recruitment onto a study and that they simply would not call. They said, however, that they would have been happy to sign a 'consent to contact' form and for the researcher to contact them to discuss the study in more detail. Through the parental feedback it

was decided that this method of initial contact would be used, therefore meeting value four of responsiveness.

Finally, value five of fairness of opportunity was met through attendance at a parent group that was open to any parent, or grandparent, who had had a baby in NICU. There was no discrimination as to race, gender, sex or number of previous children therefore it was an equal opportunity for all.

Overall the parental comments were positive. They thought that the study was worthwhile, and several mothers expressed that they wished that they had had an opportunity like this to discuss their experiences and feelings in an impartial setting knowing that it would have no bearing on their baby's management.

Survey

Following the PPI event and completion of the literature review, a Likert scale survey was designed for stage 2 of the study. The literature review allowed gaps to be identified and the questions to be devised so as to incorporate these gaps. The PPI group provided advice on the structure and wording of the questions as well as the layout and whether it was user-friendly. The survey was designed with the aim of obtaining a superficial opinion from parents regarding their experiences of participation in decision-making.

Ten statements were developed:

- 1) I understand the reason for my baby's admission to the neonatal intensive care unit.
- 2) My understanding of the reason for my baby's admission changed as time progressed.
- 3) I felt involved in the decision-making about my baby's care.
- 4) I felt involved in daily ward rounds.
- 5) I felt that staff listened to my views and concerns.
- 6) I had adequate meetings or discussions with my named consultant.
- 7) I could suggest changes which would have improved my understanding and recollection of information given.
- 8) I felt able to ask questions about my baby's care.

- 9) I felt able to challenge information given to me about my baby's care.
- 10) I felt happy with the decisions I made, or assisted to make, regarding my baby's treatment.

There were then five available answers for the parents to choose for each question; strongly agree, agree, undecided, disagree and strongly disagree. The adoption of a 5-point scale is a common compromise between the analytical strength of a seven-point scale and increasing the likelihood of completion. Since inferential statistical analysis was never envisaged, this was an acceptable decision.

As with all methods of data collection there are advantages and disadvantages to using a Likert scale survey. The clear advantages are that they are simple for the parents to understand and respond, and they allow the option of a neutral opinion of 'undecided'. One of the disadvantages is that the responses are set and so they can lead parents to express an extreme opinion or to express no opinion at all (Gee, 2015). It could be argued, therefore, that the parent's true attitude towards the question cannot be measured. With this in mind, a free text comments section was placed underneath each question allowing the parent to express further opinion if they felt that they had something more to disclose. Despite this it was known that the survey would expose a generalised picture of parental participation in decision-making and might highlight areas which could be improved. Another advantage of undertaking the survey was that it allowed theoretical sampling to take place when selecting parents for phase three of the study: interviews.

Interview

The interview guide was developed based on the statements devised for use in the survey. The survey statements, whilst allowing expression of parental opinion (even more so with the comments section), also had limitations due to the nature of a survey. It can be difficult for a parent to express true emotion or meaning in response to a printed document, particularly if space for free-text comment is limited. The interview was designed to allow some of the parents to expand on their opinions expressed in the survey.

The interview opened with a reintroduction whilst thanking the parent for participating. The parent was then reminded that the interview would be recorded, the continued respect for confidentiality and their ability to withdraw from the interview at any time if needed. Their continued willingness to participate was confirmed and the interview was then commenced. Whilst not wanting to restrict the interview in any way, an interview guide was used to allow flow and logical structure. It also ensured that all questions were explored and that the interview was opened and closed in an appropriate manner.

The ten statements from the survey were modified to result in ten open-ended questions. Probes were used as needed.

- 1) Would you like to talk to me about the time leading up to, and the reason for admission of your baby to neonatal intensive care?
- 2) If at all, in what way did your understanding of your baby's admission to neonatal intensive care change over time?
- 3) How do you feel about your involvement in the decision-making about your baby's management?
- 4) Can you talk to me about your involvement in daily ward rounds?
- 5) To what extent did the nursing or medical staff listen to your views and concerns?
- 6) What do you think about the number of meetings or discussions that you had with your baby's named consultant?
- 7) What changes can you suggest that would have improved your understanding and recollection of the information you were given?
- 8) How did you deal with asking questions about your baby's care?

- 9) Did you at any time need to challenge the information given to you about your baby's care, and if so how did you find this?

- 10) How do you feel about the decisions that you made, or helped to make, about your baby's treatment?

Once the ten questions had been asked, the parent was questioned as to whether they had any further information that they would like to provide. When the interview came to a natural close, the parent was informed once more that the information they had provided will be incorporated into a thesis for a PhD, publications for journals and presented at conferences. They were then thanked for their time and the interview was closed.

DATA ANALYSIS

Survey

The data from the Likert scale surveys was analysed into two separate ways. Firstly, the demographic data collected from the survey was examined using descriptive analysis.

Originally it was planned to analyse the Likert items through simply calculating the numerical value from the selected answers for each question. Sullivan and Artino (2013) describes the lack of meaning when trying to establish an average when interpreting Likert scale items. It is felt that the median (the middle score of the range) or the mode (the most commonly selected answer) would provide more benefit when interpreting results. Therefore, the first stage in data analysis was planned to be a simple compilation of the number of specific answers per question. Once data analysis had begun the value of the open comments box on the survey was realised. It was then clear that the descriptive numerical data would bear little value and it was decided that data analysis would focus more upon the comments provided by the parents and their subsequent meanings. Although the descriptive data of most common answers has been provided it is vital to ensure that this data is not viewed in isolation as the results could then be misleading. The categorical demographic data and the ordinal Likert scale data was represented through the use of tables.

The answers and comments were read from each survey using one question at a time. A note was made of the Likert item answer first and then any associated comments. Significant or repeated comments across several surveys were documented under the question number. This was done for all ten questions.

Once all ten questions had been studied I moved on to look for patterns and themes within the results. Once these had been identified a concept map was created.

Interview

Once the interviews had been undertaken the audio-file was sent to the professional transcription service, OutSec, for transcription.

Upon receipt of the transcripts they were read through in a two-step process. Firstly I read the transcript briefly as a whole. Then I read through more thoroughly, paying close attention to the content. Once this was complete I began to highlight the immediately relevant information, including the way parents responded to particular questions both physically and emotionally, whilst being aware of emerging patterns and themes. Notes were made regarding themes that had previously been identified and also anything significant that had not yet been explored.

The coded information was then collaborated to allow emergence of several categories which were then further divided to create five themes; admission to NICU, staff behaviour, the process of communication and information provision, parental feelings and the awareness of their own parental role. Data was then broken down further into sub-themes under each major theme except admission to NICU which was expressed in a similar manner for all parents and required no further categorisation.

As data was collected and themes began to emerge, the information, along with the survey data was developed into several concept maps showing progression and emergence of findings. These then aided the interpretation of the data. It was a means to explain the process of developing the findings, together with a way to avoid the vague gap in many reports of how analytical thinking progressed (and also back-tracked and looped) to produce the final result.

ETHICAL ISSUES

Although the study was focused on parents rather than on their babies there were still several ethical issues that needed to be considered and attended to when developing this study.

The approach to ethical issues

There are a number of possible approaches to addressing ethical issues in a research study. The application of principles is common, usually those espoused by Beauchamp and Childers (2012) of respect for autonomy, beneficence, non-maleficence and justice. This approach lies within the realm of deontological ethical theory, assuming that there are rules which must always be obeyed whatever the context or particular circumstances of a study. A common rule, for example, is it is always wrong to tell a lie or to deceive a research participant. This approach can be problematic since following one rule can prevent the ability to follow another, and most often absolute rules simply cannot be obeyed (Johnson 2017).

An alternative approach is based in consequentialist theory and requires rational consideration of issues within context in order to guide actions such as to bring about the greatest good overall. Rather than following rules blindly, the researcher is expected to analyse the specific case, seeking to identify the risks to participants, to gauge these against potential benefits, and to make a context-specific judgement of acceptability of a course of action according to the need for benefits to outweigh risks. This approach to ethics in general is argued especially clearly in seminal works by John Harris (1985) and Khuse and Singer (2009), supported by Long and Johnson (2007) with application to health and social care research. This approach was adopted for the study.

The risk of perceived coercion

There was the risk of perceived coercion of the parents at a vulnerable time. Although there was no pressure to participate, it was possible that parents would perceive such pressure or expectation, particularly while vulnerable due to concern about their baby's health and survival. Several measures were put in place in an attempt to negate this risk. Prior to parents signing the 'consent to contact' form [Appendix 1] a clear information sheet [Appendix 2] detailing the purpose and nature of the study was

provided. This was given to potential participants by members of the clinical care team who were not involved in the study, ensuring that no pressure was placed on the parents to participate. Parents would sign and return this form to the same staff. Parents were followed up after having time to consider completion of the consent to contact form, but if they decided not to participate then the study would not be discussed any further. If the parent did sign the consent to contact form, then I would contact them and arrange to meet with them on the NICU. During that first meeting I confirmed that they were still happy to hear more information about the study before starting further conversation. If the parent was still happy to continue then I discussed the voluntary nature of their participation and their right to withdraw at any time without giving a reason and without negative consequences. I explained what their participation would entail, and how to obtain further information, and, if necessary, to express any concerns. This was done whilst the parent could visualise the consent form [Appendix R] which showed clear itemisation of elements for participant. The parent would then initial each element and print, sign and date the consent form.

The risk of breach of confidentiality

The potential for breach of confidentiality was identified. Information governance e-learning was undertaken on a yearly basis allowing knowledge to remain up to date and compliant with NHS recommendations. Confidentiality was addressed through the use of secure storage of personal and study data, and compliance with the Data Protection Act, 1998. Data was stored on university computers with password protection. Personal data (names and telephone numbers) was stored separated from study data. NHS regulations required the local PI (a clinician) to hold the register of participants for that site. When the SPOONS group was added, there was no NHS involvement, so the researcher maintained the register of participants. Hard copies of data were stored in a locked filing cabinet in a single-use office which was, in turn, always locked when not occupied. Access was restricted to the researcher and supervisor. Data was backed up by the supervisor on in personal space on a secure server as well as on non-rewritable CD stored in the same filing cabinet. The university Data Management Policy was followed. Upon provision of a study pack each parent was assigned with a participant or study number. This was used to replace personal identifiers and allowed anonymisation during the reporting and publishing process

when using direct quotations. No identifiable information was contained in reports or publications.

The risk of distress

Due to the sensitive and emotional issues being discussed there was a risk of parents becoming upset during the research process, though there was no reason to suspect that this would be as severe as distress that might be prompted by events associated with clinical care. Parents were required to express their opinions and some to discuss in detail their experiences and desires of being a parent in NICU. Even when the baby was seen to have a relatively smooth course during their stay, it was not something that had previously been planned or prepared for. The impact of this was minimised through information-provision by the researcher (an ANNP within this specialist area with extensive experience dealing with distressed parents within this context). A plan was made so that if necessary, parents could be referred to existing support services in the NICU.

The potential over-burdening of parents as research participants

One issue that was expressed particularly by senior staff of one unit was the appropriateness of approaching parents on numerous occasions asking for their participation in different studies. This deterred the research team from handing out a research pack, even if the parent met the inclusion criteria, if they knew they had already been approached about other studies previously. Upon discussion with a nurse from the family care team it was established that she was very keen to get involved with the study and to follow the parents up once they had had time to consider their participation. Despite this, during my absence she discussed this further with the research team and advised me that she no longer felt that this was appropriate. She advised me to discuss this issue further with the research team.

While this situation had to be accepted, it might be argued that the same concern was not expressed about being approached for multiple medical studies. Perhaps the non-medical, non-clinical trial nature of this study meant that it was seen as low-priority and of lesser value. Furthermore, parents were denied the opportunity to express their thoughts on an issue that other parents clearly felt to be important. Given the later findings that many parents felt that they were denied the opportunity to take part in

decision-making about their baby's care, it might be seen that they were also denied the opportunity to participate in decisions about their own well-being.

Formal approval

Approval was secured from an NHS research ethics committee and from the research and development departments of the two NHS trusts. In order to include the local parent support group, additional approval was secured from the University of Salford research ethics committee for the students' school. (Appendices X & Y)

EFFORTS TO ENHANCE RIGOUR

It has been argued that qualitative research lacks the same scientific rigour as quantitative research with poor method justification, a lack of transparency during the analysis process and ultimately that findings are simply a collection of personal opinions (Noble and Smith, 2015). Due to the lack of consensus regarding how such rigour can be applied to qualitative research it then becomes difficult, especially for the more inexperienced researcher, to demonstrate (Rolfe, 2006). In quantitative research, there are various tests and measures that can be used to demonstrate the validity and reliability of a study however it is questionable as to whether these are appropriate for use on a qualitative study and whether the terms 'validity' and 'reliability' are suitable descriptions at all. Long and Johnson (2000) apply these terms to qualitative research. They identify that validity refers to the integrity and application of the methods used and how accurately the findings are represented within the data, while reliability describes a consistent approach when analysing data. Despite this, it could be argued that as philosophical positions and approaches differ from that of quantitative studies, an entirely different framework should be used (Noble and Smith, 2015).

The purpose of adopting strategies to assess the credibility of a qualitative study is to establish the trustworthiness of the findings. Noble and Smith (2015) feel this is imperative during the research process. There were many strategies that were employed in this study although some of these were compromised in the latter part due to poor recruitment.

A mixed method approach was used to ensure representativeness of cases and in support of any generalisations. The numerical and demographic data provide purely

descriptive statistics. This allows visualisation of the overall response to the survey questions and the differences of answers between mothers and fathers.

Theoretical sampling was guided by the numerical data sourced from the surveys however it was aimed to review the sample throughout collection to ensure a representative sample was obtained.

Various tactics were used that encourage honesty from the participants. Through use of a 'consent to contact' form only parents who truly wished to take part responded. This eliminated the risk of coercion or feelings of pressure from parents to participate. During the consent process parents were made explicitly aware that they were entitled to refuse to participate or to withdraw from the study at any time without giving reason and without it having any impact on the care of them or their baby. Alongside this was my impartial relationship to the participating trusts. I was not an employee at either trust and therefore parents never saw me working clinically and then were expected to disclose information about their experiences and desires on NICU. It was made clear to them that this study was to fulfil PhD requirements and was not affiliated to the trust. They were aware that the staff were not entitled to read or hear any data until publication.

The open comments section of the surveys allowed parents free expression of their thoughts on each particular question. Interviews were audiotaped allowing me to listen closely to the parent's discussion and use probes as needed. Once interviews were completed I would listen to comments made by parents and send the audio file for digital transcription. Once the basic transcription had returned I would read through and add in parental expression and body language that I had visualised and noted during the interview. This allowed different levels of detail throughout the transcription.

Data analysis was aided through use of Nvivo software. This allowed development of concept maps and identification of themes through the use of coding. Through this, data analysis was undertaken in a systematic manner.

Frequent meetings were had with my supervisor both in person, at least once a month, and through e-mail. These meetings and discussions allowed my research visions to be widened whilst discussing alternative approaches especially due to the difficulties

faced with recruitment. These discussions allowed me to consider my own biases and perceptions regarding the research process especially being new to research. Various tools were used, such as a white board and photographs, to allow effective reflection and discussion which in turn promoted productive academic progress.

Throughout the process I have been required to undertake compulsory university assessment, which included outside scrutiny. The initial assessment required a 4,000-word report which identified a basic outline of the study, current progress and a plan for future deadlines. The second assessment demanded a 40,000-word report which was compiled of around half of my completed thesis. These chapters allowed discussion of the effectiveness of the methods used, recruitment issues and initial impressions of data collection with emerging themes and theories. Through this discussion with other academics that are impartial to my research, a fresh view was expressed and allowed continued development of thought towards the research process and my emerging data.

My personal background as a mother of four young boys and my professional background as a neonatal nurse for fourteen years and an ANNP for seven years all provide me with personal credibility but also with biases. This awareness allows continuous consideration to maintain an open mind whilst having a good understanding of the functioning of neonatal units and the challenges parents face.

CHAPTER FIVE: SURVEY FINDINGS

Although only a total of 21 parents were recruited to complete the survey, the open comments section ensured that the data obtained was very rich, and this contributed significantly to the initial construction of the interview guide. Pseudonyms have been used to protect the identity of the parents. Whilst themes have been identified, the importance of not closing analysis down prematurely was recognised. Throughout data collection and analysis, the aim was not to fit subsequent data into current themes but to remain open and to allow new themes to emerge as data collection increased. Miles et al (2014) have highlighted the importance of continuing past the preliminary data analysis. This allows better quality data analysis with a deeper meaning. This iteration and development of understanding has been represented in this study through the use of concept maps (pp.104-111) which clearly identify the progression of the data analysis.

In this chapter, the demographic characteristics of the participant are detailed, then the survey data is presented using descriptive statistics. The free text responses from the survey are then explored separately following thematic contents analysis using an inductive approach.

PARTICIPANT DEMOGRAPHIC CHARACTERISTICS

Thirty-nine parents from two participating NHS trusts returned their 'consent to contact' form and were approached by the researcher through their specified preferred method of contact, either telephone or e-mail. Twenty-six parents consented to complete a survey and a subsequent interview, if required, but five did not return their survey. Eleven parents did not respond to contact after two telephone calls and/or two e-mails. Two parents responded but did not consent to participate stating that they were '*too busy*'. Mothers and fathers to the same baby completed their surveys separately. All 21 participants completed the five specified demographic details stated on the survey of age, sex, occupation, religion and number of other children.

Ten of the participants were recruited from the tertiary unit and eleven from the level 3 unit. Eight of the parents were aged between 21 and 27 years old, 12 parents were aged between 30 and 39 years old and one was aged 42. The mean age of the study

participants was 29.9 years. Eight of the participants were male and 13 were female. Nine of the participants identified themselves as having no religion; ten participants were Christian, one Muslim and one Hindu. Occupations were grouped into six categories: unemployed, managers, skilled (e.g. electrical engineer), unskilled (clerk), student and HM Forces. Four of the participants were unemployed, four were managers, four were skilled workers, seven were unskilled workers, one was a student, and one was employed by HM Forces.

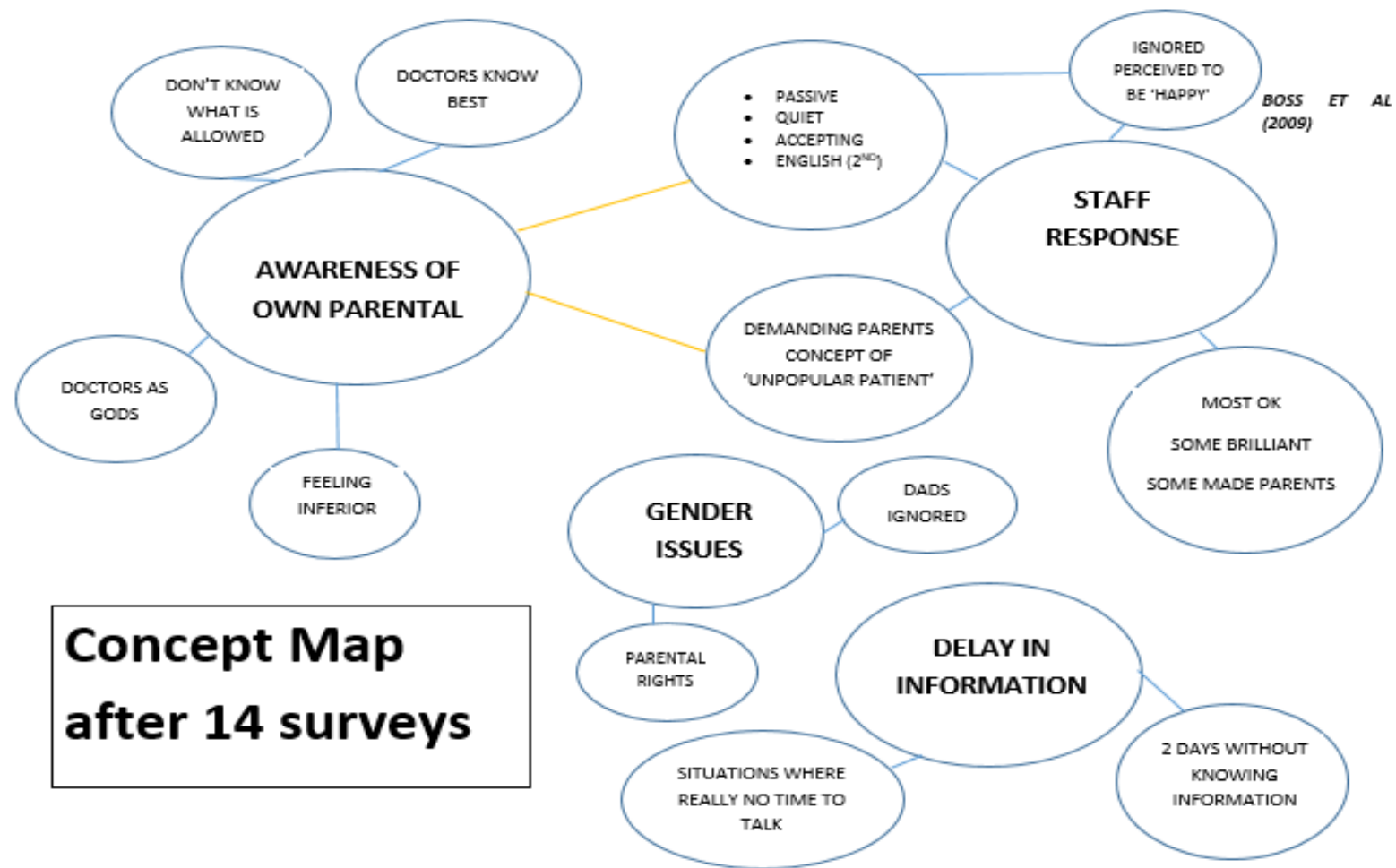


Figure 2: Concept map after 14 surveys

The concept maps were developed as part of framework analysis. The initial map (see Figure 2) was created after 14 surveys had been completed and submitted. The initial major themes that were identified were awareness of own parental role, staff response, gender issues and delay in information. At this stage the development and meaning of these themes was very primitive and it was clear that more in depth information was required in order to establish a meaning and identify the true parental experience.

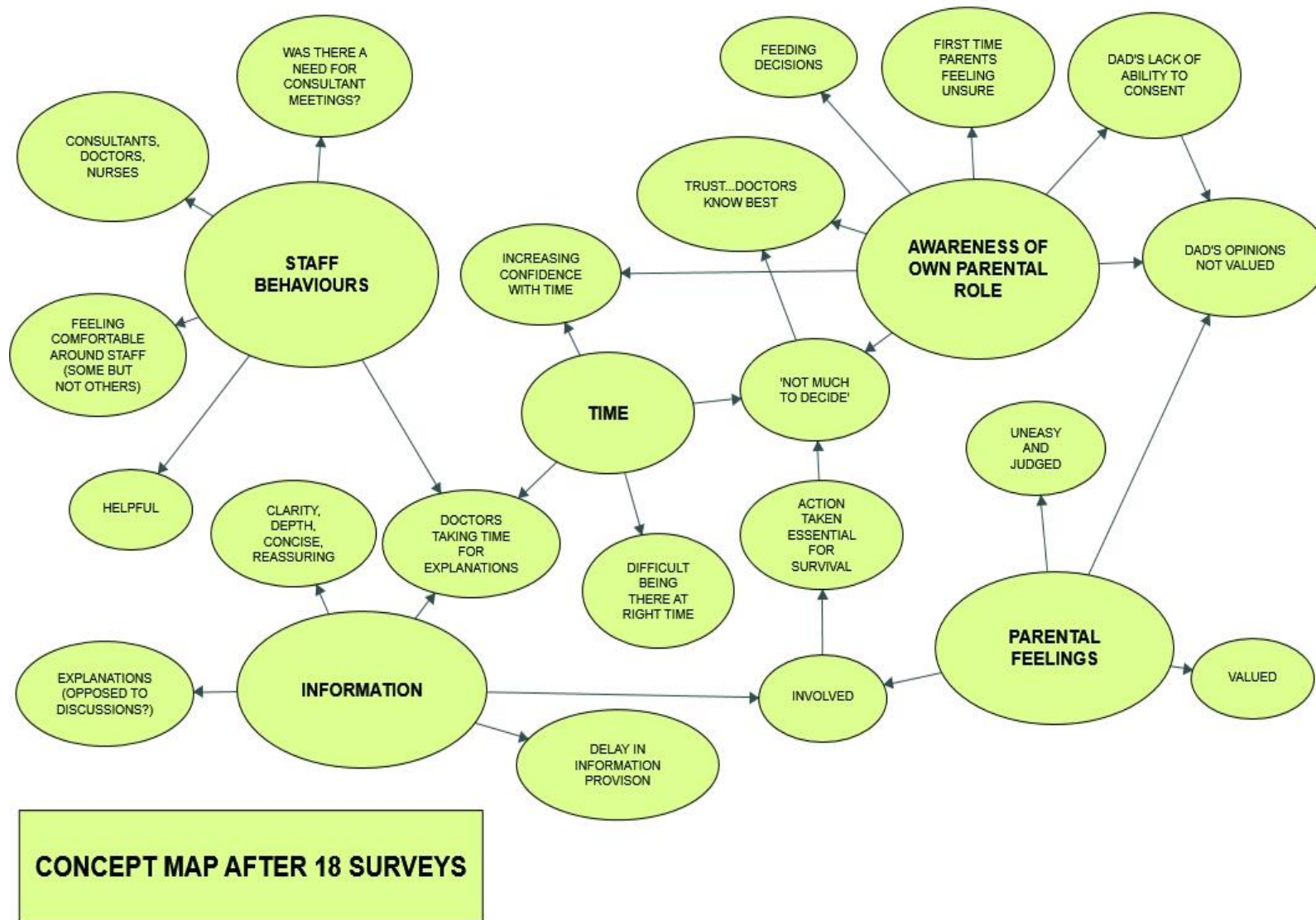


Figure 3: Concept map after 18 surveys

A second concept map was developed after a further four surveys were completed. During this stage the major theme of gender issues was found to be personal to only one father and was not an issue that continued to be relevant to other fathers. This theme was therefore incorporated into parental feelings whilst developing a new theme of time. Staff response from the previous map developed into staff behaviour as it was found not only to be communication issues but also the actions of staff. It is clear from this map that as the amount of data was increasing as was the development and understanding of the parental issues and experiences. Despite this, it is still clear at this stage that there is no definitive understanding and that ideas are still developing and changing.

The third map incorporated data from two interviews as well as the survey data. This allowed a deeper understanding of the issues already highlighted whilst also allowing emergence of any new ideas. This is visually demonstrated through the use of colour coding and shapes. Red shows the major identified themes. Again, as with the previous maps, although development and understanding of data was demonstrated through the map and many of the issues were still interlinking, specific findings were beginning to emerge such as disempowerment and the specific significance of the daily ward round. The application of transactional analysis as a means to explain the findings was identified in this map.

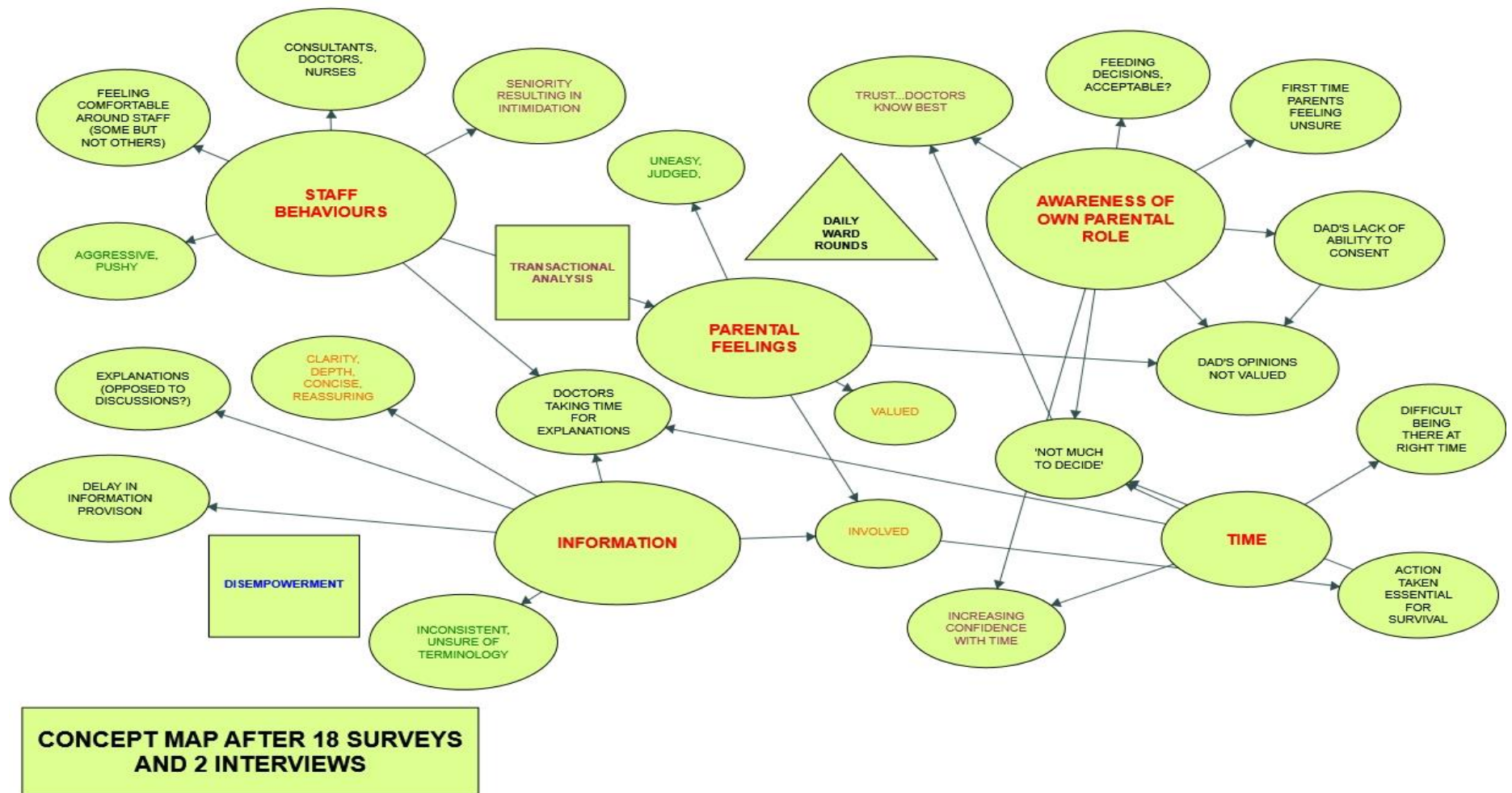


Figure 4: Concept map after 18 surveys and 2 interviews

SURVEY DATA

Twenty-one parents completed the survey. Table 5 shows that all parents clearly expressed their awareness of the reason for their baby's admission to NICU. Only two mothers stated 'Agree' rather than 'Strongly Agree'.

Table 5: Qu1: I understand the reason for my baby's admission to the NICU.

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
	n	n	n	n	n
Male (n=8)	8	-	-	-	-
Female (n=13)	11	2	-	-	-

Table 6 identifies parental understanding of the reason why their baby was admitted to NICU and whether that understanding changed over time. Responses were divided with an overall 13 parents selecting either 'Strongly Agree' or 'Agree' that their understanding changed over time and 8 of parents expressing either 'Disagree' or 'Strongly Disagree'. When exploring these results in collaboration with the other survey answers it is questionable as to how this question was interpreted by parents. The majority claimed that their understanding changed over time, but they also suggested that they were consistently updated and fully aware of their baby's progress.

Table 6: Qu2: My understanding for my baby's admission changed as time progressed

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
	n	n	n	n	n
Male (n=8)	5	1	-	1	1
Female (n=13)	6	1	-	3	3

Table 7 shows that although the majority of parents felt that they were involved in decision-making regarding their baby's care, two mothers and one father were undecided, and one mother and one father did not feel involved. The two parents that did not feel involved at all were a couple.

Table 7: Qu3: I felt involved in decision-making regarding my baby's care

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
	n	n	n	n	n
Male (n=8)	4	2	1	-	1
Female (n=13)	3	7	2	1	-

Table 8 indicates that just over one third of parents (n=8) were either undecided or did not agree that they felt involved in daily ward rounds, with over half of those parents (n=6) being mothers.

Table 8: Qu4: I felt involved in the daily ward rounds

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
	n	n	n	n	n
Male (n=8)	4	2	1	-	1
Female (n=13)	3	4	5	1	-

It can be seen from Table 9 that the majority of parents (n=19) felt that staff listened to their views and concerns, however three were undecided and one parent expressed 'Strongly Disagree.'

Table 9: Qu5: I felt staff listened to my views and concerns

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
	n	n	n	n	n
Male (n=8)	6	-	1	-	1
Female (n=13)	8	3	2	-	-

Table 10 shows that overall, slightly less than two thirds of parents were happy with the number of meetings or amount of discussions that they had with their named consultant. One third of parents selected 'Undecided', 'Disagree' or 'Strongly Disagree' with no difference in proportion between mothers and fathers.

Table 10: Qu6: I had adequate meetings or discussions with my named consultant

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
	n	n	n	n	n
Male (n=8)	1	4	1	2	-
Female (n=13)	2	6	4	-	1

The details in Table 11 demonstrate that only five parents felt they could make recommendations for changes which would improve their understanding and recollection of information. Slightly more parents (n=8) were 'Undecided' and a further eight did not feel they could make any recommendations. Upon reflection it could be suggested that this question was open to interpretation by the parents. It does not allow a clear interpretation of whether the parents were able to confidently make recommendations, were unsure and or not wishing to make any recommendations. It could be that the issue was not that the parents felt unable to make recommendations only that they had no recommendations to make.

Table 11: Qu7: I could suggest changes which would have improved my understanding and recollection of information given

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
	n	n	n	n	n
Male (n=8)	-	1	2	2	3
Female (n=13)	1	3	6	1	2

It is clear from Table 12 that all parents except one, who was 'Undecided' felt that they could ask questions about their baby's care.

Table 12: Qu8: I felt able to ask questions about my baby's care

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
	n	n	n	n	n
Male (n=8)	5	2	1	-	-
Female (n=13)	7	6	-	-	-

Table 13 shows that half of parents (n=11) felt they were able to challenge information about their baby’s care however, equally, ten parents were either ‘Undecided’ or did not feel that they could challenge information. When exploring the half of the parents that felt they could challenge care, they indicated in the open comments section that they had not actually come across the need to challenge information and therefore these are hypothetical answers. If a parent were in the position where they needed to challenge care their answer may have been different.

Table 13: Qu9: I felt able to challenge information provided to me about my baby's care

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
	n	n	n	n	n
Male (n=8)	2	2	3	-	1
Female (n=13)	2	5	5	1	-

Almost all of the parents (n=17) felt happy with the decisions they made and no parents were unhappy (Table 14). Two mothers and two fathers were ‘Undecided’ about their treatment decisions. This answer was contradictory to the other answers expressed in the surveys. At times parents disclosed that they felt that there were no real decisions to make or that they hadn’t made any decisions. Despite this, they still answered that they were happy with the number of decisions that they made for their baby: effectively, none.

Table 14: Qu10: I felt happy with the decisions that I made, or assisted to make, regarding my baby’s treatment

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
	n	n	n	n	n
Male (n=8)	2	4	2	-	-
Female (n=13)	6	5	2	-	-

SURVEY COMMENTS

Only four of the 21 parents did not provide any comments on their surveys. The remaining 17 parents all provided comments on between one and ten questions. The average number of comments per survey was four.

Four themes were identified. The impact of staff behaviour on parents; provision of information; the impact of time; and awareness of own parental role. Throughout the reporting of these themes the impact of the findings on parental feelings can be appreciated.

Staff behaviours

Both positive and negative experiences were had with parents expressing particular concern over their involvement with nurses in a general context and doctors when reflecting upon their attendance on the daily ward round. A clear inconsistency of staff behaviour was identified, not only towards different parents but also on a day-to-day basis. Some parents had only positive experiences and were completely happy. Some had only negative experiences, whilst others were clear that the way they behaved and felt was based upon which particular members of staff were caring for them on a particular day.

Ten parents commented on staff behaviour in general. Five expressed positive comments towards staff behaviour. Two parents described nurses as being especially helpful particularly with updating parents and helping them to understand information.

Oliver: *'The staff always listened to our views'*

Lucas: *'Staff have been incredible...'*

Five parents commented on the inconsistencies of staff behaviour. One mother felt *'more at ease and comfortable with certain staff members than others'* - with this affecting many areas of her neonatal experience such as her ability to challenge information, her involvement in daily ward rounds and her ability to ask questions.

All of these parents identified the daily ward round as a particular time for these inconsistencies.

Liam: *'Doctor dependant' [on who was conducting the ward round].*

Isabelle: *'Some nurses involve us, and some don't.'*

This then led to parents feeling 'undecided' regarding their confidence that staff would listen to their concerns, and in their ability to ask questions and to challenge information.

Elijah: *'Some staff put me off asking them questions although these were in the minority.'*

Elijah: *'Most staff were great, but a couple seemed a bit 'pushy' and we felt a little uneasy when they were around.'*

Ella: *'Some staff were easier to ask questions than others.'*

Elizabeth: *'Sometimes I felt very involved and valued by staff and other times I felt as though they didn't see why we wanted to be there.'*

Provision of information

It was clear that information was provided to parents by both nurses and doctors. It was often expressed that nurses and doctors '*explained*' information regarding reasons for admission and also the baby's progress however the term 'discussed' was never used. All parents were completely clear about the reason for admission of their baby to NICU. Parents seemed content with the explanations as expressed here.

Ella: *'It was very clearly explained at admission.'*

Chloe: *'I understood everything I was told.'*

Oliver: *'The consultants explained my baby's condition in depth and the course of action required to repair the defect.'*

Positive terms were used to describe the quality of the information provided such as *'informative and reassuring'*, *'clear and concise'* and *'in-depth.'* One mother conveyed how information provision had been tailored to her needs: -

'Explained in more depth as I understood more about NICU' (Ava)

Only eight parents commented on their experience of meeting with their named consultant. Seven of these parents highlight a lack of one to one meetings.

Zoe: *'Not sure who my named consultant is.'*

Charlotte: *'Not met with our named consultant, spoke only once on the telephone in five months.'*

Lucas: *'I have only seen her twice.'*

Elijah: *'Consultant usually too busy. Not their fault I'm sure.'*

Liam: *'Believe we only met once, but unsure.'*

Despite this, the lack of meetings was not expressed as a particularly worrying issue for parents. Eleven of the remaining parents were happy with their meetings and two were undecided but without making further comment. Comments revealed that in circumstances where parents were not being visited by their named consultant, other consultants were updating and discussing treatment plans.

As well as inconsistencies in staff behaviour, inconsistent attendance at daily ward rounds was expressed. The survey data identified that many parents were happy with their involvement in the daily ward round however, other parents stated that they were not allowed to attend or that this was difficult. Despite one mother stating that she was

not allowed to attend the daily ward round, she still agreed that she was happy with her involvement.

Charlotte: *'Certain times you were [involved in daily ward rounds], but in intensive care you weren't present most of the time.'*

Zoe: *'I've not always been present at ward rounds.'*

Abigail: *'Parents aren't present during the ward rounds but always kept up to date afterwards.'*

Oliver: *'Consultants, doctors and nurses have always taken the time to answer our questions.'*

Time

Several different issues were declared that related to time. One mother experienced difficulty in trying to attend the daily ward round at the correct time. There were occasions when she was able to attend, and this was found to be helpful. Timing of information was a factor for several parents. One father was not provided with the full details of his baby's condition and management until two days after the birth. From a more positive stance, a link was identified between the length of time spent in NICU and a parent's growing confidence.

Oliver: *'The longer my baby has been here, the more confident I've become to challenge information.'*

Lucas: *'Care is changing to more self-reliant.'*

This father alluded to an early level of dependence on neonatal staff. His growing self-confidence is displayed through his awareness of his changing role as a father and his abilities to provide more independent care to his baby.

Awareness of own parental role

Parents expressed comments of a relatively passive nature suggesting the overall control of the doctors.

Lucas: *'I trust in the professionals to make an informed decision on our behalf'*

Leah: *'I am not medically trained therefore I put my trust in doctors'*

Alongside this concept of the doctors having the best knowledge to make the right decision for their baby, parents also justified their lack of decision-making by stating that the decisions made, and actions taken were out of their control as they were essential for their baby to survive.

Abigail: *'The surgery was needed for the babies to survive'*.

Elizabeth: *'There wasn't much I could decide initially as her care she received was paramount in order to recover.'*

Despite this there was allusion towards their knowledge of parental responsibilities. One mother expressed a desire to be more involved in her baby's care. She did not feel involved stating *'some nurses involve us, and some don't...they hardly ask for our consent to do things.'* She was also concerned that when something was wrong with her baby the staff took a long time to inform her. Conversely, some other parents expressed lack of awareness of their ability to be involved.

Sophia: *'There wasn't much to decide.'*

Aidan: *'90% of decisions were talked about, the other 10% had to happen.'*

Zoe: *'I didn't know we could make decisions about my baby's care whilst he is here.'*

One father was aware of his limitations although expressing his disapproval in an accusatory manner *'Dads are not allowed to sign any consent forms unless married.'* It was clear from his comments that he felt gender issues were involved. This comment

shows a lack of understanding of parental responsibility. If the baby had been registered with him as the father on the birth certificate he would then be entitled to consent for his baby. It is unclear as to whether he had expressed his concerns to neonatal staff in which case he may have been more accurately informed regarding his parental responsibilities and may have felt more involved in his baby's care. No other father commented on gender discrimination.

The majority of parents (n=11) agreed that they felt able to challenge the information provided to them about their baby's care. One father felt that time was needed to allow parents to feel this way. For him, as time progressed, so did his confidence in feeling he could challenge information if required. One father did not agree, feeling that he could not challenge the information as *'the staff do not value the dad's opinions*

CHAPTER SIX: INTERVIEW FINDINGS

SAMPLE AND DEMOGRAPHICS

Five parents who had completed a survey then went on to participate in a one-to-one interview. The remaining parents were recruited from the local parent support group.

One interview was undertaken with a first-time father in his own home with his wife and new baby present. The other interviews conducted in neonatal units were with three first-time mothers and with one mother who already had one other child. These were all held in a quiet, private room on the neonatal unit. Two of the babies had been discharged home at the time of the interviews, the others remained as inpatients. The interview with the mothers from the local parent support group was held at their usual place of meeting. All of their children were present and playing during the interview. All five of the mothers were first-time mothers, with one being a mother of premature twins, and their experience on NICU was new.

Following the one to one interviews, a group interview was undertaken with five mothers at the local support group which was used for the PPI session to originally inform development of the survey. For the purposes of confidentiality these parents will be identified under the pseudonyms Claire, Sandy, Louise, Marie and Nanditha. These parents all had had their babies discharged from NICU up to 18 months prior to the interview. They recollected their experiences very promptly and with great detail, highlighting that it was unlikely that they had forgotten details occurring in an experience that had clearly had an impact on their lives. This data supported the data collated from the one to one interviews with parents currently in NICU and has been incorporated into this section.

The interview findings are structured to begin with responses about the initial reasons for the babies' admissions to the NICU; followed by issues of staff behaviour; and then the process of communication and information provision. Parental emotions are considered next; and awareness of their own parental role forms the final theme. Throughout, pseudonyms are used to indicate the protected identities of the participants.

ADMISSION TO NICU

The parents whose babies were still in NICU or had recently been discharged began by recalling their experience of the birth of their babies and the progression to admission to the NICU.

Elijah: *'The health care assistant was winding him, and he started [having seizures]. I was staying because my wife had some issues. She called the emergency unit. He went into resus. The Resuscitaire was there on the post-natal ward. They woke me up. He was still seizing, and they rushed him to the neonatal unit. I think they gave him emergency medicine and put him into an incubator. I think he had acidosis then. His oxygen saturations were very low. Yeah, that's when we first went to the neonatal unit.'*

Ella: *'He had been in distress and his oxygen levels were low... because it was something like four and a half hours from my waters breaking to him being born. It just turned into an almighty hurry. So, they knew they had to get him on the oxygen. They got the oxygen on him but as soon as they took the mask off, obviously they knew something was wrong because he couldn't breathe properly. So, he was whizzed off down the back corridor and admitted to the NICU.'*

Charlotte: *'They were admitted to intensive care because they were born premature. They were born at 24 weeks and 2 days.'*

Beth: *'I experienced a little bit of bleeding at 24 weeks and 3 days and they told me to come in, and pain, and on the way to the hospital my waters broke. So, they monitored me, I got an infection, so they induced me.'*

Hayley: *'I was in hospital for three weeks prior to my baby being born. He was actually a twin, but we lost the other twin. Obviously, we knew he was going to neonatal because he was so early.'*

Sandy: *'I was only in labour for 15 minutes; I didn't really have time to come to terms with the fact that he was going to be born early. He was just here and that's that.'*

The parents seemed to have no difficulty in recalling their baby's admission, and the father gave a detailed account. Their understanding of the reasons for admission did not change throughout their stay, however problems associated with each baby's medical or surgical conditions occurred which left the parents with new information to process and understand.

Three of the babies were extremely premature so the parents were fully aware of the need for admission to NICU. The other two babies were born at full-term and had conditions that were not diagnosed prior to delivery. Although the father clearly understood that his baby was having seizures, he made it clear that no-one understood why this was happening. It was somewhat similar for one mother whose baby was not diagnosed in the antenatal period so although the doctors considered several differential diagnoses (possible causes of the signs of disease), they could not immediately say what was wrong with her baby. This then posed the challenge for the parents that they understood that something was wrong with their baby and that the need for admission was imperative, however the exact reason was not known immediately.

Researcher: *'So you understood your baby's reason for admission to be seizures?'*

Elijah: *'Well at that point, yeah. They did an ultrasound and initial tests. They said he had some brain swelling indicating low oxygen levels. They said it might be a one-off seizure...it was very unclear at that point. They were taking loads of blood to rule out infection. They were giving him antibiotics in case he had an infection.'*

Researcher: *'So they gave you a few reasons why the seizure could have occurred?'*

Elijah: *'Yeah. But it was very early days and they said they didn't know.'*

Ella: *'I don't know whether they [the doctors] had an idea [about his diagnosis] in the delivery room but I was losing quite a lot of blood and things, so they weren't going to try and have a conversation.'*

Once the reasons for admission to NICU had been established with the current neonatal parents, the interview moved on to discuss the questions asked in the survey in more detail, or, in the case of the later local parent support group interview, to pursue both personal experiences and reflections on emerging theoretical understanding of the research problem. Despite the difference in experience, all but one of the parents who completed the survey discussed all of the themes identified in the survey findings. Not all of the parents had an overall negative experience, but there were negative aspects to all of their neonatal journeys. One of the interviews highlighted an overall positive experience. This mother, Beth, was a first-time mother and her interview highlights a particularly passive response. In all aspects of the interview she appeared to be especially grateful for her baby to have received care in NICU and therefore simply accepted the clinical situation at face value. Wigert et al (2013) also identified that parents expressed a level of satisfaction that did not correlate with corresponding free-text answers in a survey. This was explained through the perceived need of parents to evaluate NICU in positive terms because they were generally grateful for the care their baby had received.

STAFF BEHAVIOUR

A good professional relationship between parents and staff should be paramount for many reasons. 'Effective staff-family interactions enable parents to be the best advocates for their baby, to attach and bond with their baby, to make informed decisions about their baby's treatment, and to feel comfortable, respected and valued in the NICU environment' (McGann, 2010). Fegran and Helseth (2009) claim that the quality of the nurse parent relationship has a clear bearing on parent's overall experience whilst in NICU.

Despite this it was found in this study that staff behaviour was experienced inconsistently between parents. From the current neonatal parents, two had wholly

negative experiences, one had a completely positive experience, one did not comment on staff behaviour and one had a mixed experience. The parents of the local parent support group had similarly mixed experiences, with one having a good experience, one having a negative experience and the other three being mixed.

Negative behaviours

Two identified negative behaviours were identified in both doctors and nurses. These were the demonstration of a poor attitude towards parents and a general display of disregard not only parents but also for each other as colleagues. Although seldom mentioned by participants, Wigert et al (2013) described a lack of professionalism from staff, with descriptions behaviour that indicated incompetent, rude and stressed staff.

Poor attitude

Elijah: *'Some of the nurses were pushy. Some of the nurses, not all, only one or two were having a bad day. Like anywhere you've got good and bad workers, or, yeah, good or bad people.'*

Elijah: *'Some of them were quite confrontational. I do remember a couple of incidents where I had come to find her [my wife] being told off for things she was doing. So, for example, we were told, and this was in the leaflet, that expressed breast milk (EBM) is OK at room temperature for four hours. So, say she [my wife] had just fed him, and he had another feed in two hours, she expressed, and I would say keep that [EBM] out. I came and found her [my wife] being told off. The nurse saying, 'why the hell is that out?' The way she came across, the way she said it.'*

Researcher: *'Was she aggressive?'*

Elijah: *'Very. I was shaking [tightly grasping the paper he was holding]. Obviously, we are in a very stressful situation there. I started shaking because she came over very aggressive. I said 'No, it's not four hours yet' and she said 'No, no, what are you talking about?' I don't know the exact words, but she came across like we were doing something unsafe for our baby.'*

Louise: *'I remember being shouted at royally for putting my hands in the incubator.'*

It has been suggested that nurses can exhibit an authoritarian manner at the cot-side resulting in increased vulnerability in parents (Reid et al, 2007; Jones et al, 2007). Unfortunately, several parents identified times where they were shouted at or spoke to in an aggressive manner. It could be hypothesised that some of this behaviour may be attributed to occupational stress. The causes of occupational stress in nurses is well documented (Happell et al, 2013; Glazer and Gyurak, 2008; Mark and Smith, 2012). One of these documented causes of stress is high workload. As discussed earlier in this thesis, inadequate skill mix, shortages of staff, too many patients, using specialised equipment, patient acuity and missing breaks are all reasons attributed to occupational stress (Happell et al, 2013).

One mother commented specifically on the way a senior nurse conducted herself.

Ella: *'The senior nurse who was doing the ward round was checking some information with us, but she used slightly different terms to what they had used in the NICU and that was a little bit confusing. Some people are a little bit more intimidating.'*

She highlighted a sense of intimidation that promoted disempowerment and a feeling of inferiority.

Respect

There were several occasions where parents experienced a sense of general disregard in that the staff would promise to do something but then neglect to do so.

Elijah: *'They wanted to do the observations. He cried himself to sleep, missed a feed or two, tired for his feed and is struggling from his issues and battered from the seizures. That was like bloody hell! We understand the nurses are busy and things come up. She kept saying 'I'm coming, I'm coming'. I said, 'I know*

you guys are understaffed' and she said, 'No. No, we're not understaffed.' OK so why is this happening regularly and affecting him?'

Hayley: *'I'd say 'Are they doing the ward round? Have they seen my baby yet?' They say 'No, they haven't. We will come and get you' but they didn't. It would only be if I was walking past at the right time or if I stood right outside the room.'*

Hayley: *'This morning, the doctor was sat there. Now he's gone without even speaking to me.'*

This could be identified as a lack of respect for the parents not only as a parent but also as a partner in their baby's care. A strong parental need for respect has been established with extra stress being experienced when this is neglected (Fegran and Helseth, 2009).

Hayley: *'I happened to speak to a doctor that was walking past who turned it [oxygen] down, and then the nurse comes along and says 'Oh' and whacks it [oxygen] back up again and said, 'I don't know what he's doing!' and that was it.'*

There was also a sense of disregard between colleagues. One mother was concerned that her baby's oxygen saturations were high, and the oxygen needed to be turned down. She explained how she relayed her concern to a passing doctor who reduced the oxygen. Moments later the nurse returned and increased it again suggesting that the doctor did not know what he was doing.

Positive behaviours

Although it was mentioned with only minimal detail, there was clear expression of times when positive behaviours were experienced - usually when emotional support was being provided.

Ella: *'Yes, so the nurses that were with him were really helpful with that [listening to parent's concern]. Actually, they were brilliant with the*

breastfeeding, so he was fully breastfed by the time I got him home 15 days post-surgery. That was entirely because of the staff being really helpful.'

Ella: *'So, we felt very able to ask [questions]. If the nurse who was with him couldn't answer it, they were really good at ... like they always wrote it down. You know if someone writes down your question you know it's not just likely to be never seen again. We always got information back, even if she [the nurse] doesn't answer straight away. They were really good at getting back to us.'*

Charlotte: *'They have always been very nice with me. Always listening to my problems, especially in the first weeks where I couldn't talk about anything, just crying all of the time. They spent time with me chatting and reassuring me. They were professional but at the same time very sympathetic.'*

Sandy: *'It depended what nurse was on [shift] and how much they wanted you to get involved. One nurse said 'Oh, do you want to feed him?' when he was still tube-fed, and I said 'Pardon! What do you mean?' She said, 'We can show you how to do it.' I was just worried. What if I break him? [laughs].*

Louise: *'The staff are amazing, they really are. I had a really positive experience. But they are just so busy. With all of the things that are going on and you see how pulled they [nurses] are in what they are doing. They were busy, and they just got on with it that's why I didn't bring it [problems] up because I probably thought about how busy they are.'*

The positive emotional support was found to be received from the nurses rather than from the doctors as also found in a survey-based study by Wigert et al (2013). The most common term used to describe was "helpfulness". As found in the Bliss National Survey (Howell and Graham, 2011) parents reacted most positively to their involvement in providing care as opposed to their involvement in actual decision-making.

Staff preferences

Parents have been found to adapt their communication dependent upon particular staff member's personalities and communication skills (Wigert et al, 2014). Parents in this study described how they would prefer certain staff over others based on how they behaved clearly displaying a change in communicative behaviours. This was directed at nurses more than doctors.

Hayley: *'There are certain ones [nurses] that you wouldn't say anything to, and you know which ones they are. But it shouldn't be like that.'*

Elijah: *'I remember getting quite worried in terms of who was going to look after him next, which nurse, [thinking] we hope it's not going to be that one or "Crikey! It's that one". One of the [other] parents said, 'go down to the PALS (Patient Advice and Liaison Service) and tell them you want a named nurse'. But then we felt like we didn't want to kick off. Because then the next nurse after would be fine.'*

Sandy: *'I found you'd get there in the morning and find out who your nurse was, and you'd know if you'd have a good day or a bad day.'*

Three comments were made regarding parental preferences for the general age of the nurse, whether that is older or younger. Despite this, the comments were contradictory to each other and therefore are possibly coincidental and more likely down to personal preference.

Elijah: *'We would be, like, we don't want the younger ones, we want the older nurses. They seemed to be better. They seemed to be easier-going in terms of listening to what you said. It's the way they came across. They would be more open to discussing. Even though they are busy, you can see that they are trying.'*

Hayley: *'It's always the old-school ones that you're more reluctant to ask. I think that's probably the way they have been trained in the manner of 'we do what we*

do and not what the parents tell us to'. Whereas the new ones are more responsive to it.

Louise: *'You just hoped that the older ones [nurses] would be actually easy but sometimes it could be the opposite. They weren't as willing for you to do things, the older ones.'*

When exploring the concept of staff behaviour, the inconsistencies in attitude and communication were evident, and the parents were acutely aware of this. Latour et al (2010) suggests that although it is known that good staff-parent relationships and parental involvement in care are beneficial for parents, it seems that these practices are not consistently applied and that neonatal nurses may not routinely work to these expectations. NICE (2010) quality statement 5 makes evident the requirements to encourage parental involvement in their baby's care. Quality statement 5 provides expectations of neonatal units to provide evidence that this quality statement is being achieved through evidence of local arrangements to involve parents in decision-making, local audit showing parental involvement in providing care for their baby and regular surveys of parental experience. These actions in turn should then allow parents to be actively encouraged and supported in decision-making and providing care for their baby whilst also allowing neonatal services to be reviewed and improved.

It is unclear as to why this should be so, yet parents in this study attempted to rationalise poor behaviour through the distinct reality of how busy the staff were. Again, parents were acutely aware that there was too much work and insufficient staff. Despite this, some parents felt that the staff somehow managed to remain helpful, and they could identify readily the staff that they liked and with whom they felt comfortable. It is concerning that some staff members were not approachable to parents and this exerted an impact on their ability to be involved in decision-making about their baby's care.

PROVISION OF INFORMATION AND COMMUNICATION

Daily ward rounds

The daily ward round should be a pinnacle time for communication and exchange of information between parents and health care professionals. Although parents were allowed to attend the ward round for their own baby, difficulty was found in doing so. The presence of other parents was not a concern for the participants in this study, and spending time with their baby outweighed the perceived need for confidentiality. Many issues were highlighted such as parental presence, waiting, and use of terminology. All parents identified problems with the daily ward rounds.

Parental presence

Ella: *'We didn't get to see the doctors very often. I think the thing that we found the most difficult was getting involved in the ward rounds because we only live just a mile away, so we were living at home and coming in. You can be there for your own baby's ward rounds but not when they're dealing with the other babies. That means getting through rush hour traffic and then possibly just spending two and a half hours just sitting here waiting for someone to say 'OK. You can come in for ten minutes'.*

Charlotte: *'In intensive care I was just outside waiting because you are not allowed to stay in the room during the ward round, but they would call me if I was outside the room, just for my baby's review.'*

Beth: *'You're not allowed to come to the ward rounds, but you can for your own baby. That was very difficult because you were hanging around. You came and hung around, which is most frustrating when you can't be with your baby. It was very, very difficult.*

Charlotte: *'I mean the fact that they get you involved in the daily ward round if you want to get involved is good.'*

One mother discussed a time when she was breastfeeding her baby and she was asked to stop and leave due to the ward round taking place. Another mother stated

she was asked to stop breastfeeding and leave whilst an x-ray was being taken on another baby in the room.

Marie: *'Depending on the nurse, some of them would let me stay. I had two of them [babies] and I wasn't feeding them at the same time. So, they end up not being fed.'*

Participants identified that the main reason for parents not being invited in during the whole daily ward round was confidentiality for other babies and their families. However, as found in the PPI group and subsequent local parent support group interview, this was not a concern for parents. This then raises concerns about the prioritisation of confidentiality over establishing and prioritising parental preferences.

The researcher asked explicitly *'Would it bother you if other parents were in during ward rounds, seeing their babies?'*

Ella: *'I don't think it would actually. You're just aware that you wouldn't like someone else rubber-necking your baby, so you just don't, so it wouldn't bother me. It's very quiet in the NICU. Everyone keeps their voices down and we wouldn't have minded.'*

Charlotte: *'Personally I wouldn't mind it because you know we are all in the same situation.'*

Hayley: *'At that point in time all you want to know about is your baby. Nobody else is listening around you. Everybody is engrossed in what is going on with their own [baby]. You're in your own world.'*

Lack of attendance on the daily ward round resulted in parents not always being updated by a doctor. Two mothers had to rely on the nurses to be the main providers of information due to the difficulties that they faced in attending the daily ward round. It has been identified previously that parents associated a lack of their presence on the daily ward round with a discredit to their own parental role (Wigert et al, 2014). Despite

this, parents conveyed that as long as they were being provided with the correct information in a timely manner they had no preference over whether it was from a doctor or a nurse. One mother communicated a sense of gratefulness. She depicted the daily ward round as more of a privilege than a right as a parent.

Inconsistent information and terminology

The father in this study had the opportunity to stay in a room near the NICU in the hospital with his wife and baby. He therefore attended daily ward rounds on a regular basis, but for him this brought about challenges of its own.

Elijah: *'We had to go in the morning for the morning rounds to be checked by the registrar. We would have to repeat everything from start to finish with the registrar again and again. I was thinking 'are the notes not adequate?' Fair enough, some things may need clarification, I understand but not everything from start to finish. It's like they are trying to practise asking us stuff.'*

He was met with contradictory advice regarding the care of his baby as well as feeling that the doctors were 'practising' talking to parents. The father seemed to have lost confidence in the nurses through their inconsistent information and this was further compounded by the way he was made to feel on the ward rounds. He developed a lack of trust for the staff. Alongside this was a feeling of poor communication between staff and other multi-disciplinary team members which again resulted in a lack of trust. For one parent, seeing the doctors write in the medical notes to which she was prohibited access to and then storing these in an unlocked trolley next to her baby's incubator, made her suspicious and again affected her trust.

Hayley: *'First of all they told me they were going to operate at two kilograms, and then all of a sudden it changed to two and a half kilograms. When you've got a target in your own head and you're thinking he is almost there, and then the next thing it's like you've been hit from behind by a bus.'*

Marie: *'They were telling me something is the right thing and then a week later someone tells you something else. You just don't know what you're doing.'*

The use of terminology prevented parents from asking questions.

Hayley: *'You didn't know enough about terminology. It is a foreign language more or less.'*

Ella: *'She used slightly different terms in HDU (High Dependency Unit) than what they used in NICU and that was a bit confusing. She asked me 'Is he on a seesaw?' I thought 'What's a seesaw?'*¹

Through the use of technical medical terminology, a disempowering environment was created. Parents were overwhelmed and lacked understanding therefore impairing their ability to formulate and ask questions. Lack of interpretability is one of the most common causes for complaint when discussing information provision with parents (Jones et al, 2007).

It is interesting to consider the process of how staff converse with each other in contrast to how they converse with parents. It may be felt that the use of technical terminology and speaking to parents in the manner in which staff would speak to each other, is inclusive and a means of making parents feel equal. Sadly, it would seem that the opposite is true, leaving parents feeling intimidated, confused and guilty.

Despite parents expressing their wishes to attend the ward rounds, issues of inconsistent information and the use of terminology were raised when attendance was achieved. Inconsistent information provision is a longstanding problem in neonatal units with parents having previously expressed concern with conflicting, confusing or ambiguous information (Jones et al, 2007).

¹ The term 'seesaw' refers to a feeding regime for a baby who is receiving intravenous (IV) fluids. The baby will be commenced on milk, usually via a nasogastric tube, and as the volume of milk is increased, the IV fluids will be reduced. The 'up' action of the milk increase combined with the 'down' action of the IV fluid reduction thereby results in the term 'seesaw'.

Waiting

Two parents expressed a concern regarding their lack of ability to be physically comfortable whilst waiting. One mother simply accepted that she might have to wait outside the room for several hours.

Elijah: *'He'd been seen by the doctor. Then we were just waiting instead of going back to the room where it is a bit more comfortable. She [my wife] is more comfortable there.'*

Ella: *'With my recovery and stitches and all of that kind of thing, the hospital chairs...you've got to balance up your own recovery so that you're in a fit state to look after him and sitting up for two hours on a hospital chair when you're not contributing anything is a really poor use of time.'*

Charlotte: *'Me and the other parents were just stuck outside waiting because it [the ward round] is from half past nine to half past eleven but usually they extend it until twelve.'*

Both neonatal units had either a waiting room or a parent sitting area/kitchen. Despite this it is likely that the parents would prefer to be in a comfortable chair at their baby's cot-side whilst waiting. It could be considered whether waiting outside of the room during the ward round could contribute to anxiety and fear. The inability for parents to hear what is being discussed about their baby may be distressing for them.

General communication

Information provision and communication obviously extend well beyond the daily ward rounds even throughout the night.

Ella: *'We felt very able to ask [questions]. If the nurse who was with him couldn't answer, they were really good at...they always wrote it down. You know if someone writes down your question, you know it's not just never to be seen again and we always got the information back even if she doesn't answer it straight away.'*

Charlotte: *'Even if I wasn't asking [questions], just because I was in the room, the doctor came around just to speak to us and just to give us an update.'*

Despite this, one parent of an extremely premature baby, found that there was so much new information to deal with continuously that she felt that she was being left behind.

Hayley: *'It was all new to us. We just couldn't keep up to be honest.'*

Parents disclosed that they would seek information throughout the day whilst visiting their babies. This seemed a more positive time for the exchange of information with parents feeling more able to ask questions and more satisfied with the response from the nurses. Parents also expressed contentment with doctors proceeding to visit them and answer questions if they had not been available on the daily ward round. During the group interview, there was a lack of agreement regarding what type of information was important enough to warrant an overnight phone call. Some parents felt they would want to know everything from a new cannula whereas other parents felt an overnight phone call would concern them and make them worry that there was something seriously wrong with their baby.

Parents discussed both communication and information provision regarding the daily ward round but also in a general context. As with staff behaviour, communication and information provision, whilst at times being positive, left somewhat more to be desired in many cases. The provision of poor and unclear information in NICU has been experienced by many parents who have found the use of medical jargon difficult to understand (Wigert et al, 2013; Wiebe and Young, 2011). In this study the use of terminology was found, in this study, to be received negatively by parents alongside inconsistent information which resulted in confusion and worry. While in a highly emotional state in the early weeks in NICU parents are faced with a significant amount of information about topics that are completely new to them. The ability to absorb and retain information is, understandably impaired, and the desire for something tangible, such an information sheet - which could be referred back to several times or at a more

appropriate time was expressed. Parents have a need for accurate, understandable information which in turn facilitates their desire to be actively involved in decision making for their baby (Cleveland, 2008).

PARENTAL EMOTION

Unavoidable emotions

Emotions such as guilt and fear were clearly expressed during several interviews.

Hayley: *'You were afraid when you first come in.'*

Marie: *'In the early days I was really scared of him [baby]. I didn't enjoy being on the unit in the early days, I found it really stressful.'*

One unavoidable emotion that was experienced was fear especially around the time of admission. The parental emotions of fear and guilt are well documented in the NICU (Caeymaeux et al, 2011; Heidari et al, 2013; Arnold et al, 2013; Vazquez and Cong, 2014; Barr, 2015). Vazquez and Cong (2014) discusses parental fear, more specifically, their fear of harming their baby through dislodging IV or endotracheal (ET) tubes which contributed to fear of touching or holding their baby. This then may impact on the development of a bond between parents and baby.

Hayley: *'Sometimes you couldn't think. You would be listening to them [doctors] but you couldn't interrupt. By the time you had absorbed everything they had said, you had forgotten [what you wanted to ask] by the time they had finished talking.'*

Beth: *'You might hear bad news. You don't necessarily absorb it properly.'*

Ella: *'It just made me feel a little bit guilty for not being there in that sort of vague way.'*

Marie: *'My confidence had gone, and I didn't feel that they [doctors and nurses] empowered me really. They were very happy to get on with things and not include me.'*

The feelings of guilt felt by the parents in this study were not directly related to decision-making but expressed as a general feeling a parent with a baby in NICU will have. Although it is known that emotion influences decision-making (Resnick, 2012), it is not only decision-making that make parents feel guilty, but many other aspects associated with having a baby in NICU such as less physical contact potentially affecting the parent-baby bond (Caeymaeux et al, 2011) and seeing the baby in distress resulting in parents wishing it was them in hospital instead of their baby (Heidari et al, 2013). Barr (2015) suggests that these feelings of guilt are a result of parental self-blame for their baby's hospitalisation. This is supported by Arnold et al (2013) who found parental guilt was an emotion experienced very early in the parent's neonatal experience and this was associated with the continuous questioning as to whether their baby's admission to the neonatal unit could have been prevented.

The interview with Elijah alluded to feelings of guilt compounded by staff through inappropriate communication leading to him questioning the way he was caring for his baby and whether he was being unsafe. This confusion resulting from inconsistent information provision lead to guilt and behavioural changes. The mother who had the overall positive experience still described feelings of helplessness and worry despite feeling that her baby was receiving the best care. Guilt was expressed from lack of attendance at the daily ward round. It could be argued that this feeling of guilt was likely to be felt regardless of whether the parents attended the daily ward round or not due to the uncontrollable nature of the situation. These feelings, compounded with poor staff behaviour, decreased parental confidence and impaired the parent's ability to process information and to ask questions.

Potentially avoidable emotions

There were situations where parents explained feelings of being 'stupid'.

Hayley: *'It made you feel vulnerable [daily ward round] because you feel as if 'Am I asking something really thick?'*

Marie: *'You would feel like it was a stupid question 'Can I feed my baby?' because it all looked so medical. I never got a cuddle for two weeks because they forgot and because I wouldn't ask as I thought it was a really stupid question 'Can I cuddle him?' because he was so poorly.'*

A plethora of emotions were experienced by the parents, some of which were likely to be unavoidable in these situations, but others which were clearly instigated through poor behaviour and poor communication. This was likely to influence parental ability to make sense of their current situation. As found by Zeelenberg et al, 2008, emotion can affect decision-making therefore through stimulation of potentially avoidable negative emotion the parental ability to make decisions can be undesirably impacted.

AWARENESS OF OWN PARENTAL ROLE

Fenwick et al (2008) identified that from admission parents are likely to be unaware of their role in NICU. It is therefore the role of the neonatal staff to assist them in finding their place and establishing their role.

Decision-making

One parent recalled her experience of being asked if she consented to her baby having surgery despite the doctors not providing a definite diagnosis. Parents were not only unsure as to their role in decision-making but also their role in NICU as a parent caring for their baby. It was clear that parents were being asked their opinion on certain courses of management such as surgery or the administration of steroids. However, some parents recall signing consent forms without deliberation as they felt they would not be approached if the treatment were not essential.

Hayley: *'On the night he was admitted to NICU, and we met with the surgeons, they were still undecided, and they said, 'What do you want us to do?' That was a really difficult thing. We asked, 'What would you do?' It was a joint decision. We needed that from him [doctor].'*

She was aware that the surgery was potentially life threatening however upon taking the opinion of the doctor, opted for surgery.

This situation reflects Van Manen's (2014) category of decision '*The decision that was never a choice*'. These decisions are made by parents based on the feeling that any option would not be provided if it was not at least minimally beneficial for their baby. This mother felt that without the surgery, her baby would possibly die, so she chose to give him a chance and opted for surgery knowing that he might well die during the operation. This was also shown through another mother's opinion on decision-making in which she felt that if she was being provided with a consent form for treatment then the proposed treatment must be beneficial for her babies.

Marie: '*No [I don't feel we are in a position to make decisions]. However, if they [doctors] would have been different and made me feel like it's OK for me to make decisions, maybe.*'

Parents expressed that there were either no or very little decisions to be made and tended to consider life-saving aspects of care such as surgery or ventilation as decisions that were not really a decision to be made. They expressed that they had no choice and that due to the nature of the baby's condition such as severe prematurity or specific surgical conditions the actions undertaken were needed for the baby to survive. As above, this can be compared to Van Manen's (2014) category of '*the decision that was never a choice*' although for life-saving opposed to life ending treatments. Van Manen discussed this concept in an EOL situation whereas in this study the babies were at the beginning of their lives and the actions taken were life-saving.

As with the parents who feel that all they can do is let their baby have a chance at life by continuing with the current situation and not making a choice to withdraw treatment, the parents in this study do not see a decision to be made, they are simply letting the doctors do what is necessary to let their baby have a chance at life. Although extreme, in practical terms there is still a choice to have surgery or not to have surgery, to

ventilate or not to ventilate but in legal terms if a parent did not consent action would be taken with the parental choice deemed as inappropriate and irresponsible. It may be assumed that any parent would allow what was necessary for their baby to survive however this is not always the case for example with a Jehovah's Witness and blood transfusion. Regardless of this, it is questionable as to whether any doctor would accept a parent saying they did not want life-saving surgery or assisted ventilation in an otherwise healthy baby due to both legal and moral implications.

Charlotte: *'We've been asked a lot of times to sign forms and give our consent to treatment. I don't really feel like saying "no" to a treatment that they think is going to be good for the health of my babies.'*

Due to constantly receiving inconsistent information alongside the challenges faced by first time parents, the father in this study was particularly unsure of his role. He attempted to do what was best and safe for his baby. Unsuccessfully, he attempted to participate in decision-making regarding the management of his baby, offering a reflection on one particular occasion that he remembered especially clearly.

Elijah: *'He kept seizing over a period of two or three days. The management of his seizures seemed totally ineffective. So, we would have to push to stay [in hospital] so that they could check his [medication] levels. If he had another seizure, we knew what other nurses or doctors had ordered in terms of tests which made sense. We tried to say 'Look, it might be a good idea if you do this because that's what they had to do at the last seizure'. They sort of wouldn't take it on board.'*

He was using his knowledge of previous experiences that he had had with his son in an attempt to participate in shared decision-making. Caeymaex et al (2011) identified shared decision-making as a positive experience for parents, however, in this situation, the feelings that father shared about the decision were ignored resulting in a decision being made solely by doctors. It would seem that the main type of decision-making applied for the parents in this study was medical decision-making. As expressed in previous studies (Van Manen, 2014., Kavanaugh, 2005) although procedures that

required consent were explained to the parents they were done so in a manner that the parent saw the consent process not as an opportunity to make a decision but as a formality. The only decision that parents felt to have actually made themselves was the choice to breast or bottle feed.

Others felt that it was not their role to make decisions as they were not qualified doctors. None of these parents felt that they would want to make any decision solely on their own. Parents expressed the need to trust the doctors and nurses fully to do the right thing for their baby. Despite this, trust was jeopardised in several ways.

Charlotte: *'I'm not graduated to decide what is best for my baby. The consultants are the experts in this kind of situation, so they know what is best for them [babies]. They know what is best for them, and you just need to, at some point, rely on what they say.'*

Charlotte: *'I don't have a degree in medicine so I'm not able to [make decisions]. I don't have any qualifications in this field so it's not my job.'*

Hayley: *'We're not the experts, especially at that point we weren't. Maybe now it would be different if someone asked us something, but at that time we weren't.'*

One mother recognised the need for both informed parental decision-making and shared decision-making. She felt that it was her role to challenge the doctors on alternative treatments, harbouring some concern that financial implications were an issue.

Beth: *'There are only so many decisions you can make on your own. I'm not a doctor. I'm not qualified. These people have trained for many years to do what they do so they know best. It's more about challenging them on different alternatives. I don't want to be caught on a budget, like 'This is what we do because it costs less.'*

Despite this, she was quite clear about her perceptions of what was best for her baby.

Beth: *'I don't want him to have a shunt, so they're not putting a shunt in at the moment. He's too small. They say that he might need one later, but I know that he won't...I'm telling them that he won't.'*

Kavanaugh et al (2005) noted that there are times when doctors make recommendations to parents but do not involve them in the decision-making process, instead merely seeking approval. This was highlighted in this study through parents stating that they had signed consent forms for particular procedures or treatments but had no involvement in a decision-making process. They felt that if they were being provided with a consent form then it must have been the correct course of action.

Although the parent's found that management of daily life got in the way of their ward round attendance, one mother justified her lack of attendance through her perceived lack of ability to have any influence over her baby's management. Again, this could be linked to confusion over her role as the parent. She made one similar statement suggesting her feeling of inferiority on three separate occasions. This is concerning as she had concluded that her presence had no bearing on her baby's management. She seemed to have no awareness regarding her role and her right as a mother to speak up for her baby if she felt the need to do so.

Ella: *'I don't think it would have made any difference [if I were present on the ward round] but I think I would have liked to [have attended] ... because there is so little you can do.'*

Ella: *'I think it just made me feel a little guilty for not being there in that sort of vague, unspecified way that you feel guilty about everything when your baby is in NICU. Yes, so not that it would have made any difference at all [being present on the ward round] except for the fact that it would have been one less thing to feel a little bit guilty about.'*

Ella: *'My initial reaction is always to be the rational person, so my first reaction is "does it make any difference to his care, yes or no?" And then you think, well*

it is making me feel guilty but it's not making any difference [to his care], but it would have been nice to not feel guilty about that.'

There were times when parents had recognised that a decision had been made but that they had had no part of the process.

Marie: *'I always just found decisions were made before you even knew they were being discussed. 'He's having such a thing today' or 'He's had such a thing this morning.' 'Oh right, okay.' I just sort of accepted it really.'*

Rules and permission

Elijah: *'We had to wait. We felt that we had to keep asking before we did stuff. In the beginning that was good, we were asking just to make sure. We felt like we were under scrutiny and under pressure as new parents.'*

Charlotte: *'I still ask for permission, or I wait for them to say to me 'Do you want a cuddle or skin to skin?' I can see when it is a good time but I would still ask for permission from a nurse.'*

There was a feeling from parents of having to obtain permission from the nurses before any interaction took place despite the understanding that the baby was tangibly theirs. Swift and Scholten (2009) described how parents felt that nurses 'inappropriately owned' their baby, thereby producing feelings of confusion and no more than a visitor. The term 'gatekeepers' has been used previously to describe the role of the NICU nurse, with parents feeling the need to gain permission to interact with their baby whilst being under constant supervision (Cleveland, 2008; Aagaard and Hall, 2008).

Ella: *'You accept the rules. I am not the first person to be in hospital so if it has always been like that...'*

Hayley: *'You accept it [the rules] because that's the way we are. You are told something, so they are the rules and that is the way it works. It can be frustrating.'*

Louise: *'All the time we were in there it was 'Am I allowed to do it?' I felt like I had to ask before I did anything, permission for your own baby.'*

Although parents talked about rules, it was expressed that over time the rules allowed parents to understand the workings of the neonatal unit as a whole.

Ella: *'I felt a bit left behind when we changed rooms. We learned our lesson when we went to another nursery. We asked 'What's the routine here? How does the day work?'*

Although there were rules that were communicated, at times they were inconsistent and led to parents being made to feel that they were doing things that were unsafe for their baby even though they had been previously told that this action was acceptable. This confused the parental role. Other parents also felt the need to obtain permission before doing anything with their baby and were strongly aware of the 'rules' within NICU and their obligation to abide. Parents felt the need to follow the routines of the NICU, even if these were contradictory to their own opinions (Wigert et al, 2013). Fenwick et al (2008) termed this as 'learning and playing the game'. They concluded that in order to be successful in their neonatal journey, mothers must quickly adapt and adjust to the neonatal environment and the nurse-mother relationship.

Change in behaviour

There were two identified changes in behaviour from parents. One was a subconscious progression of confidence that increased with the duration of stay in the neonatal unit. This was usually associated with the progression out of intensive care and into the high dependency nurseries. The other was a conscious change due to the negative aspects of behaviour and communication experienced by the parents.

Hayley: *'Now I would challenge behaviour because I know most of them [nurses] now which makes a big difference.'*

Hayley: *'We're not the experts, especially at that point we weren't. Maybe now it would be different if somebody asked us something, but at that time, we weren't.'*

Hayley discussed how her confidence in asking questions had increased with time. This also occurred in the father's experience but in a more negative manner. As confidence in knowing and caring for their babies grows, mothers begin to feel more comfortable and attempt to assert more control over their baby's care (Fenwick et al, 2008). She also recognised a conscious change in her behaviour due to an unsatisfactory experience in staff 'forgetting' to regularly update her about her baby's management including tests and investigations as well as inconsistent information.

Elijah: *'Later on in his stay I started getting pushy. Asking 'Right Doctor, when are we going to see you?' and we would remind them three days in advance. Just to remind them.'*

Researcher: *'Were you changing your behaviour?'*

Elijah: *'Big time yeah. I had to anticipate every-day issues. In the beginning, they said 'Let us know when you want to see a doctor and you can see him' but then it became 'Sorry you missed the ward round so you have to wait. It might be this evening, it might be tomorrow, and you understand it will be busy.'*

Elijah: *'I didn't want to keep phoning. I didn't want to be one of those parents. I keep holding myself back.'*

The father also claimed he had to change his behaviour in order to make sure he was well updated and planned management was being undertaken.

Hayley: *'Sometimes they'd forget to tell you things. I said, 'Well he's not had a scan for so many weeks' and they'd say, 'Oh he had one on a particular date.' As far as I was concerned he was also nil by mouth. He was having some*

medication and I was thinking ‘You’re not giving him anything [by mouth] are you?’ and they said, ‘We’ve been doing this for the last few days.’ It was the [brain] scan that was the turning point where we realised you’ve got to keep on asking and asking.’

She went on to explain how she had been given weight targets and dates for her baby’s surgery which, when she came to confirm them, had been changed. This then triggered her behaviour to constantly double check her baby’s management and thereby affecting her trust in the staff.

Hayley: *“Don’t say something if you don’t know” is what I would say. Just say “I don’t know”. You’re always double-checking. I will always double-check.’*

Hayley: *‘We’ve had to change. I would have trusted somebody, especially in the position they [staff] are all in. I’d like to think that the information they are giving you shouldn’t have to be double-checked. It should be correct. Just give me a photocopy of what we have just talked about.’*

Parents expressed an intentional change in their behaviour in order to adapt and improve their continuous involvement in the management of their baby. They believed that this change in their behaviour facilitated them to have an understanding of their baby’s management and to keep up-to-date with any changes. Wigert et al (2014) focussed their study purely on communication in the NICU and found that parents felt the need to take on an unwanted responsibility to enable successful communication. As in this study, there were times when parents felt that they were not receiving information regarding their baby’s care and management plans. They then had to request the information themselves which they found difficult due to their limited knowledge. This supports the findings in this study, with parents consciously changing their behaviour through constant checking with staff that they have been fully updated on their baby’s care and that management plans have been executed.

CONCLUSION

The primary aim of this research was to gain information regarding parental experiences and desires of decision-making for their baby in NICU. The data collected highlights an issue with overall communicative practices in the NICU thereby disempowering parents and obstructing their ability to become capable, involved decision makers. Effective communication between parents and NICU staff is vital in order to facilitate informed decision-making and parental satisfaction (Jobe, 2010). Alongside this is NICE quality standard 5 which doctors and nurses in NICU should be striving to achieve.

It appears that parents are not currently partners in their baby's care. They are often unsure of their role in the NICU and despite looking to the doctors and nurses for advice and support are sometimes left feeling confused, guilty and unable to make any decisions for their baby. It is obvious that parental needs differ between families, in spite of this, it is clear that all of the parents have a primary goal of doing what is best for their baby and should be empowered to feel that they can whilst promoting bonding.

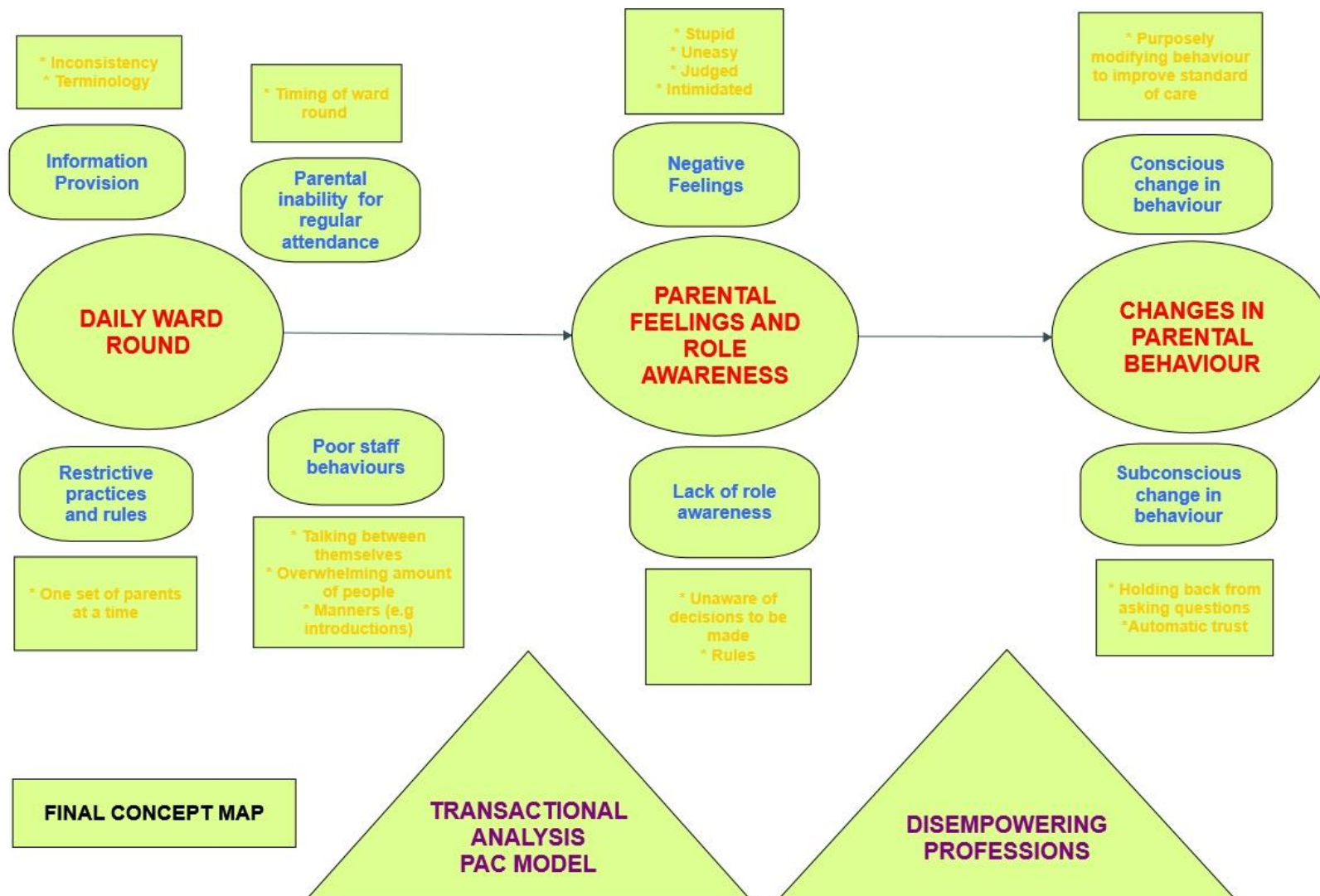


Figure 5: Final concept map

The final concept map demonstrates the clear understanding of the parental issues surrounding their involvement in decision-making in the NICU. This map was created once all of the data had been collected. The original five major themes were more concisely defined into three interlinked issues: daily ward round, parental feelings and role awareness and changes in parental behaviour whilst identifying associated issues. To demonstrate these issues on a conceptual level, works from Eric Berne and Ivan Illich are independently identified within a triangle underpinning the process of communication and behaviours between staff and parents.

CHAPTER SEVEN: DISCUSSION

Although the overall recruitment number for this study was small (n=21), the richness of data obtained has allowed a valuable insight into parental experiences on NICU. This study aimed to explore parental experiences of decision-making in NICU, however, it has been discovered that there are many other issues that need to be addressed before steps can be made towards truly collaborative decision-making. Parents' general knowledge and experience of decision-making for their own baby in NICU was found to be unsatisfactory. When combining the survey and interview data themes, two more conceptual issues begin to emerge.

The data collected does not depict parental dissatisfaction with their participation in decision-making directly but their lack of role awareness and in some cases disempowerment through the behaviour and attitudes of staff. Some parents expressed no concern about their participation in their baby's management but then claimed that there were no real decisions to be made. This then highlighted their lack of awareness of the potential for their participation which in turn provokes disempowerment. Parental comments were sometimes contradictory claiming that they were happy with their level of involvement in decision-making or the daily ward rounds but then commenting that they could not make a decision as the treatment was essential for survival, or they were not allowed to attend daily ward rounds, but they were updated afterwards.

During the process of synthesis and raising the findings to a conceptual level, Berne's (1964) transactional analysis (TA) came to mind as a fitting way to explore what had been happening in the NICU as described by parents. Through this, the work of Illich (1962) describing doctors and nurses as 'disabling professions' came to be viewed as a means of expressing the potential risk should there be no intervention to address the currently observed issues.

TRANSACTIONAL ANALYSIS

A sense of parental disempowerment emanated from all sources of data. This in turn led to the consideration of how TA could be applied in the NICU not only to help with understanding of the reported behaviour, but also as a way to improve it.

Principles of TA

TA is a theory of personality. Dr Eric Berne first developed TA as a model for understanding human personality, relationships and communication in the 1950s (Berne, 1964). Berne was a practicing psychiatrist in California at that point. He treated hundreds of patients during which time he noticed particular changes, although not always verbal, throughout conversations.

TA can be used by anyone as a tool to allow communication to be observed and analysed (Berne, 1964) and whilst it allows an explanation towards the processes of communication in NICU, it can also be used as a tool for positive change and growth (Cooke, 2018). In the modern-day TA is taught to professionals to promote an increase in emotional intelligence and improvement in communication skills (Stuart and Alger, 2011).

Studied not only in the field of psychotherapy but, albeit in limited numbers, in the education sector (high-school, college and university) (Stuart and Alger, 2011; Barrow, 2015) and the healthcare environment (Booth, 2007; 2008), the concepts of TA can be uncovered through establishment of the process of communication between people. This begins initially with thoughts and feelings which are then expressed behaviourally. This has been enabled in this study through the parental sharing of their thoughts, feelings and subsequently their behaviour during their time on NICU. TA includes many components, however the specific area related to this study is the interactions between the ego-states of the parents and of the doctors and nurses. To allow an understanding of TA in the NICU, one must have an understanding of the development and action of the ego-states. The ultimate aim of TA is for people to work towards autonomy, allowing them to live the way they want to live without being influenced, to stay in a particular ego-state, by other's messages (Cooke, 2018).

The Ego-state model

There are two versions of the ego-state model which will be explored here, also known as the PAC (Parent, Adult, Child) structural model and the PAC functional model which both lie at the heart of TA. TA is defined as an observable pattern of behaviour directly related to the way a person is feeling and experiencing a situation (UK Association for Transactional Analysis, 2016). The key concept is that the way a person behaves is consistently related to their feelings and experience with a clear difference between each ego-state (Stewart and Alger, 2011). Due to all people having different experiences as a child and different ways of being raised by their parents and other authoritative figures, each person will behave slightly differently when adopting the ego-states. This would be one of the explanations as to why parents in NICU are having good experiences with some members of staff and not others.

The structural model examines the content of the ego-states and the associated thoughts and feelings developed from historical childhood memories (UK Association for Transactional Analysis, 2016). There are three identified ego-states: Parent, Adult and Child.

Parent

The ego-state of Parent relates to external experiences that the person will have encountered as a child, usually up the age of around five years (Eric Berne Family Members, 2017). These experiences may not have been associated only with a parent but with any adult acting in a parent-like manner. An example of this would be the awareness of rules to maintain manners and safety such as *'always chew with your mouth closed'* or *'always look both ways before crossing the road.'* These external experiences are likely to have been imposed on the child due to their inability to analyse or filter these events (Eric Berne Family Members, 2017). In simplified terms, the Parent concept is derived through a taught process. The Parent communicates in a more authoritative manner with an air of confidence. They have a certain level of knowledge regarding their topic of communication and will instruct another on how to think or behave in a particular way. Although done in good intention, almost in a protective manner, the Parent can be seen to overwhelm others thereby limiting or preventing them from speaking or acting in their preferred manner. It may be that an

experience was had where the parent had no time or patients for their child, therefore as an adult assuming Parent, little tolerance is had for someone adopting Child.

Adult

The Adult ego is more complex. It is developed through the processing of information from the here and now, but also from previous experiences. This allows an understanding of situations therefore promoting the Adult ego-state. Information learned in both Parent and Child is processed to allow the emersion of Adult. Overall the Adult concept is learned. The Adult will communicate in a way which promotes an equal relationship. They will be considerate of other opinions and feelings and will attempt to rationalise based on equal communication. There is no perceived seniority.

Child

The Child ego is an internal process developed through thoughts and feelings provoked by external influences experienced as a child. An example of this would be *'I saw the monster's face and I felt really scared'* or *'There was a clown at the party and he was really funny!'* Overall the Child concept is felt. There will be a lack of confidence portrayed when communicating as Child. There is an awareness of a dearth of knowledge subsequently stimulating feelings of inadequacy. Dependent upon the ego-state to which they are communicating will likely result in a need for support and encouragement to allow a change of ego-state.

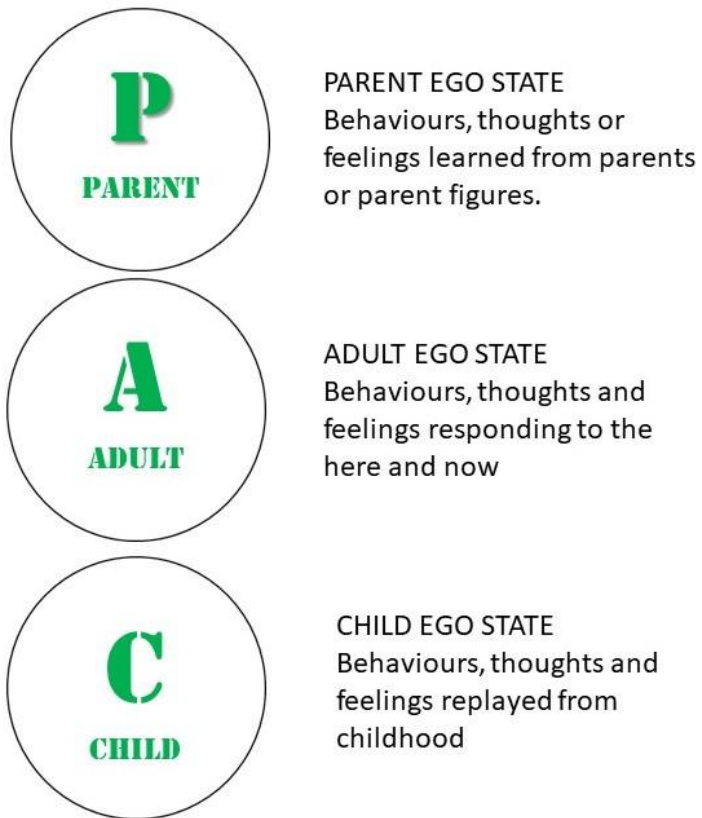


Figure 6: PAC Structural Model (Author's Own adapted from Campbell, 2011)

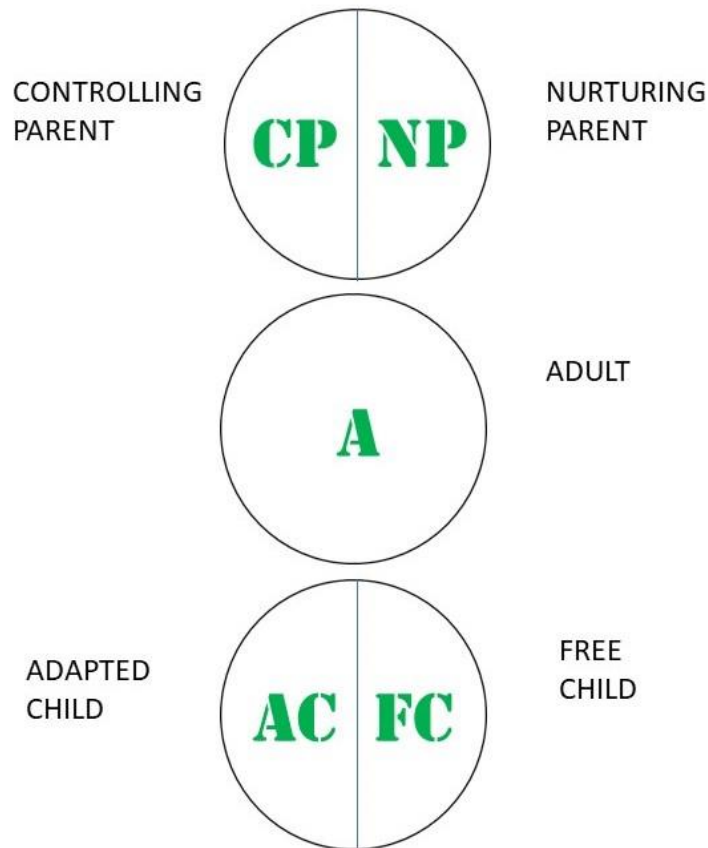


Figure 7: PAC Functional Model (Author's Own adapted from Stewart et al, 2000)

The ego-states have also been developed further into a more detailed functional model (see Figure 6). The functional model deals with how each ego-state affects a person's behaviour and their subsequent interactions with others, allowing strong relationships to be built whether that is at home, in the workplace or in education (UK Association for Transactional Analysis, 2016).

The functional model clearly demonstrates a further breakdown of the parent and child ego states. This is identified through the division of Parent into Controlling Parent and Nurturing Parent and the division of Child into Adapted Child and Free Child. Awareness of these more detailed ego states allows an acknowledgement of which part of the ego state is functioning.

Controlling and Nurturing Parent

Stewart et al (2000) identify how during childhood, a parent will spend an amount of time controlling a child or telling them what to do. Examples of this may be telling them

to 'Go to bed!' or 'Don't run out into the road!' Telling someone what to do or criticising their behaviour is acting within the ego of Controlling Parent.

Conversely, parents also spend a significant amount of their time being loving towards their child. A mother may cuddle her child, or a father spend time playing games. Stewart et al (2000) uses an example of a child falling and cutting their knee which subsequently results in the parents comforting the child and applying a plaster. When a person behaves in this nurturing, caring manner, they are said to be behaving as the Nurturing Parent.

Adapted and Free Child

Behaviours learned as a child were usually done so as a result of parental response to particular types of behaviour. When an adult behaves in a way that has been learned and remembered from parental expectation such as being polite to people even if the child does not like them very much or eating with your mouth closed at the dinner table, it would be said that the adult is acting within the Adapted Child ego-state. Even when behaviours are rebellious, and the adult is purposefully behaving in ways which they know are not acceptable, there is still that knowledge and awareness of the childhood rules and therefore still applies to the Adapted Child ego state. A significant amount of time is spent in this state due to the countless amounts of rules that people subconsciously abide by on a daily basis (Stewart et al, 2000). However, should a lot of new rules be imposed onto someone at one time, the continuous need to remember how to behave can be mentally exhausting.

There are times when a child may act in a way, not because their parents expect them to or because they are being rebellious, but because that is simply the way they feel at that time. Spending time playing a game because it was pleasurable or crying when something made them sad are both examples of acting within the Free Child ego-state.

Adult

Within the functional model, the Adult ego-state is not subdivided. Due to the response to the here and now within the Adult ego-state, it is felt that all of a person's grown-up resources need to be used to achieve this.

Transactions

Once the understanding of ego-states has been established, how they function during conversation and interaction needs to be identified. Berne terms these as 'transactions'. This being the *'unit of social intercourse'* (Berne, 1964). The initial person to speak in a conversation is identified as providing the *'transactional stimulus'* and the person replying as providing the *'transactional response'*. These are then used as the basic unit of analysis. The ultimate aim is exploration of interactions between individuals which has then been applied to the interactions between parents and doctors or nurses in this study. There are two types of transactions that can occur. Healthy transactions, known as *'complementary transactions'*, requires the initiator ego state to receive a response from the ego state to which it was directed. A *'crossed transaction'* is when the initiator ego receives a response from an ego state different from the one which received the stimuli. The latter seeming to occur with the doctors and parents in this study.

Despite the simplistic nature of this model there are three defined egos per person therefore identifying the complexities of communication and relationships. Figure 7 visually demonstrates these transactional complexities.

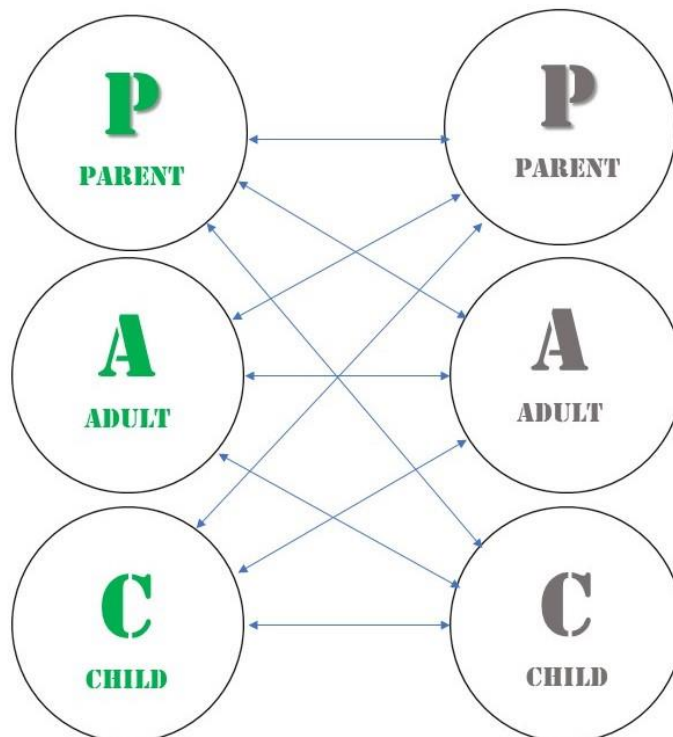


Figure 8: Transactional options (Author's Own adapted from Tomkinson, 2017)

TA in the workplace

There are no research studies exploring the use of TA in the NICU. Dzik (1976) discussed the role of the nurse using TA theory for crisis intervention. She does not explore how TA would be directly beneficial in NICU only referring to transactions between a new mother and a nurse regarding her sick new-born. She provides dialogue for potential scenarios exploring how the mother and nurse may assume various egos and how this would result. TA was a relatively new theory around this time and has not continued to be explored within the NICU setting.

More recently Booth (2007, 2008) has studied both relationships and communication using a TA approach within radiography within the NHS. As in this study, these studies were undertaken following government initiatives highlighting the need within the NHS for a patient-centred approach to care with effective communication. She highlights how interpersonal communication is so natural to people that the importance of doing it well is often overlooked. In 2016-2017 Data on Written Complaints in the NHS (NHS Digital, 2017) demonstrated communications as a primary source of complaint with 28,274 written complaints being made in this time. Values and behaviours of staff were ranked third with 19,287 written complaints being received. This highlights that the issues found in this study are likely not isolated to NICU but throughout the NHS.

Stuart et al (2011) appropriately assert how self-awareness and awareness of others improves the ambience of the workplace and allows strong and effective communication channels to occur between both individuals and groups. Although their study was exploring the application of TA between teachers and pupils in a high-school setting it was found that those with TA skills were increasingly self-aware with an improved sense of understanding for others thereby improving relationships. These findings could be made more applicable to this study by applying them to the roles of parents and doctors and nurses.

Rationale for TA in the NICU

There is a clear relevance when exploring the use of TA in the NICU. This study demonstrates the inability of parents to make participatory informed decisions about their baby's care due to the inconsistent patterns of behaviour and communication arising from the neonatal team. This was demonstrated through the broad difference in experiences between parents. Some parents were entirely happy with the care and attention that they received whereas some parents voiced concerns pertaining to being 'told off' and spoke to, in what they perceived as, an inappropriate manner. These concerns regarding inconsistent behaviour and communication are not entirely new findings; previous studies have also highlighted problems (Wigert et al, 2013; Wigert et al, 2012; Jobe, 2010; Biasini et al, 2012) although these have not been directly linked to the decision-making process. There have been various recommendations over several years to improve parental involvement in, not only caring for their baby, but in making decisions (NICE, 2010). Seemingly, despite this research and these recommendations, any attempts to improve this situation have been unsuccessful.

When applying the theory of the ego-state concept to the process of interaction between parents, doctors and nurses, it becomes clear why the parents may assume the ego of Child as opposed to Adult. The Parent ego is assumed through taught knowledge. Although the parents are aware of societal rules they demonstrate an immediate lack of awareness of the rules and running of the NICU, though this has been shown to improve with time. The parents in this study referred to their growing confidence over time and their awareness of the changing dynamics of care provision from closely supported care to more parent orientated. This was described aptly by Oliver when he said that as his time in NICU progressed; an increase in confidence was experienced, allowing him to challenge information if needed (p121). This therefore suggests the observed lack of knowledge and understanding experienced by parents especially during the early period of their neonatal experience, thereby hindering the ability of a parent to act as Adult. This was not the case for all parents and it could be assumed that the parents that felt growing confidence with time would only be able to do so through a nurturing and supportive environment. It may be that the longer the parents are in NICU the more they learn thereby allowing them to

gradually develop the Parent ego which will ultimately develop into the Adult ego, with an attempt to change the dynamics of their relationships with the doctors and nurses

Parents have minimal to no prior knowledge upon which to base their understanding of what is going on around them. It seems inevitable that from the initial admission process the doctors and nurses assume the Parent ego, informing or 'teaching' parents. Although this may be so, parents in this study conveyed a reality of doctors and nurses at times assuming the Controlling Parent by telling them what to do opposed to nurturing and supporting them to assist in making decisions for their babies. This was done in several ways. Several parents explained how their inclusion in the daily ward round was limited (p120, 132-134). This could be construed as a form of control which ultimately limits parental knowledge, understanding and the ability to be actively involved in decision-making. Again, this lack of involvement in the daily ward round may reinforce the Child ego due to the perception of the parents that they are the outsiders looking in, and they are therefore not knowledgeable or distinctive enough to be fully involved. Another way in which nurses and doctors are assuming Controlling Parent is through inconsistent information and the use of terminology. Although non-intentional, nurses and doctors are constantly providing parents with inconsistent information and using terms and language that is not familiar to parents. This then leaves them confused and with a feeling of inadequacy (p135, 139).

The Child ego of which parents appear to be assuming is done so through a felt concept. They have a significant ability to experience feelings and emotions in response to what they can see and hear in the NICU. Their visual experiences are unfamiliar causing fear and insecurity. Fear is an emotion frequently described by parents in NICU both in this study and in the literature as previously stated. Fear is an unavoidable feeling for parents in NICU and is triggered by many factors. Parents deliberate the reasons why they feel afraid and it becomes apparent that there are several contributing factors. They are not only afraid of the intensive care environment with the unfamiliar sights and sounds, multiple sick babies and procedures being performed which are sometimes witnessed by parents, but fear was also expressed of their own baby (p138). They were frightened of touching their baby in fear of dislodging ET or IV tubes. Stewart et al (2000) assists with the understanding of how these

situations may facilitate a parent's Child. This ego is triggered based on memories from childhood. A parent feeling that they don't understand terminology or an explanation regarding their baby's condition may relate back to a time when they were a child at school listening to a teacher explain a science project using particular terminology that they didn't understand. This then may have made them feel worried and insecure about completing their project. These feelings then resurface subconsciously as a parent in NICU, again through a lack of understanding surrounding a particular situation and may have associated behaviours such as lip-biting, foot-tapping or hand-wringing.

Due to their inability, from lack of knowledge and experience, to assume the Parent ego they cannot then amalgamate the taught and felt concept to allow validation of data and the establishment of the Adult ego.

These scenarios are more applicable to the relatively new parent in NICU. Some parents will have had a baby in NICU previously and have already gained some knowledge and experience. Despite this, their current situation is likely to be different and time will have passed since their last visit. They will still need to contend with new information and need time to refresh any knowledge they had previously gained. In these scenarios, it may be that the parent attempts to assume the Adult ego from the point of admission. Through poor behaviour and communication from doctors and nurses, this is then inhibiting the parental ability to assume the Adult ego, forcing them to remain in Child. This is demonstrated several times in this study, with parents attempting to be involved in decision-making but feeling they were not heard and therefore relinquishing this part of their role. Elijah, the father who was especially upset about being excluded (p142) revealed his attempts to assist in management of care for his baby whilst being overlooked, ultimately resulting in an unwanted change in his behaviour. Marie demonstrated a sense of parental control (p143). She spoke about how she didn't want her son to have an intraventricular shunt inserted therefore he did not have one. However, she then stated that he was too small. She felt it would be recommended that he would need a shunt at a later time but still claimed she did not want this. Despite her feeling this way, she had not verbalised her wishes, this gave her a sense of control for the future. Although Marie felt she was in control of the circumstances it is clear that it was not entirely her wishes that were followed but that

her son was actually an inappropriate weight to have a shunt inserted at that time. It is interesting to consider how the situation may transpire in the future when he is an appropriate weight and whether Marie will still feel in control.

The doctors and nurses, however, are not solely responsible. Parents have a defined lack of confidence when dealing with particular doctors and nurses which may result from unavoidable feelings of intimidation by people who are assertive and highly qualified. While some parents identified that they had a personal preference for some nurses over others (p132) they did not specify their reasoning. It would be reasonable to suggest that the personal preference for nurses may arise from a combination of both undesirable behaviour and communication and the effects of unintentional intimidation due to seniority or assertiveness.

Morrell (2000) identifies that patients can add to their own disempowerment through their lack of belief that they have anything significant to contribute but also that some patients may wish to absolve all responsibility onto the doctors and nurses thereby allowing them to blame them if anything were to go wrong. Prior to the development of a decision-making partnership needs to grow a working partnership allowing a feeling of empowerment and safety to flourish.

DISABLING PROFESSIONS

'Our age will be remembered as the time when the professionals took control and we lost the ability to think and do for ourselves.' (Illich, 1977, p.17)

Illich was an Austrian philosopher, born in Vienna in 1926 who trained to become a Roman Catholic priest (O'Mahoney, 2016). He was forced to leave the priesthood due to his personal opinion and disputes over the Catholic hierarchy and developed his fame through his publications regarding modern society, work and schooling (O'Mahoney, 2016). Most relevant to this study is his work exploring disabling professions, in particular, doctors (Illich, 1977) and medical nemesis (Illich, 1976).

Edwards (2003) considers Illich's proposal that people have become dependent on the health service and medical treatment which in turn has likely affected people's

autonomy. Illich declared that many professionals use their 'power' to manipulate and disable people into believing that things need always to be conducted in a particular way. He brings attention to teachers who announce that education is best placed in school, discounting the quality of education elsewhere, and other professions that stop people shopping elsewhere or making their own alcohol. These examples can be denounced as being out of date as it is known that in the modern-day children can be legally and appropriately home-schooled, people have the freedom to shop in an abundance of places including online with no human contact if desired, and, although the making of certain alcohol is not permitted, home-brewing is legal. In spite of this criticism of these examples and Illich's views being regarded as extreme in the 1970s, it could be argued that his concerns regarding the medical profession could still hold true today (Wright, 2003). Illich was discussing the likelihood of iatrogenicity 20 years before the term 'evidence-based medicine' was coined and when the healthcare system was very different. He uses the term 'iatrogenicity' not only to relate to doctor-inflicted injuries and useless medical treatment but also to social and cultural iatrogenesis. Although these situations occur occasionally today, when applying these views, the social aspect of doctor-patient relationships becomes more significant than the clinical care aspect (Wright, 2003).

Illich's best-known work in this field was *Medical Nemesis* (Illich, 1976). Mahoney (2016) describes this publication as an attack on modern medicine. Illich uses doctors as *'the most striking and painful example'* (Illich, 1977, p.18) of domineering professionals identifying the characteristics that set doctors apart from other professions. He describes how shopkeepers sell goods that a person chooses to buy and how a skilled worker may tailor a product to a person's own desire. Doctors, however, tell people what they need, alluding to specialist training and a superior knowledge. He describes the process of prescribing medication as a *'power'* due to the suggestion that doctors not only know what is right for people but that they have the unique ability to provide it.

Although such dire consequences are not envisaged in NICU, it is a concern that if the findings in this study were continued to be experienced by parents in NICU without action to improve the current situation, nurses and doctors may become categorised

as disabling professions as historically highlighted by the work of Illich. Some would say that this trait in medicine has been cultured and nurtured deliberately over centuries, with a deliberate endeavour to exclude others from the business in order to ensure a monopoly of practice. Indeed, the medical lobby remains especially strong despite being damaged by medical scandals and the moulding of the NHS into a pseudo market place in which the rise of the manager has been a central feature.

In contrast, the characteristics that “disabling professions” demonstrate may be viewed as learned behaviour in practitioners who entered their profession with determination to help and to provide the best possible service. Gradual socialisation may occur into behaviour which, while appearing to be increasingly efficient, serves also to disempower parents, however unintentionally.

There was no concern with the quality of practical aspects of caring for the babies in this study, but the staff attitudes towards parents and how that made them feel was experienced negatively. Illich terms this psychological result as ‘*social iatrogenicity*’ or the medicalisation of everyday life (Illich, 1976). Parents expressed feeling more comfortable with some nurses than others resulting in a change of behaviour for the parent depending on who was looking after their baby. This presented in different ways for different parents. The use of unfamiliar terminology resulted in feelings of ‘being left behind’. Inconsistent information and scolding affected their confidence and prompted worry that they were unintentionally doing things that were unsafe for their baby. These experiences all demonstrate a level of social iatrogenicity.

This is when it is felt that when people are ill or suffering they should be hospitalised rather than managed at home, describing the home as ‘inhospitable’ to birth, sickness and death (Illich, 1976). Illich alludes to the confusing use of terminology as a controlling device and how patients should adopt a patient role or are otherwise felt to be deviant. One father from this study felt particularly discriminated against as an unmarried father, feeling that he had very little involvement in his baby’s care due to his lack of legal abilities to sign consent forms. He strongly disagreed that staff listened to his views and opinions and concluded that, as a father in particular, his opinions were not valued by the staff. This could be further supported by another father offering

opinions about the management of his baby's seizures due to his previous experience during his stay. He also felt that his opinions were not considered, so the need to challenge the staff arose.

At the time, due to the perceived radical nature of Illich's opinions, they were dismissed and never taken seriously by the medical profession (O'Mahoney, 2016). More than 40 years on, it would be easy to leave these thoughts and opinions in the past. However, when explored more deeply, the relationship between the attitudes of doctors, and in this case nurses, can be identified and seen as a current potential problem if not addressed. O'Mahoney (2016) agrees that although Illich's work is difficult to read and potentially over-stated, it still conveys a powerful argument that continues to serve as a potent warning.

LIMITATIONS OF THE STUDY

Although this research achieved its aims, I am still aware of its limitations and shortcomings. First, the study was undertaken in only two NICUs in the UK. This only provides a small glimpse of the experiences of parents in these units. A study exploring parental experiences across the UK would be preferable. Despite this, findings did correlate with the National Bliss Parental Survey (Howell and Graham, 2011). Second, a relatively small sample size was recruited. This was strengthened through the use of data from the local parent support group interview, but the small sample size may not accurately represent all parental experiences across the UK. As previously discussed in this thesis, the small sample size could be partly attributed to the barriers faced surrounding recruitment from the NICU staff themselves. In the level 3 unit there was initial obstruction to the commencement of the study thereby resulting in a delay in recruitment. Recruitment commenced on time in the tertiary unit, but staff communicated their lack of priority for the study and were not strictly applying the inclusion and exclusion criteria, using their own ethical opinions regarding who should be recruited. It is therefore unknown as to how many potentially eligible parents were not recruited. Finally, a limited amount of data was collected from fathers. There is far less available data exploring the experiences of fathers in NICU than of mothers therefore more of this data would be beneficial. This was a difficulty in this study as it was not aimed directly at fathers therefore the mothers tended to take responsibility for

participating in the study for several reasons. The fathers were often at work or at home caring for the other children therefore were not present during recruitment. They did not spend as much time in the NICU as the mothers. It also seemed to be assumed that as the mother was the primary carer of the baby, that she should be the one to participate in the study, therefore fathers would, at times, stand back and encourage the mother to participate.

CHAPTER EIGHT: CONCLUSIONS

SUMMARY

This study was undertaken based on both personal experience of a lack of parental involvement in decision-making in NICU and also current publications identifying disparities in care across all neonatal units in the UK and the consequent need to improve this, more specifically parental involvement in decision-making.

REVIEW OF THE RESEARCH QUESTION

How can the frequency and extent of parental participation in clinical decision-making in the NICU be harmonised more closely with parents expressed wishes?

The question was answered in the study. First the experiences of parents showed that, to a large extent, most had not been involved to any considerable degree in decision-making about their baby. Many expressed a feeling that there were no decisions to be made and a minority reported that attempting to become involved was futile. Some parents who declared that there was no decision to be made, or that the decision was too important for them to be involved, might, on reflection, have desired a level of involvement, had that been offered. It was clear that a number of issues relating to communication between staff and parents required attention and that some apparently inappropriate responses had been met from some staff. TA helped to show that the negative staff behaviour was not intentional and that review of this using TA as a training method might well be an effective solution.

MESSAGES FROM THE STUDY

1) This was the first known study in the world to study the whole of decision-making in NICU whether decision-making was allowed or not.

Previous studies have addressed only specific aspects of care such of EOL care, feeding decisions, neonatologist opinions on decision-making, decision-making at the extremes of prematurity. These have focussed on decisions that were made by parents rather than on the degree to which participation in decision-making was allowed,

encouraged or practised by parents. Previous studies have dealt only with occasions on which participation in decision-making had been agreed.

The impact of this is that there is now understanding, at least from these parents, about what parents want and what is allowed regarding participation in decisions about their baby.

2) A further novel finding from this study was that staff-parent communication and relationship building require considerable attention first before the issue of participation in decision-making can be addressed effectively.

Previous studies have been based on occasions when parents have been either invited to agree with a medical decision while ignoring circumstances in which medical decisions are made without reference to parents.

The impact is that staff need to review routine practice to identify missed opportunities for parents to be invited to participate in decision-making. Accepting that on most occasions parents will agree, it remains, never the less, important that they are allowed and encouraged to play an active part.

3) The use of TA as a means of understanding the dynamics and potential for change in relationships in NICU was a further novel aspect to the study. No other such application has been found anywhere in the world.

TA has been used in radiology departments within the NHS and within educational institutes. Its use in NICU is particularly unique in that the Parent ego state and the social role of parent have both been considered in the model so that the changing ego state of the baby's parent can be understood.

The outcome of this is that staff in NICU could come to understand the complexities of parental responses and the nature of their own interactions with the parents. Repeatedly in the thesis it has been stated that the staff involved were dedicated, caring professionals who would not have recognised the ego-state which they were

adopting. Revealing this provides the potential for change. At the same time this work has identified the potential consequences of failure to address the issue.

4) The application of Van Manen's explanation of categories of decisions led to a new way of understanding and decoding parental acceptance of exclusion from decision-making.

This was a novel application of a theory developed from EOL care and applied to general decision-making in neonatal care. This is the first time, as far as it is known, that the prima facie stance of parents as not wishing to be involved in decision-making has been revealed to be masking de facto acceptance of the inability to become involved.

If professionals were to recognise this then underlying preferences about involvement in decision-making would be made apparent. Consequently, practice may change to allow more opportunities for professionals to include the desires of parents in the process of deciding clinical options.

MESSAGES FOR CLINICAL PRACTICE

Clinical practice was excellent, and this study did not aim to evaluate the quality of clinical care for the babies.

It was clear that NICU staff are currently unaware of the experience that parents have of engagement in decision-making and their feelings of disempowerment. It is likely that this will be a considerable surprise to staff who in other ways were evidently caring and committed to providing high-quality care in all domains. Parental perceptions of staff, the need to adapt to the routines prescribed by individual practitioners, and expectations of compliance with medical decision-making are clearly not currently appreciated by the staff.

The use of TA training and role-play with staff could be both an acceptable and an effective means of achieving understanding of the current situation and of the means to effect change in practice.

Daily ward rounds remain a particular issue for parents and their exclusion from decision-making about their babies. Not only did parents feel excluded but information resulting from the ward round was often delayed or not fully communicated to a satisfactory extent. Neither did parents have the opportunity to ask questions of the consultant. Review of such exclusion would be welcomed by most parents who felt no risk of breach of confidentiality should they be allowed to remain with their own baby. Parents rejected arguments that they would be distressed by theoretical discussion of alternative scenarios and medical discussion of treatment and progress.

MESSAGES FOR RESEARCH

While a number of fathers were included in the study, only one consented to be interviewed in depth. Future efforts should be made to secure the detailed views specifically of fathers. While in this study, couples were interviewed individually, this usually led to the mother being nominated to undertake the interview. Again, specific effort to ensure that both parents are equally represented should be ensured.

This study focussed entirely on parental perceptions, and the next study will address practitioner's perspectives on the same issues. This will be done before TA training is provided or at a different site. Parents appeared to absolve senior doctors from the requirement to communication with the assumption that they were too busy, yet they also acknowledged that the nurses were far too busy. Further research should capture the perspectives of senior doctors, senior nurses, such as ANNPs, as well as staff nurses since parents have different perceptions and expectations of each of these groups.

The importance of independent research of a clinical population is undoubted. Practitioners' evaluating their own practice with their own patients has considerable limitations. However, attempting to access a sample externally in the NHS proved especially trying and recruitment was consequently considerably limited. The study needs to be replicated with a larger population and more neonatal units, but the associated issues of access would need to be resolved first. At the same time, it would also be useful to compare parental experiences of involvement in decision-making

across HDU and SCBU. This is pertinent because of the finding that parental confidence to ask questions and challenge information grew over time.

The impact of TA training and role-play could be evaluated, and observational methods would probably be ideal, particularly with before and after assessment.

REFERENCES

- Aagaard, H., Hall, E.O (2008) Mother's experiences of having a preterm infant in the neonatal care unit: a meta-synthesis. *Journal of Paediatric Nursing*. 23(3): e26-e36.
- Albersheim, S.G., Lavoie, P.M., Keidar, Y.D (2010) Do neonatologists limit parental decision-making authority? A Canadian perspective. *Early Human Development*. 86: 801-805.
- Aliev, R.A., Zeinalova, L.M (2014) Decision making under Z information. *Human-Centric Decision-Making Models for Social Sciences*. Vol 502. Springer. Berlin.
- Allen, K (2014) Parental decision-making for medically complex infants and children: an integrated literature review. *International Journal of Nursing Studies*. 51: 1289-1304.
- Anwar, R., Shah, Z (2012) How to pursue a postgraduate fellowship [online] Available at: http://careers.bmj.com/careers/advice/How_to_pursue_a_postgraduate_fellowship [Accessed 03 August 2016].
- Arnold, L., Sawyer, A., Rabe, H., Abbott, J., Gyte, G., Duley, L. & Ayers, S (2013) Parents' first moments with their very preterm babies: A qualitative study. *BMJ Open*, 3(4): 1-7.
- Ashcroft, R., Dawson, A., Draper, H., McMillan, J.R (2007) *Principles of health care ethics*. Second Ed. John Wiley and Sons. Chichester.
- Bailey, S.M., Hendricks-Munoz, K.D., Mally, P (2013) Parental influence on clinical management during neonatal intensive care: a survey of US neonatologists. *Journal of Maternal, Fetal and Neonatal Medicine*. 26 (12): 1239-1244.
- Bancalari, A., Araneda, H., Echeverria, P., Alvear, M., Romero, L (2016) Arterial oxygen saturation and heart rate in newborns with and without maternal bonding. *Paediatrics International*. 1-5

Barr, P (2015) Guilt, shame and fear of death predict neonatal intensive care unit-related parental distress. *Journal of Reproductive and Infant Psychology*. 33:4 402-413.

Barrow, G (2015) Transactional analysis in the classroom, staffroom and beyond. *Pastoral Care in Education*. 33(3): 169-179.

Bauer, A., Parsonage, M., Knapp, M., Lemmi, V., Adelaja, B (2014) The costs of perinatal mental health problems [online] Available at: http://eprints.lse.ac.uk/59885/1/__lse.ac.uk_storage_LIBRARY_Secondary_libfile_shared_repository_Content_Bauer,%20M_Bauer_Costs_perinatal_%20mental_2014_Bauer_Costs_perinatal_mental_2014_author.pdf [Accessed 02 March 2016].

Beauchamp T, Childress J (1994) Principles of biomedical ethics (4th Ed), Oxford University Press.

Beresford, B., Sloper, T (2008) Understanding the dynamics of decision-making and choice: a scoping study of key psychological theories to inform the design and analysis of the panel study [online] Available at: <https://www.york.ac.uk/inst/spru/pubs/pdf/decisionmaking.pdf> [Accessed 20 February 2017].

Berne, E (1964) *Games People Play*. London. Penguin Group.

Bettany-Saltikov, J (2012) *How to do a systematic literature review in nursing*. Open University Press. England.

Bevilacqua, G., Corradi, M., Donzelli, G., Fanos, V., Gianotti, D., Magnani, C., Orzalesi, M., Parmigiani, S., Pedrotti, D., Salvioli, G (2011) The Parma charter of the rights of the newborn. *Journal of Maternal-Fetal and Newborn Medicine*. 24 (1):171.

Biasini, A., Fantini, F., Neri, E., Stella, M., Arcangeli, T (2012) Communication in the neonatal intensive care unit: a continuous challenge. *The Journal of Maternal-Fetal and Neonatal Medicine*. 25 (10): 2126-2129.

Bliss (2015a) Different levels of care [online] Available at:
<http://www.bliss.org.uk/different-levels-of-care> [Accessed on 08 November 2015].-

Bliss (2015b) Bliss baby report 2015: Hanging in the balance. [online] Available at:
file:///C:/Users/NSP367/Documents/Baby_report_WEB_low.pdf [Accessed 27 July 2016].

Bliss (2017) Our accredited units. [online] Available at:
<https://www.bliss.org.uk/health-professionals/bliss-baby-charter/our-accredited-units>

Bliss (2011) *The Bliss Baby Charter Standards* (2nd Ed) Bliss Publications. London.

Blossom, P (2015) My child is not in heaven: your religion only makes my grief harder [online] Available at:
http://www.salon.com/2015/10/24/please_stop_telling_me_my_daughter_is_in_heaven/ [Accessed 03 August 2016].

Booth, L (2007) Observations and reflections of communication in health care – could transactional analysis be used as an effective approach? *Radiography*. 13(2): 135-141.

Booth, L (2008) The radiographer-patient relationship: enhancing understanding using a transactional analysis approach. *Radiography*. 14(4): 323-331.

Boss, R.D., Henderson, C., Wilfond, B (2015) Decisions regarding extremely premature infants: should social context matter? *JAMA Paediatrics*. 169: 521-522.

Boss, R.D., Hutton, N., Donohue, P.K., Arnold, R.M (2009) Neonatologist training to guide family decision making for critically ill infants. *Archives of Paediatric and Adolescent Medicine*. 163 (9): 783-788.

British Association of Perinatal Medicine (BAPM) (2015) North West Neonatal ODN – Greater Manchester [online] Available at: http://www.bapm.org/networks_info/gm.php [Accessed 08 November 2015].

British Medical Association (2008) Parental responsibility [online] Available at: <file:///C:/Users/NSP367/Documents/parentalresponsibility.pdf> [Accessed 12 August 2015].

British Medical Journal (1979) 'Patients first': government proposals for the NHS. *British Medical Journal*. 1605.

Brosig, C.L., Pierucci, R.L., Kupst, M.J., Leuthner, S.R (2007) Infant end-of-life care: the parents' perspective. *Journal of Perinatology*. 27: 510-516.

Burger, S (2015) Parents experiences of neonatal care: Findings from neonatal survey 2014 [online] Available at: http://www.pickereurope.org/wp-content/uploads/2014/12/P2725_Neonatal-Survey-2014_-Online-Version_Final.pdf [Accessed 04 July 2016].

Caeymaex, L., Jousseleme, C., Vasilescu, C., Danan, C., Falissard, B., Bourrat, M., Garel, M., Speranza, M (2013) Perceived role in end-of-life decision-making in the NICU affects long-term parental grief response. *Archives of Diseases in Childhood Fetal and Neonatal Edition*. 10: 1-7.

Caeymaex, L., Speranza, M., Vasilescu, C., Danan, C., Bourrat, M., Garel, M., Jousseleme, C (2011) Living with a crucial decision: A qualitative study of parental narratives three years after the loss of their newborn in NICU. *PLoS ONE*. 6 (12): 1-7.

Campbell, J (2011) T3 who is saying what? [online] Available at: <http://charactertherapist.blogspot.com/2011/02/t3-who-is-saying-what.html> [Accessed 16 December 2017].

Carter, J.D., Mulder, R.T., Bartram, A.F., Darlow, B.A (2005) Infants in a neonatal intensive care unit: parental response. *Archives of Diseases in Childhood Fetal and Neonatal Edition*. 90: F-109-F113.

Child Law Advice (2015) Parental responsibility [online] Available at: <https://childlawadvice.org.uk/information-pages/parental-responsibility/> [Accessed 19 January 2016].

Cleveland, L.M (2008) Parenting in the neonatal intensive care unit. *Journal of Obstetric, Gynecological and Neonatal Nursing*. 37: 666-691.

Cockcroft, S (2012) How can family centred care be improved to meet the needs of parents with a premature baby in neonatal intensive care? *Journal of Neonatal Nursing*. 18(3): 105-110.

Cooke, B (2018) Transactional analysis and ego states [online] Available at: <https://mcpt.co.uk/transactional-analysis-and-ego-states/> [Accessed 15 December 2017].

Coricelli, G., Dolan, R.J., Sirigu, A (2007) Brain, emotion and decision making: the paradigmatic example of regret. *Trends in Cognitive Sciences*. 11(6): 258-265.

Critical Appraisal Skills Programme (CASP) (2013) Appraising the evidence [online] Available at: <http://www.casp-uk.net/appraising-the-evidence> [Accessed 24 June 2016].

Daboval, T., Shidler, S (2014) Ethical framework for shared decision making in the neonatal intensive care unit: Communicative ethics. *Journal of Paediatric and Child Health*. 19 (6): 302-304.

Davies, S., Rawlinson, H (2012) Bigger is not always better! *AIMS Journal*. [online] Available at: <http://www.aims.org.uk/Journal/Vol24No4/biggerNotAlwaysBetter.htm> [Accessed 28 July 2016].

Department of Health (2009) Toolkit for high-quality neonatal services [online] Available at: <http://www.scottishpatientsafetyprogramme.scot.nhs.uk/Media/Docs/MCQIC/Neonatal%20Care/DOH%20Toolkit%20for%20High%20Quality%20Neonatal%20Services.pdf> [Accessed 5 August 2015].

Department of Health (2010a) Equity and excellence: Liberating the NHS [online] Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213823/dh_117794.pdf [Accessed 11 February 2016].

Department of Health (2010b) Liberating the NHS: Greater choice and control [online] Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216149/dh_130451.pdf [Accessed 11 February 2016].

Department of Health (2012a) Health and Social Care Act [online] Available at: <https://www.gov.uk/government/publications/health-and-social-care-act-2012-fact-sheets> [Accessed 25 May 2016].

Department of Health (2012b) Liberating the NHS: No decision about me, without me [online] Available at: https://consultations.dh.gov.uk/choice/choice-future-proposals/supporting_documents/Choice%20consultation%20%20No%20decison%200about%20me%20without%20me.pdf [Accessed 11 February 2016].

Department of Health (2014) The Mandate [online] Available at: <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachm>

ent_data/file/383495/2902896_DoH_Mandate_Accessible_v0.2.pdf [Accessed 27 February 2016].

Department of Health (2016) The NHS choice framework: what choices are available to me on the NHS? [online] Available at: <https://www.gov.uk/government/publications/the-nhs-choice-framework/the-nhs-choice-framework-what-choices-are-available-to-me-in-the-nhs> [Accessed 03 April 2016].

Dietrich, C (2010) Decision-making: Factors that influence decision making, heuristics used, and decision outcomes. *Inquiries Journal*. 2 (2): 1-3.

Disabled Living Foundation (2016) Key facts [online] Available at: <http://www.dlf.org.uk/content/key-facts> [Accessed 12 March 2016].

Donzelli, G (2010) Declaration of the newborn's rights. *Journal of Maternal-Fetal and Newborn Medicine*. 23: 241-243.

Dowler, C., Heritage, A., Wallis, S (2012) Labour of love: making a maternity services reconfiguration successful [online] Available at: <http://www.hsj.co.uk/topics/efficiency/labour-of-love-making-a-maternity-services-reconfiguration-successful/5041433.fullarticle> [Accessed 28 July 2016].

Dowling, D., Shapiro, J., Burant, C.J., Elfetoh, A (2009) Factors influencing feeding decisions of black and white mothers of preterm infants. *Journal of Obstetric, Gynecologic and Neonatal Nursing*. 38 (3): 300-309.

Dzik, R.S (1976) Transactional analysis in crisis intervention. *Journal of Obstetric, Gynecologic and Neonatal Nursing*. Vol 5(1): 31-36.

Edwards, R.H.T (2003) Nemesis, Sisyfus, and a contribution from the medical humanities to health research. *Journal of Epidemiological Community Health*. Vol 57: 926-927.

Einarsdottir, J (2009) Emotional experts. *Medical Anthropology Quarterly*. 23 (1): 34-50.

Fegran, L., Helseth, S (2009) The parent-nurse relationship in the neonatal intensive care unit context – closeness and emotional involvement. *Scandinavian Journal of Caring Sciences*. 23 667-673.

Fenwick, J., Barclay, L., Schmied, V (2008) Craving closeness: a grounded theory analysis of women's experiences of mothering in the special care nursery. *Women and Birth*. 21(2): 71-85.

Finlay, L (2002) "Outing" the researcher: the provenance, process and practice of reflexivity. *Qualitative Health Research*. 12(4): 531-545.

Gallagher, K., Aladangady, N., Marlow, N (2015) The attitudes of neonatologists toward extremely premature infants: a Q methodological study. *Archives of Diseases in Childhood Fetal and Neonatal Edition*. 0:F1-F6.

Gallagher, K., Martin, J., Keller, M., Marlow, N (2014) European variation in decision making and parental involvement during preterm birth. *Archives of Diseases in Childhood Fetal and Neonatal Edition*. 99: F245-F249.

Gee, N (2015) A study of student completion strategies in a Likert-type course evaluation survey. *Journal of Further and Higher Education*. 1-11.

General Medical Council (GMC) (2016) Colleague and patient feedback for revalidation [online] Available at:

http://www.gmc-uk.org/doctors/revalidation/colleague_patient_feedback.asp

[Accessed 12 August 2016].

Gillam, L., Sullivan, J (2011) Ethics at the end of life: who should make decisions about treatment limitation for young children with life-threatening or life-limiting conditions? *Journal of Paediatrics and Child Health*. Vol 47: 594-598.

Giubilini, A., Minerva, F (2012) After-birth abortion: why should the baby live? *Journal of Medical Ethics*. 39:1-4.charter

Glazer, S., Gyurak, A (2008) Sources of occupational stress among nurses in five countries. *International Journal of Intercultural Relations*. 32 (1): 49-66.

Glover J (1977) *Causing death and saving lives*. Pelican: Harmondsworth.

Grant, M.J., Booth, A (2009) A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Information and Libraries Journal*. 26(2): 91-108.

Guimaraes, H., Rocha, G., Bellieni, C., Buonocore, G (2012) Rights of the newborn and end of life decisions. *Journal of Maternal-Fetal and Newborn Medicine*. 25: 76-78.

Gushee, D (2006) The sanctity of life [online] Available at:
<https://cbhd.org/content/sanctity-life> [Accessed 20 May 2016].

Halbesleben, J., Wakefield, B., Wakefield, D., Cooper, L (2008) Nurse burnout and patient safety outcomes. *Western Journal of Nursing Research*. 30: 560-577.

Happell, B., Dwyer, T., Reid-Searl, K., Burke, K.J., Caperchione, C.M., Gaskin, C.J (2013) Nurses and stress: recognising causes and seeking solutions. *Journal of Nursing Management*. 21(4): 638-347.

Harris J (1985) *The value of life: an introduction to medical ethics*. Routledge: London.

Hawthorne, D.M., Youngblut, J.M., Brooten, D (2015) Parent spirituality, grief and mental health at 1 and 3 months after their infant's/child's death in an intensive care unit. *Journal of Paediatric Nursing*. 31: 73-80.

Health Foundation (2012) Helping people share decision making [online] Available at: <http://www.health.org.uk/sites/default/files/HelpingPeopleShareDecisionMaking.pdf> [Accessed 12 August 2015].

Heidari, H., Hasanpour, M., Fooladi, M (2013) The experiences of parents with infants in neonatal intensive care unit. *Iranian Journal of Nursing and Midwifery Research*. 18:3 208-213.

HM Government (1989) Working for Patients. London. The Stationery Office.

Hoehn, K.S., Wernovsky, G., Rychik, J., Gaynor, J.W., Spray, T.L., Feudtner, C., Nelson, R.M (2005) What factors are important to parents making decision about neonatal research? *Archives of Diseases in Childhood Fetal and Neonatal Edition*. 90: F267-F269.

Holdgraf, C (2015) Decisions in the brain [online] Available at: <http://neuroscience.berkeley.edu/decisions-in-the-brain/> [Accessed 15 November 2016].

House of Commons Health Committee (2007) Patient and public involvement in the NHS [online] Available at: <http://www.publications.parliament.uk/pa/cm200607/cmselect/cmhealth/278/278i.pdf> [Accessed 20 June 2016].

Howell, E., Graham, C (2011) Parents' experiences of neonatal care [online] Available at: <http://www.pickereurope.org/wp-content/uploads/2014/10/Parents-experiences-of-neonatal-care....pdf> [Accessed 5 August 2015].

Illich, I (1976) *Medical Nemesis*. First American Edition. Pantheon Books. New York.

Illich, I (1977) The age of disabling professions. *Inquiry*. 17-21.

Institute of Child Health (2015) PREVenting infections using Antimicrobial Impregnated Longlines Protocol [online] Available at:
http://prevailtrial.org.uk/documents/Protocol%20V3.0_%20Full%20Signatures.pdf
[Accessed 12 September 2016].

Jobe, A.H (2010) Communication in the NICU. *The Journal of Pediatrics*. 157 (2): 215.

Johnson, M., Long, T., White, A (2001) Arguments for 'British pluralism' in qualitative health research. *Journal of Advanced Nursing*. 33: 243-249.

Jollye, S (2009) An exploratory study to determine how parents decide whether to enrol their infants into neonatal clinical trials. *Journal of Neonatal Nursing*. 15: 18-24.

Jones, L., Woodhouse, D., Rowe, J (2007) Effective nurse parent communication: a study of parents perceptions in the NICU environment. 69 206-212.

Kavanaugh, K., Moro, T., Savage, T., Reyes, M., Wydra, M (2009) Supporting parents' decision making surrounding the anticipated birth of extremely premature infant. *Journal of Perinatal and Neonatal Nursing*. 23: 159-170.

Kavanaugh, K., Savage, T., Kilpatrick, S., Kimura, R., Hershberger, P (2005) Life support decisions for extremely premature infants: reports of a pilot study. *Journal of Paediatric Nursing*. 20 (5): 347-359.

Kennedy, I (1988) *Treat me right: Essays in medical law and ethics*. Clarendon Press. Oxford.

Khuse, H., Singer, P (2009) *A companion to bioethics*. 2nd Edition. Wiley-Blackwell. Oxford.

Kincheloe, J.L (2001) Describing the bricolage: conceptualizing a new rigor in qualitative research. *Qualitative Inquiry*. 7(6): 679-692.

Klein, G (2016) The naturalistic decision making approach [online] Available at: <https://www.psychologytoday.com/us/blog/seeing-what-others-dont/201602/the-naturalistic-decision-making-approach> [Accessed 17 February 2017].

Klugman, C (2013) When parents disagree with the doctor [online] Available at: <http://www.bioethics.net/2013/12/when-parents-disagree-with-the-doctor/> [Accessed 12 August 2015].

Knox, K (2004) A researcher's dilemma – philosophical and methodological pluralism. *Electronic Journal of Business Research Methods*. 2(2): 119-128.

Koehler, D.J., Harvey, N (2004) *Blackwell handbook of judgement and decision making*. Blackwell Publishing Limited. Oxford.

Lachman, P., Jayadev, A., Rahi, M (2014) The case for quality improvement in the neonatal intensive care unit. *Early Human Development*. 90: 719-723.

Latour, J.M., Hazelzet, J.A., Duivenvoorden, H.J., Van Goudoever, J.B (2010) Perceptions of parents, nurses and physicians on neonatal intensive care practices. *The Journal of Pediatrics*. 157: 215-220.

Lerner, J.S., Li, Y., Valdesolo, P., Kassam, K (2015) Emotion and decision making. *Annual Review of Psychology*. 66: 799-823.

Levers, M.D (2013) Philosophical paradigms, grounded theory and perspectives on emergence [online] Available at: <http://sgo.sagepub.com/content/spsgo/3/4/2158244013517243.full.pdf> [Accessed 11 May 2016].

Lewenson, S (2008) *Capturing nursing history*. Springer Publishing Company. New York.

Livesey, C (2016) Theory and methods: methodologies [online] Available at: <http://www.sociology.org.uk/cload.htm> [Accessed 11 May 2016].

Lizarraga, M., Baquedano, M., Cardelle-Elawar, M (2007) Factors that affect decision-making: gender and age differences. *International Journal of Psychology and Psychological Therapy*. 7(3): 381-391.

Long, T., Johnson, M (2000) Rigour, reliability, and validity in qualitative research. *Clinical Effectiveness in Nursing*. 4(1): 30-37.

Lyndon, A., Jacobson, C.H., Fagan, K.M., Wisner, K., Franck, L.S (2014) Parents' perspectives on safety in neonatal intensive care: a mixed methods study. *BMJ Quality and Safety* [online] Available at: <http://dx.doi.org/10.1136/bmjqs-2014-003009> [Accessed 28 July 2016].

Manning, A (2012) The NICU experience: How does it affect the parents' relationship? *Journal of Perinatal and Neonatal Nursing*. 26(4): 353-357.

Mark, G., Smith, A.P (2012) Occupational stress, job characteristics, coping, and the mental health of nurses. *British Journal of Health Psychology*. 17 (3): 505-521.

Marlow, N., Gill, B (2007) Establishing neonatal networks: the reality. *Archives of Diseases in Childhood Fetal and Neonatal Edition* 92: F137-F142.

McEwan, T., Pollard, M., Rankin, J., (2014) Newly qualified children's nurses experiences of supporting postnatal women within Scottish neonatal units. *Journal of Neonatal Nursing*. 20: 95-101.

McGann, E (2010) Staff-family communications in the NICU: An expert interview with Liza Cooper, LMSW. [online] Available at: <https://www.medscape.com/viewarticle/729514> [Accessed 11 November 2017].

McGurk, V., Bean, D., Gooney, T., Markland, J., Fillingham, K., Tebbutt, T., Brewer, P (2007) Treating patients well: improving the patient experience. *Journal of Neonatal Nursing*. 13: 225-230.

McHaffie, H (2001) *Crucial decisions at the beginning of life: parents' experiences of treatment withdrawal from infants*. Abingdon. Radcliffe Publishing Limited.

McKay, C (2010) A partnership approach to transforming the neonatal workforce. *Journal of Neonatal Nursing*. 16: 147-149.

Medical Protection Society (2012) Parental responsibility [online] Available at: <http://www.medicalprotection.org/docs/default-source/pdfs/factsheet-pdfs/england-factsheet-pdfs/parental-responsibility.pdf?sfvrsn=7> [Accessed 12 August 2015].

Meill, A., Ericson, G (2012) The trouble with treating patients as consumers [online] Available at: <https://hbr.org/2012/01/the-trouble-with-treating-pati> [Accessed 29 March 2016].

Merriam-Webster (2015) Autonomy [online] Available at: <http://www.merriam-webster.com/dictionary/autonomy> [Accessed 14 August 2015].

Miles, M.B., Huberman, M., Saldana, J (2014) *Qualitative data analysis: A methods sourcebook*. Third ed. London. Sage.

National Audit Office (2007) *Caring for vulnerable babies: The reorganisation of neonatal services in England*. The Stationery Office. London.

National Health Service Digital (2017) Data on written complaints in the NHS, 2017-2018 quarter 1, experimental [online] Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/data-on-written-complaints-in-the-nhs/data-on-written-complaints-in-the-nhs-2017-18-quarter-1-experimental> [Accessed 12 January 2018].

National Institute for Health and Care Excellence (2010) Specialist neonatal care quality standard: quality statement 5: Encouraging parental involvement in care [online] Available at: <https://www.nice.org.uk/guidance/QS4/chapter/Quality-statement-5-Encouraging-parental-involvement-in-care> [Accessed 1 September 2015].

National Institute for Health Research (2013) The NIHR Performance in Initiating and Delivering Clinical Research (70-day benchmark) and the NIHR Clinical Research Network High Level Objectives: a description of purpose, definition and differences [online] Available at: <http://www.nihr.ac.uk/documents/policy-and-standards/Faster-easier-clinical-research/NIHR-Metrics-Comparison-CCF-December-2013.pdf> [Accessed 12 August 2016].

National Institute for Health Research (2014) Patient and public involvement in health and social care research: a handbook for researchers [online] Available at: <http://www.nihr.ac.uk/funding/how-we-can-help-you/RDS-PPI-Handbook-2014-v8-FINAL.pdf> [Accessed 20 June 2016].

National Institute for Health Research (2015a) Welcome to INVOLVE [online] Available at: <http://www.invo.org.uk/> [Accessed 20 June 2016].

National Institute for Health Research (2015b) Public involvement in research: values and principles framework [online] Available at: <http://www.invo.org.uk/wp-content/uploads/2015/11/Values-and-Principles-framework-final-October-2015.pdf> [Accessed 20 June 2016].

National Society for the Prevention of Cruelty to Children (NSPCC) (2014) 'We have the right to be safe.' Protecting disabled children from abuse [online] Available at: <https://www.nspcc.org.uk/globalassets/documents/research-reports/right-safe-disabled-children-abuse-report.pdf> [Accessed 20 March 2016].

NHS Choices (2014) The history of the choice. [online] Available at:

<http://www.nhs.uk/Tools/Documents/The%20history%20of%20choice%20timeline%202013.htm> [Accessed 24 May 2016].

NHS Commissioning Board (2012) Developing operational delivery networks. [online] Available at:

<https://www.england.nhs.uk/wp-content/uploads/2012/12/develop-odns.pdf> [Accessed 27 July 2016].

NHS England (2016) Shared decision making [online] Available at: <https://www.england.nhs.uk/shared-decision-making/> [Accessed 27 September 2016].

Noble, H., Smith, J (2015) Issues of validity and reliability in qualitative research. *Evidence-based Nursing*. 18: 34-35.

Nursing and Midwifery Council (NMC) (2010) *Standards for pre-registration nursing education*. NMC London.

Nuffield Council on Bioethics (2006) Critical care decisions on fetal and neonatal medicine: ethical issues [online] Available at: <http://nuffieldbioethics.org/wp-content/uploads/2014/07/CCD-web-version-22-June-07-updated.pdf> [Accessed 1 June 2015].

Nuffield Council on Bioethics (2007) Critical care decisions on fetal and neonatal medicine: ethical issues. A guide to the report [online] Available at:

<http://nuffieldbioethics.org/wp-content/uploads/2014/07/CCD-Short-Version-FINAL.pdf> [Accessed 20 May 2016].

Office for National Statistics (2018) Childhood, infant and perinatal mortality in England and Wales: 2016 [online] Available at:

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/childhoodinfantandperinatalmortalityinenglandandwales/2016>

Office for Public Management (2014) Evaluation of Making it Better [online] Available at:

<http://www.opm.co.uk/wp-content/uploads/2014/09/Evaluation-of-Making-it-Better.pdf> [Accessed 28 July 2016].

O'Mahoney, S (2016) Medical Nemesis 40 years on: the enduring legacy of Ivan Illich. *The Journal of the Royal College of Physicians of Edinburgh*. 46: 134-139.

Orasanu, J., & Connolly, T (1993) The reinvention of decision making. In G. A. Klein, J. Orasanu, R. Calderwood, & C. E. Zsombok (Eds.), *Decision making in action: models and methods* (pp. 3-20). Westport, CT, US: Ablex Publishing.

Paparella, G (2016) The state of maternity services in England [online] Available at: <http://www.pickereurope.org/wp-content/uploads/2016/07/Maternity-services-policy-briefing-V2.pdf> [Accessed 16 September 2016].

Parfitt, Y., Ayers, S., Pike, A., Jessop, A.C., Ford, E (2014) A prospective study of the parent-baby bond in men and women 15 months after birth. *Journal of Reproductive and Infant Psychology*. 32: 441-456.

Peedell, C (2014) The NHS is not like a supermarket. Patients are not consumers. NHA news. [online] Available at: <http://nhap.org/nhs-like-supermarket-patients-consumers/> [Accessed 20 July 2016].

Penacoba-Puente, C., Monge, F.J., Morales, D.M (2011) Pregnancy worries: a longitudinal study of Spanish women. *Acta Obstetrica et Gynecologica Scandinavica*. 90: 1030-1035.

Provoost, V., Cools, F., Deconinck, P., Ramet, J., Deschepper, R., Bilsen, J., Mortier, F., Vandenplas, Y., Deliens, L (2006) Consultation of parents in actual end-of-life decision-making in neonates and infants. *European Journal of Paediatrics*. 165: 859-866.

Queensland Government (2011) Child protection intervention with high risk infants [online] Available at:

<https://www.communities.qld.gov.au/resources/childsafety/practice-manual/intervention-with-high-risk-infants.pdf> [Accessed 12 March 2016].

Queensland Health (2012) Guide to informed decision-making in healthcare [online] Available at:

<https://www.health.qld.gov.au/consent/documents/ic-guide.pdf> [Accessed 02 December 2015].

Rapoport, A (1998) Decision theory and decision behaviour. Second Edition. Palgrave Macmillan. United Kingdom.

Redshaw, M., Hamilton, K (2006) Networks, admissions and transfers: the perspectives of networks, neonatal units and parents [online] Available at: <https://www.npeu.ox.ac.uk/downloads/files/reports/New-Neonatal-Survey.pdf> [Accessed 04 July 2016].

Reid, T., Bramwell, R., Booth, N., Weindling, M (2007) Perceptions of parent-staff communication in a neonatal intensive care: the findings from a rating scale. *Journal of Neonatal Nursing*. 13 64-74.

Resnick, M (2012) The effect of affect: decision making in the emotional context of healthcare. [online] Available at: <https://pdfs.semanticscholar.org/4601/050527ee66fef32bcb0502e9705f973de81b.pdf> [Accessed 16 November 2016].

Rocchi, B (2013) Why should the baby live? Human right to life and the precautionary principle. *Journal of Medical Ethics*. 39: e6-e10.

Rolfe, G (2006) Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Journal of Advanced Nursing*. 53(3): 304-310.

Ross-Davie, M., Butcher, G., Davidson, M., Alleley, C.S., Fergie, J., Puckering, C., Trevarthen, C (2014) Bonding and attachment in the perinatal period: Supporting rich and enjoyable relationships for life [online] Available at:
<http://www.maternal-and-early-years.org.uk/file/a9f7e9d6-c784-4015-9f2d-a3760101ff8f>

Royal Australasian College of Physicians (2008) Decision-making at the end of life in infants, children and adolescents [online] Available at:
<https://www.racp.edu.au/docs/default-source/advocacy-library/decision-making-at-the-end-of-life-in-infants-children-and-adolescents.pdf?sfvrsn=8> [Accessed 02 December 2015].

Royal College of Paediatrics and Child Health (RCPCH) (2015a) National Neonatal Audit Programme (NNAP) [online] Available at:
<http://www.rcpch.ac.uk/improving-child-health/quality-improvement-and-clinical-audit/national-neonatal-audit-programme-nn-3> [Accessed 08 November 2015].

Royal College of Paediatrics and Child Health (2015b) National Neonatal Audit Programme 2015 annual report on 2014 data [online] Available at:
<http://www.rcpch.ac.uk/system/files/protected/page/NNAP%20report%20updated%2004.11.15WEB.pdf> [Accessed on 08 November 2015].

Schiller, C (2016) Critical realism in nursing: an emerging approach. *Nursing Philosophy*. 17(2): 88-102.

Scotland, J (2012) Exploring the philosophical underpinnings of research: Relating ontology and epistemology to the methodology and methods of the scientific, interpretive and critical research paradigms. *English Language Teaching*. 5: 9-16.

Simon, H (1967) Motivational and emotional controls of cognition. *Psychological review*. 74 (1): pp 29-39.

Spence, K (2000) The best interest principle as a standard for decision making in the care of neonates. *Journal of Advanced Nursing*. 31 (6): 1286-1292.

Stanworth, S., Curley, A., Deary, A., Willoughby, K (2015) PLANET 2 [online] Available at: <http://www.planet-2.com/> [Accessed 22 October 2015].

Steele, K., Stefansson, O (2015) Decision theory [online] Available at: <https://plato.stanford.edu/entries/decision-theory/> [Accessed 16 November 2016].

Stuart, K., Alger, A (2011) The use of transactional analysis in secondary education: a case study. *Teacher Education Advancement Network Journal*. 3(1): 1-29.

Sullivan, G.M., Artino, A.R (2013) Analysing and interpreting data from likert-type scales. *Journal of graduate medical education*. 5(4): 541-542.

Sundean, L.J., McGrath, J.M (2013) Ethical considerations in the neonatal intensive care unit. *Newborn and Infant Nursing Reviews*. 13: 117-120.

Swift, M., Scholten, I (2009) Not feeding, not coming home: parental experiences of infant feeding difficulties and family relationships in the neonatal unit. *Journal of Clinical Nursing*. 19 249-258.

Tahirkheli, N.N., Cherry, A.S., Tackett, A.P., McCaffree, M., Gillaspay, S.R (2014) Postpartum depression on the neonatal intensive care unit: current perspectives. *International Journal of Women's Health*. 6: 975-987.

Ultanir, E (2012) An epistemological glance at the constructivist approach: constructivist learning in Dewey, Piaget and Montessori. *International Journal of Instruction*. 5(2): 1308-1470.

Umass Dartmouth (2017) 7 steps to effective decision making (online) Available at: <https://www.umassd.edu/fycm/decisionmaking/process/> [Accessed 16/11/2017]

United Nations (1948) The universal declaration of human rights [online] Available at: http://www.ohchr.org/EN/UDHR/Documents/UDHR_Translations/eng.pdf [Accessed 15 August 2016].

United Nations International Emergency Children's Fund (UNICEF) (1989) The United Nations convention on the rights of the child [online] Available at: http://www.unicef.org.uk/Documents/Publication-pdfs/UNCRC_PRESS200910web.pdf [Accessed 25 August 2016].

University of Cambridge (2017) Guidelines for the critical literature review (online) Available at: <https://www.hps.cam.ac.uk/students/partiii-guide/essays-dissertation/clr> [Accessed 01/04/2018].

UK Association for Transactional Analysis (2016) Ego states [online] Available at: <https://www.uktransactionalanalysis.co.uk/transactional-analysis/key-concepts/ego-states> [Accessed 15 December 2017].

Van Manen, M.A (2014) On ethical (in) decisions experienced by parents of infants in neonatal intensive care. *Qualitative Health Research*. 24(2): 279-287.

Vazquez, V., Cong, X (2014) Parenting the NICU infant: a metaethnographic synthesis. *International Journal of Nursing Sciences*. 1(3): 281-290.

Vigod, S.N., Villegas, L., Dennis, C.L., Ross, L.E (2010) Prevalence and risk factors for postpartum depression among women with preterm and low birth-weight infants: a systematic review. *British Journal of Obstetrics and Gynaecology*. 117 (5): 540-550.

Walker, S (2014) Potential persons and the welfare of the (potential) child test. *Medical Law International*. 14: 157-171.

Watts, R (2016) *BFFAS*. [email].

Wiebe, A., Young, B (2011) Parents perspectives from a neonatal intensive care unit: a missing piece of the culturally congruent care puzzle. *Journal of Transcultural Nursing*. 22:1 77-82.

Wigert, H., Blom, M., Bry, K (2013) Strengths and weaknesses of parent-staff communication in the NICU: a survey assessment. *BMC Pediatrics*. 13:71 1-15.

Wigert, H., Blom, M., Bry, K (2014) Parents' experiences of communication with neonatal intensive care staff: an interview study. *BMC Pediatrics*. 14:304 1-8.

Wright, P (2003) Ivan Illich. *Lancet*. 361: 185.

Wyatt, J (2007) End of life decisions, quality of life and the newborn. *Acta Paediatrica*. 96(6): 790-791.

Zarei, E., Khakzad, N., Reniers, G., Akbari, R (2016) On the relationship between safety climate and occupational burnout in healthcare organisations. *Safety Science*. 89: 1-10.

Zeelenberg, M., Nelissen, R.M., Breugelmans, S.M., Pieters, R (2008) On emotion specificity in decision making: why feeling is for doing. *Judgement and Decision Making*. 3(1): 18-27.

APPENDICIES

APPENDIX 1: Consent to contact form

CONSENT TO CONTACT FORM

(Version 2, 01 November 2015)

A qualitative study examining parental views and desires regarding participation in decision-making in two neonatal intensive care units.

I agree that my contact details as given below can be given (in person or by telephone or secure fax) to the researchers carrying out the above study. This will enable them to contact me and arrange a time/place to explain the study in more detail so that I can then decide whether or not to take part.

BLOCK CAPITALS PLEASE:

Name of baby: _____

Name of parent/guardian: _____
(Mr/Mrs/Miss/Ms, Forename, Surname)

Address: _____

Postcode: _____

Main contact number: _____

Alternative contact number: _____

E-mail address: _____

Preferred time to be contacted: _____

Signature of parent/guardian: _____

Date: _____

Patient identification number for this study

APPENDIX 2: Parent information sheet

A mixed methods study examining parental views and desires regarding participation in decision-making in two neonatal intensive care units

Chief Investigator: Mrs Natalie Fairhurst Principle/Local Investigator: Dr Michelle Parr

Information sheet for parents or guardians of babies in neonatal intensive care (Version 2, 01 November 2015)

We would like to invite you to take part in a study. Before you decide we would like you to understand why the research is being done and what it would involve from you. Please ask us if anything is not clear to you.

Introduction

In 2003, neonatal services were divided into 23 networks across England. Through past research it has been identified that there are differences between the quality and consistency of care that babies are receiving throughout these networks. Research by Bliss, the neonatal charity, highlighted that parental involvement in care is an area where significant improvements can be made. There are many important decisions to be made about a baby's care whilst in neonatal intensive care. It is known that all parents have different desires and needs, and care should be amended accordingly.

What is the purpose of the study?

This study is designed to discover what parents or guardians experience when making decisions for their babies in neonatal intensive care, as well as finding out what they want and need. This would help nurses and doctors to improve the quality of care they provide to parents and their families.

Why have I been asked to participate in this study?

You are the parent or guardian of a baby who has been in neonatal intensive care at St Mary's Hospital between 1 and 3 weeks. You are very likely to have had some experience in making a decision for your baby whether that is about feeding or an intensive care treatment.

Do I have to take part in the study?

No, taking part is entirely up to you. If you do not wish to take part, you do not have to give a reason. Your nurse and doctor will not be upset and it will not affect your baby's treatment in any way. If you do take part but later change your mind, you can withdraw from the study at any time and without influencing the future care of your baby, but we would ask that we could use the information that we have up to that point in the study. If you agree to take part in the study, we will ask you to sign a consent form. You will be given a copy of the consent form and this information sheet to keep. Any information you share will be anonymous, and access to the information will be limited to the research team.

What happens during the research study?

You will be asked to take part in the study when your baby has been in neonatal intensive care between 1 and 3 weeks. The study will be in 2 parts as follows:

1. **Questionnaire.** The questionnaire will consist of 10 questions about your involvement in decision-making about your baby whilst in neonatal intensive care. You will have 48 hours to complete and return it. The questionnaire should take around 10 minutes to complete.
2. **Discussion.** Once the survey has been returned to the researcher you may be contacted and asked to participate in a discussion to talk further about the answers you gave on the questionnaire. This will not be requested of all parents. It will be undertaken in a quiet, comfortable location on the neonatal unit and will be a one-to-one discussion with the researcher. The discussions will be recorded so that the researcher can concentrate on listening to what you say rather than writing. You can request for the recording to be stopped at any time and for words to be deleted or replaced. The discussion will usually last around 30 minutes, though this will depend on how much you would like to discuss.

Are there any possible benefits for me or my baby?

As we are trying to find out what parents are currently experiencing and what they would like to happen, this research is unlikely to benefit you or your baby directly. However, some parents may find it beneficial to talk in confidence to someone who does not work at the hospital about their experiences in neonatal intensive care.

What are the risks of taking part in the study?

We hope that taking part in this study will be a good experience for everyone involved. However, it is possible that you may become upset when discussing issues about decision-making for your baby. If this is the case then we can offer all the necessary support through the neonatal unit staff.

What happens to the information and results you get from studying me?

Information from the study will be kept securely on computers at the University of Salford. The data will be made anonymous and kept confidential, accessible only to members of the research team. The results of the study will be shared widely with other healthcare professionals working in neonatal intensive care through publication in journals and presentation at conferences, but neither you nor your baby will be identified by your name or any other details. Anonymised direct quotes may be used with your consent. The information from this work will be stored for 5 years as required by the NHS.

What if I have any concerns?

If you have any concerns about the study or the way in which it is being carried out you should contact your baby's consultant, or the hospital PALS (Patient Advice and Liaison Service) co-ordinator on 0161 276 8686. Alternatively, you can contact the Chief Investigator, Natalie Fairhurst at n.fairhurst@edu.salford.ac.uk or the Principal Investigator, Dr Michelle Parr, Consultant Neonatologist at the Neonatal Intensive Care Unit on 0161 901 2700.

Finally, thank you for the time you have spent reading this information sheet. It is given only as an outline of what will happen and if you have any further questions or concerns then please do not hesitate to discuss them with us.

APPENDIX 3: Consent form

Patient identification number for this study

PARENT/GUARDIAN CONSENT FORM (Version 2; 01 November 2015)

A qualitative study examining parental views and desires regarding participation in decision-making in two neonatal intensive care units

Chief Investigator: Mrs Natalie Fairhurst. Principle/Local Investigator: Dr Michelle Parr

Name of patient

Name of parent.....

**Please
initial**

- 1. I confirm that I have read and understood the information sheet(s) (version 2, 01.11.15) for the above study and have had the opportunity to ask questions.
- 2. I understand that my participation is voluntary, and I am free with withdraw at any time, without giving reason, and without my baby's medical care or legal rights being affected.
- 3. I agree to be invited to discuss my responses to the survey in further detail (if selected) with the researcher.
- 4. I give permission for the discussion session to be audio-recorded, with access to the transcripts being restricted to the research team.
- 5. I give permission for anonymised direct quotes to be used in study publications
- 6. I agree to take part in the above study.
- 7. I understand that sections of my baby's medical notes may be looked at by responsible individuals from the University of Salford or Central Manchester University Hospitals NHS Foundation Trust, who are regulating the research, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my baby's records.

Name of parent

Date

Signature

Name of researcher

Date

Signature

APPENDIX 4: Survey

Parental Survey

(Version 2, 01 November 2015)

This survey consists of ten structured questions with a choice of five possible answers ranging from *strongly agree* to *strongly disagree*. Please circle the answer you feel is most appropriate to your experience whilst in neonatal intensive care and add a comment if explaining your response would help.

Age: _____

Sex: _____

Occupation: _____

Religion: _____

Number of other children: _____

1) ***I understand the reason for my baby's admission to the neonatal intensive care unit.***

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
----------------	-------	-----------	----------	-------------------

Comment: _____

2) ***My understanding of the reason for my baby's admission changed as time progressed.***

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
----------------	-------	-----------	----------	-------------------

Comment: _____

3) ***I felt involved in the decision-making regarding my baby's care.***

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
----------------	-------	-----------	----------	-------------------

Comment: _____

4) ***I felt involved in the daily ward rounds.***

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
----------------	-------	-----------	----------	-------------------

Comment: _____

5) ***I felt that staff listened to my views and concerns.***

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
----------------	-------	-----------	----------	-------------------

Comment: _____

6) ***I had adequate meetings or discussions with my named consultant.***

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
----------------	-------	-----------	----------	-------------------

Comment: _____

7) ***I could suggest changes which would have improved my understanding and recollection of information given.***

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
----------------	-------	-----------	----------	-------------------

Comment: _____

8) ***I felt able to ask questions about my baby's care.***

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
----------------	-------	-----------	----------	-------------------

Comment: _____

9) ***I felt able to challenge information provided to me about my baby's care.***

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
----------------	-------	-----------	----------	-------------------

Comment: _____

10) ***I felt happy with the decisions that I made, or assisted to make, regarding my baby's treatment.***

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
----------------	-------	-----------	----------	-------------------

Comment: _____

Please complete this survey within 48 hours and return to the researcher, Natalie Fairhurst. You can also post this survey in the allocated box at the reception desk on neonatal intensive care.

Patient ID

APPENDIX 5: Interview guide

Interview Guide
 (Version 1, 04 September 2015)

<p>Introduction</p> <p>Key Components</p> <ul style="list-style-type: none"> • Thank you • My name • Purpose • Confidentiality • Duration • How interview will be conducted • Opportunity for questions • Confirmation of consent 	<p>I want to thank you for taking the time to meet with me today. We have met before, but my name is Natalie Fairhurst and I would like to talk to you in further detail about the answers that you gave on the survey about your involvement in your baby's management in neonatal intensive care.</p> <p>The discussion should take around 30 minutes. I will be audio-recording the session as I don't want to miss any of your comments. Although I may be taking some notes during our conversation I cannot possibly write fast enough to take it all down</p> <p>All responses are kept confidential and will have no bearing on your baby's management. This means that your responses will only be shared with the research team and any information published in the future will be completely anonymised. Remember, you don't have to talk about anything you don't want to and you can end the discussion at any time.</p> <p>Do you have any questions about what I have just explained?</p> <p>Are you still happy to continue with the discussion?</p>
---	---

<p>Questions</p> <ul style="list-style-type: none"> • No more than 10 open-ended questions • Use probes as needed 	<ol style="list-style-type: none"> 1) Would you like to talk to me about the time leading up to, and the reason for admission of your baby to neonatal intensive care? 2) If at all, in what way did your understanding of your baby's admission to neonatal intensive care change over time? 3) How do you feel about your involvement in the decision-making about your baby's management? 4) Can you talk to me about your involvement in daily ward rounds? 5) To what extent did the nursing or medical staff listen to your views and concerns? 6) What do you think about the amount of meetings or discussions that you had with your baby's named consultant? 7) What changes can you suggest that would have improved your understanding and recollection of the information you were given? 8) How did you deal with asking questions about your baby's care? 9) Did you at any time need to challenge the information given to you about your baby's care, and if so how did you find this? 10) How do you feel about the decisions that you made, or helped to make, about your baby's treatment?
<p>Closing</p> <p>Key components</p> <ul style="list-style-type: none"> • Additional comments • Next steps • Thank you 	<p>Is there anything more you would like to add?</p> <p>Once all the information is collected I will analyse it. Eventually I will submit the results in my thesis, publish journal articles and present at conferences.</p> <p>Thank you very much for your time.</p>

APPENDIX 6: NHS REC approval


Health Research Authority
National Research Ethics Service

North West - Preston Research Ethics Committee

Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 01616257818

09 November 2015

Mrs Natalie Fairhurst
10 Kirkstile Crescent
Winstanley
Wigan
WN3 8TE

Dear Mrs Fairhurst

Study title: A mixed methods study examining parental experiences and desires regarding their participation in decision-making in two neonatal intensive care units
REC reference: 15/NW/0840
IRAS project ID: 173169

Thank you for responding to the Committee's request for further information on the above research and submitting revised documentation.

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

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Mrs Carol Ebenezer, nrescommittee.northwest-preston@nhs.net.

Confirmation of ethical opinion

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

Conditions of the favourable opinion

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

Management permission or approval must be obtained from each host organisation prior to the

APPENDIX 7: University of Salford REC Approval



University of
Salford
MANCHESTER

Research, Enterprise and Engagement
Ethical Approval Panel

Research Centres Support Team
G0.3 Joule House
University of Salford
M3 4WT

T +44(0)161 295 2280

www.salford.ac.uk/

27 April 2018

Dear Natalie,

RE: ETHICS APPLICATION–HSR1718-045 – ‘An interview-based study examining previous parental experiences and desires regarding participation in decision-making in neonatal intensive care units.’

Based on the information that you have provided, I am pleased to inform you that ethics application HSR1718-045 has been approved.

If there are any changes to the project and/or its methodology, then please inform the Panel as soon as possible by contacting Health-ResearchEthics@salford.ac.uk

Yours sincerely,

Professor Sue McAndrew
Chair of the Research Ethics Panel