THE PERCEPTIONS OF NEONATAL NURSES' TOWARDS EXTREMELY PRETERM INFANTS

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Why?

This study began over 6 years ago when I was working on a tertiary level neonatal intensive care unit. I was amazed and intrigued by the advances in technology, and the ability that we had to sustain the lives of the smallest infants I had ever seen. As I spent more and more time on the neonatal unit, I began to experience something which I had not expected in such an emotional environment during the decisions which being made for these infants; the disengagement of parents with their infant's carers at the precise moment when they needed their support the most.

One particular case stood out to me and has stayed with me ever since, reinvigorating my enthusiasm for this study every time it faltered. An extremely preterm infant on the unit was dying and the health care team had reached the conclusion that the extraordinary technology which was maintaining the infants' life should be withdrawn. The discussion was initiated with the parents about what course of action they would like to take with their infant.

The parents did not agree that the technology should be removed from their infant. Over the next few days, the tension between the family and the health care team grew as the parents 'refused' to withdraw the technological care from the infant. Several nurses began to 'refuse' to look after the infant due to their 'disagreement' with the situation and their views that what the parents were doing was 'cruel' to the infant. Whatever support the parents had initially on the neonatal unit from the nurses, they had somehow lost in their desperation to save their infant.

It was a week later that the infant died without the withdrawal of intensive care. Gradually his heart rate stopped, and, with the parent's agreement, resuscitation was not attempted. It struck me how the parents were likely to remember the death of their infant as being surrounded by tension, and not as a peaceful or positive experience for them all.

This situation, along with others, led me to the conclusion that there had to be a reason why there were disagreements in respect of decisions with such preterm infants. The breakdown in the communication with the parents also led me to believe that there were things that could be done to improve this relationship, to improve not only the parent's experience on the neonatal unit, but also the nurses in question.

I put together a successful research application to the Economic and Social Research Council (ESRC) to study neonatal nurse's perceptions towards extremely preterm infants, and during the three years which I have taken to complete this study, my experiences have stayed with me and have been joined by new ones as my clinical experience continues. The perceptions of neonatal nurses now, just as much as then, are vitally important in how they judge the situation they face.

Abstract

Technological advances in neonatal care have meant that the survival rates of preterm infants have dramatically increased. Improvements in mortality have not been reflected in improvements in morbidity, however, and the chances of extremely preterm infants surviving free from serious morbidity remain low.

Concerns regarding mortality and morbidity rates have resulted in a plethora of ethical debates surrounding extremely preterm infants. The application and cost of advancing technology has been questioned. The impact that the risk of severe disability should have on decision making, along with who should make these decisions, the parents or the health care professionals, remains under debate. The influence that advancing fertility treatment has on decision making has yet to be explored, despite causing controversy in the media. Improving mortality rates have also prompted a proposal to reduce the current abortion limits in the United Kingdom.

Despite a wealth of research into these ethical dilemmas, the voices of neonatal nurses towards these debates surrounding the infants which they care for have remained silent. The aim of this study is to therefore explore the perceptions of neonatal nurses towards extremely preterm infants.

Q methodology was used to explore the attitudes of 36 nurses working in a perinatal network in the United Kingdom. Nurses ‘sorted’ a set of 53 statements developed from literature and previous research which represented the debates surrounding extremely preterm infants. Nurses then participated in a 'post Q sort' interview to explore the rationale behind their placement of the statements.

The findings indicated that there were three types of nursing perceptions towards extremely preterm infants, centred on the involvement of parents in making difficult decisions. Some nurses reported their belief in accounting for parental choice is making difficult decisions. For others, they discussed their beliefs that the health care professional should undertake difficult decisions. The remaining nurses reported a belief in technology over and above decision making, suggesting that technology would prevail and allow more preterm infants to survive. The findings reflected the complex neonatal environment where core 'learnt' nursing values were often difficult to implement.

Highlighting the perceptions of neonatal nurses' towards extremely preterm infants allowed for an in-depth exploration of the rationale behind these patterns of perceptions. Conclusions were drawn from this regarding how to improve the engagement of not only neonatal nurses, but the parents also, in the infant's care. A palliative care policy is suggested from these findings in order to help nurses make the transition from curative to palliative care. The conceptual framework developed for the study was adjusted accordingly, and future clinical and research recommendations made.

Acknowledgements

As I sit writing these acknowledgements, I realise that they symbolise a chapter of my life drawing to a close. The highs and the lows that I have gone through during this time have astonished me, and if it were not for the following people, may have meant that I would not be sitting writing these words today.

To my wonderful supervisors: Davina Porock, Alison Edgley, and Neil Marlow. You provided encouragement when required, advice when necessary and more than anything made me believe in myself that this was possible. After years of incessant questions, you can finally rest. Davina, you have made me giggle so much over these 4 years. May our paths continue to intertwine, and who knows where they will meet again?

To my fabulous friends, who have provided words of encouragement and nights out when needed; you know who you are, but you will never know how much this helped me. In particular to Jo, Lynn, Nicola and Odessa, who have shared my journey and provided more support than I can ever thank them for.

To my family, especially my mum and dad. You have endured my nightly phone calls for many years, and have never complained. You have been there for me when I needed you, and are more than parents; you are my closest friends. Thank you. I hope I have made you proud.

And so to you, Alex. How you put up with me for all this time I will never know. You have made me smile, you have made me laugh, you have wiped away the tears, and you have shared in my successes. You have kept me grounded. You have helped to make me who I am. There are simply no words which could ever do you justice. How sweet it is to be loved by you.

This thesis is for all of those nurses who graciously gave up their time and for the infants and their families who find themselves on the neonatal unit. May we never stop to trying to improve the experiences of these heroic people.

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Chapter 1: Introduction

1.1 Introduction

Technological advances in neonatal care have meant that the chances of survival for premature infants have dramatically increased. Smaller and smaller infants can now survive who would not have survived 10 years ago. The chances of survival free from morbidity for the smallest infants has not mirrored these ‘successes’, however, and remains high. The limits of infant viability therefore remain “a grey zone of gestational age in which the prognosis for survival and quality of life are uncertain” (Payot, Gendron, Lefebvre and Doucet 2007 p.1487). In parallel with the medical advancements enabling these infants to survive, the ethical debates regarding whether these infants should be treated have proliferated. The attitudes of physicians towards this dilemma have been reported; the voices of the neonatal nurses working with the infants’ and their families have remained silent. As arguably the group of health care professionals who spend the most time with the infant and their family, the importance of nurses’ perceptions have been missed as a significant factor when determining how parents are influenced in the decision making for their extremely preterm infants.

This thesis presents a study into the perceptions of neonatal nurses towards extremely preterm infants, with the aim of making explicit the perceptions which arguably neonatal nurses have but have remained unvoiced. Through recognising these perceptions and the impact of current debates on neonatal nurses, any potential to improve the parental experience of having an extremely preterm infant on the neonatal unit can be addressed from the nurses perspective, and build the foundations for exploring the experiences of the parents.

1.2 Thesis Aims

The aims of the study are to:

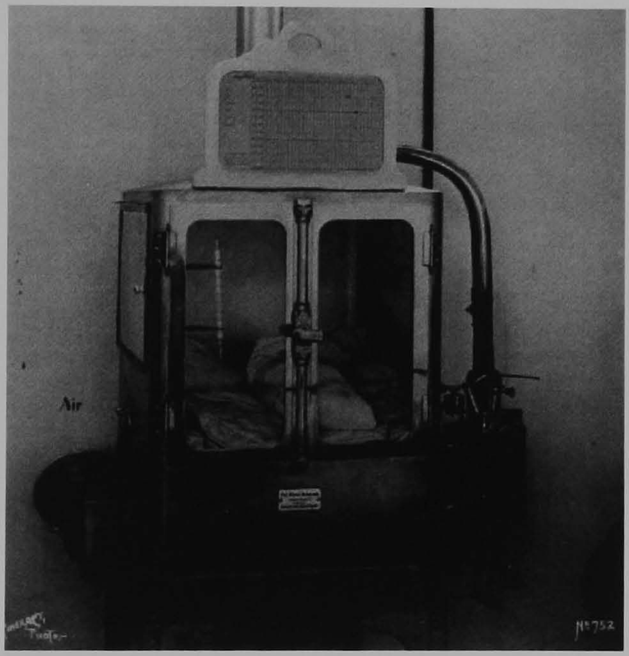
1. Discover neonatal nurse's perceptions towards viability and its surrounding debates.
2. Determine any patterns of perceptions towards viability amongst neonatal nurses.

1.3 The Context of the Study

Neonatal care only emerged as a specialty of care within the last few decades in the UK. Understanding the historical development of neonatal care places into the context the great advances which have been made in a relatively short space of time, highlighting the relevance of the current debates which are now surrounding extremely preterm infants. An overview of the history of neonatal care will therefore be presented. This is intended to introduce the reader to the subject area, provide a context to the study and highlight how the current historical moment has been achieved in which extremely preterm infants at 24 weeks gestation and less can survive.

1.3.I The Historical Development of Neonatal Care

Prior to the late 1880's infants held little interest for doctors, reflected in a lack of institutions which had dedicated care for newborn infants (Lussky 1999). Concerns over severely declining birth rates along with high infant mortality rates in the 1880's, spurred a French Obstetrician, Etienne Stephanie Tarnier, to build a device which he claimed could lower the infant mortality rate by up to 50%. Tarnier named the device, created from the modification of a warming chamber for the rearing of poultry (Lussky 1999), the 'incubator' (Davis, Mohay and Edwards 2003 picture 1.1).



Picture 1.1: Trans-Mississippi Exposition, Nebraska, 1898 (Omaha Public Library 1998)

Pierre Constant Budin, a fellow obstetrician and associate of Tarnier, was named by Tarnier as the person he would like to see continue his work following his death in 1897 (Dunn 1995). Budin excelled in the area of neonatal care and his work went on to see him referred to as the 'father of modern perinatal care' (Dunn 1995). In 1907 Budin published 'The Nursling', and in a series of lectures in Paris discussed the contents of this work. Budin had identified three crucial elements which he believed required consideration when striving for the survival of preterm infants: "temperature and chilling, feeding, and disease" (Oppenheimer 1996 p.871). Budin also highlighted the problems of infant prematurity, stating that "to appreciate the vitality of infants born before term, it is necessary, not only to take into account their weight, but also the time they have remained in the uterine cavity" (Budin 1907 Lecture 1 p.2). Budin classified infants born as a result of preterm labour 'weaklings', and rarely referred to infants born at less than 1000g as these were "seldom saved" (Budin 1907 Lecture 1 p.2).

Budin was keen raise the profile of caring for premature infants and their subsequent potential survival rates, and in the late 1800's asked a colleague, Dr Martin Couney, to demonstrate the effectiveness of the incubator at world fairs and exhibitions (Davis et al 2003; picture 1.2 & 1.3). Couney travelled to America to display the incubators, and complete with live premature infants, highlighted the successes of Budin and Tarnier. Admission fees were charged to see the infants (exceptions were made for the mothers), and despite the questionability of mass marketing of premature babies, the exhibits laid the foundations for future premature care nurseries by promoting a clean enclosed environment for infants to thrive in (Davis et al, 2003).

Due to the high number of mothers losing interest in their infants following the separation from their infants to 'weakling units' at birth (Dunn 1995), Budin was a strong advocator of a mother's involvement in caring for her preterm infant. Despite this, the promotion of incubators in enclosed environments further emphasised the separation of the mother and her infant (Davis et al 2003).

Picture 1.2: “Infant Incubators with Living Infants” Exhibition at Luna Park in Coney Island (Neonatology 2009a)

Picture 1.3: Nurses from the Coney Island Exhibition holding the “Living Infants” of the incubators (Neonatology 2009)

As France was experiencing the decline in birth rates and increases in infant mortality rates, so was Britain. In 1900, infant mortality rates were high, reaching 140 deaths per 1000 births (Hicks & Allen, 1999). These figures prompted physicians to attempt to preserve the lives of infants born at all gestations for "economic and sentimental" reasons (Silverman, 1980 p.10). The gradual hospitalisation for child birth in Britain throughout the 1920's saw infants indirectly placed under the care of the obstetrician (Wrede, Benoit & Sandall 2001). Infants born under this care displayed higher chances of survival than infants being born at home, where little specialised care was available.

The move of Couney to the United States in 1896 for the infant exhibitions introduced the first specialist neonatal care facilities and specialist to the country, and generated interest in this area (Lussky, 1999). It spurred academics such as Julius Hess to establish the concept of research into the newborn, subsequently publishing the first book devoted to prematurity in 1922 entitled 'Premature and Congenitally Diseased Infants' (Hess 1922). This advancement of newborns into an academic setting ensured that paediatricians began to take notice of premature infants (Lussky, 1999). Despite this achievement, a limited understanding of infant pathology prevailed during this time leading to preterm infants who were poorly understood and consequentially poorly managed (Oppenheimer, 1996). An example of this was seen during the 1930's, when it was discovered that oxygen therapy lowered the mortality rate of infants. The use of concentrated oxygen in incubators was therefore increased throughout neonatal units. Not until nearly 10,000 infants worldwide had been diagnosed as being blind was it was recognised that the increased use of concentrated oxygen had contributed towards this outcome (Oppenheimer, 1996). Another example followed the discovery of Penicillin in 1929 by Alexandra Flemming (Drews 2000). This lead to the subsequent dissemination of antibiotics for clinical use during the late 1930's and early 1940's, which were often used on infants with little evidence for their application. As a result many infants were left suffering deafness (Goldberg & DiVitto, 1995) and fatal brain damage (Oppenheimer, 1996).

In 1946 the first premature baby unit opened in the United Kingdom, following the principles of newborn care by Hess in his landmark publication (Corner 2001). This led to neonatal care emerging as a recognised speciality within Britain during the 1950's and 1960's. Throughout the world, advances in specialist areas of care were also impacting on newborn care. Obstetrics was becoming a more sophisticated specialty, and so the role of caring for the premature infant gradually became assumed by the paediatricians (Thomas 2008). The discovery of the cause of Respiratory Distress Syndrome (RDS) by Avery and Mead in the 1950's reduced one of the major causes of infant mortality (Lussky, 1999). Virginia Apgar in early 1950's also ensured that newborns got the prompt attention they required through the development of a method to enable rapid medical assessment of newborns, the 'Apgar' score. This widely adopted practice further reduced infant mortality rates and helped to make newborn infants hospital patients and not merely delivery room 'by-products' (Apgar, 1953). A lack of evidence surrounding treatment decisions during this time meant that advances in neonatal care remained problematic.

Infants were often starved from birth for up to 4 days for fear of aspiration (Avery, 1992), resulting in increased mortality rates due to severe acidosis (Oppenheimer, 1996). The role of the parents in their infants care remained that of an outsider to the unit. A fear that parents may facilitate the spread of infection, along with a belief that 'handling' was too stressful for the infants (Davis et al 2003) meant that parents were often only allowed to enter the nursery a few days prior to their infants' discharge, if at all.

Intensive research was clearly required. The Neonatal Society and the Ministry of Health's Committee on Prematurity were both established in 1959 in order for physicians to "get together to look at their problems" (Corner, 2001 p.6). What emerged was a recognised need for specific units for infants of all gestations requiring special care (Corner, 2001). Whilst some units had opened in Britain (Bristol had opened in 1942), the number was limited (Corner 2001). It was not to be until the 1980's that neonatal intensive care services were provided countrywide (Dunn, 2001). One of the main problems faced during this time was gaining funding for specialist equipment and staff, which as Dunn highlighted, was "virtually non-existent" (Dunn 2001 p.ii).

It was during the 1970's that neonatal care began to see significant improvements. Charities such as Bliss formed, helping to bridge the gap between government funding and the cost of expensive equipment now required in the intensive care nursery (Dunn, 2001). Advances in technology began a rapid increase paralleled by an increase in the survival rates of premature infants. With the introduction of assisted breathing machines and the

Sheldon Report (1971) stating the requirement of one intensive care cot per 1000 births, neonatal care finally marked its status as a recognised division of care. The British Paediatric Society in 1972 recognised the need for consultant Neonatal posts throughout the country. The advances in technology saw the gradual lowering of infant viability, and babies were now routinely 'saved' at 1000g or even less. Survival rates at this weight were progressively improving, from 29 per 1000 births in 1966-1970, to 183 per 1000 in 1971-1979 (Lee, Kim, Khoshnood et al 1995). The British Paediatric Perinatal Group formed in 1976 (changing to the British Association of Perinatal Medicine in 1985), with the aim of improving the standard of neonatal care and establishing specialty training for doctors wishing to enter into perinatal care (British Association of Perinatal Medicine, 1999). Major changes in how parents were viewed in neonatal care were also taking place during this time. Research at Stanford University Medical Centre had proven that allowing parents into the nursery did not increase the rates of infection, resulting in the fact that parents were finally allowed to enter the nursery and encouraged to interact with their infants (Goldberg and DiVitto 1995).

Despite advances in neonatal care, in 1980 there were only 12 neonatologists in Britain (Dunn, 2001). A report by the Committee on Perinatal Mortality in 1980 detailed the inadequacy of perinatal services, helping to improve this shortage by highlighting the importance of neonatal care. The introduction of surfactant therapy by Fujiwara in 1980 also resulted in infants suffering from RDS again having their chances of survival increased significantly (Fujiwara, 1980). Smaller, sicker infants could now be saved with birth weights as low as

500g (Blaymore-Bier, Pezzullo, Kim et al 1994, Hack & Fanaroff 1989), their corresponding gestational age around 23 to 24 weeks. Survival rates for infants between 500g – 750g in one study improved from 32% to 54% from 1980-83 to 1984-87 (Wotjulewich, Alam, Brasher et al 1993). Frustratingly, whilst these infants could now survive, their morbidity rates were not improving. Long term outcomes of infants surviving at the fore front of neonatal medicine were starting to be reported from different corners of the world, and reductions in morbidity rates did not appear to be improving in parallel with the technological successes of survival.

There had been an eightfold increase in the number of infants surviving at less than 1000g since the late 1960's; 29 per 1000 births during 1967 to 1979 as compared to 251 per 1000 births during 1980 to 1987 (Lee et al 1995). The proportion of infants surviving with some form of disability, however, had remained stable throughout the decades and showed no corresponding signs of improvement. Various studies from around the world were reporting different morbidity statistics. Lee et al (1995) found the prevalence of major handicapping conditions (defined as cerebral palsy, mental sub-normality, complete blindness, deafness, seizure disorders or hydrocephalus) had increased from 33 per 1000 births in 1966-1970 to 92 per 1000 births in 1980-1987 in industrialised countries (including the UK), although acknowledged that increased active resuscitation of smaller infants may have contributed to this outcome. Blaymore-Bier et al (1994) in an 11 year follow up of infants born at less than 750g in one intensive care nursery in the United States, found no increase in 'neurodevelopmental deficiencies'; the rate remained 'stable' at

20%. Such an increase of research activity from this part of the world may have reflected the movement of preterm infant care from public to private funding, resulting in more newborn care units being established across the country (Oppenheimer 1996).

As early as 1984, authors such as Milligan, Shennan and Hoskins began questioning the application of neonatal intensive care at extremely preterm gestations when the outcome of disability remained relatively high. Milligan et al (1984) also questioned the economic implications of providing care for infants who had little chance of survival. Hack and Fanaroff in 1989 reiterated these questions surrounding the provision of intensive care for all infants, in their paper which reviewed the active resuscitations of 129 infants in one perinatal centre in the USA. Due to a poor outlook for infants born either below 600g or at less than 24 weeks gestation, they recommended 'drawing the line' of active resuscitation at 600g. They highlighted that in some instances death was merely "postponed...by the futile continuation of respiratory support" (Hack & Fanaroff, 1989 p.1646). It was during this time that the advancement of infertility treatment for couples experiencing fertility problems was resulting in the increased number of multiple births seen in neonatal units, creating different challenges for neonatal care. Multiple births were (and are still) associated with poorer outcomes for premature infants (Hoffman & Bennett 1990, Blaymore-Bier et al 1994). The increased number of neonatal admissions to neonatal units confounded the issue of economic resources for all infants born at all gestations.

Despite these concerns, perinatal medicine continued to push the limits of viability in the 1990's, which became the decade of the 'micropremie' (Lussky, 1999). Attempts were made to 'save' infants from 22 weeks gestation, and survival at 23 weeks became more achievable. Reports of infants surviving at smaller and smaller weights from across the developed world surfaced in the literature (Muraskas, Marshall, Tomich et al 1991; Amato 1992). El-Metwally, Vohr and Tucker in 2000 reviewed survival rates for infants born between 22 and 25 weeks gestation from 1993 to 1997 in one centre in the USA, and found the rate of infant mortality to be 24%; 76% were born alive and 46% survived to discharge. At 22 weeks, the survival rate was only 1.8%; this increased rapidly to 34%, 49% and 76% at 23, 24 and 25 weeks gestation respectively (El-Metwally et al 2000). Morbidity was not reported. Table 1.1 highlights the dramatic changes in survival rates for preterm infants from the beginning of neonatal care in the UK from the 1950's through to the 1990's.

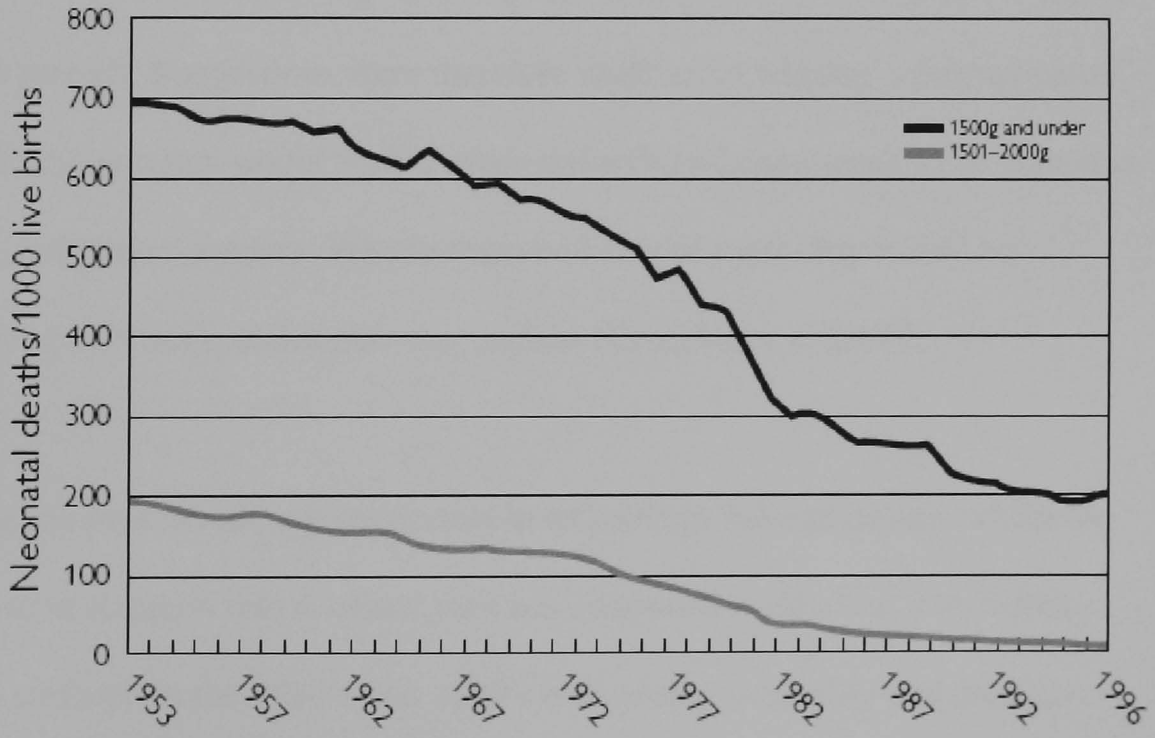


Table 1.1: Changes in mortality rates from early 1950's to late 1990's of low birth weight infants (McFarlane and Mugford Birth Counts 2000)

A lack of rigour research regarding mortality and morbidity led to the development of arguably the biggest study on neonatal outcomes, the EPICure study (Costeloe, Hennessy, Gibson et al 2000) in the UK. This study was a comprehensive evaluation of the outcomes of all infants born before 26 weeks gestation between March and December in 1995 in the United Kingdom and Republic of Ireland (Costeloe et al, 2000). From a total of 4004 births, a survival rate of 39% (314) emerged. For individual gestations, this corresponded to survival to discharge at 23 weeks gestation of 11%; at 24 weeks 26% and at 25 weeks 44% (Costeloe et al 2000). Of these infants, 62% had one or more of cerebral parenchymal cyst and/or hydrocephalus, treated retinopathy of prematurity, or oxygen dependency at 40 weeks gestation (Costeloe et al 2000). Important findings for the future of neonatal care emerged from this study; in 1995 only 15 hospitals had 10 or more intensive care cots and no one single hospital had extensive experience with infants of such small gestations (the highest number of admissions at one centre being 10 in this period). Suggestions were therefore made as to whether a centralisation of neonatal services would enable more research and experience to be gained in fewer, but bigger, centres. Whether survival free of morbidity would be improved by this centralisation was unclear (Costeloe et al 2000).

During the past decade advancements in technology have plateaued whilst the increase in research into neonatal care has continued to develop. The debates which surfaced in the 1980's and 1990's concerning morbidity and mortality rates continue, with an expanded focus on the impact of the physicians' attitudes towards extremely preterm infants and towards decision making. The impact of neonatal nurses' attitudes towards decision making have not been prioritised in this research, despite as previously stating, being the group of health care professionals who spend the most amount of time with the parents. It could therefore be hypothesised that the perceptions of the nurses have more of an impact on the parents than those of the physicians. To determine the impact of the perceptions, the perceptions themselves first need exploring, which is the intended aim of this study.

Roze and Breart (2004) predict a break in technological progress compared with the last 15 years, with a stabilising of the limits of viability. The challenge will focus on the ability to "improve the long term outcomes of extremely preterm infants" (S31). A second intake of infants into EPICure II was undertaken in 2006 to compare with the original 1996 cohort. Preliminary results indicated significant increases in survival from 1996 to 2006 at 24 and 25 weeks gestation, but not at 23 weeks (Walsh 2008).

Infants surviving at smaller and smaller gestations have attracted global media interest (for example "World's smallest baby born in US" BBC 21.12.2004). This has resulted in the ethics of neonatal care being discussed in not only the academic, but in the public arena. The economic implications of preterm infants, the role of the parents in neonatal care, the impact of disability and fertility treatments are all now areas that the neonatal 'viability' discussion has reached. These debates have rarely been discussed together, and the implications of these issues on the individuals who are involved in neonatal care have not been explored. The voices of neonatal nurses on these debates have remained silent, raising the question of what do this group of individuals involved so significantly in the care of extremely preterm infants think about current neonatal practice at the edge of viability in the United Kingdom. As previously highlighted, the importance of these perceptions may be a major factor in determining how parents are engaged in the care of their preterm infant on the neonatal unit. Researching these perceptions could therefore illuminate ways to engage parents, and inform decisions around any ethical dilemmas which may occur on the neonatal unit. The potential to improve the experience of the nurse and ultimately the family of the preterm infant can also be addressed.

1.4 The Thesis and its Structure

Following this introductory chapter to set the context for the current study, the thesis is structured around six chapters:

Chapter Two: Literature Review

Chapter two provides an in-depth exploration of the current debates surrounding neonatal care at the margins of viability. These debates include the outcomes of premature infants focusing on issues of disability; the impact of technology on the ability to offer extraordinary support at the margins of viability; the cost of infants born at the margins of viability; the difficulties of decision making in the neonatal unit between parents and health care professionals, and the debates surrounding infertility treatments, due to the increased possibility of premature birth following such treatment. The debates surrounding current abortion limits in the UK and the age of viability at which preterm infants can survive beyond this will also be explored.

Chapter Three: Conceptual Underpinnings of the Study

The conceptual underpinnings of the study will be explored in chapter three, discussing the different methodological approaches which could have been developed to explore the perceptions of neonatal nurses towards extremely preterm infants. The philosophical background to the study will also be presented. The resulting aims of the study will finally be presented.

Chapter Four: Methodology and Methods

A methodology was required which would allow for various forms of data to be incorporated into its design. It needed to be able to explore the perceptions of nurses, as well as their prioritisation of the debates. Chapter four illustrates the pragmatic decision undertaken to use Q Methodology to fulfil these aims. It provides an in-depth consideration of the principles behind Q Methodology and how a Q study is conducted. The data collected from a Q study is described, and the method of analysis presented. The development of the current study into neonatal nurses' perceptions towards extremely preterm infants is discussed as the chapter around Q methodology evolves.

Chapter Five: Findings

Chapter five presents the basic study information, along with the rationale behind the number of factors retained for extraction. The chapter is then divided into the presentation of individual factors. The first factor, the ‘consensus’ factor, explores the statements which all participants placed in a significantly similar position in their response grid. The following three factors, the ‘distinguishing factors’, explore the statements which participants in each factor respectively placed in a significantly different position in their response grid. The interview data from participants loading onto their respective factor is presented along with the statement, in order to provide participants personal rationale behind the placement of the statement.

Chapter Six: Discussion & Conclusion

The findings of the study are explored in detail in chapter six, considering the insights that this study has provided into neonatal nurses perceptions towards extremely preterm infants. Whether Q methodology was the correct methodology for the study is also discussed. Adjustments are made to the original conceptual framework in light of the findings from the current study. Clinical and research recommendations identified as a result of the study are presented.

1.5 Concluding Summary

Neonatal care has experienced many changes since the first incubators were introduced in the late 19th Century. Advancements in all aspects of care, from antibiotics therapy through to technology, have resulted in smaller infants now being able to survive. Infants weighing as little as 500g are now ‘routinely’ offered extraordinary care (defined as advanced technological care without which the infant could not survive) , compared to those who, if they were born weighing less than 1200g in the early 20th Century, were "seldom saved" (Budin 1907 Lecture 1 p.2). As the birth weights of survivors reduce, so the debates surrounding them increase, a consequence of the poor outcomes a high proportion of the survivors are at risk of developing. As parents become more involved in their infants treatment, the attitudes of doctors towards extremely preterm infants has been questioned regarding its impact upon treatment. The perceptions of neonatal nurses working alongside the infants and their families have not been questioned, despite this group of health care professionals arguably spending the most amount of time with the family. The aim of this thesis is to make these perceptions explicit, to build the foundations of exploring the impact of these upon parents. The ultimate aim is of improving the parental experience of having an extremely preterm infant in the neonatal unit. The thesis will be presented over six chapters, the first of which will explore in depth the literature behind extremely preterm infants, beginning the journey through the exploration of neonatal nurses' perceptions of extremely preterm infants

Chapter 2: Literature Review

2.1 Introduction

This chapter will present a review of the debates surrounding extremely preterm infants. This includes a detailed exploration of decision making, abortion, disability, fertility, technology, and economics, and the impact which these have on the debates surrounding viability.

2.2 Search Strategy

An extensive literature review was conducted at the preliminary stages of this study to scope the debates surrounding neonatal nurses' perceptions towards extremely preterm infants. Search engines including CINAHL, OVID, MEDLINE, INGENTA and Google Scholar were used to search systematically terms including: premature infants, neonatal viability, neonatal nursing, nursing attitudes, neonatal nursing ethics, nursing perceptions, neonatal outcomes, premature infant outcomes, micropremies, neonatal decision making, nurses decision making, parents decision making, neonatal technology, intensive care technology, abortion limits, abortion viability debate, neonatal ethics, fetal rights and preterm infant economics. Where the term 'neonatal' was used the associated abbreviation 'NICU' (Neonatal Intensive Care Unit) was also used to widen the search. Websites such as the Nuffield Council on Bioethics and the Department of Health were searched for publications. The reference lists of relevant journal articles proved a valuable resource for finding new information and for a platform for further searches on previously untried search terms. As the review progressed more search terms were explored to fully capture the debates surrounding extremely preterm infants, and terms such as euthanasia, fertility and attitudes towards disability, were added to the review. The only search limit in place was for the articles to be written in English; gathering information from a wide time span gave an insight into how the field of neonatal medicine and nursing has changed and evolved over time.

2.3 Organisation of the Literature

All retrieved articles were critically reviewed, and as the review progressed it became clear that articles could be placed into one of six categories revolving around extremely preterm infants: abortion limits, decision making, disability, fertility treatment, extraordinary technology (defined as technology without which the infant would be unable to survive, such as ventilators), and economics. Each of the themed categories then included different areas of debate within them; for example, ‘decision making’ explored the attitudes of doctors, nurses and parents towards extremely preterm infants. Disability explored areas such as the increased risk of an outcome of disability at extremely preterm gestations, and also the resulting debates surrounding euthanasia which these concerns had prompted Dutch physicians to explore. Extraordinary technology explored the attitudes of health care professionals towards survival with advancing technology, and its impact in intensive care areas. Whilst there was some cross over in the debates within the themes, for example disability and decision making, technology and economics, the central focus of the paper was chosen to represent the theme of the article. All of the literature was placed into Endnote X1 (Thomson Reuters 2007) to aid data management, and papers categorised into their respective themes.

Scoping the literature had revealed different areas of debate surrounding extremely preterm infants, which could be organised through the thematic placement into 6 categories. As the literature continued to be explored, no further categories emerged as each paper only further added to the debates in one of the primary themes. Organising the literature in this way provided a structure to the vast amount of literature found, and as will be seen in the methodology chapter impacted upon the decision to use Q methodology to investigate the research question of 'what are neonatal nurses' perceptions towards extremely preterm infants?'

The debates are presented in their respective themes, with each exploring their relation to extremely preterm infants. The internal discussions within each debate will be explored and presented through sub-categories to help the reader navigate their way through the vast amount of literature presented. Presenting the debates in this way will also aid the reader when the methodology is presented. The development of the research instrument ('Q cards' on which the main debates in the literature are written onto cards and presented to the research participants to sort in relation to their perceptions towards them) is through exploring the main debates in the literature; each category can be found easily on reflection when presented in this way. This will mean that the reader will be able to find the literature review surrounding each of the Q card statements, making the process of the creation of the Q cards transparent. The first of these debates, surrounding extremely preterm infants and decision making, will now be explored. The areas of disability, abortion, fertility, extraordinary treatment, and economics will follow. The presentation of the debates follows a logical formation where issues raised within one debate lead onto the next debate.

2.4 Debates Surrounding Extremely Preterm Infants

2.4.I Extremely Preterm Infants and Decision Making

2.4.I.a The Context: Survival Limits

In Britain, extraordinary care is now routinely offered to infants from 23 weeks gestation at birth, often weighing less than 500g (Costeloe et al 2000). Neonatal care in the United States of America has seen further advancements, observing a survival rate post hospital discharge of 17% for infants born weighing 400-449g (Salihu, Emusu, Aliyu et al 2005). In 2006, the Nuffield Council on Bioethics suggested a framework which recommended that below 23 weeks gestation resuscitation is not routinely offered; from 23 weeks plus one day (23+1) to 23+6 weeks gestation treatment is based on clinical judgement and is not a legal requirement. From 24 weeks of gestation, recommended ‘normal’ practice is to offer intensive care to the infant unless the infant’s condition dictates otherwise (Nuffield Council on Bioethics 2006). These recommendations were recently reviewed by the British Association of Perinatal Medicine, who published an agreed framework based upon these recommendations (Wilkinson, Ahluwalia, Cole et al 2009).

The benefits of technological interventions are often unclear, especially when survival is obtained at great potential cost in terms of quality of life (Orfali, 2004). The EPICure study, as previously discussed, evaluated the outcomes of all infants born at less than 26 weeks gestation between March and December of 1995 (Costeloe et al, 2000). From a total of 4004 births, 811 infants were admitted for intensive care and were eligible for inclusion in the study. The survival rate at discharge from hospital for these infants was 39% (314). Neonatal follow with these infants at 30 months of age (corrected for prematurity) found that 49% had no disabilities, 25% had some level of disability, 23% had severe disability (defined as something which "was likely to put the child in need of physical assistance to perform daily activities" Wood, Marlow, Costeloe et al 2000 p.380), and 2% had died. The remaining 1% had no data (Wood et al 2000). The authors concluded that due the high possibility of disability in this group of infants, disability clearly "remains a major challenge" (2000 p.378).

The EPIBEL study repeated a similar study in Belgium between January 1999 and December 2000, determining mortality and morbidity rates at discharge for infants born at less than 26 weeks gestation throughout 19 perinatal centers. The survival rate for the eligible 322 infants was 54%; for infants born at 24 and 23 weeks gestation this was 29% and 5.5% respectively. Results highlighted the "chance of survival free from serious neonatal morbidity at the time of hospital discharge was less than 15%" (Vanhaesebrouck, Allegaert, Bottu et al 2004 p.663). Further review of the clinical data of 4172 infants in the Vermont Oxford Network USA, born between 1996 and 2000 and weighing 401-500g (with corresponding mean gestational ages of 23.3 ± 2.1 weeks), revealed an overall survival rate at discharge of 17% (Lucey, Rowan, Shiono et al 2004). Although there is no follow up data for these infants, they experienced high rates of "serious morbidities while in the NICU" such as necrotising enterocolitis, intraventricular haemorrhage (Lucey et al 2004 p.1559). These findings prompted the authors to call for increased resources to follow up the infants who survived, as currently saving infants at preterm gestations is an "uncontrolled experiment", the results of which were "not encouraging" (Lucey et al 2004 p.1563).

2.4.I.b Making Difficult Decisions: Who Decides?

The high risk of mortality and morbidity for extremely preterm infants means that parents and health care professionals (defined as individuals involved in infants' treatment such as nurses and doctors) regularly have to participate in decisions regarding quality of life assessments (Morrow, 2000). As various authors are now highlighting, the ethical issues no longer revolve solely around how premature an infant is, but around the intellectual potential of the infant (Wilkinson 2006; Orfali 2004). Decisions surrounding the (dis)continuation of treatment are therefore often based on the attitudes of the parents and health care professionals regarding the impact of potential disability on the infant's quality of life and on the family. Whose decision leads the treatment is a question raised as a result of this.

It is widely recognised that parents should be involved in the decision making process surrounding potential end of life care of their infants (Janvier & Barrington 2005, Romesberg 2003, McHaffie, Lyon & Hume 2001, Becker & Grunwald 2000). Doyle and Larcher (2000) highlight the difficulties in situations where parents may "demand treatment which clinicians believe to be medically futile, whereas others may wish to discontinue treatment professionals regard as being in the childs best interest" (p.F61). Who has the infants 'best interests' is difficult to resolve. Boyle et al (2004) suggest that if the premature infants 'interests' supersede those of their parents, it is not clear whether resuscitation is beneficial for the infant due to current morbidity and mortality rates. This inadvertently suggests the knowledge of the health care professional is what should be assumed to be in the infant's 'best interests'. How the parents then fit into this argument is unclear. De Leeuw, Cuttini, Nadai et al (2000) in their exploration of European physicians attitudes towards treatment choices for extremely preterm infants found that in each of the 11 countries sampled, the wishes of the parents were more likely to be followed "when they ask for treatment to be continued, rather than limited or withdrawn" (p.614). The study also highlighted that there were different approaches to the same clinical situation by different physicians in different countries. This variability in attitudes had the potential to influence mortality and morbidity figures, and the counselling of individual parents (de Leeuw et al 2000).

The influence of the physician can be seen again in the study by Peerzada, Richardson and Burns (2004) exploring neonatologists' delivery room decision making at the threshold of viability. The authors found that at extremely preterm gestations, physicians reported that they would "provide treatment they think is beneficial, withhold treatment they consider futile, and defer to parental wishes when the benefit is uncertain" (p.497). This was reflected in the fact that 68% of respondents rated the condition of the infant at delivery as the most important factor in decision making, with 58% agreeing the long term suffering to the infant was also important, and only 38% agreeing that the potential burden on the parents was important. Involving parents in only the most difficult situations, where the physicians themselves are uncertain of the outcome, does not allow for parents to be given the necessary information they require to make such difficult decisions. It is therefore debatable as to whether it is surprising when there is a difference of opinion between parents and health care professionals in this ‘unknown’ territory. The provision of reliable outcome data (morbidity and mortality) and the rationale behind decision making may help parents to make their own decision and become more involved in the process (Peerzada et al 2004; Koh, Harrison and Morley 1999). As Paris, Schreiber and Elias-Jones (2005) would argue, this then allows for the decision about the benefits of aggressive treatment to rest with the parents, to whom it “properly belongs” (p.F210).

2.4.I.c The Perceptions of Health Care Professionals

The decisions which parents make are arguably influenced by the perceptions of the health care professionals participating in the care of their infant towards morbidity and mortality rates. In an investigation into the discussion of withholding or withdrawing care in the neonatal unit between parents, medical and nursing staff, McHaffie, Laing, Parker & McMillan (2001) found that whilst 58% of doctors and 73% of nurses thought parents should be involved in the decision making, only 3% and 6% respectively thought parents should make the final decision as it was “too weighty a burden for parents to bear” (p.105). Conversely, 56% of parents thought that the responsibility of deciding for their child should be met by themselves (McHaffie et al 2001).

Whilst the attitudes and potential influence of physicians have been widely reported, those of neonatal nurses have received less attention despite the fact that due to their extended contact with families on the neonatal unit, their perspectives and collaboration are particularly valuable (Harrison 1993). What research has been found highlighted that 88% of neonatal nurses in one survey had experienced conflict around ethical decision making (Elizondo 1991). The only research found which specifically explored neonatal nurses' attitudes towards extremely preterm infants was conducted from December 1984 to January 1985. Debra Armentrout sent a Likert scale response questionnaire to 578 random subscribers to Neonatal Network, a neonatal nursing journal, receiving a 59.9% response rate (346). Questions focused on ethical, economic, jurisdictional and technological issues surrounding preterm infants, at the time defined as 'fetal-infants' if born less than 26 weeks gestation or 750g at birth (1986 p.25). Sixty-eight percent of nurses agreed that "biological limitations to extra-uterine survival exist that cannot be overcome" (p.27). Fifty-four percent of nurses agreed that "treatment should not be instituted if the fetal-infant's probability of severe impairment is high" (p.26), and 66.2% disagreed that "survival, even with handicap, is better than death" (p.26). In her conclusion, Armentrout highlighted her concerns that technology had "outpaced current moral and legal responsibilities for addressing the issues involved in providing care and management to fetal-infants" (p.29). The involvement of neonatal nurses in decision making was not explored. What is striking is that the concerns that neonatal nurses were reporting over 20 years ago appear identical to current day debates involving a wider audience. The limits of viability were the only difference; preliminary results from EPICure 2, the follow up to

EPICure 1 which collected data in 2006, showed survival rates to discharge for 25 week gestation infants (the equivalent to a 750g infant which Armentrout was referring as a 'fetal-infant') of 67% (Walsh 2008). What this study importantly recognised was that neonatal nurses do indeed have attitudes towards the infants which they are caring for; what it failed to explore was the importance of theses attitudes and the potential impact on the family's of the infants on the neonatal unit. It could also be hypothesised that as the limits of viability have decreased with technological advances, the dilemmas which neonatal nurses' find themselves in have increased.

2.4.I d Neonatal Nurses and Decision Making in the NICU

Over the last 20 years a growing number of studies have looked at the role of neonatal nurses in decision making on the neonatal unit (Penticuff and Walden 2000; Becker and Grunwald 2000; Spence 2000). It has been repeatedly reported that nurses often provide different opinions from doctors based on the status of the infant and the information provided (Janvier, Lantos, Deschenes et al 2008; Spence 2000; Erlen 1994). The importance of these findings, however, has not been explored and the precise role of the cot side neonatal nurse has not been defined in relation to decision making. The question of whether it is the nurse's role to discuss the infant's treatment options with the parents has also received little attention. In 1989, Penticuff found that nurses did not view it as their role to initiate discussions surrounding infants' treatment; no further research since then has been found which supports or rejects this finding. The impact of the perceptions of neonatal nurses has also received little attention; the interaction between parents (in particular mothers) and neonatal nurses has rather taken the focus of the attention. The findings of this literature frequently report difficulties in this relationship due to poor communication and a power struggle over who is the 'expert' on the infant, the nurse or the mother (Fenwick, Barclay and Schmied 2001; Hurst 2001; Wigert, Johansson, Berg and Hellstrom 2006; Heermann, Wilson and Wilhelm 2005). Lupton and Fenwick (2001) found mothers experiencing a positive relationship with their nurse had more frequent opportunities to interact with their infant facilitated by their nurse; those who did not experience a positive relationship often felt disengaged in the neonatal nursery. How nurses engage mothers (and fathers) is instrumental to how parents experience and become involved in the care of their infant on the neonatal unit, and therefore in decision making situations also.

2.4.II Extremely Preterm Infants and Disability

2.4.II.a The Context: Outcomes of Disability for Extremely Preterm Infants

Studies which have been conducted concerning decision making have shown that when discussing withdrawal or withholding of care in the neonatal unit, one of the factors influencing neonatologists' reasons to limit treatment is the potential outcome of disability in an infant (Orfali 2004, Wall & Partridge 1997, Lee et al 1995). Rebagliato et al (2000) in their study of European neonatologists' attitudes and practices towards end-of-life decisions confirmed the importance of physician attitudes in influencing their practice. In every country it was found that the likelihood of deciding to "set limits on intensive care because of poor neurological prognosis, i.e. on quality of life grounds" (p.2456) was significantly associated with physician attitude. Country was found to be the largest single explanatory factor, with the UK, Netherlands and Sweden agreeing that quality of life must be taken into account in decision making, compared to Hungary and Italy where more agreement was found on preserving life (Rebagliato et al 2000). The work of Orfali (2004) reiterated these findings, highlighting in her ethnographic comparison of decision making in neonatal units in the USA and France, that in both units physicians seemed "determined by broader social and cultural representations regarding disability and community responsibility" (p.2018). In France, the worst 'risk' was to let a disabled child survive, whereas in the USA, society ranks letting an infant die who could have lived as far worse than saving an infant who could become disabled (Orfali, 2000).

2.4.II.b Disability and Euthanasia

The risk of morbidity in extremely preterm infants prompted two Dutch paediatricians, Verhagen and Sauer, to introduce the Groningen Protocol in the Netherlands in 2002. This protocol allows for euthanasia of severely ill newborns (not necessarily extremely preterm newborns) who fall into three categories:

1. Those who have no chance of survival due to severe underlying disease.
2. Those with a very poor prognosis and are dependent upon intensive care.
3. Those with a hopeless prognosis who experience what parents and

> medical experts deem to be unbearable suffering (Verhagen & Sauer, 2005 p.959-960).

When a decision to end life has been made according to the protocol, two further requirements must be met (informed consent from the parents and agreement from at least one independent doctor) before the procedure is "performed in accordance with the accepted medical standard" (Verhagen & Sauer 2005 p.960). The death of the infant is reviewed by a minister of justice, who makes a decision on whether the death was in accordance with the protocol, and whether the doctors will face prosecution. No doctors to date who have ended lives using this protocol have been prosecuted (Verhagen & Sauer 2005). The authors argue that actively ending the life of newborn infants in these categories is not 'murder', as their suffering through continuation of life (using intensive care treatment) is extreme and does not equate with an acceptable quality of life.

Verhagen & Sauer succeeded in raising the issue of euthanasia in severely disabled and extremely preterm infants. Many critics, however, have argued that the Protocol is "morally and ethically unacceptable, and should be shunned by the international medical community" (Jotkowitz & Glick 2006 p.158). This response appears unjustified following the review of the evidence previously presented, which found that many doctors would use severe physical or mental disability as a reason to consider withdrawal or withholding of intensive care in preterm infants (Orfali 2004, Rebagliato et al 2000, Wall & Partridge 1997, Lee et al 1995). Doctors in the UK may therefore be aware of the practice of 'active euthanasia' but are concerned about the reaction of society if they were to openly agree to a protocol which legalised active euthanasia for neonates. Implementing a policy like the Groningen Protocol would also impact on the current abortion debate, which focuses around the fact that the legal abortion limit in the UK of 24 weeks gestation is beyond that at which an extremely preterm infant can currently survive with extraordinary support. Agreeing in principle to the practice of euthanasia would potentially be interpreted as going against the argument to reduce the abortion limits. Giving parents (and doctors) the right to end the life of an infant, in the infant's and the parent's best interests, could be argued to be no different to abortion as the principles of pro-choice and quality of life drive the decision making. Gross (2000) goes so far as to suggest that parents who do not want to risk the high possibility of their infant having a severe disability following extremely preterm birth should be offered the choice of third trimester abortion, using the morbidity statistics as justification. This is a practice which has not been found in use in the literature.

2.4.II.c Perceptions of Disability

From the above it becomes clear as to how important the health care professionals view of disability is when discussing end of life decision making. This raises questions over what evidence they are forming their decisions upon. Janvier et al (2008) explored the responses of doctors (165) and nurses (115) working in a perinatal centre in Canada towards the same hypothetical infant but with the information presented in two different ways. When presented with gestational age only, 23% and 17% of doctors and nurses respectively would resuscitate a preterm infant born at 24 weeks. When presented with no gestational age, but with the survival rate and long term outcome information, 57% or doctors and 38% or nurses would resuscitate the infant (Janvier et al 2008). This work reiterated the findings of Blanco, Suresh, Howard and Soll (2005) who previously found that physicians and neonatal nurses involved in the counselling and support of parents at risk of preterm delivery "underestimated survival rates and overestimated long term disability rates for infants born extremely premature" (p.e484). Interestingly, following an educational intervention to improve their knowledge on survival and outcome rates, an increased willingness was seen in physicians to resuscitate infants born at the margins of viability, compared to a decreased willingness in nurses (Blanco et al 2005). This highlights that knowledge is not a predictor of outcome for attitudes; how this information is interpreted and acted upon by individuals varies widely and is of great importance.

The debate surrounding disability does not only revolve around the views of the health care professionals. Saigal, Rosenbaum, Feeny et al (2000) suggested that parents may have "very different perspectives…regarding the problems they perceive to be most important for their child and family" (p. 569). To explore this suggestion, Saigal et al (2000) compared the quality of life ratings from the parent's perspective of teen-aged children who were born extremely preterm with parents of normal birth weight children. Whilst a significantly higher number of parents of the extremely preterm children reported higher prevalence of functional limitations than normal birth weight children, these parents still rated their teen-aged children's health status relatively high (Saigal et al 2000). Similar research by the same team in 1999 explored the differences in preference for neonatal outcome in health care professionals and parents of extremely low birth weight and normal birth weight infants to five hypothetical 'Health States'. These states ranged from "can see, hear and talk normally" to "blind, deaf or unable to talk" (p.1993). Results showed that the health care professionals (neonatologists and neonatal nurses) and parents viewed mild to moderate disability similarly, however all parents were "more accepting of the severely disabled health states" (p.1996). Saigal and colleagues (1999) also explored the attitudes of adolescents towards these health states (both originally extremely low and normal birth weight), finding consistencies with the attitudes of the parents and leading Saigal et al (1999) to suggest that parents were indeed the more appropriate decision makers on behalf of their infants.

What these insights into the attitudes of the parents illustrate is that parents have their own personal attitudes towards and acceptance of disability, which need to be taken into account when making decisions for extremely preterm infants. Health care professionals must be able to discuss these sensitive issues with the parents and discover what their thoughts are. They can only do this if they recognise that the parents have a valid concern and input into their infant, and if they recognise that their own perceptions towards the situation may be impinging upon the discussion. Parents must be given as much available information of the medical assessment to feel confident in any decision they are making regarding their infant (McHaffie, Lyon and Hume 2001), and only through health care professionals recognising their own perceptions can this information be truly offered in an unbiased way.

2.4.II.d The Influence of Health Care Professionals

The controversy surrounding disability in infants extends into the abortion debate as their currently is no upper gestational limit placed on abortion if there "is a substantial risk that if the child were born, it would suffer from such physical or mental abnormalities as to be seriously handicapped" (Abortion Act 1967). Technical and medical advances in fetal screening, along with a better understanding of the history of many fetal diseases (Kumar & O'Brien, 2004), have made prenatal diagnosis increasingly possible for a continually lengthening list of abnormalities with various levels of severity (de Vigan, Verite, Vodovar & Goujard et al 2002). Whilst this provides parents with more information than previously thought possible, it also serves to make the decision making process about the continuation of the pregnancy more complicated. There is evidence to suggest, however, that this decision making process may not be as 'complicated' as it seems. Savulescu in 2001 surveyed the professional attitudes of practitioners working in clinical genetics (including genetic counsellors) and obstetric ultrasound towards termination of pregnancy for a range of conditions. He found that "the options open to a particular patient are likely to be determined by the subjective values of the practitioner she happens to see" (p.167). This arguably coercive practice has also been highlighted in a study by Green (1995), who found that over one third of obstetricians surveyed required women to agree to termination of an affected pregnancy before they would proceed with invasive prenatal screening.

As seen in the attitudes towards long term outcomes in neonatal care, parents' decision making is potentially influenced by the values of the practitioner. Research also suggests that blame is often attributed to parents who decline the offer of prenatal testing and subsequently give birth to a child with a disability, rather than to parents who have not been offered tests and whose infants are born with a disability (Marteau & Drake 1995). It could therefore be argued that the more disabilities that can be diagnosed prenatally, the more pressure there is on women to abort these pregnancies. John Harris, a Professor of Bioethics at Manchester University, firmly believes that "it is wrong to bring avoidable suffering into the world" (Harris, 2000 p.96) and that mothers who do so "deliberately" (i.e. following prenatal diagnosis) are "wronging" their children. This reiterates the findings of Marteau & Drake (1995) that mothers were often seen as being to 'blame' for giving birth to disabled children knowing they could have avoided doing so. Harris' rationale is based on his definition of disability which he describes as "a physical or mental condition we have a strong rational preference not to be in" (p.97). This suggests disability affects life satisfaction, and is related to a life of "suffering" (p.96).

Harris is not alone in suggesting it is wrong to bring a disabled child into the world. Green (1997) states that "in the absence of adequate justifying reasons, a child is morally wronged when he/she is knowingly, deliberately, or negligently brought into being with a health status likely to result in significantly greater disability or suffering, or significantly reduced life options relative to the other children with whom he/she will grow up" (p.10). Conversely, Edwards (2001) maintains that all life involves some suffering and therefore giving birth to any child is morally wrong (p.380). Sinason (1992) and Asch (1999) argue that just because a person is unable to communicate or articulate their views clearly (due to disability), this does not mean that their lives are not worth living, as people can still demonstrate feelings associated with being a human being such as pleasure and pain. What is not known is whether these authors feel their perspectives are relevant to the extremely preterm infants referred to in this study, whose risk of morbidity is high and yet who were not 'knowingly' brought into the world. The outcomes for these infants are the same, and so whether the same rationale would be applied when faced with making difficult decisions would be interesting to discover.

The attitudes of health care professionals towards disability raise the question of why they hold such views. Asch (1999) suggests that it is because health care professionals have "committed themselves to preventing, ameliorating and curing people of illness and injury" (p.1649), indirectly creating an acknowledgement that any characteristics of disability are undesirable. This reflects a 'medical model' of disability, where the problems that occur to people with disabilities come from the actual disability itself (Asch 1999). Shakespeare (1998), however, represents a 'social model' of disability, arguing that it is social barriers which create disability rather than the actual impairment itself. This review of the literature would suggest that health care professionals are basing their attitudes on a medical model of disability, trying to alleviate any potential problems that an infant may have. Exploring these attitudes further may illuminate precisely how they are viewing disability. Arguing for disability from a social model would imply that what is needed is improved provision of welfare services to parents of disabled children, to make it easier for parents to choose to continue a pregnancy and / or request full intensive care treatment (Shakespeare 1998). How health care professionals view this opinion may also reveal the rationale behind their opinions.

The debate presented towards disability highlights the different perspectives in the literature towards infants who are disabled; however these arguments become increasingly complex in the neonatal unit where the risk of morbidity in extremely preterm infants is high. Whether these perspectives towards disability have any currency in these infants in the neonatal environment, and whether they impact upon decision making requires investigation. The perspectives of neonatal nurses towards these debates and the extremely preterm infants whom they will be working with would provide an insight into these questions and determine what impact, if any, perspectives towards disability have in the neonatal unit.

2.4.III Extremely Preterm Infants and the Abortion Debate

2.4.III.a The Context: The History of Abortion and Neonatal Care

As previously highlighted, the debates surrounding extremely preterm infants now extend into the realms of abortion, due to advancing survival of infants beyond the current abortion limits, and the discussions surrounding disability. This controversy is not necessarily a new one; infant viability and abortion have had a tenuous relationship since the introduction of the Abortion Act in 1967. The Act was passed in order to confront the increasing concerns that unsafe abortion was the leading cause of maternal death in England and Wales (Drife 2006), and maintained the general prohibition of abortion after 28 weeks gestation. This was the limit which had been set by the Infant Life Preservation Act in 1929 on the grounds of fetal viability. In 1990, this upper legal time limit was reduced to 24 weeks gestation due to advancements in infant viability. No upper gestational limit was placed on abortion if there was a substantial risk of the child suffering from physical or mental abnormalities (Abortion Act 1967).

The improvements in neonatal medicine over the last few decades have resulted in improvements in mortality for extremely preterm infants born at 24 weeks gestation and less. These improvements have also resulted in the ethics surrounding abortion becoming more complex, as there now exists a grey area of gestation where infants can survive if born alive preterm and offered extraordinary technology, but may also be legally aborted (Boyle, Salter and Arnander 2004). A recent report discusses an infant who survived an abortion attempt at 23 weeks gestation and subsequent neonatal care, following his live delivery at 24 weeks (Clarke, Smith, Kelly and Robinson 2005). Discussions such as these led to the first major changes sought to reduce the legal time limit of abortion in May 2008. Evidence from the survival rates of preterm infants in neonatal units (EPICure I & II) was presented and analysed to suggest new abortion limits should be set, ranging from 12 to 22 weeks gestation. With the closest vote to change the limit to 22 weeks being defeated 304 to 233 votes (BBC 21.05.2008), the legal limit of abortion remained at 24 weeks gestation.

The changes which were sought to the Abortion Act 1967 brought with them renewed interest to the ethical debates surrounding abortion, focusing on the moral status of the fetus and "what rights it may lay claim to at various stages of development" (BMA 2007 p.3). Pro-life campaigners argue that a 'fetus' is an unborn child from conception and thus has a right to life and therefore a right to be born. This is directly opposed to the view of pro-choice campaigners, who assert that a women has the right to chose abortion (Griffith & Tengnah 2007, Lim Tan 2004) as a 'fetus' does not have any moral rights until birth (Lipp 2008a). The opinions of healthcare professionals who are embedded in these services remain relatively unknown, despite arguably being essential to the debates leading to potential changes in the law (Griffith & Tengnah 2007). The studies which have been conducted have explored the views of nurses working in abortion services towards abortion and the abortion limits. This provides one perspective on the debate, yet the views of nurses working in neonatal services, where the evidence for lowering the abortion limits was gathered, remain unexplored. How these nurses interpret these debates, and whether they view them as relevant to their practice, may have an impact on their views towards the infants born at the extremely preterm gestations which the debates are discussing.

2.4.III.b The Perceptions of Nurses in Abortion Services

A limited numbers of studies have been undertaken in the UK have been with nurses working in abortion services, and have explored their views towards abortion and the current abortion limits. It has repeatedly been found that nurses fully support a woman's decision to choose abortion, and think that it is part of their role to ensure that women can abort in a safe environment (Gallagher, Porock and Edgley 2010; Lipp 2008a; Wolkomir & Powers 2007; Huntington 2002). Nurses also thought that their role was to help women "exert control over their reproductive capacities" (Wolkomir & Powers 2007 p.158) as women have the "right to make decisions" (Huntington 2002 p.276). Interestingly, the nurses working in these services would not necessarily choose abortion for themselves yet were able to withhold their own personal views towards abortion to meet the needs of clients (McQueen 1997). This creates the notion of a "woman-centred service" (Lipp 2008b p.9) where nurses are able to "support and empower" (Lipp 2008b p.18) women in their decision-making. One way in which the nurses make this support explicit appears to be through the use of language, where nurses working in abortion services referred to the 'fetus' or 'pregnancy' rather than the 'baby' (as a similar gestation 'infant' would be referred to in the neonatal unit). This potentially helps to reduce any stress on a woman through disassociation between the two (Gallagher et al 2009), and arguably may help the nurses to cope in what is recognised as an emotional environment (McQueen 1997).

As the gestation of the pregnancy increases towards the upper end of the abortion limit of 24 weeks gestation where the main debates are focused, the nurses views that it is the right of a woman to have an abortion appear to become reduced (Gallagher et al 2010). Abortions undertaken at late gestations (from 22 to 24 weeks) are carried out by firstly injecting the fetus with drugs to stop the heart (usually potassium chloride); if the woman has chosen to have a medical abortion, drugs are given to induce miscarriage and the fetus is delivered vaginally. If the woman has chosen a surgical abortion, the fetus is surgically removed using forceps under general anaesthetic (Royal College of Obstetricians and Gynaecologists 2004). The difficulties which nurses have appear to lie in viewing the physical outcome of the abortion (Gallagher et al

2010; Lipp and Fothergill 2009), and not their personal attitudes towards the abortion itself. This could be due to the reduced ability of the nurses to focus primarily on the woman as the client. This reinforces the importance of Huntington's (2002) observation that nurses are often expected to cope with situations which many people would find "difficult" (p.276). The sight of the fetus appears to cause a shift in care, creating a requirement in some participants to consider the moral status of the fetus (Gallagher et al 2010). For some nurses, this could potentially lead to a questioning of priorities within their conception of the nurse's role at the upper end of the abortion limits. The ways in which they resolved these issues are paramount to how they maintained their duty of care to their clients.

Nurses working in abortion services are able to maintain their duty of care for women undergoing late gestation abortion through removing themselves from situations which they do not feel able to maintain a supportive, non-judgemental stance, by allowing someone else to take over the care of the woman (Wolkomir and Powers 2007; Gallagher et al 2010). This allows nurses to work with clients up until a certain stage of the abortion where any interaction with the fetus would be necessary; the nurses then hands over the care to another nurse or midwife who feels more comfortable with the physical outcome of abortion at this stage of gestation (Gallagher et al 2010). In this way, the clients decision is never questioned as there is continual support at each stage of the abortion.

2.4.III.c The Relationship to Neonatal Nurses and the NICU

The perspectives of nurses working in abortion services towards the legal limit of abortion do not necessarily agree or disagree with the decision to keep the current limit at 24 weeks gestation. If nurses were not allowed to tailor their care towards their clients and had to be present for the delivery or surgical removal, it would be interesting to see whether they could continue to work in the abortion environment as their opinions are not necessarily related to the rights of the client (and therefore abortion itself) but the sight of the fetus. To gain the perspectives of nurses working in the neonatal unit towards providing extraordinary care for infants at similar gestations would give an insight from the alternative position of the debate. Whether these nurses share similar perspectives may help in providing more of an academic argument towards both the debate regarding the abortion limits and the debates surrounding extremely preterm infants.

2.4.IV Extremely Preterm Infants and Fertility Treatment

2.4.IV.a The Context: Potential Parents in the NICU

The debates surrounding extremely preterm infants, disability and abortion now extend even further afield into the realms of fertility treatment. The development of In Vitro Fertilisation (IVF) in the 1970's suddenly enabled some infertile couples to be able to conceive. IVF involves the collection of a woman's eggs, which are then fertilised with her partners sperm (or donated sperm) in a laboratory. The fertilised eggs (embryos) are then placed into the woman's womb to implant (Human Fertilisation and Embryology Authority [HFEA] 2006), in the hope that this will result in pregnancy. This technique was further improved in 1992, with the development of Intra-Cytoplasmic

Spermatic Injection (ICSI), whereby a single sperm, selected for its 'healthiness', is injected directly into the egg (HFEA 2006). Advancements in technology have again allowed further refinements of infertility treatments, with the introduction of Preimplantation Genetic Diagnosis (PGD). PGD involves genetically testing a woman's embryos for specific licensed conditions (as determined by the HFEA) in a laboratory following IVF treatment. Cells in the growing embryos are tested after a few days to determine whether they contain 'faulty' genes causing specific disabling or life threatening conditions. Unaffected embryos are then implanted into the woman in the hope of development, while the affected embryos are allowed to perish (HFEA 2006).

Pre-selection of embryos has sparked controversy, as couples can chose not to implant embryos which are carriers of specific diseases. The issues of which diseases are classified as severe enough to be 'removed' from families is controversial, as what one family may term severe may not be seen as severe by another. This raises implications for the treatment options for infants born with these conditions, as if we allow for pre-selection against these conditions, do we allow for withdrawal of care when these 'disabilities' occur with no prior warning? The perceptions of health care professionals working in neonatal services towards these fertility treatments for pre-selection of infants will be increasingly important, as research has found that children born as a result of IVF treatment are 20% more likely to be premature (Fisch, Harel, Kaplan et al 1997). Health care professionals such as neonatal nurses are therefore more likely to be working with families who are potentially older, having undertaken a number of trials of IVF. This raises the question of whether the perceptions of neonatal health care professionals are influenced by these factors, and whether infants who are born to couples who have undergone infertility treatment and who are unlikely to conceive again, will receive extraordinary treatment which may not be offered to infants born to younger families more likely to re-conceive. Although these infants may be at the same risk of morbidity due to prematurity, does the chance of being the only child born to a family (following potentially repeated attempts at pregnancy) increase their chance of survival by influencing the attitudes of health care professionals towards the parents and towards treatment at all costs? Harris (1992) suggests that it is "better to have children with disabilities than no children at all" (p.72), however does this translate into neonatal practice? Singer (1993) inadvertently adds to this debate through his statement that "when the death of a disabled infant will lead to the birth of another infant with better prospects of a happy life, the total amount of happiness will be greater if the disabled infant is killed" (p.1146). Arguably the realisation that there may be no other birth would therefore mean that the total amount of happiness can only be achieved through keeping the disabled infant alive, as the measurement of happiness in this circumstance appears to be a 'healthy' family. Is a family whose only chance of happiness is with a disabled child therefore a 'healthy' family? The impact of these debates in the neonatal environment, and whether the perspectives of neonatal nurses are influenced by these factors, would provide insight into this debate which has not previously been researched. How neonatal nurses prioritise their perspectives of the parents with their perspectives of the infant (i.e. does one have an impact upon the other) would also add clarity to a debate which has of yet remained relatively unexplored.

2.4.IV.b Attitudes towards Fertility

As these debates are only just emerging in the literature with the advancement of technology, no literature can currently be found regarding health care professionals attitudes towards fertility and age of child bearing. A study by Molhom Hansen, Hoff and Greisen (2003) exploring parental attitudes towards treatment of extremely preterm infants presented parents with two hypothetical situations, with one being a 41yr old woman and her 38yr old husband, having been trying for a baby for 5 years, on their second round of IVF and having suffered a previous spontaneous abortion two years earlier. The second scenario presented was a 21 yr old woman and her 22 yr old husband in full time education, with an unplanned pregnancy but who had decided to keep the baby. The questions focused, however, on the condition of the infant. Results found that respondents were influenced by parental preference in the situations, but did not go on to analyse any potential differences between the circumstances of the parents and the impact that this may have had on decision making.

The only literature which does exist is within the media, which would appear to oppose the hypothesis that we should prolong life when there is no chance of having more children. The world's oldest mother, Adriana Iliescu, gave birth at 66 years of age through IVF, leading to the Romanian officials to call for a public debate on the medical and ethical consequences of fertility treatments

(BBC 19.01.2005). Britain's oldest mother at 62 years of age, Patricia Rashbrook, also sparked controversy in Britain as to whether her decision to have a child at her age was 'selfish', or 'whether older people made better parents' (BBC 04.05.2006). These debates raise the question of what health care professionals who treat extremely preterm infants born with potentially severe disability, to mothers of potentially post-menopausal age, think of these arguments. This ultimately leads to whether these circumstances have any impact on the treatment decisions health care professionals make regarding extremely preterm (and other) infants.

2.4.V Extremely Preterm Infants and Extraordinary Technology

2.4.V.a The Context: Technology in the NICU

The advancements in fertility treatments over the last few decades mirror the advancements in neonatal technology; some infants can only be conceived through technology, and others can only survive with technology. It is clear that technological developments more than any other phenomenon have become the most transforming force in neonatal care (McGrath 2000), creating a unique temptation to "stretch the 'boundaries of viability'" (Oei, Askie, Tobiansky and Lui 2000 p.357). Infants can now be saved who in the past would have been considered non viable (Abe, Catlin and Mihara 2001), and intensive care may be viewed as an obligation to offer every chance of survival to infants to whom intensive care may not necessarily be "beneficial or justified" (Romesberg 2003 p.213). The input of technology has arguably confused the goals of neonatal intensive care between the ability of the infant to survive and the ability of the technology to keep the infant alive, creating the potential for heroic measures of extraordinary means to be overused (Wilder, 2000). The advances in neonatology can therefore be seen, according to Fine, Whitfield, Carr and Mayo (2005) as a "blessing or a curse" (p.1219) due to the difficulties in knowing when life sustaining treatment should be maintained or withdrawn. Neonatal health care professionals and families have to make choices about how to apply technology in a humane, natural and dignified way (Barnard & Sandelowski 2000).

2.4.V.b Technology as False Hope

Zamperetti, Bellomo, Dan, & Ronco (2006) stated that "death is, and always will be, inevitable" (p.831), and the application of technology in infants in which death is a probabilistic outcome may cause a sense of unease in health care professionals. Issues around how to withdraw the technology once treatment has been initiated can also cause tension between parents and health care professionals. Zaforteza, Gastaldo, de Pedro et al (2005) found in their observations of, and subsequent interviews with, adult intensive care nurses that information regarding technology can be misinterpreted by families and generate false hopes. From personal experience, infants who are being kept alive solely by technology and who generate even the slowest heart rate are seen to be alive by parents who see the data on the monitors and find it difficult to accept that their infant is dying.

Bayès (2001) highlighted that by focusing on technology in intensive care units, health care professionals (and I would argue families also) may underestimate the amount of suffering that patients experience. This has the potential to cause tension between families and health care professionals who disagree with when and how technology should be used in certain infants. The question of the best interests of the infants may differ between the family and the health care professional (indeed between individual health care professionals on the ward) making treatment decisions surrounding the infant difficult. The suffering of the infant is not always underestimated, however. Health care professionals may feel that prolonging the application of technology in situations where the death of the infant is probable undermines their professional duty to "make the care of people your first concern" (NMC Code of Conduct 2008), as this may cause suffering to the infant which the individuals involved in the care of the infant may not want to participate in.

Yam, Rossiter, Chin Adne and Cheung (2001), in their interviews of neonatal nurses in Hong Kong about their experiences of caring for dying infants, found that nurses had competing ideologies within their professional duties. They felt that they had the "obligation to preserve life and at the same time, they were obliged to minimise unnecessary suffering and promote a peaceful death" (p.655). When nurses could not resolve these issues, due to their perceived belief that the infant was suffering, they disengaged with families to protect their own emotions. A small informal questionnaire study with 24 neonatal nurses exploring their attitudes towards viability, conducted by Hefferman and Heilig (1999), revealed similar findings towards the perceived suffering of the infant:

"It's understandable for parents to want to resuscitate their baby but it is generally a very ethically hard situation for us...we poke, prod, and torture them for weeks, give a lot of false hope to the parents, stress the staff, and then they are taken off and allowed to die…we are not God to decide if a 23-weeker will do okay, be a healthy baby, a happy adult, etc, but we have statistics…to know that the chances are slim" (Hefferman and Heilig 1999 p.176)

Interestingly, an extract from an interview study with neonatal nurses by Jacobson in 1978 highlights the same difficulties experienced in neonatal care even before the proliferation of technology had begun.

"A child was kept alive mechanically for weeks because the parents could not accept his dying. I started to avoid him and then felt guilty for it. I started questioning much of our unit's work: Is this what we are really here for? Doesn't quality of life mean something?" (Jacobson, 1978 p.147)

The dilemmas experienced on neonatal units are ongoing due to the continual advancements in technology, and appear to reinforce the findings of Armentrout in 1989 who, as previously highlighted, concluded that technology had "outpaced current moral and legal responsibilities for addressing the issues involved in providing care and management to fetal-infants" (p.29). If, as Roze and Breart (2004) predict, a break in technological progress compared with the last 15 years is upon us in neonatal care, this provides us with an ideal opportunity to reflect on the advancements in technology. The perspectives of neonatal nurses (and allied health care professionals) can be explored to discover what they think about the application of advanced technology and its future use on the neonatal unit.

2.4.V.c The Physical Presence of Technology

Advancements in technology extend the responsibility of the neonatal nurse from the moral and ethical dilemmas which it presents, to the increased skills which are required to maintain and work with the technology which is sustaining the life of the infant. The perspectives of the nurse towards this technology, therefore, could potentially impact upon their perspectives towards extremely preterm infants, as the smaller the infant the greater the amount of technology is required. The more complicated the care therefore becomes, requiring more specialist skills. How neonatal nurses react and respond to these increasing demands of technology will arguably impact upon the nursing care received by the infants and their families in the neonatal unit. The area of technology and preterm infants requires further exploration to discover the attitudes of neonatal health care professionals, and how these perceptions impact upon the care that the provide infants and families at extremely premature gestations.

The technology used in intensive care units requires highly skilled health care professionals who have the ability to find solutions for complex clinical and ethical problems which it brings with it (Haugen Bunch 2002). Today's neonatal units are filled with a multitude of technology, such as breathing machines (ventilators), incubators, monitors, and scanning equipment. Infants are often attached to various devices which monitor their breathing, heart rate, oxygen saturation, temperature, blood pH and carbon dioxide levels. The physical space that the equipment necessitates can be intimidating, for nurses and parents, and can assume the space which parents would like to interact and bond with their infant. Such space is, as Gordon and Johnson (1999) recognise, "important for developing and maintaining relationships with patients and families" (p. 405). The technology in the neonatal unit does not therefore only impact upon the nurses, but the parents also and their ability to 'parent' in the neonatal unit. These impacts upon the parents will be discussed first, followed by an exploration of the impact upon the nurse and nursing care.

As the patient in the neonatal unit is the infant, the space required by the family is not official and is often overlooked (Gordin & Johnson 1999). Nurses and parents often share the space around the infant, each trying to establish their role and responsibilities in relation to each other and to the infant. Some parents may view the lack of space the equipment necessitates as a barrier to touching and bonding with their infant. The physical appearance of the equipment itself has also frequently been reported to be stressful to parents (Franck, Cox, Allen and Winter 2005; Griffin, Wishba and Kavanaugh 1998; Jamsa and Jamsa 1998). Gordon & Johnson (1999) highlight that whilst some parents may embrace technology as a "life saving miracle" (p.404), they may still feel unable to bond with their infant through touch due to fear of interfering with the equipment. Routine 'parental' tasks such as changing their infant's nappy and washing their infant may become daunting and even out of the question for some parents who are intimidated by the machinery, resulting in parents who are disengaged from their infants care. Parents frequently identify the need for support to cope with the stress of having a preterm infant on the neonatal unit (Griffin et al 1998), and so how the neonatal nurse helps the parents through this situation is vitally important to the parents overall experience. As smaller more vulnerable infants are surviving at the margins of viability, requiring more technology to sustain their lives, the requirement of parental support will arguably increase. Neonatal nurses' perceptions towards the application of technology in these situations will be particularly important in how they communicate with the parents.

2.4.V.d Technology and the Concept of Death

Zamperetti et al (2006) argue that technology has "manipulate[d] ... virtually every aspect of the process of dying, often merely prolonging and fragmenting it...[it] could insidiously entice the protagonists of HTM [high technology medicine] and society at large into believing that the task and benefit of medicine is to defeat death" (p.831). The authors see this alteration in the social concept of death as a negative consequence of the proliferation of technology, creating a "death denying" (p.833) society. Timmermans (1998) challenges this theory, suggesting that technology addresses a distinctively western reluctance to accept death. This infers that society created the need for technology through their unwillingness to accept death, rather than technology creating a death denying society. The acceptance of technology therefore depends upon on our acceptance of death. In a study of neonatologists in Australia and New Zealand in 2004, Barr (2007) found that neonatologists with a greater fear of death were more likely to accept the hastening of an infants death when treatment was deemed non beneficiary. Neonatologists with a greater fear of being "cremated" were less likely to accept this hastening of death (Barr 2007 p.F107). Barr concluded that neonatologists' fear of death may indeed influence their attitudes towards end of life decisions.

Wocial (2000), in her exploration of parents' perceptions of their experiences in the neonatal unit during treatment withdrawal decision making, illustrated the importance of differences of opinions towards death. The discussions parents had regarding the support they received from nurses led Wocial to the conclusion that nurses must be aware of how their own emotions and how they perceive death, to be able to establish a relationship with the parents; they can only do this by recognising that although for them, a decision is about ethics, for parents, it is about their infant (Wocial 2000). Determining the perceptions of neonatal nurses towards the technology and towards death could therefore potentially improve the experiences of parents on the unit through the process of reflection of the nurse.

Bayès (2001) has suggested that the application of technology in the neonatal unit can create a sense of calm which undermines the fact that infants are fighting for their lives. This sense of calm can allow parents and staff to react to situations without a sense of panic. It may also be deceptive to parents who may interpret the prognosis of their infant as better than in reality it is. Using technology on the smallest and sickest infants gives the family time to come to terms with the impending death of the infant in certain situations, and allows for the family to say their farewells (McHaffie, Lyon & Fowlie 2001). Issues may arise when the family believe that the technology will 'fix' their infant and become reluctant to withdraw treatment once it has been initiated. The perceptions of health care professionals towards the use of technology in these situations will undoubtedly impact upon the relationship they share with the family, subsequently affecting the family's experience of the death of their infant.

A disagreement between patients and staff during the last few hours of the infants life is something that is avoided at all costs however is one of the consequences of advancing technology and its precarious control over the period leading up to the death of some infants. Zamperetti et al (2006) define this problem when they say that "death is, and always will be, inevitable" (p.831). Whether the death of a new born infant can be accepted as 'inevitable' depends on individual attitudes towards 'saving' infants at extremely preterm gestations. Whose decision is taken as representing the best interests of the infant in this situation becomes difficult to resolve, and reflects the earlier discussion on decision making in this chapter.

2.4.V.e The Integration of Technology and Nursing

The impact and acceptance of technology on nurses has been explored in recent literature. Nurses raised concerns about the domination of technology and machines because of the actual space they require in an investigation by Haugen Bunch (2002). Such large amounts of technology will naturally result in a necessity to manage the equipment and tailor it towards individual infants. Various authors have argued that a continual technological presence and its resulting requirements has 'dehumanised' the care of the patient (Gordin & Johnson 1999; Alasad 2000; McGrath 2000; Wilkin & Slevin 2004; Zamperetti et al 2006). Wilkin and Slevin (2004) argue that the proliferation of technology in the neonatal unit at such a fast rate has potentially "threatened the caring component of nursing" (p.50). Alasad (2000) reiterates this concern in his findings from interviews with intensive care nurses that "caring is technological" (p. 410). Such an increased amount of technology on the neonatal unit will necessitate an understanding of neonatal nurses regarding its functioning, potentially resulting in a nursing of the machines rather than a nursing of the infant. When asked about their experiences of technology in their work place, nurses working in an adult intensive care unit identified this particular issue (Alasad 2000). They stated that nurses coming into the intensive care environment undergo a "technological orientation" (p. 410) in which they start to develop their competence in dealing with the technology. During this period, however, the nurse may "lose sight of the patient...the emphasis of priority can be lost" (p.410).

It would therefore follow that as a nurse becomes more competent with the technology they regain sight of the patient and learn to use the technology to aid their assessment of the infant, rather than as a stand alone tool of infant assessment. For example, if the monitors on the screen are alarming that the infant's oxygen saturations are falling rapidly, the less technically competent nurse may call for help and begin emergency measures to re-oxygenate the infant. The more technically competent nurse would potentially look at the infant first to assess their status. This could lead to the finding that the saturation probe has fallen off, giving false readings. It could lead to the same result of the nurse re-oxygenating the child if necessary once the probe is replaced, however the pathway of assessment and the role that the technology assumes is different. Griffen et al (1998) highlight that in these situations of (potentially) "malfunctioning" (p.291) alarms which are stressful to parents, the nurse can reduce parental anxiety by explaining their response to the alarm, especially if unable to promptly respond.

Bunch (2002) and Alberdi, Gilhooly & Hunter (2000) reiterate the assumptions of technical competence, describing that when technology "became a tool, the nurses...only paid selective attention to it" (Bunch 2002 p.191), and that many nurses reported that their decision making frequently relies on the combination of various sources of information used in conjunction, such as monitors and examination of the infant (Alberdi et al 2000). It could be argued that whilst the application of technology for inexperienced nurses is daunting, the long term benefits to the patient of technology supersedes this period of induction. The technology adds to the assessment powers that the (in this case) neonatal health care professionals have, providing extra information to the status of the infant when required.

2.4.V.f. Technology & Nursing: Irreconcilable?

The alleged 'dehumanisation' of nursing care in the intensive care unit has led to the debate of whether the foundations of technological and nursing care are different. Fox, Aiken & Messikomer (1990) argue that medical technology is juxtaposition to nursing care. The findings of Wilkin and Slevin (2004) appear to disagree with this statement. In their investigation into the meaning of caring in an intensive care environment, through semi structured interviews with adult intensive care nurses, they found that "true technological competence in clinical nursing practice can be understood as an expression of the caring and need not always be a barrier" (p.56).

Exploring a sample of theories of nursing care (Watson 1988; Leininger 1988; Gaut 1986) they all share the same common theme; they have identified nursing care as embracing social, physical and psychological and emotional elements of a patients needs, and not the performance of isolated skills (Hewitt-Taylor 2004). Although there has been little research into the concept of caring in the neonatal environment, Cescutti-Butler & Galvin (2003) identified in their interview study with infants' parents that nurses are seen as central to parents' experiences, as they represent the human, caring quality of a neonatal environment. It was not the performance of any task or skill that parents identified that led to this conclusion, rather a feeling that their infant was special not only to them, but to the nurse caring for them. If caring is, therefore not about the performance of individual tasks, but rather a variety of elements, the argument that technology itself dehumanises care is not necessarily true. Nurses who have to acknowledge the use of technology in the treatment of their patient, tend to the technology as part of a package of care delivered to that patient. It could therefore be argued that technology and nursing care should theoretically be able to co-exist harmoniously as technological care is part of nursing care.

Barnard & Sandelowski (2000) have suggested that the "continued polarization of technology and humane care may comprise a discourse that is more in the service of maintaining a distinctive professional identity" (p.368) of nursing, using technology to advance the nursing profession. If the use of technology is allied with professional development, nurses caring for infants may welcome the proliferation of technology for the most premature of infants in order to gain the experience it brings with it. Nurses' perceptions towards technology may therefore not be confined to the infant's life that it is being used to sustain. This allegation requires further exploration, as whether nurses value the experience of technology over its application and use for specific infants is questionable. The technological environment acting as an incentive for nurses to develop their knowledge in a technical direction (Zaforteza et al 2005), however, cannot be seen to be an altogether negative outcome if it produces more skilled neonatal nurses who can care for extremely preterm infants. Barnard & Sandelowski (2000) believe that technology itself can be a humanising, rather than a dehumanising, factor. This argument is deeply rooted within the neonatal unit, as the extremely preterm infant would not be alive without the advancing technology. Dunden (1993) argues that the contemporary fetus is a "engineered construct of modern society" (p.4). The difficulty in creating a distinction between the two is created through the fact that the life of the extremely preterm infant is only sustainable with the use of technology. Dunden explores whether technology therefore constitutes part of the extremely premature infant itself, and indirectly adds a human factor to the infant who would otherwise be unable to survive at such preterm gestations. As technology and the extremely preterm infant can not be easily separated, this suggests that there is "no necessary tension" (Barnard & Sandelowski 2000 p. 370); at this gestation, they are one and the same. What technology constitutes is, at any one time, therefore wholly dependant upon "the eye of the beholder, the hand of the user" (p.368).

2.4.VI Extremely Preterm Infants and Economics

2.4.VI.a The Context: The Price of Life

Advancing technology in the neonatal unit has resulted in smaller, more vulnerable infants surviving at earlier gestations. The infants require more intensive care, and are at a higher risk of developing adverse outcomes of disability later in life. Who makes the decision to initiate, continue or withdraw treatment can cause tension between the parent and the health care professionals. To add further complexity to the debate, the cost of the treatment of these infants is steadily increasing, imposing a "considerable burden on finite healthcare resources" (Petrou, Henderson, Bracewell et al 2006 p.78). Technologies which are still advancing and being refined, such as head cooling, body cooling, and high frequency oscillation ventilation (Nuffield Council on Bioethics 2006), will almost certainly in future be increasingly subject to cost benefit analysis of the efficiency of these techniques looking at their impact on Quality Adjusted Life Years (QALY) (a measure of the value of health outcomes; Prieto & Sacristan 2003). The ethics surrounding whether these infants should be given such resource intensive treatment at extremely preterm gestations ventures into the realms of economic resource distribution within highly developed heath care systems. If treatment appears to be medically futile, as Muraskas et al (1999) asks, is it necessary to put a price tag on human life?

The perceptions of the parents and the health care professionals towards this will undoubtedly vary, and the question of who makes the decision, as previously discussed, is difficult to answer. In their study into parents and neonatal health care professionals' attitudes towards active treatment of extremely preterm infants, Streiner, Saigal, Burrows et al (2001) found that amongst health care professionals who did not believe all preterm infants should be saved, 63% and 75% of physicians and nurses respectively cited economic costs to society as a reason. Only 7% of parents of extremely preterm infants (and 26% of control parents) cited this as a reason. The priorities which individuals bring to the decision making scenario are clearly very different. How to resolve these priorities becomes increasingly complicated.

2.4.VI.b The Impact of Hospitalisation Costs

Guidelines regarding the care and treatment of extremely preterm infants vary widely from country to county and institution to institution (Hentschel, Linder, Krueger & Reiter-Theil 2006), resulting in a variation of costs and no standardised restrictions on entry to the neonatal intensive care unit. Whether health care professionals working in this environment consider the economic status of the infant as important is unknown, and the impact of economics upon the care that infants receive has gathered little attention. Academics in developed countries have sought to determine the cost of extremely preterm birth on the health care system. Difficulties in this aim are brought about by unknown outcomes for children born at extremely preterm gestations, as the number of follow up studies of extremely preterm infants for a significant amount of time is still small. The era of neonatal intensive care and the extremely preterm gestation infant is still emerging, and often the results of intensive care at such early gestation are unknown as these infants are often lost in other specialities in the health care system after leaving the intensive care unit. Comparisons between institutions and countries are problematic, due to time periods over which the costs were determined and the resulting surge in technological development between each study. How the health care systems are organised and financed also adds to the difficulties in economic comparisons, regarding where the funding originates for the infant in the neonatal intensive care unit. When the amount of funding is finite, resources concentrated in the neonatal unit ultimately equate to the withdrawal or minimisation of costs elsewhere in the health care sector.

The cost of extremely preterm infants during hospitalisation has been calculated in various studies. Infants born at the borderlines of viability have the highest risk of conditions for which a prolonged period of intensive care is required (Nuffield Council on Bioethics 2006). Petrou and colleagues (2006) investigated the societal costs (defined as use of hospital and community services, social and education services, medications and family expenses) of extremely preterm infants in their sixth year after birth. The authors found a clear inverse relationship between week of gestational age at birth and societal costs when comparing unit cost comparisons of extremely preterm infants and infants born at full term at one year. Mean societal costs for extremely preterm infants were £9541, compared to £3883 for infants born at full term (Petrou et al 2006). Russel, Green and Steiner et al (2007) also found an increase in the hospitalisation costs for infants at extremely preterm gestations when compared to their full term equivalents. The authors sampled 20% of US hospitals and weighted this to approximately >35 million hospital discharges nationwide (Russel et al 2007). They found that in 2001 384, 200 (8%) of all 4.6 million infant stays included a diagnosis of prematurity or low birth weight (defined as a birth weight of < 1000g), incurring mean costs per stay of $65, 600 compared to $600 for uncomplicated newborns.

These costs continue following hospital discharge, with the risk of adverse sequelae increasing as gestation at birth decreases. Mangham, Petrou, Doyle et al (2009) explored the costs to the public health sector using a decision analytical model, using a hypothetical cohort of infants based on live birth and preterm birth data in England and Wales in 2006. Their results indicated that the total cost of preterm birth in 2006 was £2.946 billion pounds over childhood (up until 18 years of age). Put into a broader perspective, this figure represents around 3.5% of the ~£80 billion budget that the NHS was allocated in 2006-2007 (National Audit Office 2007). The average estimated cost per surviving preterm child born at term to 18 years was £41 907, with an incremental cost of £61 509 and £94 190 for very preterm (defined as < 33 weeks gestation) and extremely preterm (defined as <28 weeks gestation) births respectively (Mangham et al 2009). Of the £2.946 billion cost of preterm birth to the public sector, almost one third is accounted for during the neonatal period, whereas the majority of the incremental costs (92%) are borne during this time (Mangham et al 2009). The study does acknowledge, however, that one limitation is that the costs to families and informal carers during childhood have not been accounted for, and so the difference between the distributions of the costs may be smaller. Further research is required to determine the exact cost of infants born at all gestation throughout childhood to explore the precise burden on society of preterm birth. What the study does suggest is that through a hypothetical intervention designed to prevent preterm delivery by 1 week across all gestations, public cost spending could be reduced from £2.946 to £1.952 billion respectively. Such an intervention remains hypothetical, however, and so other suggestions in which to reduce the economic cost of preterm birth to the public during childhood have been suggested as alternatives.

2.4.VI.c Cost Saving in the NICU

In view of these high costs and adverse sequelae resulting from intensive care for extremely preterm infants, Paneth (1992 as cited in Stolz and McCormick 1998) recommended a threshold of "birth-weight and gestational age, below which ordinarily it is inadvisable to apply the technology of newborn intensive care" (p.344). Guidelines have been created which advise clinicians as to whether to resuscitate from 21 to 25 weeks gestation (Nuffield Council on Bioethics 2006; Wilkinson 2009). The use of these guidelines in practice has yet to be investigated. Stolz and McCormick (1998) reviewed hospital charges for a retrospective cohort of extremely premature infants (<800g) to determine at what gestation it would be required to restrict entry to the neonatal unit, in order to make a significant reduction in costs. They found that in order to achieve neonatal unit savings of 10.3%, entry would have to be restricted to infants over 700g, thus in reality restricting entry to 2689 infants below this gestation annually. The cost savings were not calculated in relation to the potential long term outcomes of the infants Limiting entry to a minimum weight of 700g, however, becomes unethical as it contravenes the recommended guidelines in the UK to always initiate treatment from 25 weeks gestation, and to usually initiate treatment from 24+0 to 24+6 weeks gestation (Wilkinson et al 2009). Stolz and McCormick (1998) instead recommend more aggressive case management of infants and improved research. Clearly limiting access to neonatal intensive care was not an option which can influence health care professionals towards their decisions to treat extremely preterm infants.

2.4.VI.d Resource Allocation

The cost of hospitalisation may not impact upon the health care professional in their decision to treat an extremely preterm infant, as economic implications are often unknown to most of those working in the neonatal unit. It may be a more subtle distribution of resources which the health care professional responds to. The pressure on resources in a constrained health care system may result in health care professionals finding it unfair that life sustaining technology is offered to infants who they feel have little chance of survival, when resources could be used on another infant with a better chance of survival. The perceptions of the health care professional towards the infant and the family may become strained if this is the case, impacting upon the relationship between the two. Staffing levels at each neonatal unit may also impact upon this relationship, along with the ability to allocate resources if there are not enough nurses to achieve the intensive care guidelines of 1:1 (nurse to infant) nursing care for infants receiving neonatal intensive care, 2:1 for infants receiving high dependency care, and 4:1 for infants receiving special care (British Association of Perinatal Medicine 2001). Neonatal units may then become closed to admissions, exacerbating the issues of resource allocation. A report by Bliss, the Premature Baby Charity, in 2007 found:

- Neonatal units are, on average, understaffed by over a third.
- Over six months neonatal units were shut to new admissions for an average of 24 days.
- 1/10 units exceeded its capacity for intensive care for more than 50 days during a six month period.
- Sixty five per cent of neonatal units providing the full range of intensive care did not have enough staffed cots for the babies admitted.

("Special delivery or second class: Are we failing special care babies in the UK?" Bliss 2007)

Clinical judgements of priority, taking into account the best interests of all babies involved, have been recommended by the Nuffield Council on Bioethics (2006) to try and appease the pressure of resource allocation. To put this judgement into practice, however, would cause tension on the units between parents and health care professionals. As Turrill (2000) has previously recognised, successful management of high risk infants involves "not only the provision of appropriate resources, but the effective use of those resources" (p.49) yet such provision of resources is difficult when many high risk births are "unpredictable, making it difficult to match the populations need with appropriate provision" (Turrill 2000 p.49). It could therefore be argued that the attitudes of health care professionals towards resource allocation, technological advances, and highly specialised care for infants at extremely premature gestations, could potentially be a factor impacting upon the relationships in the neonatal unit

2.5 Summary

This literature review has provided an extensive critique of the debates which currently surround extremely preterm infants. These debates have been found to extend into the realms of decision making, disability, abortion, fertility, technology and economics. As discussed in the opening of this chapter, the perceptions that neonatal nurses hold towards these debates may impact on their perceptions towards the extremely preterm infant whom they find themselves caring for on the neonatal unit. Only if the neonatal nurse is aware of their own personal perceptions can they evaluate whether their assessment and subsequent discussions with parents about the infant is based on accurate information or personal preference. By discovering the perceptions of the nurses we can therefore begin to potentially improve the experiences of nurses, infants and families in the neonatal unit.

Chapter 3: Conceptual & Philosophical Underpinnings of the Study

3.1 Introduction

The issues which have emerged during the literature review have highlighted the main debates surrounding extremely preterm infants. These will form the background of the study, and will guide the research process. These issues will therefore create the conceptual underpinnings of the study. This chapter will explore the nature of theory and concepts, and describe the development of the conceptual framework proposed. The philosophy underpinning the study will also be explored. The resulting aims and objectives of the study will finally be presented.

3.2 Nursing Theory

The term nursing theory has been defined in many ways in the literature (see Alligood & Tomey 2002, Chinn & Kramer 2004, George 2002). At the heart of these definitions lies the belief that theory offers a structure to a phenomenon (Parahoo 2006), and a "systematic explanation about how phenomena are interrelated" (Polit & Beck 2008). The scope of the theory is determined by the phenomena the theory is attempting to explain (Kim 2000a), with the most abstract theory described as meta theory, followed by grand theory, middle range theory and practice theory (McEwen & Wills 2006). Meta theories explore the generation of nursing knowledge and theory; grand theories cover broad areas within a discipline (George 2002). Middle range theories are limited in scope as they contain a limited number of concepts, but are easily testable (McEwen & Wills 2006). Practice theories are the most specific and cover particular elements of nursing practice.

The fundamental principle running through each level of theory is that of 'nursing', or the metaparadigm of nursing. A metaparadigm represents a distinctive domain (Basford & Slevin 2003) providing a structure to the theory surrounding the phenomenon and placing boundaries on its' subject matter (McEwen & Wills 2006). Arguably the most well know metaparadigm of nursing it that developed by Fawcett, who proposed a metaparadigm of nursing that includes the global concepts of interest to the discipline of nursing: person, environment, health and nursing (Fawcett 1995). One issue which arises from this popular metaparadigm, however, is that by using the term 'nursing' as part of the definition of the discipline of nursing leads to much confusion (Basford & Slevin 2003). Further metaparadigms have therefore been proposed, such as the Human Living Concept by Kim (2000). Kim proposed a metaparadigm of nursing based on the domains of: the client, the nurse-client relationship, the practice and the environment. Nursing therefore focuses on three dimensions - living with oneself, living with others, and living in situations - and the ways in which nurses can help people live in these three dimensions. This metaparadigm has been used to develop middle range theories of nursing in clinical areas such as abortion (Gallagher et al 2010).

3.3 Conceptual Frameworks

Concepts form the elements used to generate theory, with the theory providing a direction in which to view the relationships between them (George 2002). Conceptual underpinnings, or 'frameworks' are the diagrammatic representation of concepts or theories, minimising the use of words to explain a phenomena (Parahoo 2006). As such, conceptual frameworks symbolise a less formal attempt at organising the phenomena than theory, dealing with the main concepts assembled surrounding a common theme (Polit & Beck 2008). Conceptual frameworks can be based on previous models or theories to help guide current research, or can use previous literature to create a theoretical basis for the phenomenon under investigation (Parahoo 2006). Conceptual frameworks also represent the philosophical views of the researcher who created it. Acknowledgement of the authors philosophical orientations are therefore required to be able to critique the framework presented for the study. The beliefs of the author will therefore now be presented to guide the reader in their critique of the conceptual framework which will be proposed following this.

3.4 Philosophical Underpinnings

The literature review revealed different areas of debate surrounding extremely preterm infants, yet a judgement on whether one debate or attitude was 'better' than another was not required. Indeed a debate over whether the reported attitudes were indeed the 'truth' (e.g. the abortion limits should be lowered; technology should not be advanced) was also not required. The study hoped to instead highlight the explanations behind how neonatal nurses prioritise these debates, and subsequently why they think the way that they do.

The study was therefore based on the belief that the concept of the 'truth' of the perceptions of nurses towards extremely preterm infants was grounded in the subjective reports of the participants. Such a belief concerning the notion of truth goes in direct opposition to the positivist paradigm, whereby rigid rules of logic underlie strict measurement, truth and absolute principles (Weaver & Olsen 2006). Using this belief to frame the research would require an overall result to the study which determined which of the debates was accurate, and therefore which of the debates should be used as the main rationale behind the care of extremely preterm infants.

Having the debates already identified from the literature which required exploration with neonatal nurses also goes in direct conflict with grounded theory (Glaser and Strauss 1967), which places an emphasis on generating theory from the data collected to refine the emerging theoretical framework (Charmaz 2006). Undertaking the research study in this way would have involved no prior exploration of the main issues surrounding the infants, and exploratory research with the neonatal nurses to identify their views. Constant comparison between the data gathered would have guided the data collection, analysis and subsequent theoretical proposals. This would not have added anything further to the current debate, as the issues previously identified through no consultation with the neonatal nurses themselves (i.e. the gray area of the current abortion limits) required exploration to determine whether the nurses working within these parameters prioritised these debates in reality.

The review of the literature identified the debates which required exploration in practice with the group of health care professionals (neonatal nurses) who could provide insight and highlight the practical consequences of the debates explored in their area. This notion of practicality, along with the rejection of any outcomes of 'truth' of the debates follows the principles of pragmatism. This is the philosophy which underpins this study. A brief overview of these principles will now be presented.

3.4.I Pragmatism

Pragmatism first emerged in the late 19th century through the work of the American philosopher Charles Sanders Pierce (1839-1914). This work was built upon in the 20th century by philosophers such as William James (1842-1910) and John Dewey (1859-1952), and later by Richard Rorty (1931-2007). The fundamental belief that unites the adherents of all forms of pragmatism is the agreement that traditional assumptions regarding the nature of 'truth' should be rejected (Maxcy 2003). Pragmatists believe that 'truth' is a property which all statements share, and not because they correspond to reality (Rorty 1982). 'Truth' is simply viewed as a process through which we are able to make sense of our lives, and is the name of whatever proves itself to be good in the way of belief or assignable reasons (James 1907); for example, 'it snowed yesterday' or 'today is Tuesday'. The nature of 'truth' is therefore not the aspect to focus on, as defining it will not advance us. In essence, the question of 'truth' is the wrong question to ask. By clarifying the understanding of (and misguided focus on) 'truth', pragmatism therefore becomes the mediator method between "transcendental and empirical philosophies through questioning the common presupposition that there is an invidious distinction to be drawn between kinds of truths" (Rorty 1982 p.5) and through highlighting that distinctions between 'truth' are not in competition.

This removal of attention away from 'truth' allows for pragmatists to instead focus on the practical consequences of conceivable concepts, changing the view point of the research from the antecedents of the phenomena (i.e. what is the 'truth') (Cherryholmes 1992). By focusing on these consequences, the ideas which are translated into actions can be studied and the significance of human thinking can be determined through the reconciliation of "theory and practice by making the latter the test of genuine ideas" (Diggins 1994 p.161). Pragmatic research is therefore driven by the research question and its' anticipated consequences (Cherryholmes 1992) to determine how individuals conceptualise an idea. The aim of pragmatists is to search for methods which make it possible to find answers (Kim 2005), stressing the importance of richer modes of inquiry (not bound within one particular research method) to elevate new means of communication.

As previously stated, the aim of the research was not to determine the 'truth' about which of the debates surrounding extremely preterm infants was 'correct', but rather to determine the consequences and understandings of these debates. This focus on the practical consequences of human thinking, as pragmatism emphasises, does not depend on a particular epistemological position; the desired aims of the research are stated through the proposed conceptual underpinnings developed from the literature. The most appropriate research method can then be chosen which will provide the best answer to the question.

3.5 Development of the Conceptual Framework

As previously stated, the value of a conceptual framework is to diagrammatically represent the phenomena in question (Parahoo 2006).

For this study, the literature review identified six main debates surrounding extremely preterm infants. These debates all focused on different aspects of the extremely preterm infant, such as the conflict with the current abortion limits and differences in decision making. These debates can be used to guide the study when exploring the perceptions of neonatal nurses. The diagram below provides a diagrammatical representation of these debates, reflecting the presentation of the literature review and the impact which they may have upon the neonatal nurses working with the infants the debates discuss.

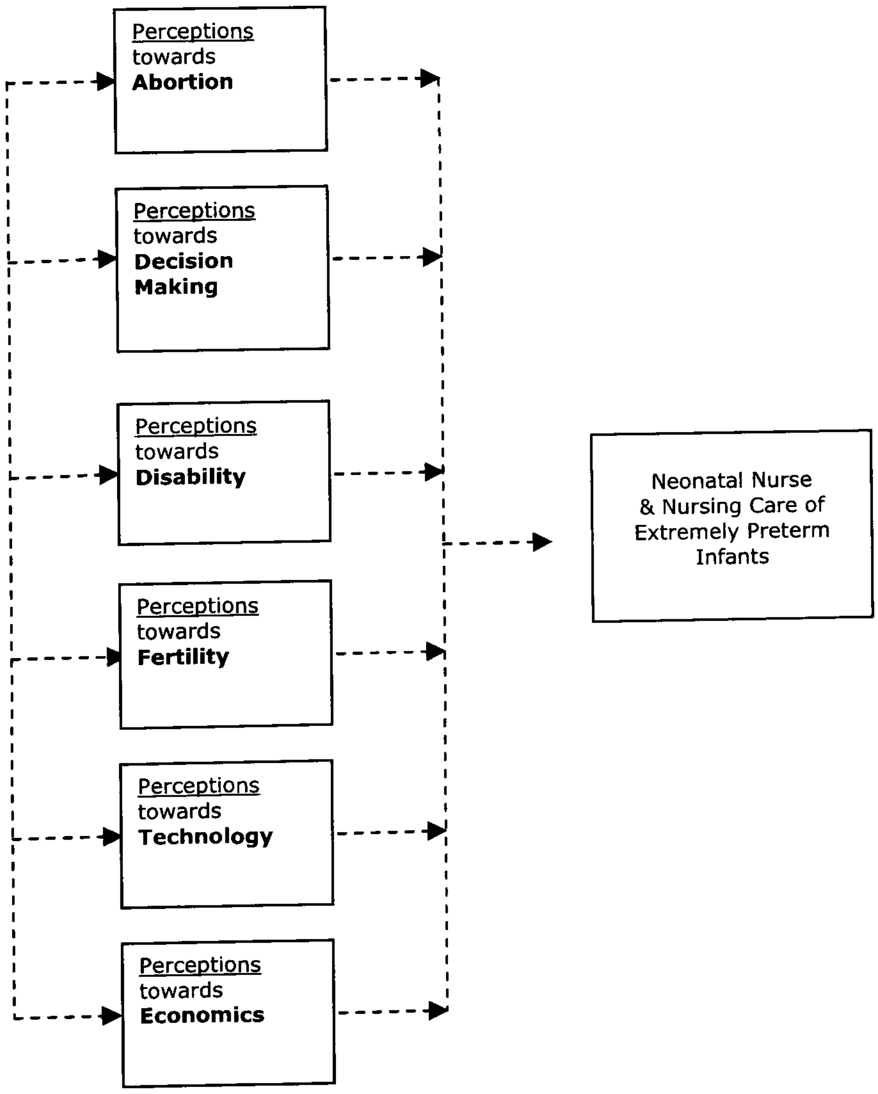


Figure 3.1: Conceptual underpinnings of the study

From this diagram we can begin to question what the impact of each of the debates on the neonatal nurses working with the extremely preterm infants in question, and their individual evaluation of the debates they are situated within. Using the conceptual framework in this way can guide the study in exploring the perceptions of neonatal nurses towards extremely preterm infants.

3.6 Study Aims & Objectives

The conceptual framework represents the different debates surrounding extremely preterm infants identified in the literature. From this, the aims of the study can therefore be identified:

1. To discover the perceptions of neonatal nurse's towards extremely preterm infants and their surrounding debates.
2. To determine any patterns amongst the perceptions of neonatal nurses towards extremely preterm infants

3.7 Summary

This chapter has explored the philosophical and conceptual underpinnings of the study. The notion of truth and practical consequences are representative of the philosophical beliefs of pragmatism, resulting in a rejection of other beliefs such as positivism. These philosophical beliefs shaped the resulting conceptual framework representing the literature review of the study, and the main debates surrounding extremely preterm infants. This framework was presented, and the resulting aims of the study identified. The following chapter will explore how these aims can be achieved.

Chapter 4: Methodology

4.1 Introduction

This chapter will discuss how the aims of the study will be achieved. A detailed introduction to the methodology chosen (Q methodology) will be presented, followed by an in depth discussion of what the methodology entails, including a presentation and critique of how it is 'created', performed and analysed. The use of interviews in Q methodology will be discussed, exploring why and how these were conducted and analysed.

Nurses perceptions of extremely preterm infants may be affected by their perceptions towards abortion, disability, decision making, fertility, technology, and economics as presented in the literature review. Whilst it is outside of the scope of this study to determine whether these perceptions impact upon the care that these nurses provide, it is interesting to note that in previous studies. Fenwick, Barclay & Schmied (2001a) and Hurst (2001) found that mothers often feel disengaged from their premature infants care in the neonatal unit. This may highlight potential difficulties nurses may have in interacting with mothers who hold different opinions about viability, and yet the nurses themselves may be unaware of how these attitudes are impacting upon their care. Cross (2005a) highlights that whilst personal attitudes may be concealed and are not directly observable in themselves, they cause actions and behaviours which are observable. Bohner (2001) expands on this theory, suggesting that attitudes also change as people learn to associate the attitude with pleasant or unpleasant contexts or consequences. Nurses may therefore base their beliefs about what is best for each individual on their prior experience in the neonatal unit, evidence or understanding of which parents have no insight. Depending on how the nurse interpreted their prior experience of caring for an extremely preterm infant, and the outcome of this situation, may therefore influence the complex relationship between nurses and parents. Whilst the National Association of Neonatal Nurses (1999) supports the right of nurses to agree or disagree with parental decisions, as Schlomann & Fister (1995) highlight, nurses must acknowledge their own personal and moral suffering to engage in ethical decision making, and provide compassionate and unbiased care for patients and their families. As Chiswick (2001) also notes, "neonatal staff have their needs, too, and it is easier to be caring and compassionate when we are at ease with our own thoughts and feelings surrounding end of life decisions" (p. F2). The purpose of this study is to make explicit the perceptions that neonatal nurses have in order to be able to provide unbiased, compassionate care and improve the experiences of nurses, infants and ultimately the families on the neonatal unit.

4.2 Determining the Methodology

To fulfil the aims of the study, a methodology is required which will take into account the different debates in the literature surrounding viability represented by the conceptual framework. The aims of the study are to determine the perceptions of neonatal nurses' towards extremely preterm infants and their surrounding debates, and to identify any patterns of perceptions amongst neonatal nurses. A pragmatic stance underpinning the study, which was highlighted in the development of the framework, means that a methodology can be chosen for its suitability in achieving the proposed aims of the study. A brief overview of the available methodology is explored, before an in-depth analysis and rationale of the chosen methodology is presented.

4.2.I Quantitative Methodology

Traditional quantitative methodology often works within the positivist paradigm previously discussed when exploring the philosophy underpinnings of the study. Quantitative methodologies use deductive reasoning to test hypotheses and gather empirical evidence (Polit & Beck 2004). Quantitative studies often employ numerical approaches to their methods (such as questionnaires, measuring tools, controlled trials) to produce objective data in an attempt to minimise the degree of error and bias (Parahoo 2006). The notion of 'truth' is accepted as a single objective reality which can be observed or measured and therefore accepted or rejected based on the evidence presented. For the purposes of this study, using quantitative measures to survey neonatal nurses' perceptions of extremely preterm infants could have added to the plethora of data; however it would not have advanced the data, simply added a further layer of information. One defined notion of truth does also not compliment the pragmatic underpinnings of the study. The debates identified within the literature need to be synthesised and analysed in relation to each other, and not simply as standalone measures; the format which they would be presented as in a quantitative questionnaire. As the area under investigation is so complex (as identified in the conceptual framework), more detailed scope of response is also required, rather than the usual scales of response identified in quantitative methodologies (such as 'agree' to 'disagree'). A more detailed explanation of the interpretation of the debates was therefore required.

4.2.II Qualitative Methodology

Qualitative methodology, as with quantitative methodology, is a collective term which encompasses a range of techniques in which to explore to research question. The main theme holding these techniques together which differs from the objective nature of quantitative methodologies, is that qualitative research explores as "a means to understand perceptions and actions of participants" (Parahoo 2006 p.63). There is no one single accepted 'truth'; the realities of the phenomenon emerge from the data collected from participants. The range of methodologies used includes ethnography and grounded theory, as discussed in the previous chapter. The methods used within these can vary from interviews to observations, depending on the phenomenon under investigation. Qualitative research is often inductive, rather than deductive, helping to generate theory which explains the phenomenon under investigation (Polit & Beck 2004). In the context of this study, a range of qualitative methods could have been used to explore neonatal nurses' perceptions of extremely preterm infants, such as semi, structured or unstructured interviews. These methods would have provided the structure to ask nurses about their thoughts towards the infants, however would have limited their interaction with the identified debates. The prioritisation of the debates would have been difficult to capture without bringing bias into the study through having pre-determined the content and context of the interviews. The validity and reliability could be brought into question.

From exploring the qualitative and quantitative approaches to nursing research, it was clear that neither could fulfil the precise aims of the study. Quantitative approaches were too objective and provided little interaction with the debates, whilst qualitative approaches gave too little structure to the aims of the study. A different methodology was required. Q methodology, one of less recognised research techniques, offered to bridge the gap between the more traditional approaches and provide subjective, yet measured, responses to the question of neonatal nurses' perceptions towards extremely preterm infants. A detailed exploration of this technique shall now be presented.

4.3 Q methodology: An Introduction

Developed in the 1930's by British Psychologist William Stephenson, Q methodology was invented to provide a means in which the subjectivity involved in any situation could be revealed (Cross, 2005a). Stephenson specifically wanted to research peoples' subjective opinions, experiences, ideas, beliefs and perspectives (Kitzinger, 1999). Q methodology involves taking samples from the literature which represent all forms of communication about the debate (known as the 'concourse'). This is the concourse that can be "socially contested, argued about and debated" (Stainton Rogers 1995 p 180). These samples are written onto cards which are given to participants. Participants are then invited to rank order the statements in relation to a condition of instruction from those they 'most agree with' to those they 'most disagree with' (Goldman 1999). The cards are collectively known as the Q sort and the process of sorting 'Q Sorting'. Factor analysis is then performed on the participants to determine clusters of attitudes towards the phenomena. Through this refining of traditional 'R' factor analysis (where the correlations between variables, and not participants, are factored), Stephenson determined that factor analysis of the data matrix by rows rather than columns, persons, instead of test items, could constitute the variables (Kitzinger, 1999). This became known as 'Q' factor analysis (the 'method') and subsequently 'Q Methodology' (the methodology). Q methodology allows for the variety of accounts that people construct to be explored, focusing on their subjective experience and understanding (Cross, 2005a). The goal of Q methodology is to uncover different patterns of thought amongst individuals (Valenta & Wigger, 1997). It allows for the expression of competing equivalent stories about a single social subject (Bryant, Green & Hewison 2006), thus allowing for participants to prioritise the debates surrounding viability according to their personal opinion. Q methodology then provides an opportunity to "reveal dynamic structures and connections of which those individuals who provide the Q sorts are often unaware" (Brown 2006 p. 376). The goals of Q methodology appeared to fit with the aims of the study and also provide the opportunity for reflection of participants upon the debates surrounding their practice; an opportunity which many may not have had the chance to do. The subjective accounts of participants could be captured, along with their rationale behind these accounts.

Q methodology has been used by various authors to determine attitudes towards ethical issues, such as end-of-life decision making (Wong, Eiser, Mrtek & Heckerlong 2004), Down's syndrome (Bryant et al 2006) and clinical decision making (Thompson, McCaughan & Cullum 2001). Wong and his colleagues (2004) concluded that “Q sort factor analysis is a useful analytical method to study clinical ethical decision making, because it provides a basis for discerning self-identified salient influences” (p. W20). Stenner & Stainton-Rogers (2004) have criticised Q methodology for violating the principle of respecting participants own definitions of situations, through forcing participants into a simplified response range and then re-coding their responses. I would argue, however, that Q methodology is not dissimilar in this ‘violation’ to other forms of investigation. In an interview situation, questions are formulated from the literature which then could arguably lead the interview in the direction that the researcher requires. The analytic process of the interviews then involves decisions by the researcher about “what are the most important views expressed by the participants and what they (‘really’) mean” (Kitzinger 1999 p. 272). Survey techniques also ask the questions which the researcher has identified as being relevant. I would also argue that the technique of ‘forcing’ participants into a normal distribution range is an extension of their daily activities. Nurses regularly participate in decision making surrounding extremely preterm infants, ranging from decisions around what to discuss with the parents, to involvement in decisions around the continuation of treatment for individuals. Nurses regularly prioritise the different factors surrounding each individual’s condition, and Q methodology extends this practice by asking nurses to illustrate this decision making process using the Q cards.

Q methodology allows for participants to interact with all the issues involved within the debates and say whether they prioritise these issues, indeed whether these issues are relevant at all. Interviews with the participants following the Q sort can then determine why they placed the cards in the positions they did, allowing for the rationale of the participants to form the basis of data analysis. The fact that Q methodology lays no claims to be measuring anything (Stenner & Stainton Rogers 2004) allows for participants subjectivity to be explored by person, rather than by factor, thus eliciting individual attitudes and beliefs in which the study is interested. As Stainton Rogers highlights, "a factor cannot emerge unless participants sort items in ways that enable it to do so" (1991 p. 130).

Q methodology provides a different and interesting way for participants to be involved in research. Participants can Q sort in their own time, at home or at work, and do not need the researcher to be present. This may remove some of the time pressures felt by participants in other forms of research. Kitzinger (1999) raises concerns about how individual participants experience the process of data collection. As with all research methods, participants give informed consent and are free to withdraw from the study at any time if they feel uncomfortable. With potentially no researcher influence, participants may feel more comfortable and more in control of the research through being able to do it in their own time. Interviews can then be arranged with the participants post-sorting, enabling the participant to reflect on their sorting of the set. This intense orientation around subjectivity means that the size of the sample is not an issue within Q methodology, rather "why and how they believe what they do" (McKeown & Thomas 1988 p.45) is the main focus. Participants can therefore be selected who represent the diversity possible within a specified group (Stainton-Rogers 1985) to ensure that all possible subjective viewpoints are explored. This allows for sampling of different grades of nurses in different levels of neonatal units to take place, fulfilling the aims of the study.

Q methodology also has deep roots within pragmatism, as it involves "synthesis, advances subjective knowledges [sic], and opens the possibility for finding truth value in subjectivity" (Goldman 1999 p.594). Whilst pragmatism allows for the best methodology to be chosen to answer the research question, a methodology which proposes the same philosophical underpinnings as that which it is based upon will undoubtedly provide a robust framework from which to develop the study. For all of these reasons, Q methodology was decided upon as the means of investigation in this study.

Performing a Q methodological study involves the following steps:

1. Definition of the Concourse
2. Development of the Q sample
3. Selection of the p set
4. Q sorting
5. Analysis
6. Interpretation (adapted from van Exel & de Graaf 2005)

How each of these steps was performed will now be presented.

4.4 Definition of the Concourse

"An effective Q study depends upon the meticulous and thoughtful sampling of the propositions. People can tell a story only if they have the appropriate statements to tell it." (Cross 2005a p. 211-212)

In Q methodology, 'concourse' refers to the flow of communicability surrounding any topic in the ordinary conversation, commentary and discourse of everyday life (Brown 1993). How this concourse is defined and developed in the Q cards is central to any Q study. Cross (2005b) asserts that the selection of the Q statements relies on the researcher's judgement of the concourse, creating potential bias from the start. The transparency of the rationale behind the concourse and the resulting statement development is therefore crucial to any Q study. An extensive literature review was therefore conducted as reported in chapter 2, to develop the theoretical framework to guide the study. This extensive literature review revealed areas of concourse surrounding viability including decision making, current abortion limits, current fertility treatments, outcomes of disability, the use of technology and economic implications of extremely preterm infants. These areas were explored in detail in chapter 2 and contributed to the development of the proposed conceptual framework presented in chapter 3.

4.5 Development of the Q Sample

A Q sample is a "collection of stimulus items that is presented to respondents for rank ordering in the Q Sort" (McKeown & Thomas 1988 p.25). It is important that the creation and selection of the Q sample is made explicit to assess the suitability of the Q sample for the study under investigation. Q samples have two characteristics, being either naturalistic or ready made, and structured or unstructured (McKeown & Thomas 1988).

4.5.I Naturalistic Sampling

Naturalistic samples are based on oral or written communication (Cordingley, Webb and Hillier 1997), such as interviews or essays designed with the specific purpose of creating the Q cards. Wigger & Mrtek (1994) used a purely naturalistic approach in their investigation into the attitudes of new pharmacy students towards their profession. Essays composed and submitted by students asking them to represent themselves as a person, student, and a future pharmacist, were used as the concourse from which to create the Q sample. A sample of the students from the course was then used as the P set during the Q sort investigation (Wigger & Mrtek 1994). An alternative approach to naturalistic design uses secondary sources to gather evidence. Exports from the media, editorials and radio talk shows provide a range of concourse that can be used in the creation of the Q sample. In her study of women's views and experiences of pornography, Senn (1996) used a mixture of naturalistic and quasi naturalistic sampling. Interview data from 30 women was used to create a Q set of 98 cards, which were then sampled on 13 of the original interviewees, and on a non random sample of female mature students and their female professors. Senn found that the use of interview data to create the Q cards provided a "wide variety of views and experiences" (Senn 1996 p.214) from which to explore how women experience pornography in their lives. The interview data also provided useful anchors to aid interpretation of the factors resulting from the Q sort.

Quasi-naturalistic samples are based on the same approach to naturalistic samples however are developed from sources external to the study (McKeown & Thomas 1988), such as interviews with people about the concourse who will not be performing the Q sort itself. In their investigation into understandings of Down's syndrome, Bryant et al (2006) used information from a variety of naturalistic sources; focus groups with nurses, interviews with family members of individuals with Down's syndrome, publications on prenatal testing, magazines, web based support organisations, and an interview with a consultant obstetrician. The use of naturalistic, secondary naturalistic and quasi naturalistic sampling in this way allowed the authors to survey the entire concourse surrounding Down's syndrome, including the 'inner discursive conflict' which they believe creates tension between personal beliefs and political correctness (Bryant et al 2006). The range of concourse used in this investigation allowed for the emergence of "some seemingly contradictory beliefs, suggesting that in reality individual viewpoints about disability do not sit easily within one theoretical framework" (Bryant et al 2006 p.1198).

There are some areas of concourse which can be seen to be "essentially contested", defined by Gallie in 1956 where "each party continues to maintain that the special functions which the [concept] fulfils on its interpretation…is the correct…or only important function which the term can plainly be said to fulfil" (Gallie 1956 p. 167). Naturalistic sampling allows for all viewpoints to be gained and analysed from the participants own subjectivity. Whilst this does not resolve the 'essentially contested' nature of the concept, it allows for those involved in the debate to prioritise the areas under contention and see how others involved prioritise their arguments. Using Q methodology in this way provides a useful insight into many areas of research in which there are opposing points of view.

Using a purely naturalistic sampling method does have potential limitations. Not including ready-made statements from sources such as questionnaires or surveys may miss important aspects of the concourse. Validated scales may offer statements for inclusion in the Q sort which have not been identified by the researcher. Using only certain populations to interview, and then using only this source to create the statements, may also bias the study by not acknowledging the existing literature. To ensure that the concourse has been systematically and thoroughly explored, a different approach to sampling may be required through ready made sampling.

4.5.II Ready Made Sampling

In contrast to naturalistic Q samples, readymade Q samples are created from sources other than the communications regarding the concourse. These may be drawn from conventional rating scales, or standardised Q sorts (such as personality assessment q samples) (McKeown & Thomas 1988). Whilst the use of conventional rating scales may seem contradictory to the nature of Q methodology itself, it can be argued that the essence of the design of the questionnaires does not rule them out as a precursor for the sample. It is also unlikely that all of the concourse regarding a subject area will come from a naturalistic setting. To not include standard ratings measures could therefore be seen as not truly capturing the essence of the concourse. McKeown & Thomas (1998) have also argued that “items derived from ratings scales can be incorporated into Q samples to examine whether personal meanings held by respondents comport with the meanings that the items are designed to measure” (McKeown & Thomas 1998 p.27). Brown and Rothenberg’s ‘Interpersonal Perception Method’ Q sort (1976) illustrates this use of sampling by using items from a pre existing scale as Q statements. Having a pure readymade Q sample, however, may miss some of the insights gained from naturalistic sampling. Using only ready made samples for a Q study has the same potential for bias as naturalistic sampling; aspects of the concourse may be missed. Whilst conventional rating scales and questionnaires may offer statements which have been found to be valid and reliable, as with purely quantitative research, the experiential aspect of an individual may be lost from the concourse through not gaining a qualitative insight.

To prevent bias in a Q sample, the sampling method does not have to be exclusively naturalistic, quasi naturalistic or readymade; approaches can be combined to form a hybrid design. Combining samples from these designs can create a true sense of immersion with the concourse, and generate a thorough preliminary Q sample from which to determine the final number of items for the study. How the original number of items are then included or removed to form the final number in the Q set then determines the structure of the Q sample.

4.5.III.a Unstructured Q Sample

An unstructured Q sample is chosen without specific attention to equal coverage of all areas of the concourse. This may result in some issues being over or under represented in the sample, and provide only a reasonable account of the concourse. This may also introduce bias into the investigation through not allowing participants to determine their weighting of the items through Q sorting. Stanton Rogers (1991) highlights that aiming for a balance of items, however, is not possible as different items will hold different meanings for different people. The decision of whether to structure or un-structure therefore becomes meaningless, and as Brown suggests, remains "more of an art than a science" (Brown 1980 p.5). Where there is a large amount of concourse surrounding an area, however, this 'art' may result in large under representation of a valid part of the concourse.

Wigger & Mrtek's (1994) investigation into pharmacy students' attitudes towards pharmacy used an unstructured method in which to finalise the number of Q statements in the Q set. Through choosing statements which they thought were most the representative of the clusters of issues, their aim was to cover the entire breadth of the concourse rather than proportionally it (Wigger & Mrtek 1994). This reflected the exploratory nature of their investigation, as there was no prior theoretical framework or hypothesis. Using an unstructured method in which to finalise the Q Sort can thus be seen to be successful in certain instances. If a theoretical framework or hypothesis developed from extensive literature review is being used for the investigation, however, an unstructured sample will not reflect the nature of the hypothesis. In these instances, a structured Q sample can be used.

4.5.III.b Structured Q Sort

A structured Q sample is more systematic and seeks to avoid the weaknesses found in the unstructured sample (McKeown & Thomas 1988). Structured samples ensure that the concourse is represented proportionally, creating a unique miniature concourse. The samples are often based around a theoretical framework, and can be deductive or inductive, promoting theory testing. Deductive designs select the cards based on a priori hypothetical or theoretical considerations, whereas inductive designs develop from the patterns that emerge from the statements themselves as they were collected, not necessarily obvious prior to statement collection (McKeown & Thomas 1988, Cordingley et al 1997).

The Q sample for this investigation was developed using a naturalistic inductive structured approach, using a literature review to build the concourse surrounding extremely preterm infants. This review resulted in a preliminary Q sample of 67 statements (appendix 1). Statements were decided upon to represent the concourse in two ways. Anywhere where an author had expressed a unique point of view, the direct quote was taken and made into a statement. This included the literature from the media or from academia. Secondly, where themes emerged from the literature where authors had either discussed a subject or their opinion on a subject, the subject and their opinions were extracted from the literature and made into statements. Creating the statements in this way allowed for the development of a mini concourse which represented the extensive concourse defined for the study.

How the final number of cards decided upon to be suitable for Q Sorting is decided upon is not widely reported upon in Q methodology literature. Where it is discussed, there appears to be little agreement on what is considered an appropriate number of cards. McKeown (1990) suggests that the total number of cards in a Q sample typically ranges from 30 to 60 statements. Cross (2005a) increases this range to between 10 and 100 statements. Stainton Rogers (1991) use between 40 and 80, and Van Exel and de Graaf (2005) between 40 and 50. Whilst Brown (1980) may have suggested that Q selection is more "art than science" (p.5), this advice does not take into account the time it takes for individuals to sort large numbers of cards. I decided that whilst the number of cards had to adequately reflect the concourse, it also had to be manageable for people to sort. I felt that 67 statements were too many for participants to sort when the cards contained emotive material surrounding difficult issues such as abortion and treatment decisions. A structured approach was therefore employed to reduce the number of the sample.

On review of the sample there were statements whose structure differed from the rest; for example, a statement beginning with the prefix 'I would…' was removed as it was the only 'I' statement in the sample. Statements which were confusing or required further information to be able to sort them were also rejected, such as:

"Health Care Professionals should not report active movements of babies born less than 24 weeks gestation if the parents request they do not want full intensive care treatment" (developed from Macfarlane et al 2003)

This analysis of the statements resulted in the removal of 15 statements from the original 67. The number of statements remaining in each area of concourse mirrored their contribution to the debate surrounding borderline viability. The statements regarding the economics of preterm infants, however, appeared to reflect not only the cost but the treatment decisions themselves and their consequences. This was separate to the decision making itself, as it was not reflective of how the decision was made, but what the actual decision was. This category was therefore re-labelled 'treatment decisions'. The resulting numbers of statements per area were: abortion ('Ab') (10), decision making ('Dm') (10), disability ('Ds') (9), fertility ('Ft') (4), technology ('Tn') (11), and treatment decisions ('Tx') (9). This resulted in a final sample of 53 Q statements. The following table (Table 4.1) illustrates the Q statements, along with the references of their origins from the literature review. The Q cards were piloted on a colleague to see how long the Q Sort would take, with a resulting time of 27 minutes. It was thought that this was appropriate as it was not too long to lose interest or get tired, yet was enough time to allow the individual to think about each statement.

Source	Card Number, Q Statement & Category
Verhagen & Sauer (2005) The Groningen Protocol – Euthanasia in Severely Ill Newborns. *New England Journal of Medicine* **352**: 959-962	1. Peaceful death is more important than full intensive care treatment (Tx)
Fine R.L. Whitfield J.M. Carr B.L. & Mayo, T. W. (2005) Medical Futility in the Neonatal Intensive Care Unit: Hope for a resolution. *Pediatrics,* **116** 1219-1222 Romesberg, T. L. (2003) Futile Care and the Neonate. *Advances in Neonatal Care,* **3**: 213-219	2. Advancing technology has made the process of withdrawing care more difficult (Tn)
de Leeuw R, Cuttini M, Nadai M, et al.(2000) Treatment choices for extremely premature infants: An international perspective. *Journal of Pediatrics*;**137**:608-616	3. Health Care Professionals should deliver the care that parents are asking for, even if parents are asking for treatment that Health Care Professionals think is futile (Dm)
Rebagliato M, Cuttini M, Broggin L, et al. (2000) Neonatal End-of-Life Decision Making: Physicians' Attitudes and Relationship With Self-reported Practices in 10 European Countries. *Journal of American Medical Association*;**284**:2451-2459	4. Life should be maintained irrespective of outcome (Tx)
Green, JM (1995) Obstetricians views on prenatal diagnosis and termination of pregnancy: 1980 compared with 1993. *British Journal of Obstetrics and Gynaecology,* **102**: 228-232	5. The more disabilities that can be diagnosed prenatally, the more pressure there is on women to abort these pregnancies (Ds)
Gallagher, K., Porock, D,. & Edgley A (2010) The concept of nursing in abortion services. *Journal of Advanced Nursing;* 66(4): 849-857	6. The care of women in the neonatal unit should not be influenced by a history of previous abortions (Ab)
Green, JM (1995) Obstetricians views on prenatal diagnosis and termination of pregnancy: 1980 compared with 1993. *British Journal of Obstetrics and Gynaecology,* **102**: 228-232 Harris, J. (2000) Is there a coherent social conception of disability? *Journal of Medical Ethics* **26**: 95-100 Marteau, T.M. & Drake, H (1995) Attributions for Disability: The Influence of Genetic Screening. *Social Science & Medicine,* **40**:1127-1132	7. It is wrong to knowingly bring a disabled child into this world (Ds)

Harris, J. (2000) Is there a coherent social conception of disability? *Journal of Medical Ethics* **26**: 95-100 Molhom Hansen, B., Hoff, B. & Greisen, G. (2003) Treatment of extremely preterm infants: parents' attitudes. *Acta Paediatrica* **92**: 715-720	8. Infants born extremely prematurely to families who have received IVF and unlikely to conceive again should always be offered full intensive care treatment at all costs (Ft)
BBC (2006) www at http://news.bbc.co.uk/go/pr/fr/-/1/hi/health/4971930.stm BBC (2005) http://news.bbc.co.uk/go/pr/fr/-/1/hi/world/europe/4186405.stm	9. Older parents are better equipped to deal with the outcomes of extreme prematurity (Ft)
Gordin. P & Johnson BH (1999) Technology and Family-Centred Perinatal Care: Conflict or Synergy? *Journal of Obstetric, Gynaecologic, and Neonatal Nursing,* **28**: 401-408	10. The amount of technology used in the neonatal unit is a barrier which is detrimental to parent-infant bonding (Tn)
Orfali, K. (2004) Parental role in medical decision-making: fact or fiction? A comparative study of ethical dilemmas in French and American neonatal intensive care units. *Social Science & Medicine,* **58**: 2009-2022 Molhom Hansen, B., Hoff, B. & Greisen, G. (2003) Treatment of extremely preterm infants: parents' attitudes. *Acta Paediatrica* **92**: 715-720	11. If life limiting disability is diagnosed prenatally, parents should be able to give birth to their child and enjoy the time they have without the option of full intensive care treatment (Ds)
Peerzada JM, Richardson DK, Burns JP. (2004) Delivery room decision-making at the threshold of viability. *Journal of Pediatrics*;**145**:492-498	12. The most important factor when deciding on resuscitation is the potential burden on the parents (Dm)
Wilder MA (2000). Ethical Issues in the Delivery Room: Resuscitation of Extremely Low Birth Weight Infants. *Journal of Perinatal & Neonatal Nursing*;**14**:44-57	13. Always initiating full intensive care treatment gives parents a chance to think that they have done everything they possibly could (Tx)
Gallagher, K., Porock, D,. & Edgley A (2010) The concept of nursing in abortion services. *Journal of Advanced Nursing* 66(4): 849-857 Wolkomir, M. & Powers, M. (2007) Helping Women and Protecting the Self: The Challenge of Emotional Labour in an Abortion Clinic. *Qualitative Sociology*; 30: 153-169 Lipp, A. (2008a) Women centred service in termination of pregnancy: a grounded theory study. *Contemporary Nurse*; 31(1): 9-19	14. Women should have the right to choose abortion up until 24 week gestation (Ab)

Zamperetti, N., Bellomo R., Dan, M. & Ronco C. (2006) Ethical, political, and social aspects of high-technology medicine: Eos and Care. *Intensive Care Medicine,* **32**(6): 830-835	15. The amount of technology surrounding the infant alters the social concept of death to something that can be overcome (Tn)
Harris, J. (2000) Is there a coherent social conception of disability? *Journal of Medical Ethics* **26**: 95-100	16. Life satisfaction is not possible if you have a disability (Ds)
Rebagliato M, Cuttini M, Broggin L, et al (2000) Neonatal End-of-Life Decision Making: Physicians' Attitudes and Relationship With Self-reported Practices in 10 European Countries. *Journal of American Medical Association*;**284**:2451-2459	17. Infants born extremely prematurely with life limiting illness should still be given full intensive care treatment (Ds)
Wilder MA (2000) Ethical Issues in the Delivery Room: Resuscitation of Extremely Low Birth Weight Infants. *Journal of Perinatal & Neonatal Nursing*;**14**:44-57. Becker PT, Grunwald PC (2000). Contextual Dynamics of Ethical Decision Making in the NICU. *Journal of Perinatal & Neonatal Nursing*;**14**:58-72	18. Full intensive care treatment should always be started as it can be withdrawn later if found to be futile (Tx)
Peerzada JM, Richardson DK, Burns JP. (2004) Delivery room decision-making at the threshold of viability. *Journal of Pediatrics*;145:492-498 Koh, THHG, Harrison H & Morley, C. (1999) Gestation versus outcome table for parents of extremely premature infants. *Journal of Perinatology,* **19:** 452-453	19. Parents should be shown morbidity and mortality statistics following premature birth to help facilitate their decision making (Dm)
Lucey J F., Rowan C.A., Shiono P. et al. (2004) Fetal Infants: The Fate of 4172 Infants With Birth Weights of 401 to 500 Grams-The Vermont Oxford Network Experience (1996-2000) *Pediatrics,* **113:** 1559-1566	20. Attempting to save babies less than 24 weeks gestation is a large uncontrolled experiment (Tx)
Peerzada JM, Richardson DK, Burns JP. (2004) Delivery room decision-making at the threshold of viability. *Journal of Pediatrics*;**145**:492-498	21. The most important factor when deciding on resuscitation is the parents decision (Dm)
Wolkomir, M. & Powers, M. (2007) Helping Women and Protecting the Self: The Challenge of Emotional Labour in an Abortion Clinic. *Qualitative Sociology*; 30: 153-169	22. Nurses who work in abortion services from 20-24 weeks gestation are merely providing a service and should not be judged (Ab)

Lipp, A. & Fothergill, A. (2009) Nurses in abortion care: identifying and managing stress. *Contemporary Nurse*; 31(2): 108-120 Huntington, A.D. (2002) Working with women experiencing mid-trimester termination of pregnancy: the integration of nursing and feminist knowledge in the gynaecological setting. *Journal of Clinical Nursing*; 11: 273-279	
Lim Tan, M (2004) Fetal Discourses and the Politics of the Womb. Reproductive Health Matters; 12(24): 157-166 Gallagher, K., Porock, D,. & Edgley A (2010) The concept of nursing in abortion services. *Journal of Advanced Nursing* 66(4): 849-857	23. There is a cross over between neonatal and abortion services as both care for women at similar gestations (Ab)
Griffith, R. & Tengnah, C. (2007) Termination of pregnancy: a case for a change in the law. *British Journal of Community Nursing*; 12(7): 317-318 Lim Tan, M (2004) Fetal Discourses and the Politics of the Womb. Reproductive Health Matters; 12(24): 157-166	24. The abortion limits should be reduced in acknowledgement and accordance with the current limits of viability (Ab)
Zamperetti, N., Bellomo R., Dan, M. & Ronco C. (2006) Ethical, political, and social aspects of high-technology medicine: Eos and Care. *Intensive Care Medicine,* **32**:830-835	25. The technology which enables the most premature of infants to survive brings with it increased ethical dilemmas over whether it should be used to ensure this survival (Tn)
Boyle RJ, Salter R, Arnander MW (2004) Ethics of refusing parental requests to withhold or withdraw treatment from their premature baby. *Journal of Medical Ethics*;**30**:402-405	26. Deciding whether to withhold or withdraw treatment is too stressful for parents and should be done by the Health Care Professional (Dm)
Paris JJ, Schreiber MD (2005) Elias-Jones A. Resuscitation of the preterm infant against parental wishes. *Archives of Disease in Childhood - Fetal and Neonatal Edition*;**90**:F208-F210. Gross ML (2000). Avoiding anomalous newborns: pre-emptive abortion, treatment thresholds and the case of baby messenger. *Journal of Medical Ethics*;**26**:242-248	27. It is not up to Health Care Professionals to decide who should live and who should die (Dm)
Zamperetti, N., Bellomo R., Dan, M. & Ronco C. (2006) Ethical, political, and social aspects of high-technology medicine: Eos and Care. *Intensive Care Medicine,* **32**:830-835	28. Death is, and always will be, inevitable, for some infants (Tx)

Bunch E.H (2002) High technology and nursing: ethical dilemmas nurses and physicians face on high technology units in Norway. *Nursing Inquiry* **9**:187-195	29. Parents are given a false sense of hope when they see all of the equipment used on their extremely premature infant (Tn)
Peerzada JM, Richardson DK, Burns JP. (2004) Delivery room decision-making at the threshold of viability. *Journal of Pediatrics*;**145**:492-498	30. The most important factor when deciding on resuscitation is the Health Care Professionals' opinion (Dm)
Stolz JW, & McCormick, M.C. (1998)Restricting Access to Neonatal Intensive Care: Effect on Mortality and Economic Savings. *Pediatrics* **101**: 344-348	31. Technology should be advanced to allow the most premature of infants to survive (Tn)
Boyle RJ, Salter R, Arnander MW (2004) Ethics of refusing parental requests to withhold or withdraw treatment from their premature baby. *Journal of Medical Ethics*;**30**:402-405 Doyle L, Larcher VF (2000). Drafting guidelines for the withholding or withdrawing of life sustaining treatment in critically ill children and neonates. *Archives of Disease in Childhood - Fetal and Neonatal Edition*;**83**:60-63	32. Resuscitation at less than 24 weeks is for the parent's benefit only, not the baby's (Tx)
McHaffie HE, Laing IA, Lloyd DJ.(2001) Follow up care of bereaved parents after treatment withdrawal from newborns. *Archives of Disease in Childhood - Fetal and Neonatal Edition*;**84**:F125F128	33. Babies born at less than 24 weeks gestation should always be resuscitated if the mother is too old to have any more children (Ft)
Oei J, Askie LM, Tobiansky R, Lui K (2000). Attitudes of neonatal clinicians towards resuscitation of the extremely premature infant: An exploratory survey. *Journal of Paediatrics and Child Health*; **36**:357-362 Spence K (2000). The best interest principle as a standard for decision making in the care of neonates. *Journal of Advanced Nursing*;**31**:1286-1292	34. Infant survival has become a secondary outcome, with determining how far technology can advance survival limits seemingly more important (Tn)
Verhagen & Sauer (2005) The Groningen Protocol – Euthanasia in Severely Ill Newborns. *New England Journal of Medicine* **352**: 959-962	35. Euthanasia protocols for extremely preterm infants should be introduced in the UK (Tx)
Stolz, J. W. & McCormick M.C. (1998) Restricting Access to Neonatal Intensive Care: Effect on Mortality and Economic Savings. *Pediatrics,* **101**: 344-348	36. NICU treatment accounts for a large proportion of NHS resources and as such admission of infants less than 24 weeks gestation should be restricted (Tx)

Edwards SD (2001). Prevention of disability on grounds of suffering. *Journal of Medical Ethics* **27**:380-382	37. It is better to have a disabled child, no matter how disabled, than no child at all (Ds)
Alasad, J. (2002) Managing technology in the intensive care unit: the nurses experience. *International Journal of Nursing Studies,* **39**: 407-413	38. The technology used on the neonatal unit allows more safety and control as the infants status is continually updated (Tn)
Gross ML (2000). Avoiding anomalous newborns: pre-emptive abortion, treatment thresholds and the case of baby messenger. *Journal of Medical Ethics*;**26**:242-248	39. Parents who do not want a disabled child should be able to make the decision to withhold or withdraw full intensive care treatment (Ds)
Gallagher, K., Porock, D., & Edgley, A. (2010) The concept of nursing in abortion services. *Journal of Advanced Nursing*; 66(4): 849-857 Huntington, A.D. (2002) Working with women experiencing mid-trimester termination of pregnancy: the integration of nursing and feminist knowledge in the gynaecological setting. *Journal of Clinical Nursing*; 11: 273-279	40. The philosophy underpinning nursing and medical care is the same in all health care settings, including neonatal and abortion services (Ab)
Shakespeare, T. (1998) Choices and Rights: eugenics, genetics and disability equality. *Disability and Society,* **13**: 665-681	41. Better provision of welfare services in the community once children are older would make it easier to continue treatment for extreme preterm infants who display evidence of disability (Ds)
Peerzada JM, Richardson DK, Burns JP. (2004) Delivery room decision-making at the threshold of viability. *Journal of Pediatrics*;**145**:492-498	42. The most important factor when deciding on resuscitation is the potential of long term suffering to the baby (Dm)
Petrou S., Henderson J. Bracewell M. et al (2006) Pushing the boundaries of viability: The economic impact of extreme birth. *Early Human Development,* **82**: 77-84 Streiner, D.L., Saigal S., Burrows E. et al (2001) Attitudes of Parents & Health Care Professionals Toward Active Treatment of Extremely Preterm Infants. *Pediatrics;***108,** 152-157	43. Saving infants at less than 24 weeks gestation is an inefficient use of NHS resources (Tx)
Orfali, K. (2004) Parental role in medical decision-making: fact or fiction? A comparative study of ethical dilemmas in French and American neonatal intensive care units. *Social Science & Medicine,* **58**: 2009-2022	44. Evidence of severe disability is a valid reason to withdraw treatment in an extremely preterm infant (Ds)

Rebagliato M, Cuttini M, Broggin L et al (2000) Neonatal End-of-Life Decision Making: Physicians' Attitudes and Relationship With Self-reported Practices in 10 European Countries. *Journal of American Medical Association*;**284**:2451-2459 Lee, K.S., Kim, B.I. Khoshnood B. et al. (1995) Outcome of Very Low Birth Weight Infants in Industrialised Countries: 1974-1987. *American Journal of Epidemiology,* **141**:1188-1193	
Griffith, R. & Tengnah, C. (2007) Termination of pregnancy: a case for a change in the law. *British Journal of Community Nursing*; 12(7): 317-318	45. The current abortion limit of 24 weeks gestation is adequate, as infants below 24 weeks gestation should not normally be resuscitated due low survival rates and high risks of disability (Ab)
BBC (2006) www at http://news.bbc.co.uk/go/pr/fr/-/1/hi/health/4971930.stm BBC (2005) http://news.bbc.co.uk/go/pr/fr/-/1/hi/world/europe/4186405.stm	46. Women who try to conceive post menopause are not thinking about the best interests of the infant (Ft)
Alasad, J. (2002) Managing technology in the intensive care unit: the nurses experience. *International Journal of Nursing Studies,* **39**: 407-413	47. Caring has become technological, shifting the focus from caring for the infant to caring for the technology (Tn)
McHaffie HE, Laing IA, Parker M, McMillan J (2001). Deciding for imperilled newborns: medical authority of parental autonomy? *Journal of Medical Ethics*;**27**:101-109. Macfarlane PI, Wood, S; & Bennett, J. (2003) Non-viable delivery at 20-23 weeks gestation: observations and signs of life after birth. *Archives of Disease in Childhood - Fetal and Neonatal Edition* **88**: f199-f202	48. Parents should not be involved in treatment decisions for extremely preterm infants as they do not understand complex medical information (Dm)
Orfali, K. (2004) Parental role in medical decision-making: fact or fiction? A comparative study of ethical dilemmas in French and American neonatal intensive care units. *Social Science & Medicine,* **58**: 2009-2022 Wall S. N. & Partridge, J.C. (1997) Death in the Intensive Care Nursery: Physician Practice of Withdrawing and Withholding Life Support. *Pediatrics,* **9**: 64-70	49. The choices that parents make about their extremely preterm infants are often prompted by the choices of the Health Care Professionals (Dm)

Lee, K.S., Kim, B.I. Khoshnood B. et al. (1995) Outcome of Very Low Birth Weight Infants in Industrialised Countries: 1974-1987. *American Journal of Epidemiology,* **141**:1188-1193	
Clarke P, Smith J, Kelly T, Robinson MJ (2005). An infant who survived abortion and neonatal intensive care. *Journal of Obstetrics and Gynaecology*;**25**(1):73-74	50. 'Infants' who are born alive following termination of pregnancy should be transferred to NICU for a trial of life (Ab)
Gallagher, K., Porock, D., & Edgley, A. (2010) The concept of nursing in abortion services *Journal of Advanced Nursing;* 66(4): 849-857 Lim Tan, M (2004) Fetal Discourses and the Politics of the Womb. Reproductive Health Matters; 12(24): 157-166	51. Abortions should not be allowed from 22 weeks gestation as the fetus is changing into a baby (Ab)
Griffith, R. & Tengnah, C. (2007) Termination of pregnancy: a case for a change in the law. *British Journal of Community Nursing*; 12(7): 317-318 Gallagher, K., Porock, D., & Edgley, A. (2010) The concept of nursing in abortion services *Journal of Advanced Nursing;* 66(4): 849-857	52. Abortion providers and Neonatal Intensive Care Units are separate entities and the actions of one should have no influence upon the other (Ab)
Oei J, Askie LM, Tobiansky R, Lui K (2000) Attitudes of neonatal clinicians towards resuscitation of the extremely premature infant: An exploratory survey. *Journal of Paediatrics and Child Health* **36**(4):357-362	53. Technological developments mean that heroic measures of extraordinary means of support are overused (Tn)

(Table 4.1: Q Statement Development Table)

4.6 Validity of the Q Sample

It has argued that the notion of validity in Q methodology is redundant as the meaning of the study is determined by the participants (Brown 1980, Valenta and Wigger 1997). Content validity can provide a form of validity, however, and is of vital importance at the beginning of the Q study. The items selected must be representative of the concourse. Providing this validity can be either through expert review of the items prior to performing the study, or though thorough literature searching providing transparent audit trails so that readers can assess the rigour of the study. This study satisfied the requirement for content validity through both the expert review and the transparency of the statements selected.

An expert review was provided by the Director of Women's Services at UCH (Professor of Neonatology at the University of Nottingham at that time), who following this review joined the supervisory team. Each statement was reviewed for its relevance and inclusion in the study. None of the items were felt to misrepresent the literature. The feedback provided reflected the second criterion for content validity; that the audit trail of the statements included was highly transparent. The referencing for each statement is clear, allowing for others to follow the rationale behind each individual item. With the addition in the thesis of the structure of the literature review reflecting each area of debate, discussing each of the sources of reference, the content validity of the study is clearly provided.

4.7 Sampling: The Selection of the P Set

"The major concern of Q methodology is not with how many people believe such and such, but with why and how they believe what they do" (McKeown & Thomas 1988 p.45).

The purpose of Q methodology is to uncover the subjective perspectives of individuals on a specific concourse, with the participants and not the statements being the units of analysis. Q methodology therefore lends itself to small samples of individuals to study in depth. Due to the method of analysis of the Q sort, however, there needs to be a minimum number of 'persons' in the 'P' set in order to define the factors that emerge from the factor analysis (Feher, Strickland & Lenz 2005). In Q methodology, concern for the subjects-to-factors ratio replaces the subjects-to-variables ratio at issue in traditional R methodology (Dennis 1986). This is because a factor in Q methodology represents a cluster of people, not a cluster of items (Senn, 1996). Brown (1980) suggests a minimum of 4/5 persons defining each factor; much beyond this number, additional subjects add little to the analysis. Dennis (1986) suggests that no more than seven factors usually emerge from any Q Sort analysis, resulting in a minimum P ('persons') set of 28 (4 [persons] x 7 [factors]). Several studies lend evidence to Dennis' hypotheses; Bryant et al (2006) in their investigation into understandings of Down's syndrome had a P set of 76, resulting in five factors. Wong et al (2004), studying clinical ethical decision in nurses, had a P set of 144 which resulted in 5 factors. Thompson et al (2001) similarly explored nurses' clinical decision making, with a P set of 122 nurses leading to the creation of four factors.

There were two studies, conversely, which had 8 and 10 factors in their investigations respectively. Ridson, Eccleston, Crombez and McCracken (2003) discovered 8 factors when investigation the acceptance of chronic pain, and Stenner and Stainton Rogers (1998) found 10 factors when exploring self generated jealousy scenarios. These studies are more recent than Dennis' hypothesis and may reflect the natural progression and expansion of Q methodology over time. The software package which analyses the Q sorts, however (PQMethod), only provides information on up to 8 factors. In light of this fact and the previous studies, all eight factors in this investigation were initially retained for rotation. This allowed for the clusters of attitudes towards the phenomena to be captured whilst at the same time satisfying the basis of Q methodology that it is not about how many people believe a factor, but how and why they do (McKeown and Thomas 1988).

The P set in Q methodology is also affected by whether the sample is 'extensive' or 'intensive', depending on the nature of subjectivity that is required from the study. A study which wanted to determine the variety of viewpoints on a subject, hence requiring 'intersubjectivity', would be 'extensive' (McKeown and Thomas 1988). The number of persons in the P set would therefore be as many persons as possible to define the number of factors which may emerge, based on who is available for participation. The statements in the Q sorts would be identical and would be sorted under the same condition of instruction. McKeown and Thomas' (1998) study into attitudes towards homosexuality in a general University population followed this principle. The study involved 53 people from a specific University (staff and students) who responded to a general appeal for research participants. All participants then rank ordered 60 statements expressing different opinions towards homosexuality on a continuum ranging from agree to disagree (McKeown and Thomas 1988).

If the study was interested in sampling a P set which had more of a theoretical relevance to the investigation, systematic criteria can be applied in the form of factorial designs. A factorial P set "marks an overt attempt to sample people of theoretical interest" (McKeown & Thomas 1988 p.38), hence who are theoretically relevant to the problem under consideration. The investigation of Bryant and colleagues (2006) into understandings of Down's syndrome typifies this factorial design. Participants in this investigation were purposefully selected to gain their specific views of their type of experience; for example, midwives, researchers in disability studies, parents and carers of children with Down's syndrome, and community support workers (Bryant et al 2006). Following the first phase of Q sampling, it was felt that the viewpoints of 'men' and 'religious diversity' were not represented. A second phase of data collection was therefore entered upon with participants specifically selected to represent these views.

An alternative approach to Q sampling involves studies which want to explore in-depth the subjectivity of an individual under different conditions of instruction. This type of Q study would be more interested in the 'intrasubjectivity' of the sample (McKeown and Thomas 1988). An 'intensive' person sample would therefore be used, where the same person completes the same Q sort numerous times under different conditions of instruction, or completes additional Q Sorts under new conditions of instruction. This sampling method would be useful when exploring the differences between health care professionals' personal and professional attitudes towards controversial subjects for which they have responsibility, such as pre-natal testing and genetic engineering. Participants who are undergoing certain procedures may also be candidates for intensive testing; for example, their attitudes towards the NHS before and after an operation. Participants who represent certain points of view following extensive analysis can also be intensively sampled for further analysis, to exemplify their respective view point.

4.7.I The P Set: Neonatal Nurses

The P set is dictated by the nature of the enquiry. The question under exploration in this study was 'what are the perceptions of neonatal nurses' towards extremely preterm infants?' A specific population was required (neonatal nurses) along with the inter-subjectivity of this population in order to identify clusters of perceptions towards extremely preterm infants. An extensive approach to sampling was therefore used. Neonatal nurses were chosen specifically as I am a neonatal nurse; it was experiences that I had, and the experiences and perceptions of colleagues around me, which shaped this investigation. I wanted to find out what these perceptions were in order to discover if they could potentially affect the nursing care of extremely low gestation infants and their families. As discussed in the concourse, attitudes themselves are not directly observable however may cause actions and behaviours that are (Cross 2005a). The impact of these actions is outside the scope of this study, as the perceptions of the nurses first had to be explored before any impact on nursing care can be investigated.

In 2003 the Department of Health reviewed neonatal care services across England in order to establish the most effective ways of providing care for very sick or very premature infants (Department of Health 2003). The recommendations suggested that neonatal care across England was managed in clinical networks. These clinical networks would ensure groups of hospitals and neonatal units provided various levels of care, whilst working together within a locality, to improve the services provided to babies and their families. Across England, 24 networks were thus created. Each network covers a specific geographical area, in which there are neonatal units within hospitals providing different levels of support for infants (Table 4.2). Each network must have at least one neonatal unit providing Level 1 (intensive) care in order to provide expert care for the smallest and sickest infants, and to offer advice and support to the smaller lower intensity units. Whilst these 'tertiary' level centres provide the most intensive care (IC), they also provide high dependency (HDC) and special care (SC). Level 2 and 3 units do not routinely provide IC or HDC respectively, however can stabilise an infant born on their unit with these requirements unit until a transport team arrive to take the infant to an IC unit. All units work together to provide short and long term care to infants, transporting infants only as and when necessary to a different unit.

Tertiary Level Unit (Level 1)	**Intensive Care** 1:1 nursing care. Critically ill babies who require continuous support for organ failure and continuous observation, examples being babies who require ventilation or very preterm babies with respiratory distress syndrome. Also provide HDC & SC
Secondary Level Unit (Level 2)	**High Dependency Care** 2:1 nursing care. Specialist care for babies who, though not critically ill, require continuous support and observation for neonatal conditions. Examples are preterm babies with recurrent apnoea spells, stable babies receiving nasal CPAP or those receiving parenteral nutrition. Also provides SC
Primary Level Unit (Level 3)	**Special Care Baby Unit** 4:1 nursing care. Continuing care for babies who require specialist support such as tube feeding or care in incubators, for example well babies who are maturing after preterm delivery or convalescing following high dependency or intensive care

(Table 4.2: Standards for Hospitals Providing Neonatal Intensive and High Dependency Care. British Association of Perinatal Medicine 2001)

Due to the shared nature of neonatal care it was decided that only through sampling an entire network would a thorough insight into the perceptions of neonatal nurses be captured. This would allow for the perceptions of nurses working with the smallest and sickest infants to be explored along with the perceptions of nurses who work in the special care units where many infants return once their needs reduce from 'intensive' to 'high' or 'special care'. This was deemed important as the nurses in these units would potentially have different perceptions than those in an 'intensive' area as they may be more likely to see the outcomes of this intensive period of care. The diversity of the care within a network would be captured by sampling in this way.

A specific network was chosen for investigation due to its geographical location and relative proximity to me as the researcher. The network contains four hospital Trusts; within these Trusts there are six hospitals, each containing a neonatal unit (NNU) of varying intensity (Table 4.3).

	NNU 1	NNU 2	NNU 3	NNU 4	NNU 5	NNU 6
Level I	✓	✓	✓			
Level II	✓	✓	✓	✓	✓	
Level III	✓	✓	✓	✓	✓	✓

(Table 4.3: Intensity levels of neonatal units in the Network sampled for investigation)

The purpose of Q methodology, as stated previously, is to uncover the subjective perspectives of individuals on a specific concourse. A large P set is therefore not the point of Q methodology; to sample all the nurses in each unit for this investigation would therefore not be appropriate. I decided on a minimum of 5 participants for each of a potential 8 factors (equalling 40 people) in line with earlier discussion of how many factors to retain for rotation. To gain an insight into the perceptions of all levels or nurses, and to provide structure to the sampling methodology, I decided to sample 2 nurses from each nursing band (5-8) from each unit. This gave me an original total of 48 nurses. Not all units had all levels of nursing band, however; smaller units were less likely to employ Advanced Neonatal Nurse Practitioners (band 8 nurses) and had fewer members of staff to sample from. The sampling in these units was therefore reduced to reflect the nursing employment. This gave a re-estimated total of a maximum of 36 participants (Table 4.4).

	Band 5	Band 6	Band 7	Band 8
NNU 1	2	2	2	2
NNU 2	2	2	2	2
NNU 3	2	2	2	2
NNU 4	2	2	0	0
NNU 5	1	1	1	0
NNU 6	2	2	1	0

(Table 4.4: Number of required participants per band per neonatal unit)

In summary, an extensive, purposeful, theoretical design was employed to sample the nurses for this investigation. Intersubjectivity about the subject (extremely low gestation infants) was required from a specific population who had relevance to the question (neonatal nurses). Neonatal nurses from a neonatal network were identified and a simple design of two nurses per nursing band was created to capture the perceptions of nurses working at each qualification band at each hospital. As not all units within the network had band 8 nurses (or more than 1 band 7 nurse), this number was reduced accordingly to create a potential P Set of 36.

4.8 Q Sorting and Conditions of Instruction

The method of 'Q sorting' is the process where participants take part in a Q methodology study. Q sorting involves the participant modelling his or her point of view by rank ordering the statements along a continuum, defined by a condition of instruction (McKeown & Thomas 1988). As participants 'sort' the cards individually, their subjectivity is revealed through their interaction with the statements (Robbins and Krueger 2000).

The condition of instruction determines how the participant is to sort the cards, and is usually the problem under construction. Von Essen and Sjoden (2003) in their study into nurse caring behaviours, asked patients to sort items according to how important they perceived them to be in relation to the following question: "in order to make you feel cared for, how important is it that the staff…" (p.489). Thompson and colleagues (2001), in their investigation into nurses' clinical decision making, asked 122 nurses to Q sort (from most useful to least useful) under the condition of: most useful sources of information for clinical decision making. Barker (2002), in her investigation into the nature of mental health nurses' knowledge, asked participants to "consider their practice as a mental health nurse and rank which knowledges they were least/most likely to use in their daily activities as a nurse" (p.167).

4.8.I Extensive or Intensive Sampling?

Extensive samples can use a variation on conditions of instruction. Stowell Smith and McKeown (1999) divided their participants and gave them one of two conditions of instruction. Participants in one group were asked to sort the statements into how they felt they were applicable to a man who was white; in the second group they were given the same instructions for a man who was black. Wong et al (2004) asked participants to complete 4 Q sorts (using identical Q sets) for four different scenarios, to determine influences in decision making. Q Sorts do not have to be confined to statements; pictures, drawings and photographs can be used, as shown by Brown in 1972 when he asked participants to rank order human body segments in terms of 'importance to me'.

Intensive samples can test the same Q set under different conditions of instruction, for example in the current study asking neonatal nurses to respond to the Q sort from the perceptive of a professional and then as a parent. This allows for behavioural hypothesis testing to see if there is a difference between the two. Whilst multiple conditions of instruction may allow for more intensive testing of an individuals response, it is also more time consuming and more psychologically demanding for the participant. Subjects undertaking multiple conditions of instruction need a clear and honest explanation of what involvement will entail, from the researcher.

4.8.II Free or Forced Free Response?

A Q sort can either be 'free' or 'forced free'. A free Q sort allows the participants to place as many items as they wish under the agree/disagree continuum in the response grid. Participants using a 'forced free' Q sort have to adhere to a fixed pattern of item distribution. A certain number of cards are prescribed for each rank of agreement to disagreement; however, participants are free to place any item anywhere within the distribution (McKeown and Thomas 1988). Cordingly et al (1997) suggests that 'forcing' people into this distribution pattern runs counter to the subjectivity of Q methodology, as the purpose of Q is to discover exactly how the individual thinks about the concourse. Brown conversely argued that having either a forced free or free distribution makes little difference to the factors which emerge, following the creation of 14 different possibilities of forced and free distribution with a Q set of 33 items (Brown, 1980). Brown also hypothesised that despite the 'forced' nature of the Q sort, with his set of 33 items there were above 11,000 times more ways to sort the statements than there are people in the world (Brown 1980).

Whether this is true is difficult to determine. What is important to take into account when deciding upon the nature of the Q distribution is the question which you wish to answer, and the participants who will be sorting the statements. Having a forced free distribution, whilst stating a number of predetermined items along the grid, gives participants more structure in which to Q sort. This not only makes the task seem less daunting, but retains the control which participants have over where they place the items in the Q sort.

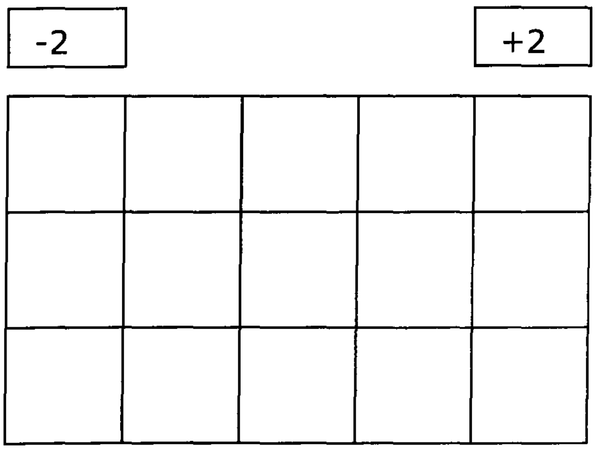
Feher et al (2005) reinforce this notion by adding that unforced sorting provides data that is often impossible to work with, as there is no clear assessment of the degree of similarity between sorts. This is particular relevant for participants in this study, for whom a free response to the task (usually based on a rectangle distribution grid) would have provided little guidance to a emotionally and mentally challenging task of sorting 53 statements.

Forcing participants into a fixed distribution (usually a normal distribution) also makes participants prioritise exactly what the most important factors are for them. For participants who have been sampled for their theoretical relevance to the study, they may already have to prioritise the principles of these statements in their every day working lives, and have just never made these decisions explicit. This reflects the participants in this study, who regularly have to prioritise issues surrounding viability on the neonatal unit on a regular basis; using forced free within Q methodology makes these decisions explicit. Thompson et al's (2001) example of nurses' decision making exemplifies this argument; the statements which the nurses had to sort were based on the information which they already used when making clinical decisions. The Q Sort allowed them to illustrate which ones they felt were more relevant and important to these decisions. This process may not only be enlightening for the researchers but for the participants who are given the chance to reflect on how and why they make the decisions that they do. Q methodology can therefore provide an interesting and useful tool for the researcher and the researched.

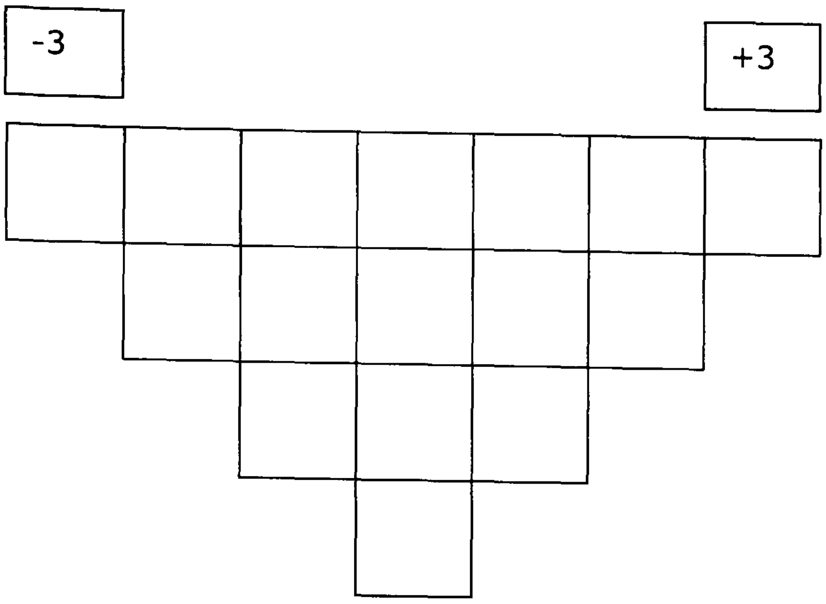
McKeown and Thomas (1988) assert that although the number of items is predetermined in a forced free Q sort, the participant alone determines the meaning of the continuum before them. Through controlling the specific ranking of the items, they determine the contextual significance of each item. This is particularly important when distinguishing amongst questionnaires and Q methodology; the statements in Q are subjectively sorted in relevance to each other, rather than in isolation to each other as found in a questionnaire format. This allows for participants to build up a picture of their thoughts around the concourse, and not just stand alone answers to individual questions. The subjective results therefore reveal a population of viewpoints, and not a population of people (Risdon et al 2003).

4.9 Response Grid Kurtosis

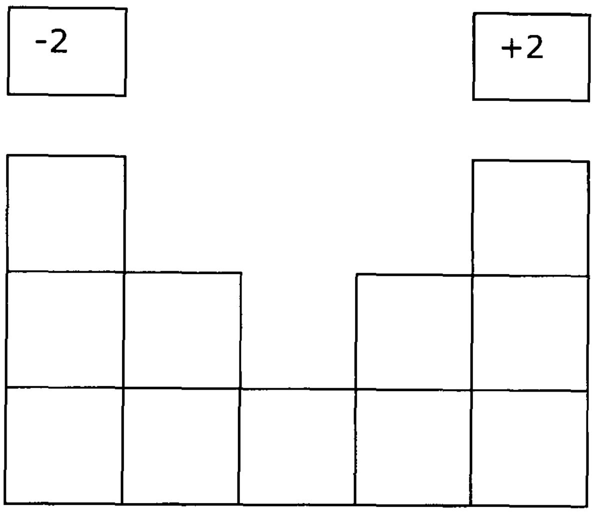
The kurtosis of the distribution grid varies depending on whether the Q sort is free or forced free, and the question under investigation. Distribution grids can be rectangle (Figure 4.1), normal (or 'unimodal' Figure 4.2), or U shaped (Figure 4.3).



(Figure 4.1: Rectangle distribution)



(Figure 4.2: Normal ('unimodal') distribution)



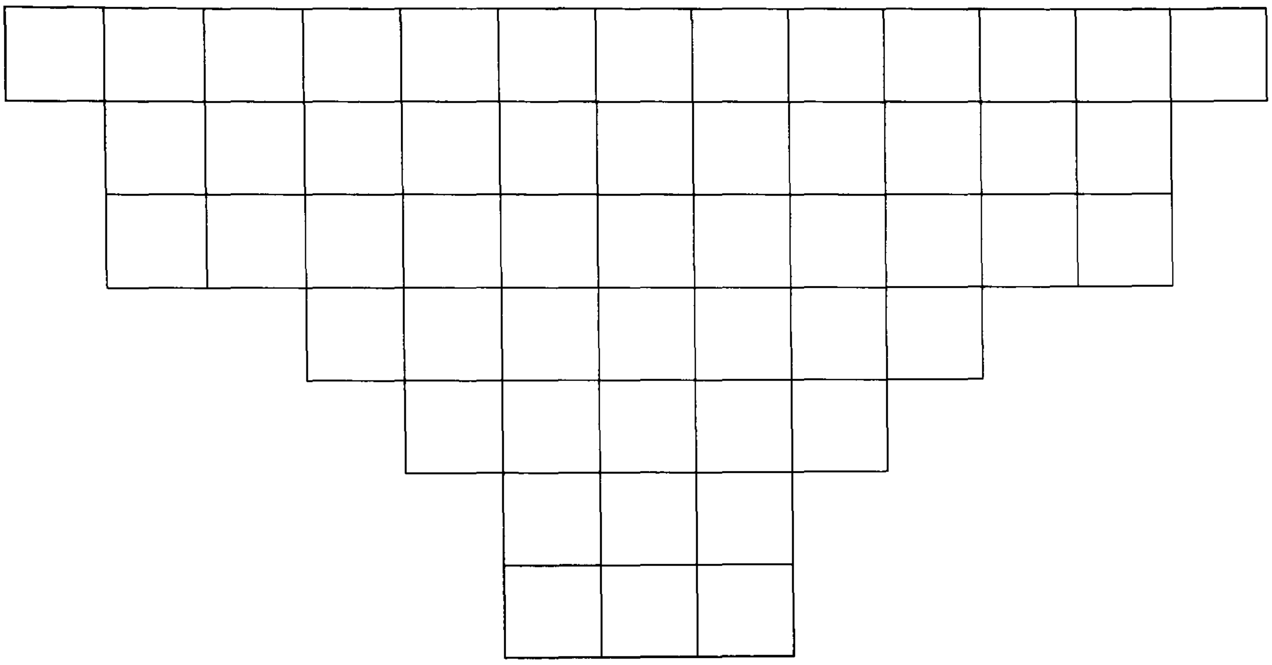
(Figure 4.3: U shaped distribution)

Van Excel and de Graaf (2005) suggest that in Q studies where knowledge is expected to be low, the distribution should be steeper in order to leave more room for ambiguity or indecisiveness in the middle of the distribution. In studies where respondents have more formed opinions on the subject, the distribution should be flatter to provide more room for strong variance in agreement. Being more informed about a subject does not necessarily lead to less indecisiveness, however. It could be argued that people who are deeply embroiled in a debate may find it harder to draw distinctions between statements than those who are encountering the concourse for the first time. As the statements in the Q set come from such a wide range of concourse, the participants may also not be as familiar with the items as van Excel and de Graaf would suggest. As participants may also have been chosen specifically to see how they prioritise the items in the Q set, a steeper distribution may not be as useful as a flatter distribution allowing for more polarity of opinion.

It could also be argued that participants would find the statements at the extreme ends of the continuum the easiest to place, and those in the middle more difficult. The more statements they have to place in the middle categories, the longer this would therefore take. This increases the risk of mechanical, rather than considered, placement of the statements. A normal distribution would aid analysis, however, as the analysis will be more sensitive to extreme item placement rather than items categorised close to the distributions average (Block, 1961). Stephenson (1974) emphasises this point by highlighting that when performing a Q sort, the participant distinguishes the common unit of measurement in that items placed at the +6 side (i.e. 'most important') will have more importance than items placed at the -6 side (i.e. least important). The middle point of the distribution is therefore not necessarily a neutral category, but potentially a point of no meaning to the participants ('most' is not necessarily opposite to 'least'). Dispersion around this point is therefore dependant upon self reference (Stephenson 1974).

Brown (1985) has argued that participants may violate the distribution of the Q sort without making any difference to the quality of the data; indeed, Brown asserts that the shape of the distribution is statistically inconsequential. The points of Stephenson (1974), along with my personal preference of making the Q sort as easy as possible for the participants to complete, resulted in the decision to use unimodal distribution for the study (Figure 4.4).With 53 statements, the continuum ranged from -6 to +6. Whilst the kurtosis was normal, a slightly flatter grid allowed for more disagreement at polar ends. This allowed the subjects to prioritise their attitudes at either end of the scale and self reference the meanings attributed to the statement placements. It allows space in the middle for items that participants think are not relevant to them. Performing the Q sort in this mode of distribution provides the advantage of easily identifying the statements placed at either end for ease of initiating discussion in the post Q sort interviews (to be discussed shortly). Making the distribution slightly flatter also allows for polar attitudes to be easily accommodated within the Q sort. Making the distribution normal automatically makes the distribution a forced free distribution; participants will have to place a certain number of cards in each category within the Q sort. This structure allows participants to place items anywhere in the grid they wish, whilst providing a structure for ease of sorting.

-6	-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5	+6
(1)	(3)	(3)	(4)	(5)	(7)	(7)	(7)	(5)	(4)	(3)	(3)	(1)



(Figure 4.4: Unimodal distribution grid selected for the Q study)

4.10 Q Sorting

To perform a Q sort, each statement is typed onto a piece of card and numbered on the opposite side. These are known as the 'Q cards'. In this study, a Q set of 53 items therefore resulted in 53 cards numbered from 1 to 53. Cards were randomly selected for numbering, however the order of the cards is irrelevant; cards are shuffled and participants 'sort' the statement on the front, using the number on the back simply to record the placement on the response sheet. Randomly numbering the cards and shuffling prior to Q sorting potentially prevents participants from reading similar statements concurrently, and allows for structured samples to appear more random.

A pile of cards is given to the participant, along with a set of instructions on how to complete the Q sort and the condition of instruction. In order to Q sort, participants require either a large space on which to sort the cards, or distribution markers in which to organise the piles of cards. The distribution markers represent the Q sort continuum (i.e. from -6 to + 6), and the number of cards to be sorted at each one. The number of cards at each pile will be representative of the kurtosis of the distribution grid. Advice is given to participants to first familiarise themselves with the statements by reading through them. It is then recommended that participants place the statements into three piles; those they agree with, those they disagree with, and those which they are unsure or neutral about. Each individual pile is then 'sorted', starting with (for example) the 'most agree' pile. Statements in this pile are re-read, and the statement which 'most' reflects the participant's opinion is placed at the most extreme end of the distribution grid under the heading 'most like my point of view'(+6). The number of statements to place in each pile is identified on the response sheet. Participants are then asked to select the statements which they think are important to them, however not as much as those in the +6 pile. These statements are then placed in the +5 pile.

Participants continue to sort the statements in this manner, with increasing numbers of statements in each rank (i.e. +4) as the participant works towards the middle of the grid, until all the 'agree with' cards are sorted in the positive side of the grid. Participants then follow the same instructions to sort the cards on the disagree side. The cards originally placed in the neutral or unsure pile are then placed in the middle of the grid as the participant feels appropriate.

Participants are asked to check the Q sort clearly represents their view point or attitude. Finally, participants are asked to write the number on the back of the statement card on a correspondingly shaped grid on the response sheet, so that participant's placement of the statements can be identified for analysis.

4.11 Q Sort Analysis

Factor analysis forms the basis of data analysis in Q methodological investigations (Dennis 1986). Q Methodology indeed takes its' name from this form of analysis. The letter 'Q' "generalised its' original meaning on an emphasis on correlating persons to include also a method which scaled data for this correlational approach" (Block 1961 p.12). The factoring and interpretation process of Q methodology are identical to the more traditional R method of factor analysis. Where Q methodology differs is that the factor loadings in Q are persons rather than items. When "people load together significantly on the same factor, it is because their Q sorts are similar and highly correlated" (Dennis 1986 p.12). The factors therefore highlight a cluster of attitudes or common perspective on the subject. As Barker (2002) highlights, where "R conceives people as a mass of characteristics...to be studied in terms of individual differences...Q deals with wholes and description" (P.156). Traditional 'R' factor analysis examines the correlations between variables to see if a small set of underlying factors can explain the variation in the original set of variables (Hinton, Brownlow, McMurray & Cozens 2004). The relationship in question in R factor analysis is the difference between the people (n) and the traits (N), exploring the differences within the sample and identifying the patterns of variation (Table 4.5).

Components

		A	B	C...........	N
People	a	axA	axB	axC.........	axN
	b	bxA	bxB	bxC.........	bxN
	c	cxA	cxB	cxC.........	cxN
	n	nxA	nxB	nxC.........	nxN

(Table 4.5: Raw Data Matrix [Brown 1980 as cited by Barker 2002 p.156])

Some authors have argued that Q methodology is merely an inverted approach to the more traditional R method of factor analysis. McKeown and Thomas (1988) have illustrated why this is not the case. If we were to invert R factor analysis to perform Q analysis, the matrix would become transposed. The columns would be people and the rows the measurements on the N traits. The columns would no longer be singly centred on a common unit of measurement, removing any meaning from the resulting factor (McKeown and Thomas 1988).

We can illustrate this using an example. If several variables are measured such as 'PhD students motivation for doing their PhD', the correlation between each pair of variables can be arranged in an R matrix (hence 'R' methodology) (Table 4.6).

	To make Change	Love of Research	Want to stay at University	Like being a student
To make change	**1.00**	**0.83**	0.13	0.025
Love of research	**0.83**	**1.00**	0.24	0.001
Want to stay at University	0.13	0.24	**1.00**	**0.91**
Like being a student	0.025	0.001	**0.91**	**1.00**

(Table 4.6: R matrix correlations)

The diagonal elements of the R matrix are 1.00 as a variable will correlate perfectly with itself. All other elements indicate how well these variables correlate with each other; the correlation coefficients for each variable. The existence of clusters of variables that correlate highly suggest these variables could be measuring the same underlying dimension (Field, 2000). The purpose of factor analysis would be to reduce this data by identifying what these dimensions could be. In the above example, there are two clusters of variables highlighted in bold which correlate, indicating that students who love research also want to make a change. Students who want to stay at university also like being a student. These dimensions could be identified as factor 1: personal drive; and factor 2: love of University life. If we inverted this matrix, we would be measuring the clusters of individuals around traits (Barker 2002). The units of measurement would become meaningless as the person would become the explanatory concept of variance. The variance cannot be explained by comparing ‘Daisy’ with ‘love of research’.

The statements (or 'items') in Q methodology form the rows and the persons the columns. The common unit of measurement in Q methodology is what enables correlation and factor analysis. This measurement is 'self significance' (Stephenson 1953), i.e. the traits composing the Q data matrix are centred on how significant they are to the participant. The factor loadings are therefore a correlation coefficient representing the degree to which each individual Q sort correlates with the various factors (Feher et al 2005). Factor loadings are thus people rather than items. The viewpoints are what are important, rather than the number of people who hold the viewpoints.

Q Sort data analysis has four distinct stages: correlation, factor analysis, factor rotation and factor computation. These will now be described.

4.11.I Correlation

Once participants have rank ordered the set of statements, their positioning of the statements are transformed into numerical data (i.e. most agree: +6 to most disagree: -6) and entered into a specific Q methodological software package, PQ Method. Participants are entered as column headings, with the statements forming the rows. This allows for by person factor analysis in the second stage of analysis. Each participant's numerical data is then inter-correlated to identify which participants sorted the statements into similar orders (Bryant et al 2006; Valenta & Wigger 1997; McKeown & Thomas 1988). The resulting correlation matrix represents the level of (dis)agreement between the individual Q sorts (Van Exel and de Graaf 2005).

4.11.II Factor Analysis

The correlation matrix is then subjected to factor analysis by person, rather than by statements, to determine the factors that represent groups of participants with similar opinions. The goal of factor analysis is to discover underlying factors (or 'themes') which summarises the patterns of correlation (or [dis]similarity) among the Q sorts (Cordingly et al 1997). Factors are therefore commonly held viewpoints amongst participants. As McKeown and Thomas (1988) highlight "factorization simplifies the interpretive task substantially, bringing to attention the typological nature of audience segments on any given subjective issue" (p.50). There are two methods of determining the unrotated factors in PQMethod: centroid analysis and principle components method. Centroid analysis is recommended by Stephenson (1953) and Brown (1980), and provides an intermediate initial factorial solution that allows more room for theoretical, or judgemental, rotation in the next step of the analysis (Aalto 2003). It is this theoretical basis that is advocated by its followers, due to the no 'one right answer' approach that it facilitates (Barker 2002). The principal component method, conversely, uses mathematically precise factoring systems (McKeown and Thomas 1988) with the aim of maximising variance on the final factorial solution (Aalto 2003). This 'best-fit' solution generally produces one factor followed by another (Barker 2002). Using either centroid or principle component method has been found, however, to have little effect on the resulting factor structures (McKeown and Thomas 1988).

The method used to determine the significance of factors, and therefore which should be retained for rotation, remains controversial. The most common method is to use the 'eigenvalues' produced by the factors. Eigenvalues are a measurement of the "relative contribution of a factor to the explanation of the total variance in the correlation matrix" (Donner 2001 p.31). Factors with an eigenvalue greater than one, thus explaining more variance than a single variable (Donner 2001), are usually kept and those with smaller eigenvalues usually discarded (Field, 2000). The number of factors retained therefore reflects the number of factors with an eigenvalue greater than one.

Using such strict criteria, however, may exclude a factor which may not be statistically significant but is theoretically significantly. Brown therefore suggested that as a 'rule of thumb', more factors than necessary (usually around 7) are kept in the initial stage of investigation, with the smaller factors removed after factor rotation (Brown 1980). McKeown and Thomas (1988) also urge the use of common sense when determining the importance of factors.

4.11.III Factor Rotation

The retained factors are rotated to arrive at a final set of factors (Van Exel and de Graaf 2005). Factor rotation effectively rotates factor axes (imagining that a factor, or viewpoint, is an axis along which people are plotted) so that participants load onto the factor which they relate to the most (Field 2000). This is helpful to distinguish between people who are likely to load highly onto all factors, heavily on one or minimally onto another. Factor rotation therefore finds 'best fit' for participant's viewpoints, optimising the separation between factors. Factor rotation does not affect the relationships between the Q sorts; it changes the vantage point from which they are viewed (Van Exel and de Graaf 2005).

There are two choices of rotation available in PQMethod, depending on whether researchers followed a theoretical (centroid) or statistical (principle component) rationale for factor extraction. A theoretical rationale allows for judgmental rotation of the factors, where the factors are manually rotated to pursue a particular Q sort (or individual) which holds particular interest. The specific Q sort can then be used as a reference variate and other Q sorts rotated around it. This is illustrated by Newman (2005) in his investigation into attitudes towards physician assisted suicide and euthanasia. Newman used judgemental rotation to maximise the Q Sorts of a Jewish rabbi and a Catholic nurse (whose opinions went contrary to her religious upbringing) onto one factor, and a Catholic philosopher onto another. Each factor therefore represented contrasting views towards the subject. Newman highlighted that through using theoretical rotation, he was able to "take advantage of the additional knowledge available (over and above the statistical features of the data) and adjust the analytical perspective accordingly" (p.101).

Alternatively, varimax rotation (commonly used alongside principle component method) uses statistical methods to identify simple structures which maximise the similarities within factors and the differences between them (orthogonality) (Baker, Thompson and Mannion 2006). As participants only load onto one factor, and as the factors bear a direct correspondence to the actual Q sorts (McKeown and Thomas 1988) interpretation of the results is arguably easier than judgemental rotation. Each resulting factor thus represents a group of individual view points that are highly correlated with each other and uncorrelated with other factors (Van Exel and de Graaf 2005). Varimax rotation is often advised as the first choice of rotation in order to simplify the interpretation of factors (Dennis 1986; Field 2000). This allows for results to emerge from the data which the investigator has not hypothesised. Performing both forms of rotation (judgemental and varimax), however, allows the investigator to determine whether the factors are independent or correlated, and the extent of this correlation. The best method of rotation can then be chosen.

4.11.IV Computation of Factor Scores

The final step prior to factor interpretation is the computation of factor scores. A factor score is the "normalised weighted average statement score of respondents that define the factor" (Van Exel and de Graaf 2005 p.9). These scores are then merged to create factor arrays, or 'model Q sorts', using a weighted average formula. The weight, 'w', is based on the participants factor 'f' loading where $w=f/(1-f^2)$ (Van Exel and de Graaf p.19). The resulting factor arrays form a set of scores (z scores) for each statement by factor, i.e. an averaging of the scores given to a particular statement by the Q sorts associated with it (Barker 2002). The factor arrays are then reverted back into the original values used in the sorting process for ease of interpretation (i.e. +6, -6), creating a 'model Q sort'. The model Q sort for a particular factor represents how a "hypothetical respondent with a 100% loading on that factor would have ordered" the items in the Q sort (Van Exel and de Graaf p.9). Statistically significant statements are identified as either ‘distinguishing’ or ‘consensus’. Distinguishing statements exceed the difference score between factors, with the difference score being equating to “the magnitude of the difference between a statements’ score on any two factors that is required for it to be statistically significant” (van Exel & de Graaf 2005 p.9). Distinguishing statements thus reflect where participants on a factor have placed a statement in a statistically significantly different position to participants in other factors. Consensus statements, conversely, are those which all participants in the study have placed in a statistically significantly similar position. Consensus statements do therefore not distinguish between any of the factors (Van Exel and de Graaf 2005). The number of distinguishing factors reflects the number of factors retained for rotation, whilst there is only one set of consensus statements.

For the current study, both forms of rotation were attempted in order to find the best possible solution. Principle component method using varimax rotation was attempted initially. A variety of different factor solutions were tested until a three factor solution was found to produce independent factors which could be interpreted using the distinguishing and consensus statements. This will be discussed further in chapter 5. Centroid analysis using theoretical rotation was next attempted to see if this method of factor analysis and rotation added anything to these results.

Initially, PQMethod extracted 7 centroids from the data. Retaining the 7 factors for rotation resulted in all Q sorts loading onto either factor one or two. The correlation between the factors was also high (0.66). For factor one, 40 distinguishing statements were identified, raising the concern that if everything is distinguishing, then nothing becomes distinguished. Exploring the factors in more detail, it was clear that there were three people on factor two who had highly negative correlations with this factor. They were therefore opposed to the view that factor two was portraying, making factor 2 bi-polar. Judgemental rotation was performed by -41 degrees to make these three Q sorts positive, to see if these individual Q sorts could be used as referential variates. Performing this rotation, however, made all of the statements distinguishing and therefore difficult to interpret. As there was also no defining information from either the demographic information or post Q sort interview data (to be discussed shortly) it was decided that this judgemental rotation was not reliable, and was thus rejected.

There was one participant in the study who strongly disagreed with extraordinary care for infants born at less than 26 weeks gestation, two weeks later than the study was discussing and what the current guidelines in the United Kingdom recommend treatment. This Q sort was the only sort to load highly negatively onto factor 2 following centroid analysis. Judgemental rotation was therefore attempted to make this Q sort a reference variate. This resulted in two highly correlated factors. In the unrotated factor matrix, however, the factor loading of this reference variate was highly similar to those of participants who strongly disagreed with this view point of view. The theoretical foundation for this variate was therefore not strong enough to justify judgemental rotation and was rejected.

Looking at the demographic information of the nurses, the main difference between participants were the amount of years which they had been practising neonatal care. Judgemental rotation was therefore attempted to determine if time spent practising neonatal care influenced the attitudes of the nurses. Following centroid analysis I rotated factors one and two by +5 degrees to separate out the biggest difference in time practicing. Factor one was referenced by least time practising (10 months); factor two by the most (35 years). Following rotation, however, both variates loaded highly onto one factor. There was therefore no theoretical rationale to justify using time spent practising neonatal care to judgementally rotate the factors as the viewpoints of the most and the least were the same. The reported religion of participants was also analysed to determine whether this could provide a rationale for judgemental rotation. Fifty percent of respondents had reported 'n/a' for religion, with a further 48% reporting a mixture of Christian, Catholic, Church of England or Scotland, and Methodist, with the differences between them unclear. The remaining 2% reported they were 'multi-faith'. Judgemental rotation based on reported religious belief was therefore considered unjust due to the limited ability to analyse any results.

Judgemental rotation was therefore rejected as the method of analysis and rotation. Principle component analysis, using varimax rotation, was considered to provide the best solution to the data through clarifying the structure of the factors by maximising the variance between the factors (Donner 2001).

4.11.V Factor Interpretation

Once the rotation of the factors is complete, interpretation is achieved through comparisons and contrasts between positioning of items, and through examining different sorting patterns to infer the accounts being told. The distinguishing statements in each factor and consensus statements highlight the main differences and similarities between participants' attitudes. Research and theory may also be used to explore the resulting model Q sorts. Using previous research, however, does not necessarily capture the rationale behind these particular participants' placement of the statements. Interviewing participants after they have Q sorted gives individuals the opportunity to explain why they placed the statements in the order which they did. Interpretation of the factor arrays can then be based on the participants' rationale. This allows for any new theory which has not previously been considered to be generated. Wong et al (2004) illustrate this method of interpretation in their investigation into clinical decision making. Completion of the Q sorts was followed by individual open ended interviews that invited participants to comment on why they placed certain items in positions of highest salience on the Q sort. Robbins and Kruger (2000) also advocate the use of interview data to interpret the factor structures. Senn (1996) suggests interviewing participants after factor interpretation has taken place to add "a certain kind of validity to the findings" (p.215). Not including participants own rationale, however, may miss the point of the accounts which they were trying to tell. Using participants own rationale to aid factor interpretation prior to determining the validity, helps to minimise the error of interpretation and therefore the validity of the study.

Using previous literature to aid analysis would also be placing the opinions of others onto the perceptions of the group which I want to explore. This is exemplified by the fact that there is little existing evidence surrounding neonatal nurses' perceptions towards extremely low gestation infants in England. This investigation will be the first which explores in detail how the different concourse surrounding viability (such as disability and abortion) affects the perceptions of nursing staff working with these infants. Using existing research will be interesting to compare the findings with other groups of health care professionals in other parts of the world, however would not be appropriate to help interpret the factors which emerge from this specific group of neonatal nurses. As Q methodology was created to measure subjectivity, interviewing participants about their placement of the cards to determine their interpretation of the statements seems highly relevant to the analysis if researcher bias is to be minimised.

4.12 The Interview Process

Interviews were undertaken with participants following completion of the Q sort. The time and place of the interviews was chosen by participants, and consent was verbally rechecked from their Q sort consent prior to their commencement. The interviews had two main aims: to explore the participants thoughts on the process of Q sorting, and to discover the rationale behind participants placing of the statements in the Q sort along with their general thoughts on infant viability. Interviews were semi-structured, developed with the recommendations of Wong and colleagues in mind of using a loose structure consisting of open ended questions inviting comments about participants' placement of statements in the Q sort (Wong et al 2004). This allowed for questions which were required to fulfil the aims of the interview around the process of Q sorting and the placement of cards, but also allowed for divergence from this structure to pursue the answers to these questions. In Q methodology, this is particularly relevant as participants will most likely place different cards at the end of the distribution grid, leading to different questions. A rigid interview structure would not allow for this divergence. Interviews conducted at the same time as the Q sort may be more intense for the participant yet allow the researcher to gain the initial reactions to the statements. However, unintentional influence may result in the participant deciding to change the position of a card as a result of the discussion with the researcher either as a result of social desirability or due to feeling challenged about a particular perspective. Interviews conducted following a certain amount of time after the initial Q sort allow for participants to have a break from the research process, although may mean that initial reactions to the statements are lost.

Immediately prior to the interviews, participant's response sheets were sought and the Q cards physically placed in the order that they had put them. This facilitated easier discussion of participant's particular placement of the Q cards. To ease participants into the interviewing process, all interviews commenced with the general question 'how did you find the Q sorting process?' Following this, participants were invited to discuss why they had placed the cards in the way that they had, starting with the card placed at the most agree end of the grid. As participants discussed the cards, their rationale was explored to gain a full understanding of their positioning. Some of the issues on the statements were discussed concurrently; for example who should make treatment decisions, the parents or the health care team. This allowed for the exploration of numerous statements on the cards in one discussion, essential with a Q set of 53. At the end of each interview participants were asked if they thought that any issues had been missed from the Q sort. All interviews took place within a few days (the longest time being one week) following completion of the Q sort. This delay between sorting the cards and the interview gave participants a chance to reflect on their sorting process, and more importantly gave the participants a break from the research process.

All interviews were digitally recorded with the permission of the participant. Notes were made during the interview process in order to follow up points which participants made during the flow of conversation. Digital recordings were transcribed verbatim by myself and were undertaken within a week of the interview, to improve the process through reflection on my ability as an interviewer. All transcripts were anonymised and transported into a computer software package NVivo (version 7) to aid data analysis by providing storage space and facilitation of data management. Participants were offered a copy of their interview transcripts for their personal development folders, to aid reflection on their perceptions towards infant viability and on their participation in the research. All participants said yes to this option.

4.13 Interview Analysis

As the aim of the interview is to facilitate interpretation of the resulting factor arrays using the participants own rationale, the analysis of the interviews can not begin until the analysis of the Q sorts is complete, as it is dependant upon which statements emerge as consensus and distinguishing. Q study results highlight the card number and the rank score of where participants placed each statement on the response grid. For cards which emerge as part of a distinguishing factor, the rank scores highlight the significantly different placement of the respective card in that particular factor. Participants can only load onto one factor, depending on whether their response to the Q sort is similar to that of other participants represented by, for example, factor one, two or three. The Q sort software package (such as PQMethod) provides the information of which participants load onto each factor. For the cards which emerge as consensus, these rank scores are not significantly different as the statements do not distinguish between any pairs of factors (i.e. all participants placed these statements in similar positions in the Q sort response grid).

As little reference to interview analysis in the case of Q methodology could be found in the literature, a series of logical steps can be followed which can be termed ‘Card Content Analysis’, or CCA (‘Card’ meaning the cards on which the statements were typed). The steps are outlined in Figure 5.8 and will be discussed in detail.

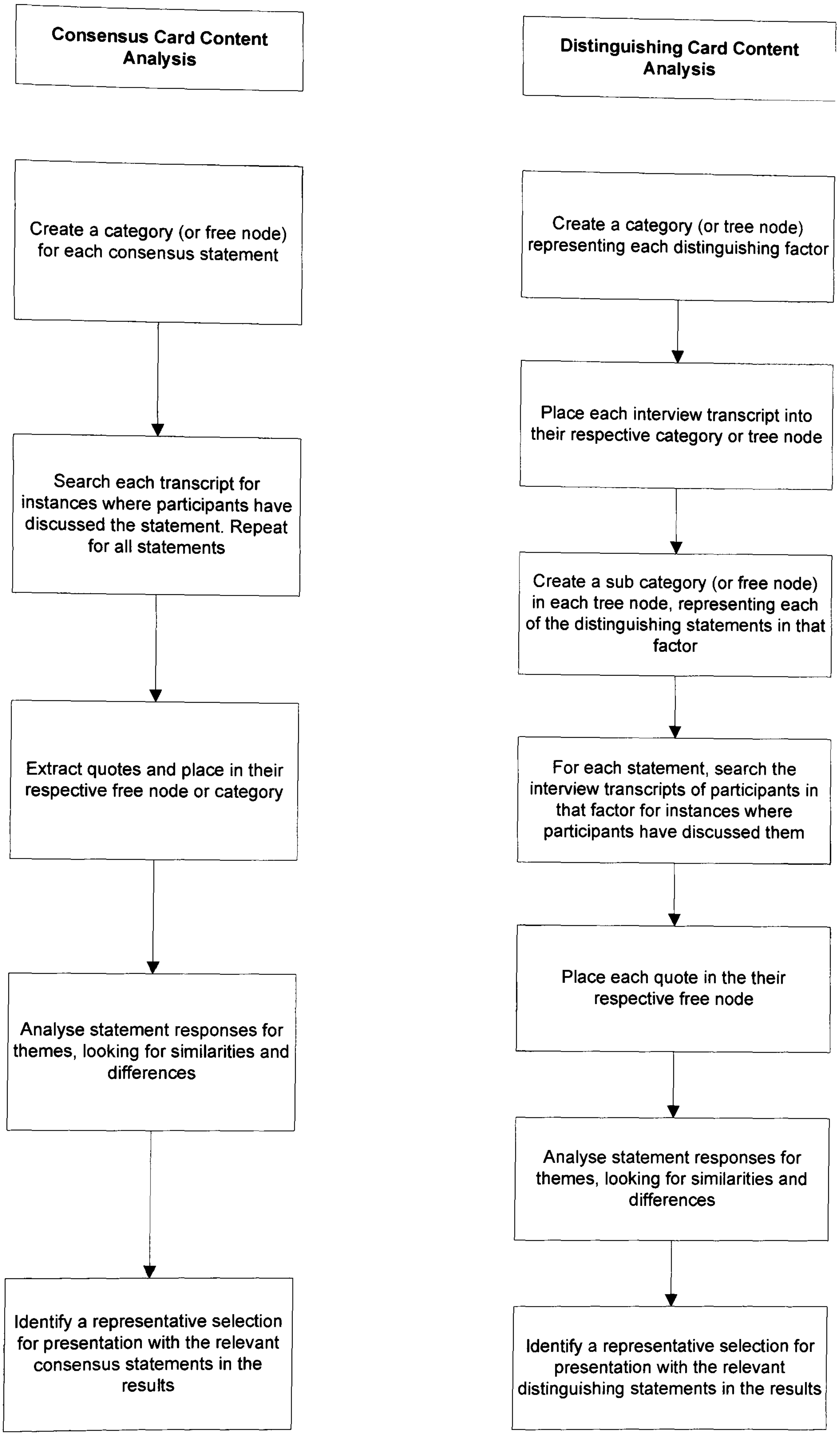


Figure 4.5: Card Content Analysis

4.13.I Consensus Card Content Analysis

All results from a Q study are presented in table format (see chapter 5 results section). The card number is shown, with the statement that is written on that card next to it. The rank score of where participants on each of the distinguishing factors placed the statement are then given. For the consensus statements, these rank scores are not significantly different as the statements do not distinguish between any pairs of factors (i.e. all participants placed these statements in similar positions in the Q sort response grid). A free node was created in NVivo for each of the consensus statements, labelled by the number of the card on which the statement was written (e.g node '28' corresponds to statement 28 which reads 'death is, and always will be, inevitable for some infants'). Each transcript was then searched to find instances where participants had discussed each particular consensus statement. These examples were then extracted from the interview data and placed into the free nodes. As not all participants discussed all statements, there was not always an extract from every participant for each statement. When this task was complete, each statement and its extracts were analysed individually. Themes were sought within each of the responses to the statement, looking specifically for similar or unique rationale. A representative selection of these views was then chosen to provide the rationale for statement placement. Combined, this data provided the basis for the discussion of the consensus results.

4.13.II Distinguishing Card Content Analysis

As with the consensus statements, the distinguishing statements emerge in table format as a number (representing the card), the statement on the card, and where participants have placed this particular card. The distinguishing statements are those which represent significant differences between their placements on different factors, resulting in a selection of statements for each factor. The collection of the particular statements in each factor provides the basis for the analysis of the factor.

Participants can only load onto one factor, depending on whether their response to the Q sort is similar to that of other participants represented by (in this study) factor one, two or three. PQMethod provides the information of which participants load onto each factor. Three tree nodes were created in NVivo to represent these: Factor One, Factor Two and Factor Three. The interview transcripts of participants who loaded onto their respective factors were placed into the corresponding nodes. Each factor was then analysed individually following the same process as the consensus statements; free nodes were created which represented each of the distinguishing statements in the factor. The interview transcripts of the participants in that factor were then searched to find instances of where participants had discussed this card. This information was then extracted and placed in the free node. When this task was complete, each node was analysed individually for themes within the responses, looking specifically for differences or similarities. A representative selection of these views was then chosen to provide the rationale for the statement placement. As with the consensus statements, the combined data formed the basis for the analysis of the distinguishing statements by factor in the discussion chapter. It is important to highlight the main difference between consensus and distinguishing CCA; in consensus CCA all transcripts will be searched for reference of the consensus items as all participants have placed these items in significantly similar positions in the Q sort response grid. In distinguishing CCA, only the transcripts of participants in each respective factor will be searched for reference of the distinguishing items as these items define the attitudes of that particular group of people. This ensures that the rationale of participants in 'other' factors is not used to analyse any other distinguishing factors.

Once all references to the items can be found, these can then be analysed for similarities or differences between them to present with the items in the factor arrays, thus contributing to the analysis of the factor. It is important to remember that the factor has already been defined through the factor array; the interview data were further justifies why the factor array has been created in that way. It could be argued that content analysis of the interview prior to this further exploration of the array could provide more rigour to this process; conversely it could be argued that this analysis has already been provided through the factor analysis of the data. The interview data were simply providing a rationale for the process and examples of the factor as reported by participants; performing further analysis of the text could dilute the rationale of the participants.

4.14 Reliability of the Q Study

The reliability of the results can be determined through reliability statistics of each factor and test-retest studies. Reliability is implicated when determining whether the factor scores are significantly different between factors, and therefore as the factor reliability increases (> 0.80) the possibility of error decreases (McKeown & Thomas 1988). This reliability reflects the possibility of each factor occurring at any other given chance; at a different point in time, or with a different sample. Test retest studies reiterate this notion of reliability through repeating the same Q study with the same participants at different points in time (and indeed with different participants) with resulting correlation coefficients of 0.8 or higher (Valenta & Wigger 1997).

The addition of a further approach to data analysis can strengthen the rigour of the study, as a single approach can often leave a study vulnerable to issues of reliability and validity (Polit & Beck 2004). The use of interviews following the Q sorting in this study, allowing for participants rationale to inform the factor array analysis, therefore improves the reliability of the study. Any errors of interpretation are minimised through this method, as the rationale behind the analysis is provided by the participants and is can be clearly identified with the results. The transparency of analysis is therefore clear to the readers, and can be analysed easily.

4.15 Ethics and Research & Development Approval

The study was undertaken with full ethical approval. National Research Ethics Service (NRES) approval for the study was sought and gained (appendix 2) along with Research and Development approval from 4 different hospital Trusts (appendix 3).

4.16 Recruitment

As previously discussed, 2 nurses from each nursing band (5-8) were chosen for sampling to meet the minimum number of participants required per factor, and also to gain an insight into the different working levels of nurses. Access to the neonatal units and their staff was negotiated with the Neonatal Ward Managers in the individual units. In order to manage data collection more effectively, the 6 units were separated into 2 different 'phases' of data collection. Three units were targeted in phase one, with the remaining three targeted in phase two. In all circumstances the same method of data collection was followed. Telephone calls were made to the ward managers and meetings arranged to discuss the research and ask for consent to recruit on their neonatal wards. At the discretion of the ward manager, I either presented the research at ward meetings or headed onto the wards to present the research to groups of nurses who were working at the time. It was made clear to nurses that no response was required at that time, and that I would be visiting the unit regularly over the next few months if they decided they wanted to participate. Recurrent visits were made on regular occasions to all the units to be available to discuss the research and answer any questions, to maintain the momentum of the study. Leaflets advertising the research were placed in the staff rooms of the neonatal units with my contact details highlighted for potential participants who wished to contact me for further information. Each unit had its own brightly coloured Q File which included: participant information sheets, consent forms, Q sort instruction sheet and Q sort response sheet (appendices 4-7). Two sets of Q cards were left at each unit along with the Q files. The folder and the cards were left in either the staff room where handover took place or the nursing station. These places were identified by the ward managers as the places where they would be most visible to the highest number of staff.

Whilst on the wards, nurses volunteered their participation into the study. Many nurses commented that they would like to opportunity to discuss their opinions around extremely preterm infants, a group of patients with whom they regularly work and yet do not get the chance to discuss the ethics behind. Participation in the study appealed to them for the opportunity to reflect upon their work. Whilst my presence on the ward may have prompted this involvement, all of the nurses who participated did so voluntarily and expressed positive comments around their experience within the study.

I negotiated the advertisement of the study on the Neonatal Nurses Association website with the Executive Officer of the association at a neonatal nursing conference. The leaflet for the study, explaining the study, the recruitment process and my contact details was placed on the front page of the website. This meant that as soon as anyone visited the site they would see my research advertisement. Despite getting only one direct email about the research, individuals at each site discussed seeing the study on the website.

Individuals who participated in the study either completed the Q sort at home or on the neonatal unit with the charge nurses permission, depending on which was convenient for them. Participants were offered the option of having me on the unit in case of any questions. Written informed consent was gained from all participants prior to the Q sorts and verbally rechecked prior to the interviews. All physical data was stored in a locked cupboard and anonymised. Data inputted into PQMethod was stored on a password protected file on my computer only. It was understood that discussing such an emotive area of infant viability and its concourse may have caused distress to participants. It was also realised that exploring participant's perceptions towards this subject may have raised concerns that individuals had with a particular infant and family from practice which may not have been resolved at the time. The study information sheet therefore made explicit the areas of concourse which would be discussed, so participants were fully informed prior to volunteering their participation. To minimise the potential for participants to get distressed during the study, it was also made explicit to all participants that they could withdraw at any time without having to give a reason. Participants were made aware that they had access to a staff counsellor should they feel it necessary, however none requested this service.

4.17 Summary

Q methodology provided an interesting and informative way in which to explore neonatal nurses' perceptions towards extremely low gestation infants, due to the focus on subjectivity and the interaction with the current debates. Principle component analysis using varimax rotation was used to analyse the data, revealing underlying clusters of perceptions amongst participants. The post Q sort interview data allowed for full exploration of these perceptions using participants own rationale. The results of the study will now be presented.

Chapter 5: Findings

5.1 Introduction

This chapter will present the results of the Q methodological investigation into neonatal nurses' perceptions towards extremely preterm infants. Basic study details will be discussed, followed by an explanation of the decisions taken to reach the final factor solution for the study. This will be followed by an introduction to the final factor solution, exploring the factor eigenvalues, loadings, characteristics and correlations.

Statements which emerged as consensus will be presented first, followed by the three distinguishing factors. Statements will be presented in order of agreement by participants (all allocated pseudonyms to maintain anonymity) and will be followed by an exploration of this agreement using post Q sort interview exerts from participants who loaded onto the respective factor. A brief summary of each of the findings will remind the reader of the highlights of the sections.

5.2 Basic Study Information

Thirty-six nurses from six different neonatal units took part in the Q study. Each participant completed the Q sort and participated in the post Q sort interview, giving in total around an hour and a half of their time to allow me to explore their perceptions towards extremely preterm infants. As one of the aims of Q methodology is to explore the different ranges of accounts of a phenomenon, nurses were sampled from all nursing bands in order to gain a wide variety of experiences, ages, and number of premature infants cared for. The youngest participant was 22 years of age, and the oldest 60 years of age. Time practising neonatal care ranged from 10 months through to 35 years. The demographic details of the participants can be found in Table 5.1. Q methodology does not seek to draw conclusions from demographic information, due to its focus on groups of perceptions, however it does help to give the reader an insight into the population who kindly agreed to participate in this study. Whether the sample is representative of all nurses working within each unit respectively is difficult to determine without the information of all nurses working within them, however as previously explored in chapter 4 Q methodology does not aim to be generalisable.

	Band	Time Practising	Specialist Neonatal Qualification?	Highest Education	Gender	Age	Number Children	Religion	Infants <24/40 Cared for
1a5	5	2.7y	Y	MN	F	26	0	RC	2
1e5	5	10mn	N	Dip	F	25	0	Chstn	7
1b6	6	7.10y	Y	Dip	F	36	0	n/a	50+
1h6	6	19.2y	Y		F	41	2	Chstn	150
1c7	7	27.7y	Y	Dip	F	50	0	n/a	30+
1f7	7	13y	Y	Dip	F	42	2	RC	30
1g8	8	10y	Y	BSc	M	36	1	n/a	Lots
1d8	8	19y	Y	MA	F	43	1	n/a	30+
2a5	5	6.2y	Y	BSc	F	27	1.5	Chstn	29+
2b5	5	1y	N	Dip	F	22	0	n/a	10
2e6	6	8.5y	Y	Dip	F	31	2	n/a	70+
2f7	7	35y	Y		F	60	0	CoS	30-40
2d7	7	16y	Y	BSc	F	44	1	n/a	30
2c8	8	18y	Y	PhD	M	43	0	n/a	50+
2g8	8	25y	Y	Dip	F	57	3	n/a	30+
3b5	5	7.11y	Y	Dip	F	30	2	n/a	2
3d5	5	10	Y	Dip	F	54	2	Multi	7-8
3a6	6	18y	Y	Dip	F	46	2	n/a	2
3c6	6	18y	Y	Dip	F	50	0	n/a	10-20
3e7	7	13y	Y	MSc	F	42	3	Chstn	5-10
3f7	7	30y	Y	BSc	F	55	2	RC	>20
4a5	5	1.6y	N	BSc	F	22	0	n/a	0
4b5	5	3.6y	Y	Dip	F	25	0	n/a	0
4c6	6	2.7y	N	Dip	F	40	2	n/a	1
4d6	5	19y	Y	Dip	F	47	2	CoE	
5c5	5	3y	N	Dip	F	52	2	CoE	5-10
5b6	6	5y	Y	BSc	F	36	1	CoE	0
5a7	7	30y	Y	Dip	F	47	2	CoE	10
6b5	5	6y	Y	Dip	F	28	0	n/a	6
6c5	5	4.4y	Y	BSc	F	29	0	n/a	2
6e6	6	10y	Y	BSc	F	43	2	Meth	0-5
6g6	6	15.5y	Y	Dip	F	36	1	Chstn	>100
6h6	6	21y	Y	Dip	F	42	2	RC	>30
6f7	7	24y	Y	BSc	F	45	2	n/a	20+
6d8	8	19y	Y	BSc	F	47	0	CoE	30+
6a5	8	25y	Y	BSc	F	48	0	RC	20

Table 5.1: Demographic information of participants

5.3 Factor Extraction using Principle Components

One of the most important decisions undertaken in any Q methodological investigation is the number of factors to retain following extraction, to explain participants' attitudes towards the desired phenomenon. This section explores the rationale behind the decisions taken to exclude certain factor solutions, before finally deciding upon a three factor solution using principal components with orthogonal rotation to explain participants' attitudes towards extremely preterm infants.

PQMethod automatically extracts 8 factors to consider for rotation. Each factor represents a different attitude type towards preterm infants. If we choose to follow the statistical recommendation of retaining all factors for rotation which have an eigenvalue of more than 1, all eight factors would remain in this study (Figure 5.1).

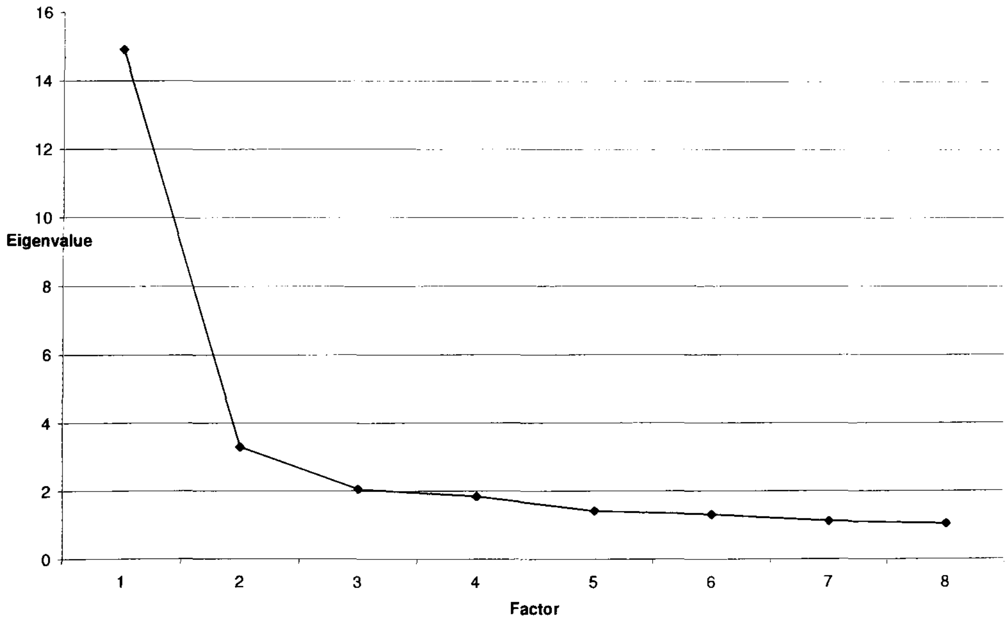


Figure 5.1: Factor Eigenvalues

Eight factors were therefore subject to varimax (orthogonal) rotation. Whilst the correlation between each of the 8 factors was low, the theoretical interpretation of these factors was not possible due to the lack of distinguishing statements on each factor, meaning that there was nothing to distinguish one factor from another. Another problem with retaining all 8 factors for rotation is that out of the 36 participants, only 16 loaded onto any of the 8 factors. This meant that the remaining 20 participants would not be included in the final analysis. Whilst this may have suggested that there were more than eight factors to be considered when exploring extremely preterm infants, as the reliability of the factors were also low. Six of the 8 factors had reliability scores of <0.89 (table 5.2), meaning that the chances of participants sorting in this way on a different occasion was low, as discussed in chapter 4. It may also have been reflective of the small number of participants on each factor. An eight factor solution was therefore rejected.

	1	2	3	4	5	6	7	8
Variance Accounted for by Factor (rotated)	16	7	12	12	6	6	5	9
Defining Q Sorts	4	2	1	3	1	2	1	2
Reliability of Factor	0.941	0.889	0.800	0.923	0.800	0.889	0.800	0.889
Number of Distinguishing Statements	0	1	1	0	1	0	3	1

Table 5.2: Eight factor solution

Rejecting an 8 factor solution also resulted in the rejection of the statistical recommendation of retaining all factors with an eigenvalue of more than 1. A solution had to be found which could be interpreted using the statements which were highlighted as distinguishing. A process of discovering the best factor solution to explain the data was therefore embarked upon, using a method of elimination of factor solutions until the best fit factor solution was found.

Seven, six and five factor solution presented similar interpretation problems to the eight factor solution. The correlations between factors were low however a lack of distinguishing statements on certain factors meant that the factors could not be interpreted. The low reliability of each factor also suggested that the factors identified were not likely to be repeated on different occasions, although may have also been reflective of the small number of participants on each factor as with the 8 factor solution. The 7, 6 and 5 factor solutions were therefore rejected for low reliability.

	1	2	3	4	5	6	7
Variance Accounted for by Factor (rotated)	19	6	16	6	7	7	11
Defining Q Sorts	8	1	5	1	1	2	2
Reliability	0.97	0.80	0.95	0.80	0.80	0.889	0.889
Distinguishing Statements	0	1	0	3	3	0	0

	1	2	3	4	5	6
Variance Accounted for by Factor (rotated)	19	11	16	10	6	6
Defining Q Sorts	7	3	2	2	1	3
Reliability	0.96	0.92	0.889	0.889	0.800	0.92
Distinguishing Statements	1	3	4	3	3	2

	1	2	3	4	5
Variance Accounted for by Factor (rotated)	20	11	17	11	6
Defining Q Sorts	8	3	4	2	2
Reliability	0.97	0.923	0.941	0.889	0.889
Distinguishing Statements	2	5	8	5	8

Table 5.3: Seven, six and five factor solutions

Whilst the four factor solution offered more reliable results, when the factors themselves were displayed in factor arrays only two of the four factors could be visually interpreted for analysis. Following numerous discussions with the supervisors of the study with the factor arrays displayed, no coherent analysis of the factors could be found. A four factor solution was therefore rejected.

	1	2	3	4
Variance Accounted for by Factor (rotated)	19	13	19	11
Defining Q Sorts	9	5	8	3
Reliability	0.973	0.952	0.970	0.923
Distinguishing Statement	6	15	13	13

Table 5.4: Four factor solution

Retaining 3 factors for rotation produced a solution in which the factors were statistically strong in terms of reliability (table 5.5), suggesting that if the Q study were repeated the same factors would emerge. This solution was therefore kept in as a possibility whilst the last possible solution, the 2 factor solution, was tested.

	Factor 1	Factor 2	Factor 3
Variance Accounted for by Factor (rotated)	20	14	23
Defining Q Sorts	9	5	17
Reliability	0.973	0.952	0.986
Distinguishing Statements	11	22	17

Table 5.5: Three factor solution

The two factor solution resulted in 40 out of the 53 statements being identified as distinguishing on factor one, making the factor too large to interpret as it was trying to display too many perceptions in one factor (table 5.6). This solution was therefore rejected.

	1	2
Variance Accounted for by Factor (rotated)	31	21
Defining Q Sorts	20	16
Reliability	0.988	0.985
Distinguishing statement	40	13

Table 5.6: Two factor solution

The three factor solution was therefore chosen to represent neonatal nurses' perceptions towards extremely preterm infants. On exploration of the factors it could be seen that the correlations appeared high between factors (table 5.7); this could be explained through visual interpretation of the factor arrays by the similarities between the consensus and distinguishing statements in each factor. Participants in factors one and three (correlation 0.67) were linked by their placement of statements involving an element of decision making. Participants in factor two, with a lower correlation between factors one and three (0.45 and 0.29 respectively) did not prioritise these statements. This resulted in distinguishing statements on this factor focusing on the importance of initiating treatment.

	Factor 1	Factor 2	Factor 3
1	1.000	0.4517	0.6746
2	0.4517	1.000	0.2938
3	0.6746	0.2938	1.000

Table 5.7: Correlations between factor scores with a 3 factor solution

It was decided that retaining three orthogonally rotated factors was reasonable for this Q study. Next, the decision to retain either pure or mixed type factor solution was considered. A 'pure' type is a participant who loads 'purely' onto one factor; a 'mixed' type loads onto more than one. The factor on which they have the highest loading is chosen to be the factor which represents that participant. PQMethod automatically opts for mixed type factor loadings. This function was disabled, however, and manual flagging of participants onto their factor loadings was undertaken and then analysed using orthogonal rotation. The resulting differences between the correlations of the pure and the mixed type factor solutions were small. Retaining only participants who loaded purely onto one factor (defined as a loading ≥ 0.36 [2.58 x standard error] on one factor only) resulted in 19 participants not loading significantly onto any factor. Retaining a mixed type solution using the automatic flagging on the PQMethod software resulted in only 5 participants not loading onto any factor (Table 5.8). As the differences between correlations were so small, along with the knowledge that retaining only pure types increased the amount of participants who would not have been included in the results, a mixed type factor solution was chosen.

Retaining a three factor solution for this investigation resulted in three individual factors represented by distinguishing statements, along with a set of consensus statements. The distinguishing statements representing each of the three factors give us three different attitudes of nurses towards extremely preterm infants. The consensus statements indicate the attitudes which neonatal nurses share, regardless of their factor loading. These 'sets' of statements give an insight into the attitudes of neonatal nurses' towards extremely preterm infants.

The focus of the results section will now turn to these factors. The consensus statements will be explored initially to explore the shared attitudes of nurses towards preterm infants. This will create a basis of shared assumptions on which to build the different 'distinguishing' attitude types. These attitude types will then be presented as factors one, two and three.

Q Sort	Factor 1	Factor 2	Factor 3
1 1a5	0.0966	0.2190	**0.7554X**
2 1b6	0.5491	0.1170	**0.5782X**
3 1c7	0.1271	**0.5782X**	-0.0473
4 1d8	0.4247	-0.0788	**0.6554X**
5 1e5	0.2606	0.2871	**0.4723X**
6 1f7	-0.0414	**0.8229X**	0.0169
7 1g8	0.1758	**0.6421X**	-0.0419
8 1h6	0.0013	0.1678	**0.7806X**
9 2a5	0.3309	0.1997	**0.5861X**
10 2b5	0.2134	0.1625	**0.3383X**
11 2c8	0.0641	0.5562	**0.5850X**
12 2d7+	0.2087	**0.5397X**	0.2693
13 2e6	**0.6655X**	0.3658	0.3458
14 2f7	0.0950	0.0121	**0.7463X**
15 2g8	0.0356	0.5047	**0.5907X**
16 3a6	0.4848	-0.0891	**0.6255X**
17 3b5	0.4158	-0.2582	**0.6613X**
18 3c6	0.4224	0.0674	**0.6425X**
19 3d5	0.2939	0.3689	**0.5742X**
20 3e7	0.2382	**0.7036X**	0.1145
21 3f7+	0.4620	0.5406	0.4173
22 4a5	**0.6046X**	0.4943	0.1481
23 4b5	**0.6598X**	0.2621	0.1149
24 4c6	**0.6701X**	0.2395	0.3403
25 4d6	0.4281	0.4463	0.2933
26 5a7	0.3969	0.4381	0.3453
27 5b6	**0.7991X**	0.3528	-0.1079
28 5c5	0.3168	0.1290	**0.5006X**
29 6a8	0.5333	-0.0666	**0.5842X**
30 6b5	**0.7864X**	0.1116	0.3835
31 6c5	**0.4707X**	0.2957	0.2723
32 6d8	**0.6960X**	0.1501	0.4370
33 6e6	**0.6044X**	0.0392	0.4569
34 6f7	0.4833	0.2089	**0.6430X**
35 6g6	0.4013	0.3967	0.2532
36 6h6	0.3955	0.3941	0.5153
% variance explained	20	14	23

Table 5.8: Factor Matrix loadings with an 'X' indicating a defining Sort

Findings: Consensus Statements

5.4.I Introduction

A three factor solution was chosen to best categorise the attitudes of neonatal nurses towards extremely preterm infants. These factors are characterised by a set of distinguishing statements, identifying which statements were placed in a statistically significantly different position by participants on factors one, two and three respectively. A set of statements placed in statistically significant similar positions by all participants also emerged. These statements are known as 'consensus' statements, as they do not distinguish between any factors (Van Exel and de Graaf 2005).

Consensus statements are important as they highlight issues upon which all participants agree, disagree or are neutral about, regardless of which factor they load onto. This translates into statements which neonatal nurses are either passionate about or feel have no bearing upon them as a neonatal nurse, identifying how neonatal nurses prioritise the arguments that surround extremely preterm infants. In order to understand what the differences between neonatal nurses' attitudes are (the three factor solution) we first have to understand what unites the participants. From this basis, an understanding and appreciation of the different characteristics of factors one, two and three can be developed.

The investigation into neonatal nurses' attitudes towards extremely preterm infants resulted in 15 out of the 53 statements emerging as consensus. Participants therefore agreed on 28% of the statements, highlighting a difference in opinion on the remaining 72%. This fact in itself illustrates that there are varying opinions about extremely preterm infants within one specific group of people working with these infants. Whilst the finding of differences of opinion is not surprising amongst professionals working with extreme preterm infants, this study is unique in its ability to identify what these varying attitudes are, along with the shared attitudes which emerged as consensus. Understanding the uniting attitudes creates a platform on which to work with nurses to try and improve their experience, and ultimately the families' experience, on the neonatal unit.

Breaking the consensus statements down into their respective concourse components from the total statement sample (Table 5.9), it can be seen that participants hold the most similar attitudes towards abortion and fertility. Statements regarding decision making and treatment decisions resulted in the smallest amount of consensus amongst participants, thus highlighting the source of the major differences between attitudes to extremely preterm infants. These statistics are important as they identify which parts of the concourse sampled are most likely to divide and unite the attitudes of neonatal nurses.

	Statements in Sample (% total sample/ cards)	Defined as Consensus (% of sub sample)	% total sample consensus (ax[b/100])
Abortion	10 (19)	5 (50)	9.5
Decision Making	10 (19)	1 (10)	1.9
Disability	9 (17)	2 (22)	3.7
Fertility	4 (7)	2 (50)	3.5
Technology	11 (21)	4 (36)	7.5
Treatment Decisions	9 (17)	1 (11)	1.9

Table 5.9: Consensus statements by concourse component

5.4.II Positioning of Consensus Statements

The following consensus statements were placed in the following positions in factors one, two and three (Table 5.10).

Card	**Statement**	**FACTOR**		
		1	**2**	**3**
6	The care of women in the neonatal unit should not be influenced by a history of previous abortions	+5	+6	+4
28	Death is, and always will be, inevitable, for some infants	+5	+4	+6
25*	The technology which enables the most premature of infants to survive brings with it increased ethical dilemmas over whether it should be used to ensure this survival	+4	+5	+5
22*	Nurses who work in abortion services from 20-24 weeks gestation are merely providing a service and should not be judged	+3	+2	+2

49	The choices that parents make about their extremely preterm infants are often prompted by the choices of the Health Care Professionals	+2	+4	+3
10	The amount of technology used in the neonatal unit is a barrier which is detrimental to parent-infant bonding	+1	+1	+1
51	Abortions should not be allowed from 22 weeks gestation as the fetus is changing into a baby	+1	+2	0
52*	Abortion providers and Neonatal Intensive Care Units are separate entities and the actions of one should have no influence upon the other	+1	0	+1
15*	The amount of technology surrounding the infant alters the social concept of death to something that can be overcome	+1	+2	+2
40	The philosophy underpinning nursing and medical care is the same in all health care settings, including neonatal and abortion services	0	0	-1
5*	The more disabilities that can be diagnosed prenatally, the more pressure there is on women to abort these pregnancies	0	0	+1
46	Women who try to conceive post menopause are not thinking about the best interests of the infant	-1	-1	0
47	Caring has become technological, shifting the focus from caring for the infant to caring for the technology	-1	-1	0
9*	Older parents are better equipped to deal with the outcomes of extreme prematurity	-3	-3	-4
16*	Life satisfaction is not possible if you have a disability	-4	-5	-5

($p<0.01$) (* $p<0.05$)

Table 5.10: Consensus Statements

To illustrate the meaning of the above table (Table 5.6), the following figure represents the 'typical' placement of consensus statements by participants in factor 1 (Figure 5.2). The 'neutral' column in the middle of the continuum ('0') gave participants the option of placing statements in this column which they were uncertain about, or had no set opinions on.

-6	-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5	+6
(1)	(3)	(3)	(4)	(5)	(7)	(7)	(7)	(5)	(4)	(3)	(3)	(1)

		16	9		46	5	10	49	22	25	6	
					47	40	15				28	
							51					
							52					

Figure 5.2: Diagrammatical representation of the Consensus Statements using Factor 1

5.4.III Consensus Statements Explained by Participants

Each statement will be presented and explored using the post Q sort interview data with all participants in the investigation. The statement will be presented in bold, followed by its statement number and position in factor one, two and three (i.e. **death is, and always will be, inevitable for some infants. 28: +5**

+4 +6). Due to the vast amount of data for the consensus statements resulting from 36 individual interviews, statements are presented in separate concourse themes to maximise the understanding of each statement in relation to others in the same theme. The themes of the concourse will be presented in the following order, reflecting as much as possible the positioning of the statements from agree to disagree:

a) Treatment Decisions (1 statement)
b) Technology (4 statements)
c) Abortion (5 statements)
d) Decision Making (1 statement)
e) Fertility (2 statements)
f) Disability (2 statements)

Where participants discussed the positioning of a statement which emerged as a consensus statement, this data will be presented after the statement to further explore the rationale of participants behind the decisions they undertook to place the statements where they did.

5.4.III.a Treatment Decisions

Statement 1

The neonatal nurses in this study held a firm belief that **death is, and always will be, inevitable for some infants (28: +5 +4 +6).** They saw the death of extremely preterm infants as a 'fact of life', which they as neonatal nurses would encounter as part of their role. Participants thought that the statement was not something which you could argue with, suggesting that they saw death as something which was out of their hands, a natural occurrence which was not preventable by medicine or something they could alter.

> "I know it sounds quite pessimistic, but I think, and I know nobody likes to think about it, but I think it's always going to be a part of your nursing the babies.... I don't know if it's pessimistic or realistic part of me. I don't know, but I think it's always there in the back of your mind, that it really is going to be part of it, and it can be inevitable for some" (Liz)

> "I just thought it is going to be inevitable isn't it, for the babies that we look after to be honest, definitely" (Carry)

Participants were also aware of the technology that was available to help these infants survive however felt that if death was inevitable then technology would not be able to prevent it. The opinion that death is an inevitable outcome for some was increased by the fact that nurses often felt that some infants were born too soon, and as such were not 'meant to be here'.

> "Ultimately you've got a baby who shouldn't be here, they should be tucked up inside mum, and should be, you know, I don't know I suppose, I think you just can't get away from it really, you can throw everything at them, you can do the best for them, but in

> many ways you're never going to change the fact that you've got a baby that shouldn't be born" (Claire)

One participant highlighted an issue which they thought affected the acceptance of the inevitability of death from the parents' perspective, stating that:

> "Yeah, I strongly agree with that, and understandably, I don't think parents always realise that. Because they don't work here and I've done neonates for a long time. And so I am not surprised when babies are terminally ill or die, but I don't think people ever expect babies to die" (Sian)

Death was not something which participants felt had to be a negative experience. Whilst they accepted that death was something which they could have no effect over, they expressed a desire to influence how the infant's death was accepted by the family through involving members in the care of their dying infant.

> "I think we have to respect, not, I wouldn't say embrace death, but actually, it's probably what I mean really, we need to be able to do that confidently, and know that we're doing the right thing, for that child and family, for that baby and family, and this one's a biggie for me, I think we need to be able to let parents who are confident in making that decision, you know, support them, and take them

> through that, we need to be there with them, and for them, I mean death is inevitable for all of us, for some it's earlier than anybody would wish for, but that to me is a very relevant statement" (Claire)

Participants were aware of how painful death can be for the family, and discussed wanting to make the death experience as nice as possible for parents who were inevitably having to experience the loss of their child. Participants discussed how they felt this was an integral part of their nursing role.

5.4.III.b Technology

Statement 1

Nurses in this study all agreed that **the technology which enables the most premature of infants to survive brings with it increased ethical dilemmas over whether it should be used to ensure this survival (25*;+4 +5 +5).** Participants discussed their concerns that technology was being used in situations where they would not consider it appropriate to keep infants alive; who participants felt would not survive.

> "Some parents will say to you, they're breathing, and it's like, well no, the ventilators breathing, the baby's not breathing, and they don't always understand that concept. And they've seen *Bella*, or *Best* [commercial magazines], and the long term, you know, my 23 weeker survived, and I just think we need to, I just don't think, although we've got it, we shouldn't always use, it, it's almost like

> regardless of the weight now, or the gestation, we're using it rather than thinking, should we be using this, just because we've got it" (Megan)

> "We've got the point now where we can do a lot more because of the machinery we have, we can keep babies alive, babies that, you know, 15 years ago we wouldn't even attempt to care for, we now have equipment that allows us to do an awful lot more, which on the one hand is good that its available, but I do think that we then try and play God and try and keep a lot more alive than we might ought, perhaps we ought" (Aimee)

The ethical dilemmas did not arise only from the technology itself. The application of the technology made the participants question their own nursing actions, along with the benefits that the technology was bringing to the infants who were receiving extraordinary care from it. The perceived benefits of technological interventions were often questioned by the participants.

> "When, you're in that situation, and its very intensive, and you're doing all these things, and you sometimes you just want to take a step back and think, what are we doing here, what are we actually doing to these children, what are we doing to these parents, what are we doing to ourselves, we're all in that, we're putting ourselves in a huge stressful position, we're putting these parents, are we giving them false hope, quite often you step back, and after, I don't

> know however long you've been doing it, you think, where are we going here, what are we doing" (Josie)

Participants also discussed their perceptions of the level of infant suffering which they saw as a consequence of the extraordinary care the infants were receiving, and the subsequent relief which they felt when they thought that the suffering had stopped following death. Participants appeared to be associating extraordinary intensive care with a negative experience for the infant, and were uncomfortable with their role as a neonatal nurse in this context.

> "You know we always have de- briefs, and one of the biggest things from a nursing perspective, is that went on 5 days too long, or a week too long, it should have stopped, 5 days ago, because we watched the baby deteriorate, we watched them suffer" (Megan)

> "It just ended up being, nobody wanted to look after the child [23 weeker], because it was so upsetting...we're expected to be professional but actually we're human, and any other human being seeing that kind of thing day in and day out, would, it would get to them. You know, and actually you end up rejoicing when the baby dies, because you think that goodness it's at peace" (Cara)

Participants described the feelings which ethical dilemmas surrounding resuscitation and death, as a result of technology, raised for them and how this affected them as a neonatal nurse.

> "I was actually, relieved for her, and I was a little cross that she had to die with a tube down her throat, or us putting a tube down her throat and us bagging her, and somebody bouncing on her chest, as opposed to, I felt like saying I'm sorry, you wanted to go, we should have just let you go, you stopped, in your cot, and we dragged you out here with all the lights, and put the tube down your throat, and kept bagging you, and squeezing your chest, and you know, her little body in the end, it was just, there was no life in it, it was just a little sac of organs, and we were sticking tubes in, and needles, and fluids, and things, and its just not fair, its not kind in the end" (Lucy)

The ethical dilemmas which participants had experienced or felt when caring for these infants led one participant in particular to try and take action to prevent their involvement in any future dilemmas.

> "I've said, if they know a 22 weekers going to come round, and they know they're going to be resuscitating, can you opt out, and they've said well no, because no has ever said anything before, so your kind of just expected to follow the crowd…I think its too early, its just too early, they're too premature, and I think yes there is always the ones the exception to the rule, which they always quote at you, well, you know this one is absolutely fine, and that was 22 weeks, but a lot of them aren't, and a lot of them have a

> very nasty short life, and I don't know if I particularly like being a part of that" (Zoe)

Technology: Statement 2

Participants slightly agreed that **the amount of technology surrounding the infant alters the social concept of death to something that can be overcome (15*; +1 +2 +2).** Participants were concerned that the technology would give parents a false impression that their infant was doing better than in reality they were. They discussed how the technology could perform many functions for the infant, such as breathing, which participants worried the parents may think was the action of their infant. Participants went on to express their concerns that the technology may give some parents the impression that their infants would survive the neonatal journey with no adverse affects.

> "Parents thinking "oh great, my baby's still alive", and what we're doing for it may just be keeping it alive, and not really, it might be making no effort at all, just because a 23 weekers put on a ventilator and is breathing, doesn't mean its going to on its own, do you know what I mean, there's so many hurdles, and I think sometimes parents come in and because their chests moving up and down they think its breathing, its all great, its going to be fine" (Daisy)

Participants explained that whilst they agreed that technology did have an impact upon parents' expectations in the neonatal unit, it was not the only influence, potentially explaining the low levels of agreement with the statement. Participants discussed the impact that the media had on the public's perception of, and thus parent's expectations of, technology and neonatal care.

> "The media do a great job in, my 23 weeker, my 22 weeker, and you know, my baby only weighed so many hundred grams, and look at me now. I think probably they have more influence on outcomes sometimes, and peoples expectations of what we can do, and I think that some people think that we can actually do an awful lot with much lower gestation babies than we really can" (Emily)

> "We're up against the press, and the television, and everything, which are coming out with these huge, expectations, raising everybody's expectations, that not only are these babies going to live, but they're going to be perfect" (Emma)

Technology: Statement 3

Participants remained neutral that **the amount of technology used on the neonatal unit is a barrier which is detrimental to parent-infant bonding (10; +1 +1 +1).** Participants thought that due to the complexity of the technology surrounding the infants, parents often felt in awe of it and became afraid to touch their infant for fear of misplacing an element of the technology, such as wires and tubes.

> "Yes it can be detrimental to parent and infant bonding, because they see it as a barrier, I've got a lady at the moment who hasn't had a lot of hands on care, because the baby's been monitored, and just down to simple things like it's cords still on, but as far as when all the monitors on, no way is she going to touch that baby, the sooner we can get him monitor free the better, it's surprising what parents see as a barrier, you know, ventilation, and lots of drips, and UVC's [umbilical venous catheter] and UAC's [umbilical arterial catheter], you know, they are a huge barrier and you know, it makes bonding very difficult" (Emily)

Participants discussed how sometimes parents were worried that the amount of technology surrounding their infant was 'hurting' the infant, reinforcing the 'barrier' between the technology, the parents and the infant.

> "I do think that you notice quite often the parents, especially initially, are very frightened of the technology, they're frightened to touch their baby as they are frightened to dislodge it. They sometimes don't even see the baby, children surprisingly quite often look past the technology, but the parents just see the tubes, the wires, they think is it hurting them… it does look very over powering, and they're petrified to touch the baby in case they dislodge something, so you've immediately got a barrier" (Lucy)

Participants were aware that the potential for technology to be a barrier was individual, and not true to all parents. They were also aware that their actions could help parents overcome this barrier and become more involved with their infants.

> "As long as you're there, and you can see the baby, and tell the parents what sorts of things to look for, because they'll sit there and they'll look, and as the baby's feet move, the sats [oxygen saturations] drop anyway, because of the contact, and they just get so twitched, and they're not looking at the baby, they're looking at the machine" (Jane)

Technology: Statement 4

Perhaps due to their awareness of the issues which they thought technology raised, participants remained neutral that **caring has become technological, shifting the focus from caring for the infant to caring for the technology (47; -1 -1 0).** Some participants felt it was too easy to lose sight of the baby in amongst the excitement and abilities of evolving technology.

> "Health care professionals of whatever description on the neonatal unit can be pretty bad at looking at what's going on with the baby, and being over impressed with what the machinery's doing, probably ventilators are the best example of that at the moment, the ventilators and what they can do has become so complex, that,

> there is endless possibility of fiddling with what the ventilator does" (Ben)

Some participants discussed the issues of using advancing technology, and how it made them aware that the infant had to remain the main focus of the care.

> "I do think the caring has got to remain the most important part of looking after these families, because if the caring goes out of it and the machinery takes over it becomes very black and white and there is always a very gray area, you know, when you cant, you know, one set of rules doesn't necessarily suit all" (Aimee)

5.4.III.c Abortion

Statement 1

Participants all strongly agreed that **the care of women in the neonatal unit should not be influenced by a history of previous abortions (6; +5 +6 +4).** Participants strongly agreed that the 'here and now' was the most important aspect of care, and that the history would have little impact on the care that the woman would receive on the neonatal unit. Participants were clear that they did not feel that it was their duty to judge previous actions of the woman.

> "I think it shouldn't matter full stop. I know we do get histories of women when they come through, you can look through all their private information, and to be honest it's none of our business why

> they had them, a lot of women have damn good reasons for it" (Liz)

> "Whatever their circumstances, you're dealing with the here and now, and what's gone on in the past should not influence the way you treat somebody...I don't think that's right, you don't know the history, you don't know the reasons behind that, you don't know what her life was like, you don't know what circumstances went, we're not in a position to judge, this is the here and now, her life might have changed dramatically, we don't know, so, I think we shouldn't judge, we've not been there" (Gemma)

Abortion: Statement 2

Similarly, participants slightly agreed that **nurses who work in abortion services from 20-24 weeks gestation are merely providing a service and should not be judged (22*; +3 +2 +2).** Participants thought that nurses who worked in abortion services were working in the same capacity as a nurse; simply in a different service. They identified that their opinions of abortion did not impact upon the fact that nurses in these services were providing a necessary service.

> "They're providing a service, and they, we're all covered by our code of practice and conduct, and you know, they're providing a service which unfortunately or fortunately is needed, because lets face it, some of the abortions we would all say well, yes, some are

> social and we might frown upon in our own social circle, but you know, that's what rights and freedom unfortunately is all about, so I think that comes down to, it's a very personal opinion of what you actually think about it, but, as a nurse, they are providing the caring and the support, in a professional capacity, and that's being asked of them in that job. So, no, I wouldn't judge the nurses, because that's what their role is" (Emily)

Abortion: Statement 3

Participants varied slightly in their slight agreement that **abortions should not be allowed from 22 weeks gestation as the fetus is changing into a baby (51; +1 +2 0)**. The statement raised dilemmas with participants. Whilst they previously agreed that abortions should not influence the care of the mother, and slightly agreed that nurses working in abortion services are providing a service, they were not so sure when it came to their attitudes towards the actual abortion itself. Whilst some participants discussed abortion from the point of the infant, others discussed it from the point of the woman, causing confusion as to where to place the card. Nurses discussing abortion from the infant's point of view agreed that abortions should not be allowed from 22 weeks gestation. They discussed that in their experience, infants they had cared for from 22 weeks gestation could survive and so the abortion limit should be reduced.

> "You see babies at twenty, well, let me have a think about this, well you see babies that are 23 plus, well almost 24 weeks that are formed, and given the adequate support, can survive" (Hannah)

One participant's experience with infants born at 23 and 24 week gestation moved her opinion towards late gestation abortion in a different direction. She discussed abortion from the point of the woman, and felt that women should still have the right to choose abortion up until the legal limits, especially in the context of the adverse outcomes of infants born at such early gestations.

> "It's up to the lady to choose, if she wants to abort, and that's what's right for her, then we shouldn't be showing her a baby and saying look what you're getting rid of, because I think that's, and when you see the 23 and 24 weekers, they're so delicate and tiny, and sometimes if they're not in good condition, they're not compatible with life, at all" (Alison)

Other participants displayed difficulty with this statement due to their inability to say whether the infant was, at such early gestation, a 'person'. Not being able to define this meant that they were unsure of how to respond to the card, placing it in the neutral category.

> "It's a dilemma almost, because you've got people who are terminating babies up to 24 weeks who have got simple abnormalities, because they're fetuses, you've got people

> delivering at 22 plus, who see this baby, have everything explained to them that this baby might become handicapped, but decide to carry on, so in the space of that, in out, if their baby is out they want everything doing, if their baby is in it's not a human being" (Gabby)

One participant in particular articulated the difficulties which she thought the current situation could potentially have on women who experience both services, neonatal and abortion.

> "Because you see mothers coming, delivering, 22, 23 weeks, perhaps a little bit out on their dates, and we get a baby that comes out and cries, and alright it's a very preterm baby, but it's still alive, it's still a baby, and the thought that, I mean even earlier, they come out and do that, but if you've had a mother, god forbid, that has had an abortion, at say 22, 23 weeks, and then the following year comes and delivers one at that gestation, I think the hang ups that she would have would be terrific" (Gemma)

Abortion: Statement 4

Participants were neutral that **abortion providers and Neonatal Intensive Care Units are separate entities and the actions of one should have no influence upon the other (52; +1 0 +1),** leading to a low prioritisation of this statement in the response grid. Some participants thought that it was not their place to comment on abortion services as it was not their area of expertise, whereas others simply did not think of the two as being linked.

> "I don't particularly have an opinion on abortion, and neonatal intensive care, because I don't think they are particularly related" (Shelley)

> "I wouldn't put neonatal and gynaecological abortion services together, they are separate, one set of adults want something, another set want something else, I don't put them in the same pot at all" (Eli)

A few participants thought that the two were either linked or were influential on the other. These participants commented upon the potential effects of seeing abortion and neonatal services as consequential, and as with the previous statement discussed this in the context of the infants which they currently cared for.

> "I suppose they are going to have influence on one another, aren't they, they are, I agree they are completely separate entities, and they should be, but they are bound to have an influence one on the other, aren't they.. a 22 week, perhaps limit, so you're talking a couple of weeks, and still, the fetus is perfectly formed from 12 weeks, really, but the viability that we've seen, and that we do see, on quite a regular basis, of 22, 23 weekers, it becomes ethically

> more difficult, more challenging I think. So I think there is going to be an influence on the two areas, but they are very separate" (Sarah)

Abortion: Statement 5

Participants placed **the philosophy underpinning nursing and medical care is the same in all health care settings, including neonatal and abortion services** in the neutral categories in the response grid **(40; 0 0 -1).**

> "I think it does make you think about the two services, which I think generally speaking I would have to say in the past, yes we say it, yes we know people are having abortions in gynae, but do we really know it, do we, does that really mean anything to us, it probably doesn't, and in black and white you probably say well we fight for life and they're not, and that's probably not actually the reality, well it isn't the reality, is it, so you, it is quite difficult, but it just makes it quite interesting in my head" (Abi)

5.4.III.d Decision Making

Statement 1

Participants across all three factors agreed that **the choices that parents make about their extremely preterm infants are prompted by the choice of the Health Care Professionals (49; +2 +4 +3).** Participants saw guiding parents through decision making as part of their role as a health care professional, and something, if done correctly, which could greatly help parents in their times of need. They also viewed this role as something which parents expected from them from.

> "As parents, they look to you as the professional, they've been shell shocked, they've had an early baby, totally unexpected presumably, and haven't even really thought about what's what, and their minds are just, blank, probably, half of them, and, but then you get others who do have some knowledge, or they think they have some knowledge, and they perhaps do need a bit of guidance in the right direction" (Jenny)

> "I think we probably have an impact, but you know, they become the patient, don't they, they ask us our opinion, they look to us for guidance because they don't know, and they expect us to know" (Shelley)

Participants did not take their impact upon parents lightly. They recognised that the nature of the situation made parents vulnerable, and were aware of how much of an influence that they could have over parents.

> "I think it's the way you can say things, can make people, it's like in everything, even feeding, you have an impact in whatever happens really, because it's the way you say things, and how much information you give them, and the way you say it, you can put the emphasis on one thing to another, and influence people very,

> because they're so fragile, parents are so fragile you can make them do what you like, really" (Jane)

5.4.III.e Fertility

Statement 1

When posed with issues concerning fertility, participants placed as neutral the statement **women who try to conceive post menopause are not thinking about the best interests of the infant (46; -1 -1 0).** Participants were keen to highlight that 'post menopausal' did not necessarily mean 'older'.

> "I thought well, you actually think of post menopausal women as being sort of, 50, 60, don't you, which actually isn't the case really, you can get younger women, can't you" (Carry)

Some participants expressed concerns about women who they did perceive as being 'older' and 'post menopausal', and the effects on the infants of having older parents.

> "It wasn't because I felt that if they were post menopausal that they were going to make good mothers, or anything like that, it was just very hard to judge really, if they're post menopausal, chances are they're going to be an awful lot older, and be quite elderly for a young child, that's why it went into a grey area, I didn't particularly feel I'd got an opinion one way or another" (Emily)

Fertility: Statement 2

Participants disagreed that **older parents are better equipped to deal with the outcomes of prematurity (9*; -3 -3 -4).** Participants disagreed with this statement on the principle that they had seen younger parents deal with the outcomes of prematurity just as well as older parents. Participants felt that age was not something which affected a person's ability to deal with either the outcomes of prematurity, but rather the individuals themselves.

> "I disagree with that because it doesn't matter what age you are, it's difficult to deal with extreme prematurity" (Charlotte)

> "You can get all different walks of life, and it doesn't matter if they're an intelligent couple who you think might be better at handling it, you can have a young girl of 16 who comes out and shows you that, in fact, she has accepted things better in the long term, you know, that, so no I think that one, although its there, because they're older and intelligent, and they've got good education, or whatever, that they're going to cope better than those that are younger" (Lynn)

A few of the participants who disagreed with this statement went on to comment about their observed differences between older parents, who due to their naturally greater 'world knowledge' did not cope as well as younger parents, who often 'just got on with it'.

> "The younger ones come along, take it, come what may, don't ask questions, I mean they're easy parents, they just go with the flow, and so I don't, you know in some ways I think they probably actually find the neonatal bit easier, because they're just, whatever, you tell us, because they're young, and they don't have the world experiences, whereas older parents actually, find it so much more stressful, because they've kind of got that worldly knowledge, they'll be on the [inter]net, they'll have read it all ...so I'm not sure that they're actually better equipped to deal with it, because in some ways I think they're actually worse, whereas the younger ones are more like, but then probably the long term consequences, maybe they are, so I don't know" (Megan)

5.4.III.f Disability

Statement 1

When faced with statements concerning disability, participants placed the statement that **the more disabilities that can be diagnosed prenatally, the more pressure there is on women to abort these pregnancies (5; 0 0 +1)** as neutral. Participants did not have particularly strong opinions on this statement. Along with the statements which solely concerned abortion, participants did not feel that this was their area of expertise and as such did not rank it as highly as other cards.

> "I'm not sure that there is any more pressure then there ever was for women to terminate, it's an entirely personal decision...I think 20 years ago, or 30 years ago, I don't think it would have altered peoples attitudes less or more, I don't know, it's impossible...it just seemed a very odd statement to make, that we were putting pressure of people to, almost like we were trying to make a perfect society really, we're just able to prepare people better" (Lydia)

There was one participant, however, who strongly agreed with this statement, raising the weighted average of this statement to +1 in factor 3. This participant, whilst discussing this statement, noted that during her time as a neonatal nurse the amount of children who she encountered with pre-diagnosed disabilities had decreased, prompting her to reflect on the notion of the 'perfect' baby.

> "The amount of women who are, I wouldn't say bullied, but who are persuaded that it's the right thing to do, we don't tolerate any type of, anything that's not normal, do we, or not perfect, rather than not normal, not perfect, we're seekers of perfection, anything that isn't perfect, isn't acceptable these days, I just think, because in my, when I first started doing neonatal nursing in the 80's, there were no scans, we had all sorts of babies, with all sorts of, all horrible things wrong with them, and we dealt with that in a different way. Now we see very little of that, and it's scary to think of how many babies are aborted because of something that they

> could live with, Downs Syndrome, even things like Trace Oesophageal Fistula, that I know it takes a long time, they never get right, there is always something not quite right, they're never made perfect, but they could live, a life, you know, and they're not damaged in any way, their brains aren't damaged, and yet they're being terminated, and I think it's quite sad" (Emma)

Disability: Statement 2

The issues concerning disability were once again seen in the statement that **life satisfaction is not possible if you have a disability (16*; -4 -4 -5),** which participants disagreed with. Participants were once again keen to highlight the parent's individual ability to cope, commenting that the attitudes of the parents who cared for children with a disability had a big impact on whether the child could experience life satisfaction.

> "I think it depends on what kind of family they're going back to, and how the family are reacting, if the family are just going to treat the baby, you know, as any other baby, and not let the fact that, I don't know, its got cerebral palsy or whatever, affect them, then I don't think its an issue, I think its more of an issue when a parent is not so happy with having a baby who's brain damaged or whatever because I don't think maybe they'll get such a good life out of it" (Daisy)

Participants also explained that they did not feel qualified to judge either what constituted a good quality of life, or the extent to which a disability could interrupt this.

> "Clearly, clearly that just isn't true, that any level of disability leads to absence of satisfaction with life...we judge societies by what we do with the weakest and the most needy, in society, and if you ask disabled people whether they would rather have been born or not been born, in most cases they will say that they would rather have been born, and many of them, although living with disabilities that many of us would consider terrible, would say that they're living very good, very satisfied, very interesting and fulfilled lives, and dealing with their disabilities, because they're, that's all that they have ever know, and so its easy for the able bodied to make value judgements about disability, and I don't think we should" (Ben)

Participants did not feel comfortable making judgements about an individual's life about which they had no experience of.

5.4.IV Summary of Consensus

This investigation into neonatal nurses' attitudes towards extremely preterm infants resulted in 15 consensus statements from a Q Sort of 53, reflecting attitudes which all participants shared about preterm infants. Interpretation of the consensus statements was enhanced through the post sort interview data with all participants in the investigation. These consensus statements can now be used as a platform on which to build the different character profiles of the neonatal nurses in this investigation, reminding us of the basic attitudes which neonatal nurses all share towards infants at the margins of viability. The attitudes which make these nurses different will be explored in the next part of this chapter to develop the characteristics of the neonatal nurses in this investigation.

5.5 Findings: Factor One - Accounting for Parental Choice in Decision Making

5.5.I Introduction

Factor one has been labelled 'Accounting for Parental Choice in Decision Making' due to the nature of the eleven statements which define it and which highlight the importance of considering the parents wishes in decision making. Factor one had an eigenvalue of 14.9 and accounted for 41% of the total variance. It was characterised by 9 Q sorts (25% of participants), 6 of which loaded purely onto this factor. Factor one had a high reliability, reflected in a value of 0.95 (SE of 0.16). The post Q sort interview data will be presented from people who have loaded onto this factor to help explore the rationale behind the placing of these statements. The following participants loaded onto factor one:

Factor 1 **(9 Q sorts)**	Sarah (2e6)	Alison (6b5)
	Hannah (4b5)	Elizabeth (6c5)
	Shelley (4c6)	Megan (6d8)
	Jessica (4a5)	Miranda (6e6)
	Jane (5b6)	

Table 5.11: Factor One Participants

Looking at the thematic classifications of the statements, the highest proportion of statements defining factor one are attributed to treatment decisions and decision making (Table 5.12). Individuals loading onto factor one have prioritised statements in which a decision has to be made; statements regarding the ethics of technology and abortion are not highlighted at all.

Sub-sample (Q statement categories)	Statements per sub-sample (% of total Q cards) (a)	Defined in Factor 1 (% of sub sample) (b)	Total % representation of sub-sample in Factor 1 (ax[b/100])
Abortion	10 (19)	0(0)	0
Decision Making	10 (19)	3(30)	5.7
Disability	9 (17)	1(11)	1.9
Fertility	4 (7)	1(25)	1.8
Technology	11 (21)	0(0)	0
Treatment Decisions	9 (17)	6(67)	11

Table 5.12: Distinguishing statements by theme in Factor 1

5.5.II Positioning of the Distinguishing Statements

The following distinguishing statements were placed in the following positions in factor one (Table 5.13).

Card	**Postn**	**Statement**
1*	**+6**	Peaceful death is more important than full intensive care treatment
39*	**+4**	Parents who do not want a disabled child should be able to make the decision to withhold or withdraw full intensive care treatment
21*	**+3**	The most important factor when deciding on resuscitation is the parents decision

13	**+2**	Always initiating full intensive care treatment gives parents a chance to think that they have done everything they possibly could
32	**0**	Resuscitation at less than 24 weeks is for the parent's benefit only, not the baby's
36	**0**	NICU treatment accounts for a large proportion of NHS resources and as such admission of infants less than 24 weeks gestation should be restricted
43	**0**	Saving infants at less than 24 weeks gestation is an inefficient use of NHS resources
35*	**-1**	Euthanasia protocols for extremely preterm infants should be introduced in the UK
8*	**-2**	Infants born extremely prematurely to families who have received IVF and unlikely to conceive again should always be offered full intensive care treatment at all costs
37	**-3**	It is better to have a disabled child, no matter how disabled, than no child at all
30*	**-5**	The most important factor when deciding on resuscitation is the Health Care Professionals' opinion

($p<0.01$) (* $p<0.05$)

Table 5.13: Distinguishing Statements Factor 1

5.5.III Distinguishing Statements Explained by the Participants

Participants in factor one strongly agreed that **peaceful death is more important than full intensive care treatment (1*: +6).** Participants felt that it was important that the parents spent time with their infant, in a peaceful manner, before they died. They did not necessarily associate being able to do this if the infant was receiving full intensive care treatment.

> "Sometimes if you're doing lots and lots of intensive care, and there's lots and lots of things going on, and the baby's going to die anyway, it's not very nice for the family, whereas peaceful, if we've done everything we can, and now it's time to slow down, it's nice that the family have time to be with the baby while they die, rather than us phoning them and saying, the baby's crashed and gone...it's nice to know if the baby's slowly going down hill, that the family can come in and it's a peaceful death with the family" (Sarah)

Participants associated intensive care treatment with being painful for the infant, and thought that allowing the infant a peaceful death would avoid this.

> "When you get the very tiny ones, you know that they are going to go through such an awful lot, and to me, sometimes we don't look at them as, not as human beings, but we forget that they are maybe, you know, in pain and suffering, and it's uncomfortable to have lots and lots of drips in, and bright lights on you, and it's the suffering, although obviously we're a lot better at pain control and that, than we were, I still think that sometimes we do put babies through unnecessary suffering, and maybe sometimes we should withdraw treatment" (Megan)

Participants agreed that **parents who do not want a disabled child should be able to make the decision to withhold or withdraw full intensive care**

treatment (39*: +4). Participants thought that they were not in a position to judge how parents would cope with a disabled child, and as such parents were the ones who should make this decision.

> “If the parents…felt they didn’t want the disabled child, and couldn’t cope with a disabled child…it’s up to them as a family to decide, we don’t know what their lives are, it should be up to them really, they might have their own personal views and think, you know, there might not be a good outcome, it probably would be for the best if things didn’t work out” (Jane)

> “It’s them that’s got to bring up the children, and if there is a lot of brain damage or whatever, then if they don’t want that… you’ve got to go for their wishes” (Alison)

One participant explored how she discussed issues of disability with families, and how she felt whilst doing this.

> “I feel quite confident to actually say “how do you feel a disabled child will fit in with you as a family”, and I’m not afraid to talk to them about, it’s really rubbish to ask that question, you know, “what is it that you feel?”, or “what do you feel about your baby in this situation?”, so I do feel quite confident at actually asking them maybe some of the difficult questions that a lot of people avoid because of the difficult situation, whereas I feel I want to ask them

> that, so they can actually…and some parents have actually said to me, I know very, very well, please stop this, can we stop this [name] because it's awful, and I've said you can, if you want it stopping, we'll stop it, and gone to the doctors and said they want it stopping" (Megan)

The importance of the parents was again highlighted in participant's agreement that **the most important factor when deciding on resuscitation is the parent's decision (21*: +3).** Participants discussed how they thought it was important that parents' opinions were considered, as it was their baby that the health care team were dealing with.

> "It's their baby, and they've got a right to say what they want done" (Hannah)

> "If it comes down to a choice, yes or no, then yes I do think it will be the parents choice, the doctors can give them all the information, but I think that's as much as they can do really, give them as much information as they need to make that choice" (Jess)

Other participants agreed that whilst the parent's opinions should be considered, they should not be the only opinion taken into account when making decisions.

> "A joint decision...[between parents and doctors] I don't think one can supersede the other, really, the parents have got to have the information...it's their right to have input into that decision, isn't it, of course, but the medical profession have the right also to give, perhaps, a more valid picture of what the outcome is" (Sarah)

Statements regarding the consideration of the parents were once again highlighted by factor one, despite participants only slightly agreeing that **always initiating full intensive care treatment gives parents a chance to think that they have done everything they possibly could (13: +2).** Participants were neutral in their positioning of the statement that **resuscitation at less than 24 weeks is for the parent's benefit only, not the babies (32: 0).** Some participants discussed how their feelings as they struggled to prioritise the needs of the infants with the parents.

> "I feel for the parents, my heart goes out to them because I'd probably do the same, you've got a baby and the first thing you want to do is keep them there, so I kind of feel for them in a way that I feel sad for them, because of what they're going through, and then also sad for them for what they're going to go through if the baby survives, it's really a mixed emotions" (Hannah)

> "A lot of parents will probably want everything doing, and that's what happens, you get the full shebang, and maybe 24 hours or a few days later, this baby really isn't going to make it, and you have

> to withdraw treatment, and you have to go through all that process. I mean I suppose you've got the theory that at least parents got to know their child, for a while, but in what state? It's having things done to them, being attached to monitors, not even being able to touch them" (Liz)

Other participants were clearer in their thoughts that the needs of the infant should be the only needs considered when discussing full intensive care.

> "Having been to the delivery of a 22/23 week baby, and it didn't make any effort at all, I think if we'd then given full intensive care treatment until we'd had chance to talk to the parents, it's almost Frankenstein-esque, you know, trying to keep a baby alive that quite clearly isn't going to survive...if there's a religious reason that the parents say please, just until we can do so and so, then fair enough we'd consider that, but I think if we can't, they're not lumps of meat, at the end of the day, you have to think of humanity and dignity" (Miranda)

Participants were neutral in their attitudes towards resources. They placed the statements **NICU treatment accounts for a large proportion of NHS resources and as such admission of infants less than 24 weeks gestation should be restricted (36: 0)** and **saving infants at less than 24 weeks gestation is an inefficient use of NHS resources (43: 0).** Participants could see why resources were discussed, however acknowledged that the parents may not prioritise their infants care in this way.

> "I'm not sure about the whole, 'inefficient use of the NHS resources', because obviously money's high on our agenda isn't it, but I'm not sure how you cost, because to our mums here, money isn't, at the end of it, but then if you think about the long term costs of having children with special needs on the community and everything, it is a big thing...I really don't know, whose right enough to say no you can't do that, because it's too much money" (Alison)

Participants also displayed neutral attitudes towards the statement **euthanasia protocols for extremely preterm infants should be introduced in the UK (35*: -1).** This statement appeared to cause some controversy amongst participants. One participant discussed how she thought that treatment should be more individualised.

> "It's individual on that baby, and I don't think they should have all these [euthanasia] protocols saying yes or no, I think it should be more based on the personal situation...some parents are desperate to have that baby, regardless of what outcome they might have, so I think to say, if it comes, if there's a 25 weeker, just below that threshold, and there was any chance that they can revive it, then those parents, it would be horrible for them, to think that their

> views aren't counted on that, because we've got this set out and that's it. I see the other side of it, it might take a little push for people to realise it's not the best, outcome, but then I do think people should have a choice, to a degree, you know, it is their child, after all" (Jess)

Another participant discussed how they thought euthanasia would not be 'nice', however may improve the experience of death for all of those involved. Whilst death would never be a 'nice' experience, this participant wanted to be able to create pleasant last memories of the infant's life for the family.

> "I think it would be easier than we expect it would be, because yeah, I just do, from how I've seen other nurses be around really, really poorly babies, sometimes everybody's saying oh, they really should just let themselves go, and so, I think it wouldn't be nice, but if you could make a death as nice as possible, so when they look back it's not, it will be horrific memories, but pleasant horrific memories" (Hannah)

Participants slightly disagreed that **infants born extremely prematurely to families who have received IVF and unlikely to conceive again should always be offered full intensive care treatment at all costs (8*: -2).** Participants were clear that all infants should be, and would be, treated equally. Consequently, no one set of parents would receive any different care from any others.

> "All babies are precious to me and we have lots of IVF babies, and they come round and they're like, oh they're extra special, you know, and you think all babies are special, all babies are important, and I don't think you should say, should give them special treatment, even if it's their last chance, I think every baby is important, you should treat every body the same in that regard, I don't pussy foot around people, because, no, everybody should be treated the same" (Alison)

Participants disagreed **that it is better to have a disabled child, no matter how disabled, than no child at all (37: -3).** Participants discussed several reasons for disagreeing with this statement. One participant discussed how they felt the impact of a child with a disability was dependant upon how the parents reacted to this.

> "I think a lot of people, it depends on how people are really, what parents are like, I mean some people will love their baby no matter what, and I've seen that, it doesn't matter that this baby's going to need 24 hour support, they will love this child whatever, and then I've seen other parents who you know it's going to be a battle, and they're really struggling with it, which is fair enough, it's a big thing to deal with, so you know, and I think it's whether the parents are ready to take on that responsibility or not. I would never wish anyone not to have children, obviously, but it's, I think it's how they adapt, how well they're going to adapt. And it's quite often the

> parents who surprise you that will take it on the chin and go for it" (Liz)

One participant discussed how they felt a child with a disability would impact upon the family unit, causing her disagreement with the statement.

> "A lot [of infants] may have the possibility, or have the high possibility of having cerebral palsy, big implications for families, especially families already with children, it's a huge impact on their lives, impact is what it is, not necessarily always detrimental, but very very difficult, for the family, for established family life" (Sarah)

Another participant discussed how she felt that the issue was not necessarily to do with her opinion of disability, but rather what was in the best interests of the child at the time, in the context that not all people are meant to have children.

> "Some people aren't meant to have children, and you have to accept that and live life, and I don't think it's better, I don't think you can say well this is my only one chance to have a child, come what may, if that's your decision, that's fine, but I don't think in life it's better to have a disabled, than no matter how disabled, I think, at the end of the day what I'm trying to say is you've got to think of the child, as well...I'm not against disability, I think at the end of the day, you have to think about the child" (Megan)

Finally, factor one participants strongly disagreed that **the most important factor when deciding on resuscitation is the Health Care Professionals' opinion (30*: -5).** This statement often got discussed along side statement 21* (+3) which read that 'the most important factor when discussing resuscitation is the parents decision'. Participants thought that whilst the health care team had knowledge about the medical condition of the infant, the infant was ultimately part of the parents family and as such the family should have an influence on the decision making process.

> "I think ultimately at the end of the day, we think we know best, you know, where there is an area of expertise we probably do a lot of the time, but its still shouldn't be our decision... I think it should be a joint decision, an informed decision by the parents, and we're here to inform them" (Shelley)

Participants also discussed that there was another factor affecting decision making; the best interests of the infant. Whilst not a distinguishing or consensus factor, participants in factor one ranked the statement 'the most important factor when deciding on resuscitation is the potential long term suffering to the infant' at +5, strongly agree.

> "Just what's best for the baby, because I know sometimes parents will disagree with the doctors, and I think the underlying factor should always be, go back to the baby's needs, and not everybody else's, it's this baby that you're treating" (Hannah)

> “The 24 weekers…and the amount of maybe, procedures and pain they’ve gone through…you sometimes, they become don’t they, all multi-organ failure, swollen, stiff, and you just think, okay, right, this is enough for anybody to bear” (Eli)

Participants were sensitive to the amount of pain they felt that some of the infants would go through because of the decision to undergo intensive care treatment, in effect mirroring their most agreeing distinguishing statement that ‘peaceful death is more important than full intensive care treatment’ (+6).

5.5.IV Summary

Factor one was distinguished by 11 statements, and had a high reliability of 0.97. It was characterised by 10 participants whose attitudes towards extremely preterm infants was reflected through the importance of getting the parents involved in the decisions around their infant. Participants thought that the wishes of the parents should be taken into consideration during decision making as it was ultimately the parents’ infant that the decisions, and the consequences, revolved around. These participants also reported that sometimes a ‘peaceful death’ was more important that providing full technological care, which they thought could be painful and stressful for the infant.

5.6 Findings: Factor 2 - Technology Can Sustain Life

5.6.I Introduction

Factor two has been labelled 'Technology can sustain life' due to the nature of the twenty two statements which define it and which highlight a requirement for a trial of life for infants born at extremely early gestations, coupled with a noticeable aversion to statements regarding absolute decision making. Factor two had an eigenvalue of 3.3 and accounted for 9% of the total variance. It was characterised by 5 Q sorts (14% of participants), all of which loaded purely onto this factor. Factor two again had a high reliability, reflected in a value of 0.97 with a SE of 0.22. The post Q sort interview data will be presented from people who have loaded onto this factor to help explore the rationale behind the placing of these statements

The following people loaded onto factor two:

Factor 2 **(5 Q sorts)**	Lynn (1c7)	Abigail (2d7)
	Josie (1f7)	Rebecca (3e7)
	Jack (1g8)	

Table 5.14: Factor Two Participants

Looking at the thematic classifications of the statements, the highest proportion of the statements defining factor one are attributed to treatment decisions, abortion and technology (Table 5.15). Statements regarding decision making for infants along with issues of disability and fertility, have not been prioritised in factor two.

Sub-sample (Q statement categories)	Statements per sub-sample (% of total Q cards) (a)	Defined in Factor 2 (% of sub sample) (b)	Total % representation of sub-sample in Factor 2 (ax[b/100])
Abortion	10 (19)	4(40)	7.6
Decision Making	10 (19)	2(20)	3.8
Disability	9 (17)	4(21)	3.6
Fertility	4 (7)	2(50)	3.5
Technology	11 (21)	4(36)	7.6
Treatment Decisions	9 (17)	6(67)	11

Table 5.15: Distinguishing statements by theme in Factor 2

5.6.II Positioning of the Distinguishing Statements

The following distinguishing statements were placed in the following positions in factor two (Table 5.16).

Card	**Postn**	**Statement**
13	+3	Always initiating full intensive care treatment gives parents a chance to think that they have done everything they possibly could
17*	+3	Infants born extremely prematurely with life limiting illness should still be given full intensive care treatment

24*	**+3**	The abortion limits should be reduced in acknowledgement and accordance with the current limits of viability
31*	**+3**	Technology should be advanced to allow the most premature of infants to survive
18*	**+2**	Full intensive care treatment should always be started as it can be withdrawn later if found to be futile
2	**+1**	Advancing technology has made the process of withdrawing care more difficult
8*	**+1**	Infants born extremely prematurely to families who have received IVF and unlikely to conceive again should always be offered full intensive care treatment at all costs
23*	**+1**	There is a cross over between neonatal and abortion services as both care for women at similar gestations
50*	**+1**	'Infants' who are born alive following termination of pregnancy should be transferred to NICU for a trial of life
4*	**0**	Life should be maintained irrespective of outcome
37*	**0**	It is better to have a disabled child, no matter how disabled, than no child at all
29*	**-1**	Parents are given a false sense of hope when they see all of the equipment used on their extremely premature infant
33*	**-1**	Babies born at less than 24 weeks gestation should always be resuscitated if the mother is too old to have any more children
42*	**-1**	The most important factor when deciding on resuscitation is the potential of long term suffering to the baby
20*	**-2**	Attempting to save babies less than 24 weeks gestation is a large uncontrolled experiment
45	**-2**	The current abortion limit of 24 weeks gestation is adequate, as infants below 24 weeks gestation should not normally be resuscitated due low survival rates and high risks of disability
53*	**-2**	Technological developments mean that heroic measures of extraordinary means of support are overused

32	**-3**	Resuscitation at less than 24 weeks is for the parent's benefit only, not the baby's
39*	**-3**	Parents who do not want a disabled child should be able to make the decision to withhold or withdraw full intensive care treatment
43*	**-4**	Saving infants at less than 24 weeks gestation is an inefficient use of NHS resources
35*	**-5**	Euthanasia protocols for extremely preterm infants should be introduced in the UK
36*	**-5**	NICU treatment accounts for a large proportion of NHS resources and as such admission of infants less than 24 weeks gestation should be restricted

($p<0.01$) ($*P<0.05$)

Table 5.16: Distinguishing Statements Factor 2

5.6.III Distinguishing Statements Explained by the Participants

The first statement which participants in factor two agreed with was that **always initiating full intensive care treatment gives parents a chance to think that they have done everything they possibly could (13: +3).** Participants discussed how, even if the infant did not survive following full intensive care treatment, they and not only the parents, would be able to feel that they had 'given it it's best shot'.

> "I've seen 23 weekers come out and cry, and you've got to do something, she might be two weeks out, what do you do, you can't stand there and do nothing, so I think initially you've got to offer support, intensive care, and then just go from there, even if you withdraw it later, there's still been a time of getting to know the child, the mother feels the childs had a chance, we've given it our

> best efforts, then if the baby dies, then that's it...they [parents] should feel that everything that could have been done for them, has been done for them, nothing more can be done for the baby" (Rebecca)

Participants equally agreed that **infants born extremely prematurely with life limiting illness should still be given full intensive care treatment (17* +3).** Whilst they still discussed elements of the inevitability of death (as with the consensus statements), technology was seen as a positive in this factor rather than negative or harmful.

> "Intensive care is also around making it right, for the parents, with their infant, however long or short that time is, so it isn't just about the intensive care...and that doesn't matter whether that's making that short time right, or that's meaning, full intensive care that for a period of time... I've had experiences of very good ways where parents have had a really nice time with a child that isn't going to survive for long" (Abigail)

Participants agreed that **the abortion limits should be reduced in acknowledgement and accordance with the current limits of viability (24* +3),** and as a direct opposite slightly disagreed that **the current abortion limit of 24 weeks gestation is adequate, as infants below 24 weeks gestation should not normally be resuscitated due low survival rates and high risks**

of disability (45: -2). Participants discussed their thoughts regarding the outcomes of infants born during the 22 to 24 week gestation period.

> "You do get the occasional 22 weeker that comes, and I know there can always be a bit of discrepancy either way with dates, so a 22 weeker could actually be a 23 weeker, or whatever, you know, you get the odd 22 weeker that comes out and does really well, and you think that child legally could still have been aborted, and it just doesn't, I don't know, to me it just doesn't seem right to take that, right to life, from the child (Rebecca)

> "I've seen 23 weekers, I've seen them do ok, I don't know in the long term what their problems are, cause I haven't seen them come back followed up or anything, but at this time, if they come out, and they're breathing...I think, you know...give them a chance" (Lynn)

Participants in factor two agreed that **technology should be advanced to allow the most premature of infants to survive (31*: +3).** Participants had seen many beneficial changes in technology to extremely preterm infants during their time spent neonatal nursing, and thought that only through advancing the technology would the care of the these infants improve.

> "When I started, and we were just doing experiments using surfactant and things, so therefore, with the development with that,

> that's obviously worked now, antenatal steroids, all those types of things that I have seen introduced in my time, that have improved viability...so that's why I think with advancing technology and things, that things have improved, different ventilation, techniques and things, so I see it from that point there are things that do help...like ventilated babies we used to have them ventilated for weeks and that, and now of course they come off quickly, go onto CPAP, and do better ...how far do we go [limits viability], well I've seen a change, you know, by 4 weeks, so therefore I couldn't be judgemental and say, absolutely, that 22 weekers shouldn't be given a chance" (Lynn)

Participants agreed that **full intensive care treatment should always be started as it can be withdrawn later if found to be futile (18*: +2).** One participant discussed how not starting intensive care treatment would be particularly 'hard' and that if the infant is born showing signs of life, they would be offered intensive care treatment.

> "We have this early care policy, that talks at length about assessing the baby, and there are clear signs of baby's that are really pre-viable, so fused eyelids, very bruised, bradycardic, or absent heart beat, that doesn't respond to gentle mask ventilation, the guideline is these babies should be allowed to die in peace in labour suite, and yet I think that's probably the hardest thing for anybody to do when they get round there, because you know, at the end of the day

> this baby has been born, and I don't know what the decision process is, that kicks in, the baby that I delivered she was not bruised, but she was clearly a tiny, tiny baby, with fused eyelids, and shockingly small, but her heart rate improved, and to me, that's, I had to give her the opportunity, the service has to give her an opportunity…and I think that's the right thing to do, because if it clearly doesn't work then yeah, you've got your answer" (Jack)

Another participant, whilst agreeing with this statement, explored further the thoughts that she sometimes had when placed in the situation of deciding upon intensive care treatment.

> "When, you're in that situation, and its very intensive, and you're doing all these things, and you sometimes you just want to take a step back and think, what are we doing here, what are we actually doing to these children, what are we doing to these parents, what are we doing to ourselves, we're all in that, we're putting ourselves in a huge stressful position, we're putting these parents, are we giving them false hope, quite often you step back, and after, I don't know however long you've been doing it, you think, where are we going here, what are we doing…I never know, you never know, if you were going to be put in that scenario again, I bet you would still do the same things, you know, just look at it and go, here we go again, and do it" (Josie)

Participants remained neutral that **advancing technology has made the process of withdrawing care more difficult (2: +1).** Participants explored the meaning of this statement in the context of their practice, and how it was their duty to give the infant a 'chance'.

> "If you have a 23 weeker, and because of some of the results we've had, if it breathes and it comes round and we give it a chance, then we give it its chance and we try, and then at such time that it does seem, you can't do anymore, then you know, I'm quite for letting the child pull out and letting the child go" (Lynn)

> "I think what generally happens is that, there's one or two things, isn't there, the baby either decides, and dies, either on the ventilator, or gives such obvious signs of dying that the parents go, oh god my baby's dying, that's it, please don't let it die on the ventilator, or sometimes they do, the other time is just allowing the parents to get used to the fact that their baby is dying, by gradually giving them that information that this is, this is what we can do, we don't know how to go any further" (Jack)

Participants only slightly agreed that **infants born extremely prematurely to families who have received IVF and unlikely to conceive again should always be offered full intensive care treatment at all costs (8*: +1).** Participants appreciated the difficulty that parents had in conceiving, however thought that all infants should be offered the same treatment regardless of their conception. Whilst the rationale behind the placement of the statement was similar to that of factor one participants, potentially the positive thinking of those in factor two towards technology moved the statement from 'slightly disagree' (factor 1) to 'slightly agree' (factor 2).

> "You do hear the phrase this is a precious baby, because it's an IVF, and I think well all babies are precious! But I know what they mean, I guess they've put a lot of, a huge amount of time, emotion, and money, into having this child, and very often, because they're late on by the time they discover they have problems with having children, it really can be their last chance, so it think everybody is aware of that, I don't know that it eventually makes any difference, to their outcomes, because theoretically we should offer that, if stuff's there, then you can't withhold it, can you, one of the main principles is if you know it, then you give it, or you do it, but yeah, I think it does pull at most peoples' heart strings" (Rebecca)

Participants emerged as neutral that **there is a cross over between neonatal and abortion services as both care for women at similar gestations (23*: +1).** Participants openly expressed their uncertainty about this statement, and shared the thoughts that it provoked.

> "I don't really know about whether we've crossed over or not, that's quite hard, I'm not sure if we've gone there" (Josie)

> "I think it does make you think about the two services, which I think generally speaking I would have to say in the past, yes we say it, yes we know people are having abortions in gynae, but do we really know it, do we, does that really mean anything to us, it probably doesn't, and in black and white you probably say well we fight for life and they're not, and that's probably not actually the reality, well it isn't the reality, is it…it is quite difficult, but it just makes it quite interesting in my head" (Abigail)

Participants were neutral that **'infants' who are born alive following termination of pregnancy should be transferred to NICU for a trial of life (50*: +1).** Participants were unsure of how to prioritise the 'issues' of the woman with the needs of the infant.

> "I agree with this that they should come to us for a trial of life, I feel very sorry, or very worried for the parents that they have gone through this and then have been given a live child, you know, and its really a premature child with a possibility of lots of problems, and they've already decided, there's a whole load of issues going to go down that road about what they're going to do, and how, I couldn't even put myself in that position, it would be such a terrible thought, you know, I don't know, but the fact is that it's a baby and its alive so it should just come to us anyway" (Josie)

Participants were neutral that **life should be maintained irrespective of outcome (4*: 0),** or that **it is better to have a disabled child, no matter how disabled, than no child at all (37*: 0).** Participants struggled between what they thought was in the best interests infants and families. Some participants discussed their concerns over the quality of life that the infant would have.

> "You're sometimes looking at a baby, of whatever weeks, 24 weeks or something like that, and thinking, what quality of life are we giving this child?" (Josie)

> "I have seen advances and I have seen improvements, I think well, you know, but by the same token, I think I know when enough is enough, if I think they're going to be so severely disabled, and I think their quality of life, I think of, what quality of life will they have. And for that will affect the rest of the family, siblings, and everything" (Lynn)

Other participants explored how they thought the impact of disability was dependant upon the reactions of the parents to it.

> "Severe disabilities is categorised, medically, we know what a severe disability is, but that's not necessarily what a parent feels" (Jack)

Participants remained neutral that **parents are given a false sense of hope when they see all of the equipment used on their extremely premature infant (29*: -1).** When discussing this statement with one participant in particular, they explored a situation where the technology did indeed make the parents think that anything was possible.

> "They can see technology, and that just gives the hope that life is going to be there, at the end of it all, and presumably a reasonably good quality of life, so I think that sometimes parents think, there's all that stuff there, that machine's doing the breathing for them, but it does get in your way, we've had a baby here where we've had the ventilator doing the breathing side of it, but we just watched the heart rate going down and down and down, and the baby getting gradually bluer, and you know, we'd done everything we could, with medication, and all the stuff, there were just pumps, and stuff going into this baby everywhere, and the parents would just not accept that we could not do anymore" (Rebecca)

Participants were also neutral in their beliefs that **babies born at less than 24 weeks gestation should always be resuscitated if the mother is too old to have any more children (33*: -1).** One participant described that providing intensive care for the infant was the main factor in a resuscitation situation, regardless of the age of the parents. The 'implausibility' of the suggestion that resuscitation depends on the mothers' age may have prompted participants to place the statement as neutral, as it was not a 'realistic' possibility.

> "It's not about whether the mother is too old to have any more children, I don't really understand why that's in there [statement 33], to me the mothers age is irrelevant if, I don't know, if the baby's born and it shows sign of life and needs resuscitating, then you resuscitate, and it's irrespective of what the background is...that's a baby and that's their life, and if they're showing signs of life and that's the job we do, then we should be doing it, we're not there to determine whether, for that mother or not, because she happens to be too old, too old to have any more children, that shouldn't matter" (Abigail)

Participants attitudes were neutral to the statement **the most important factor when deciding on resuscitation is the potential of long term suffering to the baby (42*: -1).** One participant explained why he thought that discussions around resuscitation were in the neutral area of the Q sort for him:

> "The resuscitation issues were around decisions on who should make the decision not to resuscitate, or withdraw care or whatever, and I put them all in the middle again because nobody has the right to say it should always be with the family or it should always be with the health care professional, when you get back to the issue around acute phase newborn resuscitation at birth, it depends, in my opinion, very strongly on the antenatal discussions that you've had, that you can have a whole wonderful conversation and you know what they're [parents] thinking, you know that if this

> happens, this is what you sat and talked about, its so much easier to lead the resuscitation or non intervention" (Jack)

Participants slightly disagreed that **attempting to save babies less than 24 weeks gestation is a large uncontrolled experiment (20*: -2).** Jack discussed that he did not disagree with the statement more strongly as he thought that is was not experimental in isolation to the rest of the care offered to extremely preterm infants.

> "Isn't all neonatal intensive care one big experiment? There's not a lot of evidence for any of it" (Jack)

Josie discussed this occurrence in a slightly different light, recalling her thoughts about intensive care for some infants born at the margins of viability.

> "I do think at the end we put this child through so much, in your perception, pain, heartache, grief, we did all that to this child, and we, sometimes we wonder did we just do an experiment, let people get lines in, let them have a go at doing this, we let them have a go on a human being, you know, we had a little toy to play with, I don't know if that sounds right, we had something, I don't know if that sounds right, but you know, you look and you think, and I know they've got get experience, but I just think, not like this, not here, and sometimes I look at the baby and think this is just an

> experiment, and that's horrible, you know, you think no, that's not what I should be doing" (Josie)

Participants slightly disagreed that **technological developments mean that heroic measures of extraordinary means of support are overused (53*: -2).** This potentially reflects participants' earlier agreement with the statement 'technology should be advanced to allow the most premature of infants to survive' (+3), where the improvements that technology had allowed premature infants were discussed. When discussing the current statement, participants explored how they thought that technology and support was an integral part of their nursing role. The ability of technology to only do so much was also highlighted by participants.

> "I feel that is my role, I give every child a chance, until such time it is blatantly obviously that we shouldn't be, and hope that they haven't got terrible disabilities, and that we are getting better, and that's [outcomes of disability] getting less" (Lynn)

> "I think intensivist nursing is a just a plethora of inclusion, especially neonates, it's the family, it's the baby, it's the technology, its medicine and nursing, and it's the whole things gelled together, which is great fun, we all know that technology can't replace the womb, the placenta, but it will act as second best at the moment" (Jack)

Participants also disagreed that **resuscitation at less than 24 weeks is for the parent's benefit only, not the baby's (32: -3),** reflecting discussions of how resuscitation centres on the infant showing signs of life and not necessarily the parents or health care professionals opinions. The practicalities of not starting resuscitation for these infants were once again highlighted by one participant.

> "I do look at 22 23 weekers and say don't be silly, lets not go down that route, you know, but then, it must be very hard, because they're there, aren't they" (Josie)

Participants disagreed that **parents who do not want a disabled child should be able to make the decision to withhold or withdraw full intensive care treatment (39*: -3).** Participants did not think that disability in itself was reason enough to withdraw treatment from an infant, and as such parents should not have that the ability to make that decision.

> "Parents have got to be aware of how much time these children are now going to take up, they're a lot more than you think at the start of your, but you wouldn't change, I wouldn't stop this baby, I wouldn't withdraw care or do anything different, you know every child has the opportunity of a life, and if they breathe, then we've got to go for it...the IVH [intra-ventricular haemorrhage] baby with the Grade 4 [classification], I couldn't say right well we're going to stop now, that's not our decision is it, if this baby decides it's going to live, who are we to argue with it really"(Josie)

> "It's very difficult to say that, a 24 weeker, with disabilities, should have life discontinued, because I do know people who've said at all costs they just desperately wanted that child, and they're so happy with that child, and I think you enter into things like quality of life, and who can say what quality of life that child is going to have, even if it was preterm" (Rebecca)

Issues of resources were either disagreed with or strongly disagreed with by participants when placing statements **43*(-4): saving infants at less than 24 weeks gestation is an inefficient use of NHS resources** and **36* (-5): NICU treatment accounts for a large proportion of NHS resources and as such admission of infants less than 24 weeks gestation should be restricted.** This again reflects the participant's attitudes that resuscitation should be attempted in all cases where the infant shows signs of life. Participants could appreciate the impact on resources, however did not feel that this was something that should affect the care of the infants which they cared for.

> "I don't think that's something we should be looking at. I think about nursing care, you don't think about cost you think about care of the baby" (Josie)

Finally, participants strongly disagreed **euthanasia protocols for extremely preterm infants should be introduced in the UK (35*: -5).** Participants did not feel comfortable introducing what they perceived to be a set 'policy' which would allow for no variation to the 'rules'.

> "You can't introduce a blanket protocol, because there's always the exception to the rule, and I think like I said earlier on, you get the odd, well not just the odd 22 weeker, increasingly babies are surviving, with minimal problems at the extremes of viability, so to say that, all of them at that gestation, or whatever gestation you plump for, should be euthanised, it just seems absolutely ridiculous, because there are those that are going to survive and have a really good quality of life, and again, like I said, even if they don't have a really good quality of life, that's only from your perspective, and that's your world view point that well that child's disabled therefore it doesn't, does anyone, if you've killed it, because it was 24 weeks and had minimal chances, when that child would have been 13, if you had said to that child then, would you rather have been killed, that's ridiculous isn't it, there's not chance to do that, so to introduce some sort of blanket policy, I mean I don't know how it would be done" (Rebecca)

5.6.IV Summary

Factor two was distinguished by 22 statements, and had a high reliability of 0.95. It was characterised by 5 participants whose attitudes towards extremely preterm infants was to provide all of the technological support available to give the infant every possible chance to respond to treatment. These participants have a belief that technology can help to improve the outcomes for infants born at the margins of viability, and if the infant has 'arrived' then it is up to them to provide them with all of the support possible to give then every chance at life.

5.7 Findings: Factor 3 - The Health Care Professional Having the Infants Best Interests at Heart

5.7.I Introduction

Factor Three has been labelled 'The Health Care Professional Having the Infants Best Interests at Heart' due to the nature of the seventeen statements which define it and which highlight an importance of infant centred decision making as felt appropriate by the health care professional. Factor three had an eigenvalue of 2.0 and accounted for 6% of the total variance. It was characterised by 17 Q sorts, 6 of which loaded purely onto this factor. Factor three had a high reliability, reflected in a value of 0.99 with a SE of 0.12. The post Q sort interview data will be presented from people who have loaded onto this factor to help explore the rationale behind the placing of these statements. The following people loaded onto factor three:

Factor 3 **(17 Q sorts)**	Joanne (1a5)	Emma (2g8)	Daisy (2b5)
	Nicola (1b6)	Aimee (3a6)	Ben (2c8)
	Jacqui (1d8)	Gabby (3b5)	Christy (2f7)
	Cara (1e5)	Rachel (3c6)	Claire (6a8)
	Sian (1h6)	Lucy (3d5)	Carry (6f7)
	Zoe (2a5)	Jenny (5c5)	

Table 5.17: Factor Three Participants

Looking at the thematic classifications of the statements, the highest proportion of the statements defining factor three are attributed to decision making, followed by treatment decisions and disability (Table 5.18). Individuals loading onto factor three, similarly to individuals loading onto factor one, have prioritised statements in which a decision has to be made; the decisions that are prioritised, however, are different. Individuals loading onto factor three have not prioritised statements regarding the ethics of technology and fertility, and issues of abortion are not highlighted at all.

Sub-sample (Q statement categories)	Statements per sub-sample (% of total Q cards) (a)	Defined in Factor 3 (% of sub sample) (b)	Total % representation of sub-sample in Factor 3 (ax[b/100])
Abortion	10 (19)	0(0)	0
Decision Making	10 (19)	6(60)	11.4
Disability	9 (17)	3(33)	5.6
Fertility	4 (7)	1(25)	1.7
Technology	11 (21)	2(18)	3.8
Treatment Decisions	9 (17)	5(55)	9.3

Table 5.18: Distinguishing statements by theme in Factor 3

5.7.II Positioning of Distinguishing Statements

The following distinguishing statements were placed in the following positions in factor three (Table 5.19).

Card	**Postn**	**Statement**
44*	**+4**	Evidence of severe disability is a valid reason to withdraw treatment in an extremely preterm infant
19	**+3**	Parents should be shown morbidity and mortality statistics following premature birth to help facilitate their decision making
35*	**+2**	Euthanasia protocols for extremely preterm infants should be introduced
39*	**+2**	Parents who do not want a disabled child should be able to make the decision to withhold or withdraw full intensive care treatment
26*	**+1**	Deciding whether to withhold or withdraw treatment is too stressful for parents and should be done by the Health Care Professional
34*	**+1**	Infant survival has become a secondary outcome, with determining how far technology can advance survival limits seemingly more important
13*	**0**	Always initiating full intensive care treatment gives parents a chance to think that they have done everything they possibly could
43	**0**	Saving infants at less than 24 weeks gestation is an inefficient use of NHS resources
12*	**-1**	The most important factor when deciding on resuscitation is the potential burden on the parents
27*	**-1**	Parents should be invited to learn about technology used on their extremely premature infant
32	**-1**	Resuscitation at less than 24 weeks is for the parent's benefit only, not the baby's
36	**-1**	NICU treatment accounts for a large proportion of NHS resources and as such admission of infants less than 24 weeks gestation should be restricted
41*	**-2**	Better provision of welfare services in the community once children are older would make it easier to continue treatment for extreme preterm infants who display evidence of disability

48*	**-2**	Parents should not be involved in treatment decisions for extremely preterm infants as they do not understand complex medical information
37	**-4**	It is better to have a disabled child, no matter how disabled, than no child at all
3*	**-5**	Health Care Professionals should deliver the care that parents are asking for, even if parents are asking for treatment that Health Care Professionals think is futile
8*	**-5**	Infants born extremely prematurely to families who have received IVF and unlikely to conceive again should always be offered full intensive care treatment at all costs

($p<0.01$) (*$p<0.05$)

Table 5.19: Distinguishing Statements Factor 3

5.7.III Distinguishing Statements Explained by the Participants

Participants agreed **that evidence of severe disability is a valid reason to withdraw treatment in an extremely preterm infant (44*: +4).** One participant explained what appeared to be the understanding of participants about the outcomes of intensive care provided to infants at extremely early gestations.

> “It does make a difference, and I’m not saying something mild, like they might need to wear glasses, they might have learning difficulties, some of these babies, we know from their head scans, they are going to have severe problems” (Sian)

Other participants went on to discuss their views that to keep an infant alive who had a strong chance of disability was unfair to the infant. Participants explained that they struggled to ‘see the point’ of keeping infants alive who were going to be severely disabled, as they thought this was detrimental to the infant.

> “I think it should have quite an effect on your decisions, because I think it’s a big thing, it’s a life changing thing, and you know, I think if its, its difficult to tell anyway how severe they’ve got it, but I do think that we all should be thinking, you know, is it worth it, because I don’t think its right to carry on trying to save a baby if the outcome is so poor that they’re not going to have much of a life out of it…I just don’t think its right if we’re trying to save a baby who’s just effectively going to be a vegetable, do you know what I mean, I don’t see the, I sometimes don’t see the point in that” (Daisy)

> “I think if you’re working on a baby, there should be a limited amount of time that you give full intensive care for a certain child, you know like when you discover abnormalities, it needs to be understood that if its to the detriment to the child, you know, they need to switch off” (Gabby)

Participants also agreed that **parents should be shown morbidity and mortality statistics following premature birth to help facilitate their decision making (19: +3).** Participants discussed how they thought that these statistics could help to guide parents through decisions, although were keen to point out that ‘guide’ was all that they could do; statistics were not certainty of outcome for their infant.

> “I think it’s quite helpful to be able to say, to make some broadly positive statements based on our knowledge of how our babies do at different gestations. I certainly always issue those statements with a health warning, about the use of numbers, numbers, you know, are just a guide, it doesn’t mean anything beyond that” (Ben)

Participants were also aware that parents could often interpret statistics any way that they wanted to, and any possibility of their infant having a positive outcome would be interpreted as hope.

> “We have this very complicated, I’m sure they still use it, chart thing, that they took round to labour suite in extreme prematurity, and they showed them the chances of having a handicapped baby, which obviously increase the smaller they get, but people just think, well it wont happen to me, not my child, it might happen to 99% of all the rest of them, but mine will be alright, and then you see this perfect baby, because statistics mean nothing when you know that, what is it, EPICure, three quarters of them are seriously [disabled], or dead, but a quarter of them aren’t, so my child’s going to be in that quarter, and you look at them, and they don’t look any different to any of the other babies here” (Emma)

Participants in factor three were the only participants to slightly agree that **euthanasia protocols for extremely preterm infants should be introduced (35*: +2).** One participant explained that by introducing euthanasia protocols, the decision to withdraw care could be removed from parents to help them cope.

> "I think we should, I mean I think we should have that for adults, but certainly for, because I think again it would help inform parents a lot more and I think it would help take that ownership off them, and that onus of responsibility, because I don't know how you, I don't know how they, how they live with it" (Claire)

One participant explained why she did not agree with the statement more:

> "I think if you start introducing protocols, it's too prescriptive, you're not individualising the care, it depends where you set the limit" (Emma)

Participants also slightly agreed that **parents who do not want a disabled child should be able to make the decision to withhold or withdraw full intensive care treatment (39*: +2).** Participants explained how they thought that the wishes of the parents should be taken into consideration, as it was ultimately their lives that this decision would impact upon.

> "I think they need to be told what the likely outcome is, and to go away and think very strongly, and to know that when they come back they are not going to be judged if they say no, say yes, discontinue care, because I think sometimes people must think, they'll think we're bad people if we say that, they must truly say, could they cope, because in reality, how many foster carers are there for children with profound, there's not foster carers for well, able children, so what quality of life is a child going to have if their own parents cant look for them, and maybe sometimes its better to let them go, you know, rather then try and keep them going" (Lucy)

One participant discussed her dilemma with this statement, exploring how infants who are diagnosed with 'brain damage' are sometimes 'doing ok' and not always outwardly having difficulties.

> "That's a difficult decision to make isn't it, because if you've got your baby and your baby's been ventilated and its doing ok, and they tell you your baby's got brain damage, you know, is it right to switch it off then because the baby's got brain damage, and I don't know really how you would make that decision" (Daisy)

Participants were neutral that **deciding whether to withhold or withdraw treatment is too stressful for parents and should be done by the Health Care Professional (26*: +1).** Participants did not agree with this statement more as they thought that parents should be involved in the treatment process;

however the decision to withdraw care from an infant was too much of a responsibility for them. Participants thought that giving this responsibility to parents was ‘unfair’.

> “I think we will get more and more, sort of mismatch of opinion, because we are placing more responsibility on parents, and making them own their decision, which I don’t always agree with, either, I think it takes, well it’s massive, isn’t it, I don’t know how you could ever do it, I mean it’s bad enough putting your dog to sleep, you know, making that decision, so what they must be going through, is horrendous” (Claire)

> “I’m not saying parents shouldn’t have a say, or discussion, or time, but I think it’s much fairer, because the one thing that parents will say I can’t tell you to stop, I can’t live with myself if I tell you to withdraw, whereas I think before we used to say, your baby’s going to die” (Sian)

One participant discussed how in her experience these discussions had taken place.

> “I don’t think we just say to them you’ve got to make this decision, I think its all done in a very open arena, and we discuss what’s going on and we say well, this is not happening…and give them all the facts as well, and sort of say, in our experience, this is what’s

> going to happen next, and give them choices…we don't just say that's it, we sort of say, well in the event of this happening, shall we not, you know, change the tube, so we do, its often done in little stages, so we go with what someone can deal with, its never just black and white. We allow the parents time, and I think we tailor make it to what the parents you know, in that kind of situation, would want to see, so its not, its different to each family" (Nicola)

Participants were neutral that **infant survival has become a secondary outcome, with determining how far technology can advance survival limits seemingly more important (34*: +1).** Participants discussed how they thought that the technology was sometimes used to keep infants alive who, they thought, may otherwise not survive.

> "I just feel technology is totally taking over from my ethics, I suppose, to a degree, to what nursing care is all about, and yes it's great to have machines that assist us, and can potentially save lives, but somehow I just feel we're drawing away from what is real sometimes, we get so obsessed with machines" (Jenny)

> "I think we have become a product of technology in neonatal care, I think a lot of the advancements are brilliant, we all, we've all been there, we've seen them, we've participated in them, but having said that, it's not acceptable to use the technology to keep babies alive that otherwise should, and would die" (Claire)

One participant went on to discuss how she thought that the focus should be on improving the outcomes of extremely preterm infants, rather than the advancement of technology to save younger gestation infants.

> "I think we should be making sure that what we do now we're doing properly, and that the baby's that we produce now are fit and health and well, I don't think we should spend all of our research going further and further down, if the baby's that we have now at 22, 23, 24 weeks don't come out healthy, and I think that's where we should be putting our research, the baby's that do survive, survive in a better state, have a better quality of life that some of them do now" (Rachel)

Participants again emerged as neutral in their thinking that **always initiating full intensive care treatment gives parents a chance to think that they have done everything they possibly could (13*: 0).** Participants explained the dilemmas which they encountered with this statement, which appear to be a struggle between doing the best for the parents and for the infant.

> "I did debate that long and hard, because I have heard myself saying, well at least parents can comfort themselves with the fact that we tried to do everything that we could" (Claire)

One participant discussed this statement in the context of a conversation she had had previously with the mother of an extremely preterm infant who had died, which had prompted her to think the application of intensive care.

> "The situation was the baby had an IVH Grade 4 and we thought it had extended, so obviously we put all these facts to them, but initially when the baby was first born, they were concerned about everything, they knew what, they had obviously discussed the mortality and that with them, but I think it's interesting, because the mother really, when I was talking to her because she was very upset, and I went to spend some time with her, and she said, it's alright you having all these machines, but it's more difficult you starting and then taking away, you know...I have to be honest, I thought well in a way she's probably quite right, is it better not to put these parents through that, you know" (Christy)

Similarly participants were neutral that **saving infants at less than 24 weeks gestation is an inefficient use of NHS resources (43: 0).** Some participants discussed the limitations of the NHS, and the implications of allocating resources to certain infants.

> "The NHS is not a bottomless pit, we cannot do everything for everybody, and I do think we waste an incredible amount of money...Because we don't stop as soon as we should, and we will keep baby's going for 2, 3 or 4 days, longer, in an intensive care

> bed, with all the resources, with the nurses, with the doctors, with all the drugs and stuff, and all the TPN, and everything that goes with it, when there is absolutely no hope" (Sian)

Participants explored the ethical implications of the statement, highlighting that despite the above arguments, the resource allocation argument was insignificant.

> "I think if people recognised the true cost, there might be some questions asked, but you can't, it's somebody's baby, it's emotive and it's somebody's baby, and it doesn't matter what, what rational argument you put to it, it pales into significance" (Emma)

One participant discussed this statement from the position as someone who has control over the budget on a neonatal unit.

> "That's a very contentious one in my head, because sadly I have a budget to manage now, and it doesn't sit right with me in terms of running a budget, but I still have to make the best use of the resources that I get, I don't like it, I hated it when I read it, and it's not something I believe in, because everybody has a right to use the NHS as a resource, its not something I would ever endorse, but on the other hand, I don't think I look it as a resource, I look at it as the ethical and moral dilemma, but maybe, if we took that resource

> away, we could plough it into baby's that really would benefit, but how you do that I don't know" (Claire)

Participants were neutral in their attitudes towards **the most important factor when deciding on resuscitation is the potential burden on the parents (12*: -1).** The 'neutrality' of the statement appeared to be because whilst participants discussed how resuscitation decisions should be guided by the infant, they were aware of the impact these decisions had on the parents.

> "That one was a really hard one for me, because actually not every parent sees it as a burden, some parents are more than happy, and they rise to the challenge of looking after them, and they're their life, and everything is fine, so that, and I didn't like the 'most important', that was the other difficult bit for me, it is an important factor, but I didn't like the most important bit" (Claire)

> "At that time, when you're involved in that [resuscitation], you may change your opinion later on, when you get to know more of the family, but I think the initial care, you have to aim for what you feel is right for the baby and it's outcomes" (Christy)

Participants were neutral that **parents should be invited to learn about the technology used on their extremely premature infant (27*: -1).** Participants discussed the impact they thought technology had upon parents, and how due to this impact they actively tried to stop parents looking at the machines and start looking at their infants.

> "All sorts of people look at the technology before they look at the baby, now that includes the parents, you know, parents on admission get that, sort of, 1000 yard stare look, for the first couple of days, where their eyes are glued to the monitor, and they're leaping 20 feet in the air every time an alarm goes off, and they need re-training to look at their baby, and stop looking at the machinery, and let us look at the machinery" (Ben)

> "Sometimes they [parents] become obsessed with machines, don't they, and you really just want to go and switch it off, and say look at your baby, look at your baby" (Jenny)

Participants also remained neutral that **resuscitation at less than 24 weeks is for the parent's benefit only, not the baby's (32: -1).** Participants appeared to be unsure of this statement, as no one clear reason emerged from the interviews. Participants below discussed their individual concerns regarding this statement.

> "We're not very good at being, straight forward with them sometimes, I think we always want to give them a glimmer of hope, and actually, the reality is, this is probably not going to work, you

> know, and then there's the whole question of who are we keeping the baby alive for" (Cara)

> "Because I have seen parents who have made that ultimate decision to let that baby go, and I think that is borne out of absolute love and devotion, whereas, there is that fine line isn't there, between keeping anything alive, whether it's an animal or a human being, its actually not, they're not thinking of the baby, they're thinking of themselves, and I, you know, for me, when you see parents actually come to that decision, and say enough is enough, you know, and you just think, gosh, that's amazing" (Claire)

Participants were neutral that **NICU treatment accounts for a large proportion of NHS resources and as such admission of infants less than 24 weeks gestation should be restricted (36: -1).** Participants were unsure that admission should be restricted, however acknowledged the financial constraints that infants born extremely prematurely had upon the NHS.

> "They either need to fund us properly, for what we're doing, or say don't do what you're doing, so they reduce the workload, by, and the easiest way to do that would be to say babies at 23 weeks are non viable...they've paid for EPICure, why aren't they doing anything with the results of it? So, I think you ask for research, they tell you the answers, and then nothing happens! They review what is viable, and what is not viable, and the nothing happens, so

> at the moment, one thing that shouldn't continue is what's happening at the moment, so underfunding plus having all the extra babies" (Emma)

> "In this National Health Service, it has to have an impact [saving infants less than 24 weeks], I think it has to have an impact, and that, I think we can be really really quite extravagant, but yes I think if we're really really truthful, with all the developments, and everything, I think that it has to have an impact, because what we do at this gestation, impacts on that family, plus the national health service for all these years" (Christy)

Participants slightly disagreed that **better provision of welfare services in the community once children are older would make it easier to continue treatment for extreme preterm infants who display evidence of disability (41*: -2).** Participants discussed that they did not think there was a lot of help for parents of extremely preterm infants in the community; the positioning of the statement would indicate that despite this, participants still felt that more community help would not make decision making any easier. What participants did do was discuss their thoughts on disability itself, perhaps shedding more light onto their attitudes towards the disability rather than the community service. This may reflect the fact that participants are more aware of issues of disability and not issues of community provision for disability.

> "There's not a huge amount of care and help out there, not with the day to day, I mean we don't even have a speech therapist in [county], so I do think they're pretty much on their own, so I do think you have to be very careful not to be a hero at the point of delivery, and then say right, okay, bye, here's your 22 weeker who can't see, speak, sit, stand, get on with it...I do think you've got to be very careful, if we're going to be doing that then we need to provide the after service as well, and the care needs to be there" (Rachel)

Participants slightly disagreed that **parents should not be involved in treatment decisions for extremely preterm infants as they do not understand complex medical information (48*: -2).** This reflected participants earlier discussion that although they did not think it was 'fair' to give the parents the responsibility for making decisions, parents had a right to be involved in the care of their infant. They discussed how it was up to the health care professionals to ensure this involvement.

> "It doesn't matter whether they understand complex medical information of not, for me, it's the fact that they are involved, they should have a clear understanding, of what the implications are, and we should make sure they do understand properly, and I think that's where the confidence bit comes in really, it's having somebody there that can actually impart that knowledge and know that people have taken it on board" (Claire)

Participants also discussed how they thought that parents should be involved as this was the rationale behind 'holistic care'.

> "I do think parents sometimes need to have an input definitely, but, you cannot let your overall decision affect everything that they have said, you've got to take it into consideration, but not completely ignore them, because at the end of the day, it is holistic care" (Gabby)

Participants disagreed that **it is better to have a disabled child, no matter how disabled, than no child at all (37: -4).** This statement allowed participants to explore their attitudes towards disability, and the impact that they thought this would have upon the family unit. Participants, as discussed with other statements, thought that the impact on the family was strongly dependant upon the family's reaction to the disability.

> "We all have this great expectation of the perfect child, who will move on, grow, learn, achieve, move home, but you have to move the goal posts sometimes, and I know people who do it very successfully, with and without regrets, but I just, I don't know, that a child that needed 24 hour care for the whole of their life, I don't know whether we're doing them or us any favours by keeping them alive...I think they've [parents] got to really strongly examine whether a child at all costs, or the child or their dreams" (Lucy)

One participant, whilst exploring her attitudes towards disability, discussed how she thought that she could not make the decision to say whether or not it was better to have a disabled child or no child, as she did not know 'what it's like'.

> "I think the only people who can make the decision are those who are having to face it day in and day out, I don't know what's its like to lift a 19 year day in and day out, and change nappies, mop up periods, I don't know what it's like, it must be a nightmare, and there's no respite, so I don't think I can make a decision, I think the only people who can make that decision are the people who are doing it night and day" (Rachel)

Participants strongly disagreed that **Health Care Professionals should deliver the care that parents are asking for, even if parents are asking for treatment that Health Care Professionals think is futile (3*: -5).** Participants thought that although the parents should be involved in the care of their infant, when the situation reached a point in their mind which was detrimental to the infant, the views of the health care professionals should supersede the wishes of the parents. In these situations, participants clearly felt that they were advocating the best interests of the infant, and that these sometimes differed to how the parents viewed the best interests of the infant.

> "I don't feel that it's fair for a baby to be resussed, to be kept alive, just because the parents want the child to be kept alive" (Gabby)

Participants were sympathetic to the parents and were understanding of the difficulties that the situation presented. Participants discussed how hard it was for them, and therefore how difficult it must be for parents.

> "I do think there is a place for, the medical staff to take, their actions should take over the parents actions, because I think its very hard as a parent, as a parent you can't possibly be objective, you know its hard enough for us and we're not taking this child home, so how much harder, they can't, ever be objective, and you know, there is always going to be that hope that you know, there's always the odd story that the professionals got it wrong, and everything, so they'll quite often cling onto that, so they do need to be helped to make a decision that is the fairest for the child" (Aimee)

One participant, Jacqui, explored this situation in more depth, explaining the difficulties that she felt this situation created, and how she felt as a nurse trying to deal with these. Jacqui also discussed how she tried to deal with this situation, and get the parents 'back on board'.

> "That becomes apparent when you have got a conflict of interests, i.e. the parents want everything doing, and you're feeling that the care that we're giving this baby is not appropriate. You might feel as a nurse that, that you're not getting anywhere, the baby is obviously getting sicker, and it either continues and dies on the ventilator as it is, or you make the baby comfortable. And we're

> very much touchy feely and comfort, and you know, reducing stress for the infant becomes our priority, and often the parents don't feel, and they want everything doing, and you know that everything means more invasive process, more handling, and more stress for the infant. And that's when it's sort of, hard, I think, and that's where the art comes in to trying to get them back on board, and saying we understand how you're feeling, but, do you understand that if we continue it means this this and this, it isn't pleasant. And to die on a ventilator is not a nice way for anyone to die" (Jacqui)

Finally, participants also strongly disagreed that **infants born extremely prematurely to families who have received IVF and unlikely to conceive again should always be offered full intensive care treatment at all costs (8*: -5).** Participants thought that all infants should be treated equally and should receive the same care, regardless of the situation surrounding conception.

> "No no no no no no no. Every baby should be assessed individually…when that baby delivers 23, 24 weeks, or they've been resuscitating it because it's term for 25 minutes, and they haven't got a heart rate back, for me, that baby stands alone as any other child that was born, almost, the history and stuff, is irrelevant in that decision making" (Sian)

Participants did discuss how they thought the parents of an infant born using IVF may have additional needs, and discussed their sympathy for these parents. The treatment of the infants, however, remained the same.

> "Parents need more support in that situation [IVF], just because the desire is so big to keep going, which I can't blame them for at all, but I think the treatment the baby gets is the same, because at the end of the day, if the baby is still going to be in pain, it doesn't matter whether they're IVF or not, pain is pain" (Zoe)

One participant discussed how they thought that the issue of IVF was relevant, however the outcomes of these infants were the same as any other infant, and as such the treatment decisions surrounding these infants should be the same.

> "Should it be resuscitated if its an IVF, are very relevant, but shouldn't really be taken into account, because that child had got to live with whatever we leave it with, and if it's IVF, and it's the first child, or if it's the last child, that shouldn't make it have to live with horrendous disabilities, just because the parents can't have any more, that's not fair...people do tend to say oh it's a special baby, its an IVF baby, and it is a special baby, yes, but it shouldn't have to live with disabilities just because it's IVF, it didn't ask to be IVF" (Rachel)

5.7.IV Summary

Factor three was distinguished by 17 statements and had a high reliability of 0.99. It was characterised by 17 participants whose attitudes towards extremely preterm infants was reflected through a belief that the health care professionals were in the best position to determine the best interests of the infant. These participants saw the parents and the infant as their 'patient' and as such thought that it was their role to make any decisions so that the parents did not have to undertake this responsibility.

5.8 Concluding Summary of Findings

The results of this study have revealed a set of attitudes towards extremely preterm infants which all neonatal nurses share (the 'consensus' statements). These attitudes revolve around the statements concerning abortion and fertility. The biggest difference between nurses was found in their opinions towards decision making and treatment decisions, which led to the emergence of 3 different types of attitudes (the 'distinguishing' statements). These attitudes reflect who should make difficult decisions for extremely preterm infants, and how these decisions should be undertaken. Card Content Analysis provided interview statements to explore the rationale behind both the consensus and distinguishing attitudes. The following chapter will discuss these different attitudes in depth. The appropriateness of Q methodology for the study will also be explored.

Chapter 6: Discussion & Conclusion

6.1 Introduction

The literature review of this study critically analysed the issues which surround extremely preterm infants, and their potential relevance to neonatal nurses' attitudes. The areas of abortion, decision making, disability, fertility, technology and economics were explored. The aims of the study, developed around a conceptual framework were to: 1. discover NICU nurses perceptions towards viability and its surrounding debates; 2. determine any patterns amongst perceptions of neonatal nurses towards viability amongst neonatal nurses.

Q methodology was used to fulfil these aims. Nurses from a perinatal network were given statements which represented each of the areas of the debate, and were asked to prioritise them from 'agree with' to 'disagree with' on a normal distribution response grid. Post Q sort interviews were conducted with all the participants to discuss the rationale behind their prioritisation of the statements.

The results of the study are an explicit account of the types of perceptions of neonatal nurses towards extremely preterm infants, and their prioritisation of the debates surrounding them. What has emerged is a shared (consensus) prioritisation of statements in a 'neutral' position which could indicate a value judgement, potentially representing the education and which all nurses undertake to "not discriminate in any way towards those in their care" (NMC

2008 p.2). The issues of abortion, fertility and economics fell into this category. These learnt nursing values were then built upon and became distinguished by participants' perceptions towards the remaining issues of decision making, disability and technology. These issues led to the emergence of 3 different types of neonatal nurses' perceptions towards extremely preterm infants.

What the perceptions reflected were the dilemmas which neonatal nurses routinely found themselves in when working with extremely preterm infants. These contradictions ultimately highlighted the difference in perceptions towards parental involvement in difficult decision making around their infants. This was seen to be set in a context of the changing role of technology in the intensive care unit, how the technology is impacting upon attitudes towards disability, and the diverse range of families with whom they work. The 'learnt' professional guidelines of nursing became secondary to these attitudes due to the complexity of the situation in the neonatal unit.

What this study has achieved is to make explicit the perceptions that neonatal nurses hold towards extremely preterm infants and the values that underpin these perceptions. This chapter will discuss these findings, exploring the contradictions between the perceptions. The conceptual framework originally developed will be explored in the context of the findings and adjusted accordingly. The value of Q methodology in answering the research questions and fulfilling the aims of the study will also be explored. Finally, the recommendations for practice and further research, built upon from the clinical and research conclusions of the study, will be presented.

6.2 The Findings in Context

The three patterns of perceptions of neonatal nurses, achieving the aims of the study, have been developed from the findings and can be represented through a hypothetical 'story' of an infant's journey in the neonatal unit. Each nursing perception is presented as a different neonatal nurse working with the infant and family on various shifts in the neonatal unit, highlighting the clinical relevance of the findings. They are presented as 'ideal types' of the results, however are not without variation within each 'nurse'. The parents in this story will experience three very different approaches in the way the nurse supports or advocates for parental involvement in decision making whilst providing care for their infant. The time element of the 'shift' is not important; the perceptions of the nurse being explored are what are being presented. The fewest to the greatest number of nurses belonging to each of the perceptions are described, beginning with the reported belief that all available technology should be used to give the infant the chance to respond to the treatment, and therefore be given every chance to survive (Factor 2 in the results). This will be followed by the example of the nurse who believes that the parents' choices should be accounted for in decision making regarding their infant (Factor 1). Finally, the example of the nurse who believes that the health care professionals should make the decisions regarding the welfare of the infant will be presented (Factor 3). The statements in each factor which reflect these perceptions, along with the placement in the factor, are highlighted in brackets. The interview data provides the rationale behind these perceptions. Having shown that nurses employ a range of different values to underpin decision making, there are nevertheless shared values that all nurses reported to follow (the 'learnt' principles) and these will also be described. The scene will first be set by explaining how a preterm infant arrives on the neonatal unit.

6.2.I Arrival of an Infant on the Neonatal Unit

When a women gives birth to a preterm infant in the delivery suite, a team of health care professionals (including doctors and nurses) led by a consultant Neonatologist assess the condition of the infant to decide whether resuscitation is a possible option. If it is decided that resuscitation should go ahead, the infant is stabilised as much as possible before being transferred to the neonatal unit. A team of neonatal doctors and nurses await the arrival of the infant on the unit with all the necessary equipment to continue providing the life sustaining treatment the infant requires. The plan of care is determined by the condition of the infant and their physiological response to the treatment which they receive throughout their time on the neonatal unit. There are critical points throughout this time where choices about the treatment have to be made.

6.2.II Shared Learnt Nursing Values

A preterm infant at 23 weeks has been delivered and transferred to the neonatal unit. All of the nurses on the neonatal unit share underlining nursing values which may guide their approach; the infant and their family will be treated as an individual family and will receive non-discriminatory nursing care regardless of their circumstances when they arrive on the neonatal unit. The use of clinical judgement will be exercised to assess each infant, and the resulting information will be used to base their consequent attitudes towards treatment.

6.2.III Denise: Technology Can Sustain Life

The designated neonatal nurse, Denise, on the morning shift is ready to admit the infant and work with the team in determining and carrying out the best possible plan of treatment for the infant. Denise typifies factor two in the Q study results; her attitude towards extremely preterm infants is to provide all of the technological support available to give the infant every possible chance to respond to treatment.

The infant arrives on the neonatal unit and requires life support in the form of a breathing machine. Denise has a strong belief in the ability of technology to help preterm infants (31:+3), and as such advocates the application of technology and the initiation of treatment (17:+3). She thinks that the infant should receive the maximum possible technological support to allow the infant chance to respond to treatment and be given every possible attempt of survival. Denise has seen technology greatly advance over time and vastly improve the outcomes for many infants. The fact that technology has lowered infant viability limits from 28 to 24 weeks gestation drives Denise to strive to provide all the technological care that they can as she believes technology could further improve outcomes for extremely preterm infants (53:-2).

Denise is aware of debates which have been taking place within the unit regarding the financial cost of preterm infants; she does not, however, agree that cost should be an issue when caring for these infants (36:-5). Denise believes that all infants, regardless of gestation, should be given a chance of life over and above the availability of resources, and it is her duty as a nurse to provide these chances (43:-4).

The parents arrive to meet their infant a short time after the infant's arrival on the neonatal unit. Denise welcomes the parents, and explains to them what the technology that is currently being used on the infant is and what it is doing for their child (who the parents have decided to name Mary). A few minutes later, one of the doctors arrive to discuss the potential outcomes of Mary's care with the parents. They explore the chances of survival with no adverse outcomes, and survival with an adverse outcome of disability. Denise strongly believes that the parents should be involved in this discussion, however does not believe that the possibility of disability is a reason to limit treatment or that the parent's decision is necessarily the most important deciding factor (39:-3). Denise holds a non-discriminatory attitude towards disability and thinks that if the infant is going to survive (with or without a disability) then it is not her role to question that survival, but to provide the best possible support for the infant to do so (17:+3). Denise also does not want to pre-judge the family by assuming whether or not they will be able to accept an infant with a disability. By focusing on the 'here and now' of the infant, and the benefits of the technological interventions that she is providing, Denise can retain her focus on the infant and its potential survival.

6.2.IV George: Accounting for Parental Choice in Decision Making

Denise's shift is nearing its end, and the nurse allocated to Mary and her family, George, has arrived for duty. George comes over to the cot and introduces himself to Mary's family, explaining that he will be the nurse working with the family that afternoon. Denise gives George a full handover of Mary's condition before leaving the unit.

George is an advocate for parental choice in decision making on the neonatal unit, reflecting factor 1. The parents are to find that George's attitude towards treatment is significantly different from Denise's, even though he shares some of the same underpinning learnt nursing values. George remains neutral about any potential parental circumstances (such as age of the mother or infertility issues) and does hold strong opinions regarding allocation of resources for extremely preterm infants (36:0; 43:0).

George, like Denise, thinks that the family should be involved in the decisions regarding their premature infant. Unlike Denise, however, George thinks that the parents should take more responsibility for the decision making as it is their baby that the decisions centre around (21:3; 30:-5). George therefore believes that the decisions of the parents should take precedence over those of the health care professionals.

On learning about the discussion between the Doctor and the parents regarding the outcomes of Mary's care, George is keen to emphasise to the parents their role in the decision making process. If disability is a likely outcome, he strongly believes that if the parents decide that they can not cope with a disabled child, they should be supported in the decision to withdraw intensive care (39:+4). George does not believe that it is necessarily better to have a disabled child than no child at all (37:-3).

George also believes that a peaceful death is more important than continuing with intensive care, as he perceives intensive care to be too painful and stressful for the infant if death appears inevitable (1:+6).

6.2.V Lisa: The Health Care Professional Having the Infants Best Interests at Heart

George's shift on the neonatal unit draws to a close, and the nurse allocated to the family for the night shift, Lisa, arrives on duty to receive cot side handover from George. Lisa introduces herself to the family before assessing the care of the infant and family she finds herself working with that night. Lisa reflects factor 3 in the Q study results.

Lisa shares the same learnt nursing values as George and Denise. Lisa is similar to George in her attitudes towards allocation of resources, and does not prioritise these issues when thinking about the care of extremely preterm infants (43:0; 36:-1). Lisa is also similar to George in that she does not believe that it is necessarily better to have a disabled child than no child at all (37:-4). Whilst Lisa (along with George) agrees that life satisfaction is possible if a person has a disability, she also has opinions on quality of life and thinks that if evidence of a severe disability is found in a preterm infant, it is a valid reason to withdraw treatment (44:+4). Lisa believes that an infant with a severe disability will have a huge impact on a family and that health care professionals should take this impact into account when making treatment decisions.

Lisa, like George, thinks that the parents should be involved in the decision making regarding their infant. Unlike George, however, Lisa thinks that the health care professional is ultimately the one with the expertise, and as such any decisions should be made by the neonatal team. The wishes of the family, if not in accordance with the health care professional, should not be those which direct the treatment of the infant (3:-5). Lisa thinks it is unfair on the parents to give them such decision making capacity, and thinks that it is the role of the health care team to make the parents time in the neonatal unit as stress free as possible by removing these decisions if necessary (48:-2).

The above hypothetical story illustrates the reported types of attitudes neonatal nurses hold towards extremely preterm infants which may affect the care of the infants and families. By making these attitudes explicit, it provides a basis on which to explore why neonatal nurses think in this way and highlight the impact that these attitudes may have on the infant and their family. What has emerged from the study is that it is not only the attitudes towards the infants which were under exploration, but the attitudes towards the family also. The difference that the word 'neonatal' makes to 'nursing' also emerged as an unforeseen result of the study. This reflects the clinical context of 'neonatal nursing' whereby nurses are caring for two sets of people: the infant and their family. Each party has potentially conflicting interests. A relationship dependant on various components may not always be easy to balance; the perceived 'best interests' of infant in the eyes of the nurse and the family may not always agree. The treatment which the infant receives does not change during any disagreements as the default position of the health care team is life sustaining technology driven care. The change in attitude is directed towards the parents. The infant therefore remains the 'constant' in the three different attitudes towards parental involvement in difficult decisions.

The perceptions of the neonatal nurses towards extremely preterm infants are arguably reflected in the perceptions towards parental involvement. An exploration of these perceptions will be presented following an in-depth discussion of the learnt nursing values which were reported by all nurses. Through highlighting these values, the foundations which nurses are basing their principles on will be made explicit and the perceptions which develop from these can then be discussed. From these discussions it can be seen how each of the aims of the study (determining the perceptions of neonatal nurses towards extremely preterm infants, and determining any patterns of perceptions amongst nurses) have been achieved.

6.3 Underpinning Nursing Values

There were a range of issues which all neonatal nurses in this study agreed on, independent of the different attitudes towards parental involvement which they held (the consensus statements). These included agreements on the non-discriminatory aspects of nursing which all nurses are taught to have during their nurse education, such as there being no ascribed characteristics of a woman which would influence their professional judgement of them as a mother (such as having previous abortions or being an older mother). This non-discriminatory attitude was also displayed in the disagreement that "life satisfaction is not possible if you have a disability" (Q sort statement 16). Agreements were also found on specific aspects of neonatal care, such as death being inevitable for some infants, advancements in technology increasingly causing ethical dilemmas over its use, and the suggestion that choices made by parents regarding their infants were sometimes influenced by health care professionals. There appeared to be two underlying values driving these reported attitudes, with the first reflecting a non-discriminatory attitude of 'nursing' that all parents can expect the same level of acceptance on the neonatal unit. The second value indicates a level of clinical judgement that the nurse is undertaking regarding the extremely preterm infant, and highlights a potential contradiction between the expectation of 'nursing' in education and the practice of 'neonatal' nursing.

6.3.I The Values of 'Nursing'

The prioritisation of statements illustrating that it was the participant's role to provide nursing services regardless of what they or 'society' might otherwise think of their circumstances in the neonatal unit, highlighted the shared perceptions towards nursing which participants were reporting. There were no distinguishing characteristics of a parent that made them more or less deserving of appropriate nursing care during their time on the unit. What these accounts may mean in practice are that each and every family encountered in the neonatal unit can expect a similar level of acceptance and standard of nursing care from the nurses in this study.

Individual, non-discriminatory care forms the basis of the nursing Code of Conduct (NMC 2008) which all nurses are required to work within to maintain their registration as a nurse. Learning, understanding and working within the boundaries of the NMC Code (2008) is one of the basic standards of pre registration nursing education. It could therefore be argued that the finding of these 'learnt' values as shared perceptions reported by the nurses is not surprising. That these perceptions towards nursing emerge as shared and separate to the patterns of nurses illustrated by 'Denise', 'George' and 'Lisa', would indicate a potential contradiction between 'nursing' and 'neonatal' nursing for extremely preterm infants, suggesting the values may be learnt but may not be consistently advocated. There are clearly specific issues which create difficulties for nurses and make the 'values' ascribed to nursing difficult to implement due to the complexities of the neonatal unit. It raises the question of whether the placement of 'nursing' statements was conscious or subconscious, and whether these statements emerged as nurses are aware of the rhetoric which surrounds 'nursing'. If all nurses are taught that to be a nurse they have to provide individualised non-discriminatory care, they will undoubtedly be biased in their prioritisation of the statements which reflect this and form the basis of their 'professional identity'. Whether nurses practice this in reality is difficult to conclude from these self identified accounts, however that all of the 'nursing' statements emerged as shared values raises the question of whether the nurses have become disengaged from these professional 'values' of nursing. Three distinct perceptions towards neonatal nursing emerged that potentially contradict this implementation of basic nursing 'values'.

6.3.I.a The Contradictions in Nursing

The contradictions which arise when faced with the challenge of ascribing nursing values to a complex area such as neonatal nursing is highlighted by Pask (2005), who identified that all "nurses are required to develop their professional self within a complex world ...where they are faced by a contingency of circumstances that may pose them difficulty" (p.247). The professional 'self' in this study is reflected in the rhetoric of 'non-discriminatory' practice, which all nurses placed statements around in similar positions, such as the neutral placement of statements towards abortion limits and the differences between abortion and neonatal services. Nurses also cite the Code (NMC 2008) in their post Q sort discussions, to explain why they agree that 'nurses who work in abortion services from 20-24 weeks gestation are merely providing a service and should not be judged'. Whilst in theory the application of these values appears simple, the day to day practising of 'professionalism' is not always as easy as may be anticipated, reflected in the contradictions which they then perceived with 'neonatal' nursing, which emerged as three separate perceptions towards extremely preterm infants.

Pask (2005) suggests that when nurses find a "gap between what they believe their role could be, and what in reality it is allowed to be" (p.252), they disengage their 'self' from the work that they do. That all of the 'values' of nursing emerged as shared in this study would appear to suggest otherwise. Nurses who are unsure of how their professional responsibilities fit into a more challenging role than anticipated appear to disengage not from their 'self' but from these professional 'values'. They report the 'values' which they are aware they should hold based on identification of the nursing rhetoric on the statements, however the results suggest that they find the implementation of these values difficult (in complex areas such as decision making), resulting in the emergence of three different attitudes towards extremely preterm infants. It is arguably at the point when the neonatal nurse cannot implement these 'values' easily in the difficult situation that they re-engage with their 'self' and their personal values (the three attitudes towards extremely preterm infants). Pask's argument culminates in the conclusion that although nurses attempt to disengage from their self, through doing so they remain "tied to their self" (2005 p. 252). The results of this study, despite disagreeing with the placement of the 'self' in nursing, indicate that the nurses do indeed remain a reflection of their personal perceptions towards the situation. These personal perceptions are reflected in the placement of statements which refer to the use of clinical judgement surrounding the situation of having an extremely preterm infant on the unit.

The personal perceptions of the nurses allow them to interact and deal with the situation in a way in which they think is best (resulting in the three perceptions). There were some situations where the clinical judgements of the nurses lead them to the same conclusions. What the nurse reported to believe should happen in these situations then formed the rationale behind the differences between their patterns of perceptions.

6.3.II The Values of 'Neonatal' Nursing

All nurses agreed 'the choices that parents make about their extremely preterm infants are often prompted by the choices of the Health Care Professionals'. Nurses "recognise[d]...we are in a very privileged position and by virtue of that fact, we are able to influence the choices that people make" (Megan). This 'recognition' of the uncertainty of parents prompted participants into 'advocating' for the infants and parents by guiding them through the choices which they were faced with on the neonatal unit. Participants think that as the "professional" (Jenny), it is their role "to guide them [parents]" (Emily). It is this responsibility of being a professional, however, which lead to three very different methods of involving the parents in the decision making process based upon personal values regarding what should drive decision making. The 'expectation' upon them as a health care professional was expected and accepted by participants as part of their scope of practice. Participants did not think that decisions should be taken without the parent's input, but thought that it was up to the professionals to give parents the ‘right’ “prompts” and “full facts” (Emily).

Penticuff and Walden (2000) found in their study into the influences of perinatal nurses’ characteristics in response to ethical decision making, nurses are likely to involve themselves in action to resolve ethical dilemmas in a variety of situations. These included when the nurses perceived themselves as having influence in their practice environment, when they were concerned about the ethical dilemmas they were encountering, and when they were in “morally relevant” situations that could “affect patient good or harm” (p.70). Arguably the complexity that an extremely preterm infant brings to the neonatal unit creates a “morally relevant” situation in which the nurses perceive it as their role to guide the parents through difficult decisions and help them to make the ‘right’ decision. The complexities appear when it comes to the actual decision to be made, and what is the ‘right’ decision. Guiding parents into a decision which the nurses think is the right decision, is not necessarily the autonomous decision of the parents as discussed in the literature review of this study. The perceptions of the nurses towards what this ‘right’ decision was, being the advocate for the infant or the parent (and therefore whose decision should be prioritised), emerged as the answer to the second aim of the study, highlighting the patterns (and thus the differences) between the perceptions of nurses in this study.

6.3.II.a Nurses as Advocates

The problems of advocating for parents (defined as one who 'argues for a cause' or 'pleads on another's behalf' Oxford English Dictionary 2005) in the neonatal environment are not new. Fegran, Helseth & Slettebo (2006) highlight that parents are invited to participate in the care of their infant on the neonatal unit, however are totally unprepared for this journey in comparison to the nurses who are "educated in care and experience" (p.52). Parents are therefore obliged to deliver their child into the care of the nurses (Fegran et al 2006). Who then becomes the advocate of the child, and hold the 'best interests' of the child, becomes controversial. Monterosso, Kristjanson & Sly et al (2005) argue that due to the limited knowledge of the parents, the role of infant advocacy is passed on from the parent and is assumed by the health care professional who is constantly involved with the family. In the current study, the clinical judgement of the situation by the nurse impacts on their perceptions about whose decision they think should be prioritised if a situation arises when a difficult decision needs to be made. This prioritisation between the infant and the parents differentiates the three patterns of respondents. The values of 'nursing' can only be applied in a limited context in these situations, whereby the nurse has to display a 'non-discriminatory' perception towards the decisions which the parents make (if any). The clinical judgements which the nurses reported and which subsequently formed the basis of their perceptions therefore requires further exploration.

6.3.II.b Clinical Judgement

The Code of Conduct (2008) provides the underlying values which nurses should adhere to, however the Royal College of Nursing also acknowledges the use of clinical judgement in their definition of 'nursing'. This definition was created to "clarify the role of the nurse in the multidisciplinary health care team" (RCN 2003 p.2), and states that nursing is "the use of clinical judgement in the provision of care to enable people to...achieve the best possible quality of life, whatever their disease or disability, until death" (p.3). The use of clinical judgement therefore provides more flexibility with the situation than the nursing 'values' provided by the NMC Code (2008). It facilitates an opinion on issues such as treatment decisions, allowing the nurse to synthesise and evaluate clinical (physiological) information and use this evidence to rationalise their judgement. The justification of clinical judgement, however, raises the question of whether its use is more valid than the judgement of the parents, if the two are different. Potential tension between advocating for the parents and advocating for the infant then arises, the precise problem previously articulated in the opening 'Why' section of this thesis. In this study, the clinical evidence of an extremely preterm infant has resulted in three different evaluations of the statements, resulting in three patterns of perceptions towards extremely preterm infants. The perceptions of the nurses are arguably based on more than clinical evidence and begin to reflect personal attitudes. One of the underlying issues this may reflect is the teaching of pre-registration nursing students to ascribe to a 'standardised' format of 'nursing', as nurses disengage from these non-applicable nursing values (as previously discussed) and are not aware of how to use their clinical judgement based on clinical evidence as opposed to personal perceptions.

These difficulties can be illustrated through the fact that nurses in this study were acutely aware of the issues surrounding death in the neonatal unit; how death occurred, how technology impacted upon death, and how the parents are supported when their infant is dying. All nurses shared the agreement that 'death is, and always will be, inevitable for some infants', and that 'the technology which enables the most premature of infants to survive brings with it increased ethical dilemmas about whether it should be used to ensure this survival'. Nurses thought that prolonged application of intensive care when they saw death as inevitable caused some infants to "suffer" (Lucy). The nurses in these situations explained in the post Q sort interviews that they ended up feeling "relieved" (Lucy) or "rejoicing when the baby dies, because you think: thank goodness it's at peace" (Cara). The clinical judgements of the nurses were shared in these opinions; the perceptions behind these judgements varied significantly, resulting in different perceptions towards how much involvement the parents should have in these situations. Rubin (1996) suggests that a nurse's clinical judgements and ethical reasoning cannot be separated, as they both require a judgement of the 'right' thing to do in each situation. The question of how the nurse therefore understands their clinical judgement is particularly pertinent.

Pask (2003) suggests that nurses views of themselves and professional practice is "intrinsically linked to, and dependant upon, their capacity to see good in what they do [sic]" (p.165). A nurse's 'professional' self is hence based on the moral 'worth' they gain from their actions. When nurses experienced positive affirmation that they had made a positive difference to a patient, they associated this with “feelings of achievement…that contributed to their developing professional self-image” (p.171). The nurses in this study shared ‘clinical judgements’ that the use of technology brought with it increased ethical dilemmas as it can also mean infant “suffer[ing]”. Using both of the previous suggestions it could be reasoned that due to previous negative experiences which nurses had with extremely preterm infants (and evidence from survival rates suggests there are still a number of infants born at extremely preterm gestations who die - EPICure I & II – Costeloe et al 2000 & Walsh 2008), where they believed the infant had suffered, they did not receive this ‘positive affirmation’. If the situation was made more complex by a disagreement between the views of the parents and the nurse then this feeling of negative affirmation would be confounded. The confirmation of being a ‘professional’ by doing the ‘right’ moral thing would therefore have been lost. The personal perception of the nurse towards the situation arguably would have been the prevailing thought that the nurse would have remembered, with no satisfaction arising from a resolving of the situation for the infant or with the parents. In future similar situations, this would be remembered and attempts made to resolve this situation based more on personal perception than clinical judgement. The nurse could therefore be basing their perceptions towards extremely preterm infants on previous infants, facing difficulties being able to separate the infant which they are currently caring for from the infant which they previously cared for and who may have “suffer[ed]” (Lucy). These personal opinions result in three different types of perceptions towards approaches to resolve the situation.

6.3.II.c Personal Awareness of Perceptions

It could be argued that in order to demonstrate effective clinical judgement the nurse has to be aware of these issues to be able to identity their own personal perception towards the situation and ensure that it is clinical judgement and not personal perception driving their judgement. Kohlberg, in his study into the reasoning behind moral thinking, identified 3 levels of moral development. In level one (pre conventional morality) individuals judge the morality of an action by its direct consequences and see morality as external to themselves. In the second level (conventional morality), individuals see morality as a more complex idea, however want to conform to social identities and maintain a smoothly functioning society. In the final level (post conventional morality) individuals begin to identity that people can have differing values and opinions, and can accept this difference between individuals (Kohlberg as cited in Crain 1985). Using these levels of moral development, it could be reasoned that in order to advocate effectively for the parents, the nurse has to transcend the need to conform to social identity of a 'nurse' (conventional morality) and have a strong enough 'neonatal nurse' professional identity to relay the concerns of the parents, without fear of being judged by other health care professionals as sharing the 'opposing' beliefs of the parents (post conventional morality). The nurse therefore has to have strong enough beliefs that although the opinions of the parents may not match their own personal perceptions, they are still valid opinions.

The nurse must be able to recognise that the interests of the parents may be based on a strong personal desire to maintain the life of their baby at all costs due to the emotional attachment they have with their infant. They may not be based on clinical judgements on the proximity to death. A variety of reasons may shape the parents' perceptions, as has been illustrated with the nurses. For some parents, it could be their only chance of having a baby due to fertility reasons (as discussed in the literature review of this thesis). For others, religious teachings may forbid the discontinuation of life sustaining treatment. The Nuffield Council on Bioethics (2006) states that in these instances where there is potential conflict of the parents and the infants best interests, the parental interests should "not be wholly disregarded but should carry much less weight than those parental interests directly addressing the welfare of the baby" (9.29 p.160). Determining what the rationale of the parents is, however, and therefore whether it should carry any "weight" will arguably be difficult at such an emotional time, and whose task it is to make these determinations is not reported. The statement also indirectly advocates the health care team's opinion over the parents, as it is their 'decision' as to whether the parents are being 'reasonable'. How to maintain communication in these situations and avoid potential conflict is of paramount importance for the neonatal nurse, and their perceptions towards the parental decision making will potentially impact upon this.

The 'moral thinking' argument by Kohlberg may help to explain the difficulties which nurses face when dealing with those who have opposing perceptions, and hence why they struggle to see the parent's perspective in these situations. It is arguably the role of the nurse as the health care professional, however, to engage the parents in discussions about the best interests of the infant and explore the reasoning behind the parent's decisions.

This can only be done if the nurse can accept a difference of opinion, and is clear that their own opinion is based on clinical judgement and not personal opinion to the situation. Only through doing this is the nurse able to relay the opinions of the parents to the health care team, effectively advocating for their needs. Discussing the thoughts and feelings of the parents towards the situation openly will ensure that the communication between the nurse and the family is maintained, potentially preventing a breakdown in communication.

6.3.II.d Involvement in Decision Making

From the shared perceptions of nurses in this study towards the complex situation of caring for an extremely preterm infant, it becomes evident that the nurses are discussing their views of these infants through the view point of how much involvement they think parents should have in making difficult decisions around their infants. The care of the infant and perceptions towards the parents can therefore be seen as two separate concerns. Nurses are basing their perceptions towards parental involvement on their personal opinions of what is 'best' in individual situations where decision making occurs. This separates the nurses into those who think it should be the decision of the parents, those who think it should be the decision of the health care professionals, and those who think that all available technology should be used to give the infant the chance to respond to the treatment and therefore be given every chance to survive through continuing with technology. This suggests that nurses are not actively engaging parents and exploring whether they would like to be actively involved in decision making.

Whilst there is literature to support parents desire to become involved in decision making, McHaffie et al (2001) highlight the importance of realising that some parents do not want this responsibility, and experience "horror at the prospect" (p.343). The nurse therefore needs to be aware of the preferences of the parents. As reportedly the 'gold standard' in nursing care, 'family centred care' is increasingly being discussed. In a concept analysis of family centred care, Hutchfield (1999) proposed that the parents were an "expert" in all aspects of the care of their child, that there was "collaboration between parents and the professional", that the "parents are involved in the decisions made about their child" p.1184-1185). It could be argued, however, that parents may not be the experts in their child's 'medical' care. As the analysis was developed from children's nursing literature, where parents have had the opportunity for many years to become 'expert' in their children, it may not be applicable for those parents whose infant is born so prematurely. Parents may also not want to be considered the 'expert'. They may look to the health care professional as the 'expert' to help them understand the extremely difficult situation in which they find themselves, and to provide them with guidance and support.

Having nurses who are taught to ascribe to a 'standardised' nursing format, as previously discussed, may not be the most effective way to support some parents in this situation. It could be argued that through parent's understanding the various perceptions which nurses hold towards extremely preterm infants and the decision making process, they can begin to realise the potential decision options that they have as parents. Just like nurses, parents may hold differing perceptions towards the situation and understanding the rationale behind the nurses perceptions could arguably be a way of informing parents and determining how much involvement they wish to have, if any, in potential decision making situations. The 'non-discriminatory' aspect of nursing is therefore required if the parents decide to participate in their infants decision making, and make a decision which the nurse does not agree with.

The argument here, however, can be seen to come full circle as who determines whether the decision of the parent or the nurse is correct? The differences in opinion over how much involvement parents should have in the decision making process identified in this study would suggest that there is confusion over the exact role of the parents (and arguably the nurse) in the neonatal unit. The discussions around 'clinical judgement' and 'moral thinking' highlight the necessity of a strong professional identity of the 'neonatal' 'nurse', being able to reconcile potential contradictions between the two.

6.3.III Summary

This study aimed to determine the perceptions of and patterns amongst neonatal nurses towards extremely preterm infants. Three patterns of perceptions were found reflecting different perceptions towards extremely preterm infants in the neonatal unit. These perceptions were based on the rationale of the nurses driving the evidence for their clinical judgements towards the situation. This rationale, and how they then consequently perceived the situation should resolve, was the basis for the differences between nurses. As highlighted, the main issues causing the differences between the nurses appear to focus around the areas of parental involvement in decision making, and in particular around the potential death of an extremely preterm infant in the neonatal unit. These issues will now be discussed.

6.4 Decision Making in the Neonatal Unit

There is a plethora of research into decision making in neonatal care as identified in chapter two of this thesis. I originally questioned whether the decision reached by the parents was autonomous, or rather was prompted by the selective information provided by the health care professionals. What this study has shown is that participants do indeed report an acknowledgement of their impact upon parents. The perceptions which nurses hold towards parental involvement in decision making potentially go towards explaining this perceived impact upon parents.

The differences in nurses' perceptions towards parental involvement at extremely preterm gestations raises the question of whether having nurses in the same unit with different perceptions is beneficial or not for parents. As previously discussed, differences in perception may allow for parents to 'sound out' all of their potential options on the neonatal unit, in effect giving them a complete view of the situation and the rationale behind it from different nurses. Conversely, the differences in perception of health care professionals could potentially create confusion and distress for families going through the decision making process, as different nurses caring for them will expect different things from them and have different perceptions towards them. The views of parents themselves require investigation to determine their perceptions of their own expectations and role as parents in the neonatal unit, and their expectations of nurses (and health care team) working with them. It would also be interesting to discover whether the perceptions of nurses towards parental involvement in decision making change as the gestation of the infant at birth increases, therefore determining the importance of prematurity in difficult decision making situations.

6.4.I The Explored Perceptions of Nurses

For the purposes of this study, the perceptions of the neonatal nurses towards the infants and families will be discussed. As mentioned previously, the character descriptions of the study findings are 'ideal types' and are not without variation within each 'nurse.' The perception symbolised by 'Denise' was that all of the available technology should be used by the health care team to give the infant as much chance as possible to respond to treatment. This was illustrated through the agreement with technological statements which reflected technology driven care to improve infants' chances of survival. Statements regarding decision making, including who should make decisions, were not highly prioritised by these participants. Whilst this lack of statements regarding decision making illustrates 'Denise', these nurses have indeed made a decision. Their decision is to provide sustained technological care for as long as possible. The nurses report a belief that through applying this technology, the infant is afforded the best opportunity of survival. Whether the infant does survive is therefore not in their hands but in the ability of the technology and consequently the infant's own resources. The infant born at less than 24 weeks gestation, however, would not survive without technological care. The decision is therefore not the infant's but the nurses who believe they are giving this opportunity to the infant. The nurses have made the actual decision to do something by providing technological care. This also inadvertently highlights the nurse's perceptions towards parental involvement in decision making. If nurses think it is their role to provide all available technology to help the infant survive, this is suggestive of the view that prioritises technology over and above the perceptions (or wishes) of the parents.

This is in direct conflict with 'George' who reports a belief that the family's choices should be accounted for in the decision making process for extremely preterm infants in the neonatal intensive care unit. This reported desire of nurses' to get the family involved can be viewed as being a form of 'family centred care', as previously discussed. Conversely, it may be that these nurses struggle with making any decisions themselves, and as such want parents to get involved to avoid the danger of making a 'wrong' decision (as viewed by the parents, colleagues or themselves). This would indicate that these nurses are decisive solely about the fact that it is not their decision; it is the decision of the parents. This is therefore not a decision about the infant themselves but rather how they will respond to the requirement for a decision to be made.

'George' and 'Denise' share similarities in their lack of statements regarding personal involvement in decision making. This is significant as it may highlight a lack of uncertainty from participants about what the outcome of these infants will be, potentially reflecting the importance of prematurity in the decision making process. By not being more decisive in their beliefs allows for participants to be involved in the care of these infants without having to undertake any of the responsibility. It also allows nurses to focus on the present. The differences between 'George' and 'Denise' emerged in potential end of life situations surrounding the extremely preterm infant; either through continued technological input until the death of the infant is certain ('Denise') or through withdrawal of the technology prior to this point (if this is what parents want) with the aim of working towards a peaceful death ('George').

Nurses represented by 'Lisa' in the hypothetical story are at the opposite end of the spectrum. They have firm perceptions towards the outcomes of these infants and their predicted quality of life, and appear to assume a personal responsibility around being involved in this care. Wanting to become involved in decision making is therefore prioritised by these participants to ensure that they have not participated in keeping an infant alive who they perceive to be suffering, or who displays evidence of severe disability. The nurses represented by 'Lisa' were not against disability, and believed that a quality of life was achievable by people who are classed as having a form of disability. The 'social' acceptability of participants placing this statement has to be questioned here, however, due to nurses also reporting that evidence of a severe disability is a valid reason to limit treatment. Participants explained in their post Q sort interviews that if they could stop a person from having to suffer all of the perceived problems that go with a severe disability (and here is where their perceptions of disability and quality of life are so important), this was better than trying to save an infant who they thought was destined to suffer not only in the neonatal unit, but during their lives.

Whilst all of the nurses in this study displayed a desire to resolve decision making situations, the specific desire to halt any suffering by nurses represented by 'Lisa' highlighted a particularly overt display of self-reported compassion. This particular group of nurses may have felt a sense of responsibility for the 'graduates' of neonatal intensive care, potentially explaining their attitudes towards extremely preterm infants. Self-guided 'compassion', however, may be problematic if the nurses' desire to alleviate suffering from a perceived high risk of disability stopped participants from assessing each infant as an individual. Through displaying an element of 'I know best' by prioritising their thoughts and perceptions, out of a desire to make the situation as stress free for the parents and as pain free for the infant as possible, they run the risk of taking away any control that the parents may want over the situation. The perceptions of parents towards any decisions surrounding their infant's treatment are therefore not necessarily considered by these participants.

6.4.II Decision Making in the Neonatal Unit

Arguably the largest study performed to investigate ethical decision making in neonatal units was the EURONIC study (Cuttini, Kaminski, Saracci & de Vonderweid 1997), which explored practices in eight European countries. In Great Britain it was found that 78% of respondents involved parents in ethical decision making, 11% indirectly sounded out parental wishes and took them into account, but only 11% allowed parents to choose the course of action for their baby (Cuttini et al 1999). A low response rate to the questionnaire of 41% may make the results of the study difficult to generalise, and it is unclear what proportion of these 'respondents' were nurses or doctors. Despite this, the findings appear to be reiterated in the current study which shows that nurses think that parents should be involved in the decision making process. but only a small proportion think that parents should have the ultimate decision.

Previous research has shown that most parents want some involvement in decision making (Kavanaugh, Savage, Kilpatrick et al 2005; McHaffie et al 2001; Partridge, Martinez, Nishida et al 2005). Unlike the results of the EURONIC study, they do not always feel that they have been involved in this process (Kavanaugh et al 2005 Ellenchild Pinch & Speilman 1996). It is possible that the nurses in the current study who reported that the health care professionals should make decisions do not involve the parents in the decision making due to their pre-conceived perceptions of the parents 'needs'. As the desire of some parents to be involved in decision making is openly reported in the literature it may suggest that nurses need more support to give parents a more active role in making decisions surrounding their infant. This, along with determining the preferences of individual parents on the neonatal unit, could help to engage parents who would like to undertake an active role in the treatment of their infants.

The recommendations from the Nuffield Council on Bioethics (2006) state that "parents have interests and that it is reasonable for those interests to be given some weight in any relevant deliberations about critical care decisions for a child who is, or who will become, severely ill" (2.29 p.17). It is unclear whether nurses in this study are aware of these recommendations, but it is significant to find that whilst the nurses represented by 'Lisa' do involve parents in decision making, they are reporting that they do not give the thoughts of parents any "weight". Here, 'Denise' and 'Lisa' share a small similarity; their perceptions towards the infants are the prevailing ones, albeit for different reasons. Nurses represented by 'George' reported a willingness to take parents perceptions into account, however may take the guidelines to the extreme and give the parents ultimate decision making responsibility for their infant. For parents to have this 'ultimate decision making' responsibility, they must arguably be fully informed of their infant's condition. Whilst 'George' would support the parents in making this decision, the question arises of how this information is delivered and whether, as previously discussed in the literature review of this thesis, the information is 'unbiased'. The question of whose decision is the right decision inevitably returns in this context.

There is a clear difference amongst nurses in the way in which they reportedly perceive parents should be involved in the decisions which are made surrounding extremely preterm infants. It could ultimately be argued that the thoughts of the nurses are irrelevant, as the communication between the health care professionals and the parents about how much involvement the parents want in decision making is more important in coming to an agreement. Store, Brinchmann, Forde and Nortvedt (2002) in their investigation into parent's experiences of life and death decisions concerning premature infants, found that parents who have experienced "difficult ethical decisions emphasise health personnel's ability to communicate and their ability to include parents, over and above parental autonomy" (p.402). This would indicate that for parents, a need to have the ultimate decision regarding their infants treatment options may not be as important as being involved in the discussions which surround this. Having nurses who hold different perceptions towards extremely preterm infants in these circumstances would therefore not be problematic; the parents would be able to hear the rationale behind the attitudes the health care team held. One of the potential consequences from this would be that communication and involvement would be enhanced between all parties. The debate of whose decision is the correct decision may never be resolved; how to make the best of this difficult situation to work together as a collective 'team' surrounding the infant may be the aim which needs addressing.

The three patterns of perceptions towards parental involvement in decision making also highlight different perceptions towards the death of extremely preterm infants on the neonatal unit. These perceptions encompass who makes the decision to withdraw the treatment, and how death should occur (peaceful death versus full technological input). What these perceptions ultimately reflect are the nurses' overall perceptions towards nursing on the neonatal unit, the negotiation of care between parents and health care professionals, and what nurses perceive their role to be. Death is still a realistic possibility for infants born at the margins of viability (results from EPICure I & II), and the issues surrounding death are obviously of utmost importance to the parents as well as nurses. The participants' concerns regarding death therefore require further attention in this chapter to see how the experience of death can be improved for nurses and ultimately the families on the neonatal unit. Potentially better management of these situations could also result in re-engagement of neonatal nurses with these infants and families, improving the ability of nurses and families to deal with the death of an extremely preterm infant.

6.5 Death in the Neonatal Unit

The nurses in this study reported an underlying shared perception that death was something that was inevitable for some extremely preterm infants. Nurses also reported that they agreed the technology enabling the most premature of infants to survive brought with it increased ethical dilemmas over whether it should be used to ensure this survival. Post Q sort interviews with the nurses revealed they were concerned with these issues, as they did not want to care for infants who they perceived to be 'suffering' when death was inevitable. It was significant that despite these concerns, nurses did not share the belief that euthanasia protocols for extremely preterm infants should be introduced in the UK. This may be an issue with the term 'euthanasia'. It may also be explained by the fact that the statement regarding euthanasia in the Q sort was not clear. It does not make any distinction between active and passive euthanasia, or the circumstances under which euthanasia might be introduced. In my original literature review, euthanasia was identified as a practice which can be carried out under strict guidance and control in the Netherlands for any infant (not necessarily preterm infants) who fall into three specific categories:

1. Those who have no chance of survival due to severe underlying disease.
2. Those with a very poor prognosis and are dependant upon intensive care.

3. Those with a hopeless prognosis who experience what parents and medical experts deem to be unbearable suffering (Verhagen & Sauer 2005 p 959-960).

The infants being discussed in the current study could potentially fall into any of these categories, however the nurses' acceptance of euthanasia remained low. The nurses represented by 'Lisa' (agreeing that the decision of the health care professional should be prioritised) were the only nurses who slightly agreed that euthanasia should be introduced. This was possibly a reflection of their desire to take the "onus of responsibility" (Claire) from parents in having to make the decision of whether to withhold or withdraw treatment. I originally argued that euthanasia may not be accepted in Britain as health care professionals would be concerned about the reaction of society if they were to openly agree to a protocol which legalised active euthanasia for neonates. Having reflected on the findings of this study, it would seem that participants themselves are unsure of the actual implications of euthanasia.

6.5.I Caring for the Dying Infant

In the UK, using information from the EPICure I study it can be seen that active care was withdrawn in 55% of infants who were born below 26 weeks gestation and admitted to an intensive care unit. It was highlighted that it was "probable that these infants would have died regardless of whether intensive care was actively withdrawn" (Costeloe et al 2000 p.668). It is likely, therefore, that nurses in this study will have encountered situations of active withdrawal of care from an infant who is born at the margins of viability. The issues which nurses had in this investigation highlighted that nurses often felt that the prolongation of intensive care through the application of technology caused suffering to the infants which they were caring for. This in itself raises the question of whether euthanasia is the correct recommendation for these infants and therefore the correct term to have used in the Q Sort. It also raises the question of the difference between withdrawal of care and euthanasia.

The difference in theory lies in the intent of the action and whether the death of the infant is actively sought. In euthanasia, action (i.e. the administration of lethal amounts of drugs) is taken with the sole intention to end life (British Medical Association 1998). The purpose of withdrawal of care, conversely, is to alleviate the perceived suffering of the patient. If through the withdrawal of care the patient dies as a consequence, as this is not the original intention, it is not euthanasia. It falls into the so-called 'Double Doctrine effect' (Mason & Laurie 2005). This principle states than an action "may be permissible provided that the bad outcome (i.e. death) is only foreseen, not intended, and is proportionate, that is, the bad that could be caused is not such as to outweigh the good intended" (Mason & Laurie 2005 as cited in the Nuffield Council on Bioethics p.20). The Nuffield Council on Bioethics (2006) therefore agrees that "potentially life-shortening but pain relieving treatments are therefore morally acceptable" (2.38 p.20). It is important to note that euthanasia in the United Kingdom is illegal, whilst the withdrawal of care is 'accepted' by Working Parties such as the Nuffield Council on Bioethics.

The debate between euthanasia and withdrawal of care is not central to this thesis. Whilst some nurses may have been uncertain about the difference between euthanasia and withdrawal of care, others may have been clear and this also led to the 'neutrality' of card 35 regarding euthanasia. This requires further investigation yet remains a distinct possibility. What nurses did report is that euthanasia is not what they think should be introduced to resolve difficult end of life situations. Nurses reported their concerns about the perceived suffering of the infant, and a desire to alleviate their 'pain'. The alleviation of symptoms is of key concern to them. It could therefore be argued that nurses in this investigation are unclear about the distinction between curative, aggressive treatment and a peaceful death. How this transition of care between the two is managed is therefore extremely important in determining how participants (and therefore potentially how parents) will cope with the death of an infant.

The participants in this investigation are not alone in their concerns. Yam and colleagues in 2001 explored the experiences of neonatal nurses in Hong Kong caring for dying infants, and identified that nurses found it "stressful to cope with the transition from curative to palliative care in the NICU setting" (p.655). Yam also highlighted the "urgent need for professional and personal development in palliative care nursing education" (p.656). Catlin, Volat, Hadley and colleagues (2008) went on to explore the notion of conscientious objection in neonatal nursing in the USA, following their literature findings that nurses often felt morally distressed when providing high technology support to infants when they felt palliative, or comfort care, would be more humane. Words such as 'torturing' the patient were often found in their review of the literature (Catlin et al 2008).

Catlin and her colleagues defined the concept of ‘conscientious objection’ as “occur[ing] when the nurse interprets that the care that has been assigned for a patient is harmful or causing suffering. The nurse does not wish to provide this form of care and feels sincerely and has felt for some time that this is a question of conscience. The nurse objects to the nature of the care orders, willing to assist in other forms of care and not wishing to abandon the patient” (Catlin et al 2008 p.104-105). Catlin et al tested the acceptability of this concept with 66 nurses (53 neonatal and 13 paediatric) and found that, using this definition, 45% of nurses had conscientiously objected to a situation and 52% would like to have objected to aggressive interventions that they felt do not change outcomes (Catlin et al 2008).

6.5.II Neonatal Palliative Care

The provision of withdrawal of care, along with studies such as the above, has led to an increase in the literature regarding the implementation of ‘palliative care’ in neonatal units. Palliative care has been defined as “a team approach to relieving the physical, psychological, social, emotional, and spiritual suffering of the dying infant and the family…[it] focuses on the prevention and relief of physical pain and suffering for the infant” (Catlin and Carter 2002 p.184-5). Palliative care follows the principle that “as illness progresses, pain and symptom management and psychosocial support are increased as cure-directed therapy that is no longer helpful is gradually withdrawn” (Gale and Brooks 2006 p.40). Palliative care works in partnership with the parents through joint decision making, and recognises the parent’s requirement for extra support around this time. It also arguably allows the nurses to concentrate on providing a 'peaceful death' (card 1), rather than suddenly realising that they "don't know how to go any further" (Jack, factor 2). Practical implementation of palliative care following the withdrawal of intensive care focuses on activities such as the keeping the infant warm, avoiding invasive procedures, giving the family time and support during the infant's death and ensuring adequate pain relief (Walther 2005).

Gale and Brooks (2006) identified the moral distress that end of life care issues often caused in the neonatal unit. They went on to develop and implement a palliative care policy on their neonatal unit in California, which involved education, workshops, and training with neonatal unit staff along with caregiver grief support meetings following the death of an infant. Whilst they have yet to formalise the results of the implementation, they have noted that feedback from staff and parents has been "positive" and that availability of grief support has "reduced moral distress" (Gale and Brooks 2006 p.44). A previous study by Engler, Cusson, Brockett et al (2004) in their study of neonatal nurses' perceptions of bereavement care reiterate these anecdotal results. Findings highlighted that "respondents from NICU's with bereavement or end of life policies were significantly more comfortable caring for critically ill and or dying infants and the infant's families than were respondents from NICU's without such policies" (p.496). Arguably, nurses who are more comfortable caring for these infants would be more comfortable caring for the families of these infants; communication would improve, creating the potential for not only improving the experience for the nurse but also for the family.

Implementing a palliative care policy in the neonatal units in which nurses in this study work could potentially provide the basis for more engagement of nurses and families in the death of infants on their units. It could facilitate communication around the infant to help parents get a better understanding of the situation, and allow nurses to discuss their perception of the treatment. Discussions of what this policy would encompass and how it would be implemented would lead the way in opening discussions regarding the death of an infant in the neonatal unit. Due to the shared nursing values which emerged from this study, a policy such as the above would potentially be accepted by the nurses in this study. The nurses represented by Denise may find the implementation of this more distressing than those represented by George or Lisa, due to their belief in the advancement of technology in neonatal care. A palliative care protocol would arguably ensure the best care at the end of an infant's life, however, which would be in accordance with 'Denise's' desire to improve neonatal care for infants born at the margins of viability.

Further research is required on how to best create this policy, using the examples of authors such as Catlin and Carter (2002) who outline a Neonatal End-of-Life Palliative Care Protocol. The Nuffield Council on Bioethics (2006) recently recommended that "the NHS should train all professionals working in neonatal medicine in the basic principles of palliative care so that these can be applied when a need is identified" (6.21 p.98). Despite this, formal palliative care training is currently not underway with neonatal nursing staff in the network in which this investigation took place. The involvement of a palliative care team is also not routine. Training and policy creation could improve the experiences of infants, nursing staff, doctors, and ultimately parents on the neonatal unit, and one of the recommendations of this study is to initiate research into palliative care with the goal of the creation and implementation of a palliative care protocol for the appropriate infants in the neonatal unit.

6.6 Personal Identity

It has been argued that neonatal nurses in this study have three distinct types of perception towards the care of extremely preterm infants and their families. The two main areas that have been focused upon in this discussion are the way in which these perceptions differ towards decision making, and how this impacts upon perceptions towards end of life situations. What has been highlighted throughout the discussion of these areas is that they represent a specific point where a negotiation of care has to be reached with the family. Decisions have to be made regarding whose decision is ultimately taken into account regarding the infant, and if death is to occur, how is it going to be managed. This negotiation strategy reflects nurses' perceptions towards their role as a neonatal nurse. Not only do these perceptions highlight what the nurses think is their role, they also illuminate what participants think the role of parents should be in the neonatal unit. This reflection of their role mirrors the contradictions which nurses have in respect to their professional identity (their learnt nursing values) and their ability to implement these as a 'neonatal' 'nurse'. The consequences of this appears to be that nurses use their personal perceptions towards the situation to try and resolve any perceived issues for themselves, the infant or the parents. This 'personal identity' will now be explored in relation to the role of the nurse on the neonatal unit.

The existence of a personal identity was highlighted by Hermansen (1987) to be essential for the development of a professional identity, and was further described as the "commonality of the nursing profession" (Ohlen & Segesten 1998 p.721) and the representation of "her/his philosophy of nursing...the values and beliefs held by the nurse that guide her/his thinking, actions and interaction with the patient" (Solveig Fagermoen 1997 p.435). A nurse can therefore approach nursing either from "the goals which all nurses have in common, or from the self-perception of the nurse as a professional" (Ohlen & Segesten 1988 p.721-2). What the current study displays is that nurses do indeed have a 'commonality' of nursing values, as highlighted by the shared nursing values which emerged. The personal identity 'essential' for the development of this professional commonality, however, is what makes the nurses differ from context to context.

6.6.I The Neonatal Unit and the NMC

The personal perceptions of the nurses in this study towards their a profession creates three distinct approaches to neonatal nursing in the absence of a clear outline of the role of the cot side neonatal nurse, or the ability to implement the learnt nursing 'values' stipulated by the NMC as easily as expected. The commonalities of 'nursing' therefore become secondary to the complexities of 'neonatal' nursing, and the 'professional' aspects of neonatal nursing are lost to the personal perceptions of participants in their roles. In practice this may mean that participants' personal values towards decision making, death, disability and so forth become their distinguishing characteristics rather than a common theme which binds them together. Nursing care therefore becomes a "form of self-presentation through which nurses actualize their values and communicate their personal meanings" (Solveig Fagermoen 1997 p.436). The concept of professional identity appears to go some way to explain and therefore offer a chance to reconcile differences and improve the experiences of nurses, families and ultimately infants on the neonatal unit.

These findings reiterate the question briefly discussed previously of whether a 'commonality' of approach is the aim of nursing, or if it is important for nurses to retain their personal identity to be able to perform individualised nursing care. The simplicity of the Code (NMC 2008) allows for nurses of all specialities to have similar principles, however provides no basis for how nurses should implement these in their areas of speciality. The contradictions of being a 'nurse' are then highlighted in particularly difficult situations, such as the ever changing context of the neonatal unit. Here, the learnt values of nurses are constantly forced to adapt as technological advances change limitations of viability, death and the acceptability of disability as an outcome of care. How nurses retain their nursing values and therefore their professional identity is paramount to how they can cope with the complexities of the situation. Potentially the reported perceptions of nurses towards parents are ultimately a measure which protects the nurses from the uncertainties and complexities of neonatal care for extremely preterm infants which they struggle to cope with on a daily basis. Their 'coping' strategy towards extremely preterm infants becomes reflected in how much involvement in decision making they want to resolve the situation, and how much they then want to give away to the parents.

As displayed in this study, some nurses reported a desire to undertake difficult decision themselves, others did not want to make these decisions, and the results of others highlighted the ability of technology supersedes the decision making process in the short term. How much involvement the parents want is made all the more relevant in these situations, as whether they are 'satisfied' with the outcome of treatment (particularly if this is the death of their infant) will arguably be their lasting memory of the neonatal unit. The question of who makes the ultimate decision, as previously discussed, may never be answered. How the communication is maintained between all individuals involved in the care of the infant at this time, may be the best way to resolve any difficulties. Implementing a palliative care policy is one of the steps to facilitate this communication.

It could be concluded that a consistent approach to neonatal nursing could is not the answer to these debates. Nurses may need to feel that their concerns are being taken into consideration. Parents may not want all nurses to give them the same answers to all of their questions. They may want a nurse to individualise the care of their infant by giving them their personal opinion if they ask for it. This may help them to form their own perceptions, be it against the opinion of the nurse or not. Providing a common 'value' for nursing provides the rationale behind 'non-discriminatory' care when parents have made their decision, however the personal identity of the nurse is arguably required for parents to feel that their infant (and themselves) are important to their health care team, and not simply another ‘patient’ that the ‘commonalities’ of nursing allow them to care for.

6.6.II The Role of the Neonatal Nurse

These debates ultimately question the nature of the professional identity of neonatal nurses, and what their precise role at the cot side is. This clearly requires further investigation, along with the perceptions of parents towards the health care team participating in the care of their infant. A clear definition of cot side neonatal nursing would allow nurses to practice their values within their professional identity, and potentially improve current confusion over the contradictions between ‘neonatal’ ‘nursing’. Presently, it could be argued that this confusion is leading to the development of strong personal values which are potentially leading nurses to disagree in conditions which they are expected to conform (such as continuing treatment for an extremely preterm infant whom they think is suffering, or for whom they think death is inevitable) (Horton, Tschudin & Forget 2007). This dissatisfaction with their work could lead to a distancing of themselves from patients (Horton et al 2007) and from nursing tasks (Demeronti, Bakker, Nachreiner & Schaufeli 2000). In the scenario of the neonatal unit, this would ultimately lead to distancing from parents, potentially creating a barrier between the parents and the nurse. As the neonatal nurse often provides a major source of support for the parents (Van Riper 2000) this could leave the parents feeling isolated, and arguably reinforce the feelings of dissatisfaction of the nurse. It may not only be the nurses who distance themselves from the parents. Parents who are not happy with the care which is being provided may distance themselves from the health care team.

once again creating a barrier between the two. This may help to explain reported feelings of disengagement of some parents towards their infant's care whilst in the neonatal unit (Fenwick et al 2001; Hurst 2001), and once again articulates the issues I identified in the 'Why?' opening section of this thesis. Whilst I originally hypothesised in the literature review that this may be because of differences in opinion towards viability and its surrounding debates, it would appear that it is more complicated. It is how the family and the nurse interact as a team and how the members of this team deal with their perceptions, which affects the interaction.

The idea that the dynamic nature of health care staff impacts upon a family's experience in the neonatal unit has received little attention in the literature (Van Riper 2001), despite there being documented negative effects on families being there (Franck, Cox, Allen & Winter 2005; Miles & Holditch-Davies 1997). For parents of infants born at the margins of viability, the time which they spend on the neonatal unit can be extremely prolonged and so their experiences with the health care team are pivotal to their overall experience of the neonatal unit. Difficulties in communication between health care providers and families may occur in this stressful environment if different approaches to care are used by different nurses, and personal opinions towards care giving and decision making occur (Van Riper 2001). The importance of communication in these situations is paramount. If the health care providers and parents can discuss their thoughts, the situation could potentially be improved. Van Riper (2001) identified that the ability of the child's primary health care provider (PHCP) to communicate effectively with the family was ranked third most important (out of 16) in a scale assessing parental satisfaction with different aspects of their child's care. The amount of time the family were allowed to spend with their child, and the amount of "trust and respect that exists between your family and your child's PHCP" were ranked first and second respectively. Interestingly, whilst 91% of parents 'agreed' that they tried to "help our child's PHCP understand how we feel about important issues", only 23.6% of these parents 'strongly agreed' with the statement (67.3% agree) (Van Riper 2001 p.79). Along with van Riper, this study highlights that parents may not always feel able to communicate their needs to their nurse if they are aware of the differences in perceptions (and therefore potentially behaviours) of different health care professionals. This ability to (consciously or subconsciously) determine individual care givers perceptions may also explain why some parents can relate more to some nurses than others.

In line with the advancements in technology and medicine over the past few decades, the role of the neonatal nurse has developed and matured to meet these increasing demands. Despite this, the precise role of the cot side neonatal nurse has received little attention. The responsibilities of the neonatal nurse are therefore not clear; are they involved in decision making? Are they to initiate discussions of life with a disabled child with parents? Are they to discuss issues of death with the parents? What the three types of perceptions have shown is that currently, the answers to these questions rely on the personal identity of the neonatal nurse in question, and not the concept of the professional identity of the participants as neonatal nurses.

All participants shared a common goal; they have the perceived interests of infants and parents at heart. The difficulty is that their perceptions of these best interests vary. Sharing a common goal, however, allows for the three different views to be united in order to try and improve the nurses and the family's experience of caring for extremely preterm infants. Getting nurses to talk openly about how they feel discussing sensitive issues with the parents could help nurses to develop a stronger sense of professional identity, and Apker, Ford & Fox (2003) found that nurses who feel socially supported by their co-workers are more likely to identify with their nursing profession. Potentially opening up this communication with other members of the health care team could also help to foster a team approach to parents which may presently get missed.

A more open inclusive approach, which increases and improves the professional identity of the nurse, could improve the confidence of the nurses to be able to deal with difficult situations knowing they are able to discuss it with all members of the infants' care team. A precise understanding of what the parents would like from the health care team, in particular neonatal nurses who spend so much time with the families, would help to facilitate this communication. Kavanaugh et al (2005) recommend that nurses should document the time spent with the family providing support and counselling so we can begin to articulate what it is we are doing with the family. As Kavanaugh et al (2005) also highlight, this has potential resource implications; if we can account for the time spent with the family it may provide the evidence required to allocate full time staff purely for the role of family counselling and support on the neonatal unit. This is an example of the assumed work done by neonatal nurses for which there is no evidence. Documenting this work could also facilitate more open discussions around the infant and their condition.

A palliative care pathway was previously suggested in order to aid the nurses in the transition from curative to palliative care. Implementing this policy would also provide some guidance for nurses when dealing with end of life situations, and arguably improve communication stemming from the development of the policy on the unit. Creating the policy this way (using other models as guidance) would allow nurses to have full involvement on the issues which are happening in their units, and again foster a team approach towards the care of all infants, not just those born at the margins of viability.

6.6.III Summary

What this study has revealed through the achievement of its' aims are the inherent contradictions in 'neonatal' 'nursing' for extremely preterm infants. This finding led to an exploration of the differences between the ambiguous professional learnt values of nursing in this context, and the resulting importance that 'neonatal' nursing values assume. The differences between these 'neonatal' nursing personal values led to the different types of perceptions towards extremely preterm infants and their families. Neonatal nurses are facing challenges in such a difficult area, due to unexpected difficulties of upholding their 'professionalism' in highly complex, sensitive and ever changing areas such as decision making and death. Recognition of nurses' perceptions towards infants and the role of the family, along with an understanding of the perceptions of the parents, could facilitate more open communication between the nurse and the parents. This could improve the experience of both the nurse and the family during these emotional situations, allowing the neonatal nurse to support parents when they (and their infant) are at their most vulnerable, and when they need it the most.

6.7 Implications for the Conceptual Framework

The conceptual framework for this investigation organised the literature (p.75), helped to develop the study aims and guided the content of the Q study to determine the perceptions of neonatal nurses towards extremely preterm infants, also looking for patterns of perceptions amongst them. The empirical evidence from this study has shown that neonatal nurses do have defined perceptions towards extremely premature infants and families on the neonatal unit, and do have shared perceptions towards of certain aspects of the infants. Having achieved the aims to determine the nature of these perceptions, the conceptual framework can be further developed to incorporate the empirical findings of the study. The diagram below shows the new empirically based conceptual framework.

The empirical findings suggest that nurses have shared learnt nursing values; these shared perceptions are then highlighted in the dichotomy between learnt nursing values and personal identities resulting in three different types of perceptions towards extremely preterm infants in the neonatal nurses in this study. A prioritisation of the choices of the parents, the infant, and the health care team reflected the different perceptions the nurses held which they thought could resolve difficult decision making dilemmas.

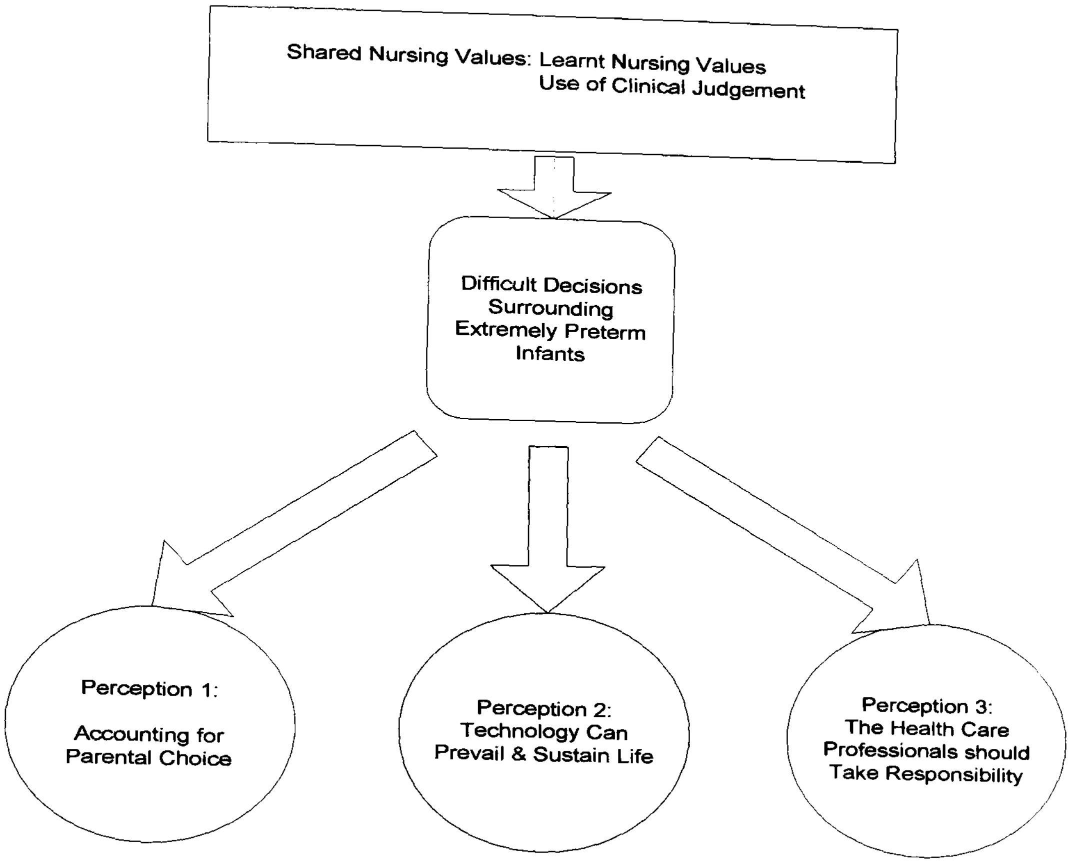


Figure 6.1: Empirically based conceptual framework

Using this evidence we can now create a more defined conceptual framework in which the direction of the relationships can be visualised. The shared learnt nursing values are brought to the neonatal unit with the nurses, and frame their perceptions towards nursing care. When the nurse then encounters a situation where the implementation of these shared nursing values is difficult to achieve (in the case of this study when providing nursing care for an extremely preterm infant), three different perceptions of how to provide nursing care and involve the family ensue. These perceptions revolve around involvement in decision making, taking into account the role of the health care team, the role of the parents, and the role of technology. The empirical conceptual framework highlights these relationships and organises the findings to minimise the use of words (Polit & Beck 2008). Further research can then be guided by the conceptual framework to determine where more research is required to investigate the potential impact of neonatal nurses' perceptions towards extremely preterm infants. These research (along with clinical) recommendations will be discussed in the concluding section of this thesis.

6.8 Q Methodology: The Right Method for the Question?

The success of any study relies on the methodology used to answer the question. Q methodology was employed in this study in order to gain an insight into how nurses prioritise the debates surrounding extremely preterm infants and to allow nurses to discuss their perceptions towards these debates. For these purposes, Q methodology fulfilled its role; I was able to answer the research questions. As I undertook the study I went from being an inexperienced to a competent Q researcher, and learnt many things about the methodology as I went. My experiences will be drawn upon to discuss Q methodology in the context of this study.

The main feature which attracted me to Q methodology was its ability to allow participants to order and prioritise the statements, reflecting the daily task of prioritisation of influential factors in the neonatal unit. Conducting post Q sort interviews would then allow me to explore in depth the rationale behind participants "discerning self-identified salient influences" (Wong et al 2004 p.W20). Q methodology therefore offered a new and unusual way in which to study neonatal nurses' perceptions towards extremely preterm infants. Cross (2005) highlighted that the selection of the Q statements relies on the judgement of the researcher, creating potential bias from the start. The transparency of this Q study, however, from the development of the statements from previous research, literature review and interviews, to the interpretation of the findings, allows for others to critique and repeat it as they desire. It also offers a basis to go on to further research, either using the same statements or using the factor types deduced as 'character types' (summarising the thoughts of 'George', 'Lisa' and 'Denise') to re-test with participants, old and new, to see which they think they identify with. These character types could potentially be used on a larger scale with other members of the health care team, to gain an insight into the workings of the neonatal unit team. Statements can be adapted for use in other countries, and can be updated through the omission or addition of certain statements over time.

The experience of participants is an important factor in any study, and one of the most beneficial aspects of using Q methodology came from the positive reactions it received. As an unusual method of performing research, participants were curious about it, and as the statements on the cards were often controversial due to the delicate subject area, participants often commented that they provoked debate on the ward when they were reading through them. In this way, Q methodology has already fulfilled one of the clinical recommendations of the study; to get neonatal nurses talking about the issues which are going on around them. The statements proved so successful in provoking debate, that in hindsight I would have altered my data collection around these initial reactions. In the current study, I gave participants the option of performing the Q sort and the interview on the same day, or separately at a time convenient for them. Participants requested a mixture of the two. If I were to perform a similar study again, I would perform the interviews as participants were sorting the cards to capture their initial reactions.

As discussed in the methodology chapter, all nurses were offered a copy of their transcript for their personal development portfolios in order to be able to reflect upon what was discussed in the interview. Following the data collection phase, there were a few of the participants on a neonatal course on which I was teaching. The feedback which I received from them regarding the ability to read through their transcripts was extremely positive.

It has been suggested that Q methodology limits the scope of the respondents due to the predetermined nature of the statements (Cross 2005b). This study has shown, however, that by conducting the post Q sort interviews along with the Q sorts, an added depth of understanding into these areas can be found. This can be highlighted by the recommendation of a palliative care pathway;

this was not identified in the literature review as being integral to the concourse, and thus was not part of the Q Sort. The struggle between the personal and the professional identity was also not identified prior to the Q Sort. It could therefore be argued, that without conducting the interviews, these attitudes would not have been sufficiently developed to identify patterns within them. Q methodology does thus not limit the scope of the respondents, however the opportunity has to be provided to them through post Q sort interviews to discuss the statements which they have sorted, and discover their rationale for prioritisation.

The in-depth use of Q methodology, using the Q sorting along with the interviews, proved to be the best method for this particular study to gain participants prioritisation and rationale behind this. Limitations on the scope of the respondents was also overcome through asking all participants whether they felt that there were any issues missing from the statements. Only one participant commented that she thought there should have been statements regarding pain control in extremely preterm infants; as such, this subject was then explored to determine why this participant felt this way. This meant that participants were very much in control of the interview, allowing their subjectivity to be explored.

Q methodology does have its limitations. One of the weaknesses of the methodology is that the rule of weighted averages can potentially distort the prioritisation of the cards in small samples. In factor 2, which was defined by only 5 people, the polarisation of responses of one of the statements was neutralised by the positioning of a statement differently by one person in the sample. This creates a dilemma, for do you remove this person from the factor despite, only having a slightly different response to one statement? The fact that the statement emerged as a distinguishing statement makes the answer more difficult. Removing the person means they have to be totally removed from the study, an option which was not thought to be ethical following the time and effort the participant had put into the research. Manually placing the person onto a different factor becomes subjective from my personal perspective of where they should 'fit'. From attempting various angles of rotation, this person was not noted to be an 'outlier', or 'special case'; potentially as it was only one response which differs from the rest. My response to this dilemma is to acknowledge its existence and highlight the weakened correlation. As Barchak (1984) also highlights, the basis of Q methodology is to shape thinking, generate theory, and allow us to "deal with whole persons, not parts of persons" (p. 118). No methodology is perfect, and this is one of Q methodology's flaws. Validation of the findings through re-testing of existing and future participants with 'character type' cards would prove an interesting addition to this study, to determine the scale of this flaw.

The time and effort which participants put into this study reflects the fact that participant involvement in a Q study is a long process. The initial Q sort procedure can take up to an hour, followed by up to another hour for the post Q sort interview. I appeared to have similar experiences to that of Barker (2008), who reported that participants were often wary of the task ahead of them when they saw the pile of cards, although this wariness appears to lessen as participants become more involved in the task. Participants also found it difficult to prioritise all of the statements, leading to participants adding boxes to the polar ends of the response grid, in order to fit in all of the statements which they wanted at the extreme ends. Whilst this did not affect the analysis of the data (see methodology chapter), it clearly identified that participants wanted the choice of more polarised responses, an option I would take into consideration next time. What the response grid did do was to provide an initial structure for participants to understand and begin the task. In future, I would have fewer Q statements to take less time from participants and also reduce the risk of convenient, rather than considered, placement of the statements (Dennis 1986).

A further weakness of Q methodology comes not from the research itself, but from the way it is portrayed (or not) in the literature. Q methodology is an increasingly popular method of research, yet does not currently have the high number of publications that the more 'popular' types of research, such as questionnaire development. The articles that are available do not go into detail of how to perform a Q study, instead focusing on the rationale behind Q and the results of the particular study. This makes discovering how to perform a Q study particularly difficult. The creation of the Q cards is discussed in detail in certain texts (Barker 2008, Bryant et al 2006, Corr 2001) however no literature could be found regarding how to perform the post Q sort interviews, despite several authors discussing their use of them. This meant that in reality it took several attempts at interviewing participants to fully get to grips with how to perform the interview, a limitation of this study at its early stages. This lack of guidance in the literature may deter a lot of researchers from undertaking a Q study. This one limitation can be overcome, however, as it has prompted me to follow the examples of contemporary Q methodologists and make Q methodology more transparent in the literature through dissemination of my study in relevant journal articles (Barker 2008, Bryant et al 2006). This will prompt discussion on Q methodology, and allow more people to interact with this 'mystical' methodology.

Overall I would agree with Senn (1996) who wrote that Q methodology's "strengths far outweigh its weaknesses" (p.215). In this study, it has proved a powerful tool not only to see how nurses prioritise debates about extremely preterm infants, but also to understand their own rationale behind these attitudes. This understanding was invaluable and proved an essential part of the study which would not have been possible had Q not been employed. The distinction between the personal and professional identity of neonatal nurses may also not have been realised had Q methodology not been used. Q methodology provides an excellent methodology with which to organise and further complex debate, through the requirement of a thorough literature review and prioritisation of the issues by those who are involved in the debate. I look forward to building upon the results of this study to further improve the experiences of nurses and ultimately families with extremely preterm infants in the neonatal unit.

6.9 Conclusion & Recommendations

This study aimed to determine the perceptions of neonatal nurses' towards extremely preterm infants, and patterns of perceptions amongst them. It was conducted at a particular historical moment where the limitations of viability have been lowered to unprecedented levels. The debates which have evolved, as the gestation which infants can survive at decreases, capture the current context in which neonatal care is situated.

Within this context, the findings of the study indicated that neonatal nurses hold different patterns of perceptions towards extremely preterm infants. These perceptions culminated in a difference of opinion towards who should undertake difficult decisions surrounding extremely preterm infants. For some nurses, a belief that the parents' choices should be account for guided their perception. For others, it was a belief that technology would prevail over viability and enable more infants to survive. For the final group of nurses, a belief that difficult decisions should be undertaken by health care professionals was underlined by a belief that parents should not have to shoulder this responsibility.

What these perceptions reflected were the contradictions between the implementation of 'learnt' nursing values, and the complexities of 'neonatal' nursing. Shared concerns regarding extremely preterm infants united the nurses, with their personal perceptions towards the situation, based on the same clinical evidence but a different evaluation of information, creating three different perceptions towards how they thought the 'situation' could be resolved. It was concluded that it was not necessarily problematic that nurses held different perceptions, as these perceptions do not automatically imply differences in behaviours. The concerns which nurses held regarding decision making and the potential death of an infant required further exploration, however, to determine how these issues could be improved. A palliative care protocol with which to increase and improve communication between nurses about their attitudes towards treatment decisions and death was one suggestion arising from these findings.

The perceptions which the nurses held may or may not impact upon their nursing care. Further research is required to expand upon this work and determine whether their perceptions do indeed impact upon nurse and parent relationships. Determining the perceptions of others involved in the care of these infants, such as the parents themselves and the doctors, will allow for the findings and recommendations of this study to be built upon. This study is the first small step in improving the experiences of the health care professionals, the family and the infant on the neonatal intensive care unit.

6.9.I Clinical Recommendations

From these findings and discussion of this study, the following clinical recommendations can be made:

- Initiation of discussion regarding the precise nature of the interaction of the neonatal nurse with the parents of extremely preterm infants, with specific focus on issues of decision making, death and disability.

- Initiation of discussion regarding the development of a palliative care protocol for implementation on the neonatal units in Perinatal Networks
- Initiation of a forum specifically for nurses to engage nurses in up to date, evidence based research.
- Improved ward based clinical research by neonatal nurses exploring issues such as implementation of new policies, parents attitudes and requirements
- Potential rotation of nurses into infant follow up clinics to enable nurses to learn about the outcomes (if any) of the infants they have cared for
- Documentation of the time spent with parents discussing issues such as decision making, end of life issues and disability

6.9.II Research Recommendations

The results and discussion also lead to the following research recommendations for the future:

- Further validity and reliability testing of the character types developed by the Q cards, with the neonatal nurses in the study and other health care professionals
- More detailed research with neonatal nurses to explore the exact nature of the role of the cot side neonatal nurse

- Further research to determine if the attitudes of neonatal nurses impact on the nurse and parent relationship
- Further exploration of perceptions of the doctors towards issues such as decision making and death
- Further exploration of the parents perceptions of their desired involvement in decision making, death, and issues of disability
- Dissemination of methodological issues in relevant journals to make explicit the use of Q methodology in this study with the aim of encouraging more discussion and use of Q methodology.

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Appendices 1-7

Appendix 1: Original 67 Q Statements

1. The technology used on the neonatal unit allows more safety and control as I the infants status is continually updated
2. Infants born extremely prematurely with life limiting illness should still be given full intensive care treatment
3. It is not up to Health Care Professionals to decide who should live and who should die
4. The production of ethical dilemmas is controlled by health care professionals through their selection and presentation of facts
5. There is no comparability in care practices between neonatal and abortion services, despite similar gestations
6. The most important factor when deciding on resuscitation is the parents decision
7. The care of women in the neonatal unit should not be influenced by a history of previous abortions
8. It is better to have a disabled child, no matter how disabled, than no child at all
9. If life limiting disability is diagnosed prenatally, parents should be able to give birth to their child and enjoy the time they have without the option of full intensive care treatment
10. Technological developments mean that heroic measures of extraordinary means of support are overused
11. Parents should be invited to learn about technology used on their extremely premature infant
12. Full intensive care treatment should always be started as it can be withdrawn later if found to be futile
13. Abortions should not be allowed from 22 weeks gestation as the fetus is changing into a baby
14. Parents should be shown morbidity and mortality statistics following premature birth to help facilitate their decision making
15. The margin of error on antenatal scanning means that the abortion limit should be reduced to cover for this ±14 day error
16. Nurses who work in abortion services from 20-24 weeks gestation are merely providing a service and should not be judged
17. Parents are given a false sense of hope when they see all of the equipment used on their extremely premature infant

18. Young parents (i.e. teenagers) should not be involved in the decision making process as they do not understand the implications of prematurity

19. Peaceful death is more important than full intensive care treatment

20. Resuscitation at less than 24 weeks is for the parent's benefit only, not the baby's

21. Older parents are better equipped to deal with the outcomes of extreme prematurity

22. The more disabilities that can be diagnosed prenatally, the more pressure there is on women to abort these pregnancies

23. The abortion limits should be reduced in acknowledgement and accordance with the current limits of viability

24. NICU treatment accounts for a large proportion of NHS resources and as such admission of infants less than 24 weeks gestation should be restricted

25. Quality of life is more important than quantity of life

26. The current abortion limit of 24 weeks gestation is adequate, as infants below 24 weeks gestation should not normally be resuscitated due low survival rates and high risks of disability

27. Advancing technology has made the process of withdrawing care more difficult

28. Abortion providers and Neonatal Intensive Care Units are separate entities and the actions of one should have no influence upon the other

29. Neonatal Intensive Care should be publically funded

30. There is a cross over between neonatal and abortion services as both care for women at similar gestations

31. The amount of technology surrounding the infant alters the social concept of death to something that can be overcome

32. Technology should be advanced to allow the most premature of infants to survive

33. 'Infants' who are born alive following termination of pregnancy should be transferred to NICU for a trial of life

34. The most important factor when deciding on resuscitation is the Health Care Professionals' opinion

35. Infants born extremely prematurely to families who have received IVF and unlikely to conceive again should always be offered full intensive care treatment at all costs

36. Health Care Professionals should not report active movements of babies born less than 24 weeks gestation if the parents request they do not want full intensive care treatment

37. The choices that parents make about their extremely preterm infants are often prompted by the choices of the Health Care Professionals

38. The philosophy underpinning nursing and medical care is the same in all health care settings, including neonatal and abortion services

39. The amount of technology used in the neonatal unit is a barrier which is detrimental to parent-infant bonding

40. Nurses should use technology to support their decision making, not use technology to make decisions

41. Women who try to conceive post menopause are not thinking about the best interests of the infant

42. The terminology should be different when referring to 'infant' in the NICU and infants of a similar gestation in abortion services

43. I would feel comfortable welcoming a nurse onto the NICU nursing team who had previously worked in abortion services

44. Women should have the right to choose abortion up until 24 week gestation

45. Death is, and always will be, inevitable, for some infants

46. 'Infants' who are born alive following termination of pregnancy should be left to die in comfort and with dignity

47. The technology which enables the most premature of infants to survive brings with it increased ethical dilemmas over whether it should be used to ensure this survival

48. Better provision of welfare services in the community once children are older would make it easier to continue treatment for extreme preterm infants who display evidence of disability

49. Evidence of severe disability is a valid reason to withdraw treatment in an extremely preterm infant

50. Euthanasia protocols for extremely preterm infants should be introduced in the UK

51. Health Care Professionals should deliver the care that parents are asking for, even if parents are asking for treatment that Health Care Professionals think is futile

52. Attempting to save babies less than 24 weeks gestation is a large uncontrolled experiment

53. The most important factor when deciding on resuscitation is the potential burden on the parents

54. Parents who do not want a disabled child should be able to make the decision to withhold or withdraw full intensive care treatment

55. Infant survival has become a secondary outcome, with determining how far technology can advance survival limits seemingly more important

56. Living with a disability can still mean that you can enjoy life

57. Caring has become technological, shifting the focus from caring for the infant to caring for the technology

58. Life satisfaction is not possible if you have a disability

59. Always initiating full intensive care treatment gives parents a chance to think that they have done everything they possibly could

60. It is wrong to knowingly bring a disabled child into this world

61. Parents should not be involved in treatment decisions for extremely preterm infants as they do not understand complex medical information

62. Life should be maintained irrespective of outcome

63. Babies born at less than 24 weeks gestation should always be resuscitated if the mother is too old to have any more children

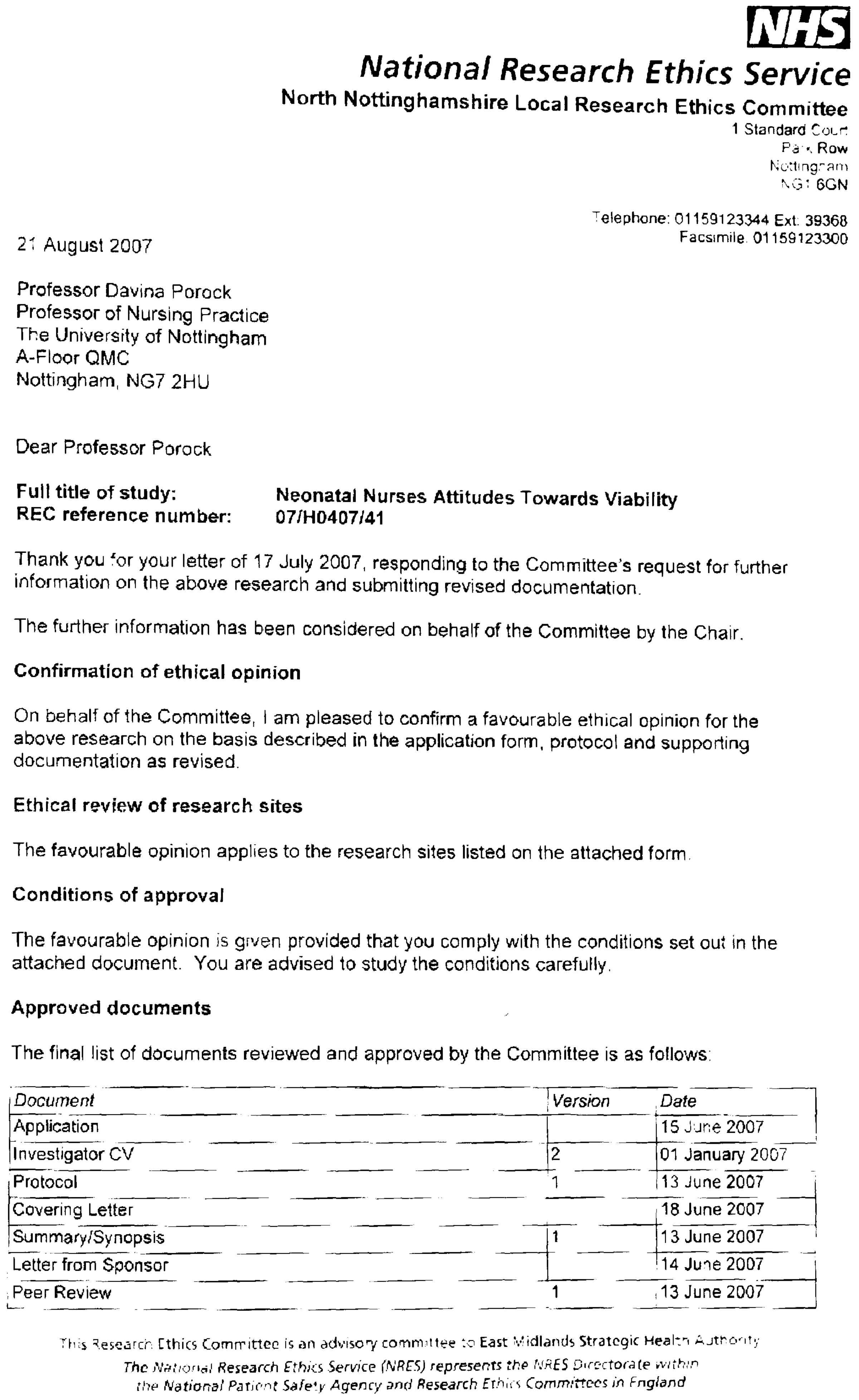
64. Refinement of admission to the NICU would decrease the prevalence of disability among survivors

65. The most important factor when deciding on resuscitation is the potential of long term suffering to the baby

66. Saving infants at less than 24 weeks gestation is an inefficient use of NHS resources

67. Deciding whether to withhold or withdraw treatment is too stressful for parents and should be done by the Health Care Professional

Appendix 2: Ethical Approval Letter



NHS
National Research Ethics Service
North Nottinghamshire Local Research Ethics Committee
1 Standard Court
Park Row
Nottingham
NG1 6GN

Telephone: 01159123344 Ext. 39368
Facsimile. 01159123300

21 August 2007

Professor Davina Porock
Professor of Nursing Practice
The University of Nottingham
A-Floor QMC
Nottingham, NG7 2HU

Dear Professor Porock

Full title of study: **Neonatal Nurses Attitudes Towards Viability**
REC reference number: **07/H0407/41**

Thank you for your letter of 17 July 2007, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

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

Ethical review of research sites

The favourable opinion applies to the research sites listed on the attached form.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

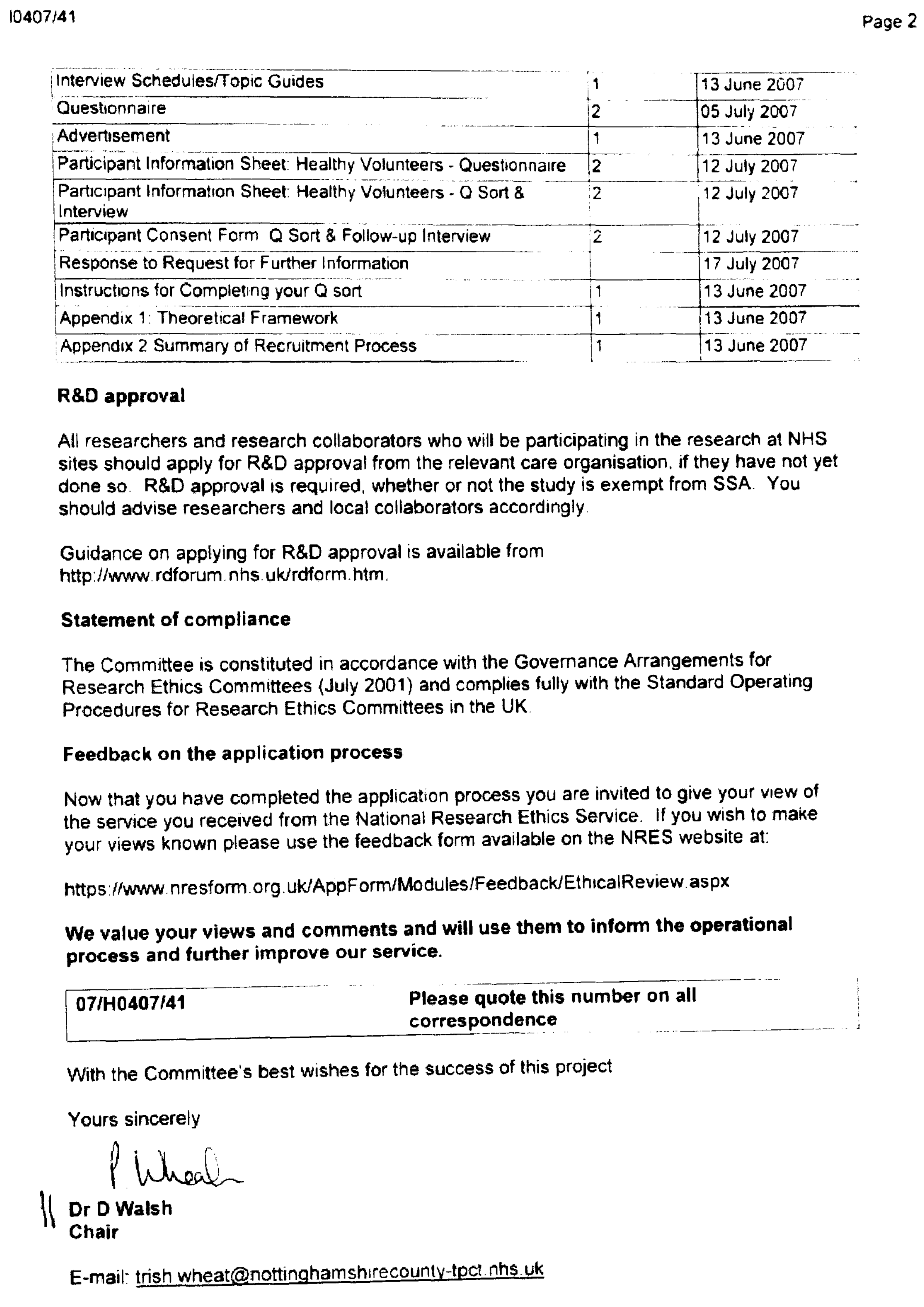
Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Application		15 June 2007
Investigator CV	2	01 January 2007
Protocol	1	13 June 2007
Covering Letter		18 June 2007
Summary/Synopsis	1	13 June 2007
Letter from Sponsor		14 June 2007
Peer Review	1	13 June 2007

This Research Ethics Committee is an advisory committee to East Midlands Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England



Interview Schedules/Topic Guides	1	13 June 2007
Questionnaire	2	05 July 2007
Advertisement	1	13 June 2007
Participant Information Sheet: Healthy Volunteers - Questionnaire	2	12 July 2007
Participant Information Sheet: Healthy Volunteers - Q Sort & Interview	2	12 July 2007
Participant Consent Form Q Sort & Follow-up Interview	2	12 July 2007
Response to Request for Further Information		17 July 2007
Instructions for Completing your Q sort	1	13 June 2007
Appendix 1: Theoretical Framework	1	13 June 2007
Appendix 2 Summary of Recruitment Process	1	13 June 2007

R&D approval

All researchers and research collaborators who will be participating in the research at NHS sites should apply for R&D approval from the relevant care organisation, if they have not yet done so. R&D approval is required, whether or not the study is exempt from SSA. You should advise researchers and local collaborators accordingly.

Guidance on applying for R&D approval is available from http://www.rdforum.nhs.uk/rdform.htm.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Feedback on the application process

Now that you have completed the application process you are invited to give your view of the service you received from the National Research Ethics Service. If you wish to make your views known please use the feedback form available on the NRES website at:

https://www.nresform.org.uk/AppForm/Modules/Feedback/EthicalReview.aspx

We value your views and comments and will use them to inform the operational process and further improve our service.

07/H0407/41	**Please quote this number on all correspondence**

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

Yours sincerely

P Wheat

Dr D Walsh
Chair

E-mail: trish.wheat@nottinghamshirecounty-tpct.nhs.uk

North Nottinghamshire Local Research Ethics Committee

LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION

For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.

REC reference number:	07/H0407/41	**Issue number:**	0	**Date of issue:**	21 August 2007
Chief Investigator:	Professor Davina Porock				
Full title of study:	Neonatal Nurses Attitudes Towards Viability				

This study was given a favourable ethical opinion by North Nottinghamshire Local Research Ethics Committee on 21 August 2007 The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed

Principal Investigator	*Post*	*Research site*	*Site assessor*	*Date of favourable opinion for this site*	*Notes* [1]
Professor Davina Porock	Professor of Nursing Practice	Nottingham University Hospitals NHS Trust	North Nottinghamshire Local Research Ethics Committee	21/08/2007	
Professor Davina Porock	Professor of Nursing Practice	United Lincolnshire Hospitals NHS Trust	North Nottinghamshire Local Research Ethics Committee	21/08/2007	
Professor Davina Porock	Professor of Nursing Practice	Sherwood Forest Hospitals NHS Foundation Trust	North Nottinghamshire Local Research Ethics Committee	21/08/2007	
Professor Davina Porock	Professor of Nursing Practice	Derby Hospitals NHS Foundation Trust	North Nottinghamshire Local Research Ethics Committee	21/08/2007	

Approved by the Chair or behalf of the REC

(Signature of ~~Chair~~/Co-ordinator)

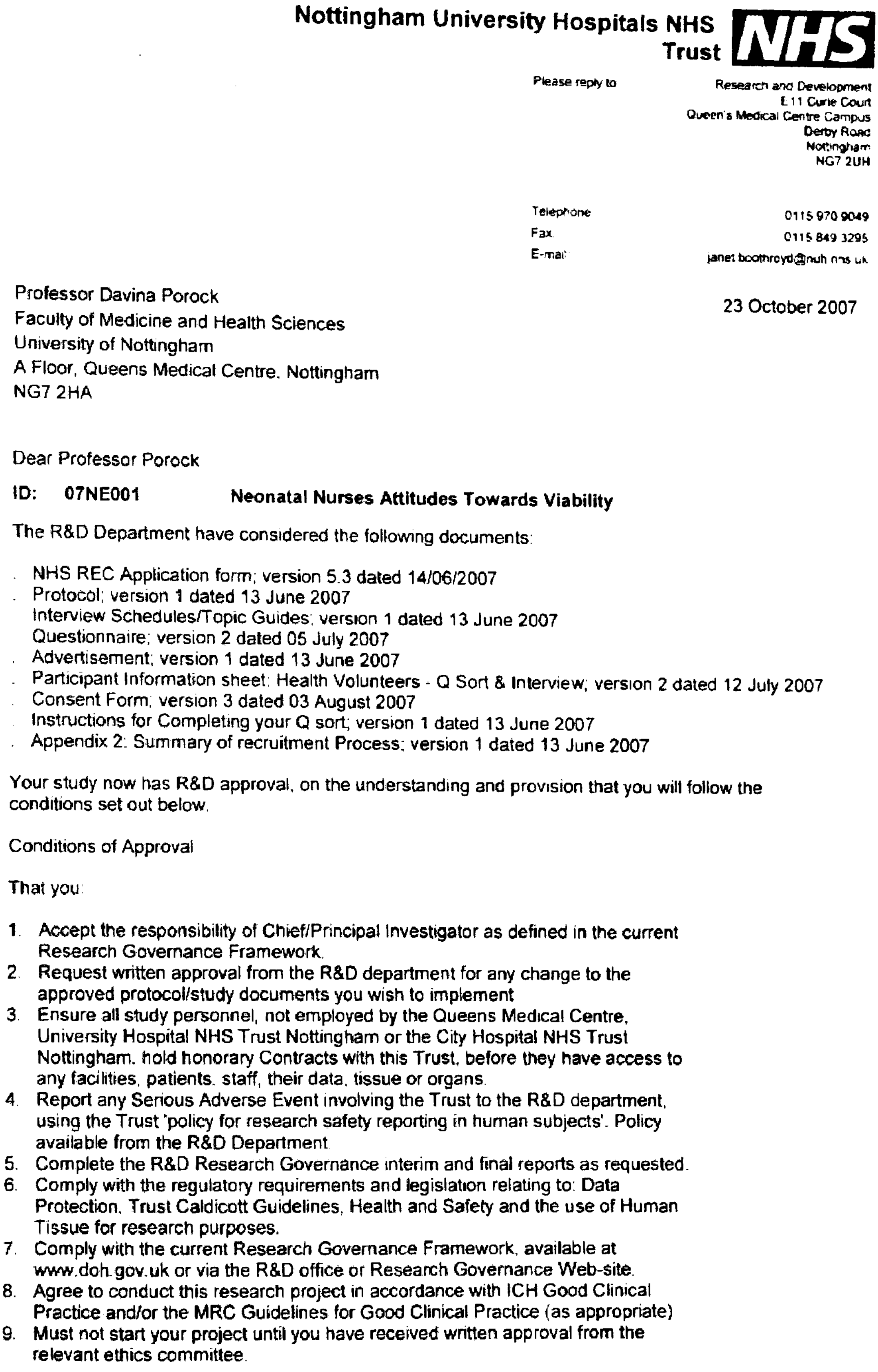
(Delete as applicable)

TRISH WRIGHT (Name)

---

(1) *The notes column may be used by the main REC to record the early closure or withdrawal of a site (where notified by the Chief Investigator or sponsor), the suspension of termination of the favourable opinion for an individual site, or any other relevant development. The date should be recorded.*

Appendix 3: Research and Development Approval Letters



Nottingham University Hospitals NHS Trust

Please reply to

Research and Development
E 11 Curie Court
Queen's Medical Centre Campus
Derby Road
Nottingham
NG7 2UH

Telephone 0115 970 9049
Fax 0115 849 3295
E-mail janet.boothroyd@nuh.nhs.uk

23 October 2007

Professor Davina Porock
Faculty of Medicine and Health Sciences
University of Nottingham
A Floor, Queens Medical Centre, Nottingham
NG7 2HA

Dear Professor Porock

ID: 07NE001 Neonatal Nurses Attitudes Towards Viability

The R&D Department have considered the following documents:

- NHS REC Application form; version 5.3 dated 14/06/2007
- Protocol; version 1 dated 13 June 2007
- Interview Schedules/Topic Guides; version 1 dated 13 June 2007
- Questionnaire; version 2 dated 05 July 2007
- Advertisement; version 1 dated 13 June 2007
- Participant Information sheet: Health Volunteers - Q Sort & Interview; version 2 dated 12 July 2007
- Consent Form; version 3 dated 03 August 2007
- Instructions for Completing your Q sort; version 1 dated 13 June 2007
- Appendix 2: Summary of recruitment Process; version 1 dated 13 June 2007

Your study now has R&D approval, on the understanding and provision that you will follow the conditions set out below.

Conditions of Approval

That you:

1. Accept the responsibility of Chief/Principal Investigator as defined in the current Research Governance Framework.
2. Request written approval from the R&D department for any change to the approved protocol/study documents you wish to implement
3. Ensure all study personnel, not employed by the Queens Medical Centre, University Hospital NHS Trust Nottingham or the City Hospital NHS Trust Nottingham, hold honorary Contracts with this Trust, before they have access to any facilities, patients, staff, their data, tissue or organs.
4. Report any Serious Adverse Event involving the Trust to the R&D department, using the Trust 'policy for research safety reporting in human subjects'. Policy available from the R&D Department
5. Complete the R&D Research Governance interim and final reports as requested.
6. Comply with the regulatory requirements and legislation relating to: Data Protection, Trust Caldicott Guidelines, Health and Safety and the use of Human Tissue for research purposes.
7. Comply with the current Research Governance Framework, available at www.doh.gov.uk or via the R&D office or Research Governance Web-site.
8. Agree to conduct this research project in accordance with ICH Good Clinical Practice and/or the MRC Guidelines for Good Clinical Practice (as appropriate)
9. Must not start your project until you have received written approval from the relevant ethics committee.

Please note that the R&D department has a database containing study related information and personal information about individual investigators e g name, address, contact details etc This information will be managed according to the principles established in the Data Protection Act

Yours sincerely

Dr Brian Thomson / Mrs Janet Boothroyd

Director of R&D / Assistant Director of R&D

cc Nottingham Research Ethics Committee

SDAH R + D OFFICE
ISSUED
-8 OCT 2007

Derby Hospitals NHS
NHS Foundation Trust

Derby City General Hospital
Uttoxeter Road
Derby
DE22 3NE

Tel 01332 340131
Minicom: 01332 254944
contactus@derbyhospitals.nhs.uk
www derbyhospitals.nhs.uk

Research and Development Office

TRUST APPROVAL LETTER

Professor D Porock
Professor of Nursing Practice
University of Nottingham
A Floor School of Nursing
Queens Medical Centre
Nottingham
NG7 2HA

Dear Professor Porock

Re: **Neonatal Nurses Attitudes Towards Viability (Ref. DHRD/2007/061).**

Further to the Research Ethics Committee approval for the above study, I am pleased to confirm Trust management approval for you to proceed in accordance with the agreed protocol, the Trust's financial procedures for research and development and the Research Governance Framework (which includes the Data Protection Act 1998 and the Health & Safety at Work Act 1974).

Please supply the following to Dr Teresa Grieve, Assistant Director of R&D:

- the actual start and end dates of this study (**before the study commences**).
- details of any publications arising from this research project.
- a final report and a report every six months if the study duration is greater than six months.
- notification of any adverse event or changes to the protocol or if the trial is abandoned.

Please note that approval for this study is dependent on full compliance with all of the above conditions.

I would like to take this opportunity to wish you every success with this study

Yours sincerely,

Prof. Richard Donnelly MD, PhD, FRCP, FRACP
Director of Research & Development

Cc Katie Gallagher

A Smoke Free Trust

Chief Executive Julie Acred OBE Chair Brenda [illegible]

United Lincolnshire Hospitals **NHS**
NHS Trust

RESEARCH & DEVELOPMENT DEPARTMENT
Telephone: 01522 512512 Etx 2059
Fax: 01522 573499
Email: rosana.pattison@ulh.nhs.uk

Lincoln County Hospital
Greetwell Road
Lincoln
LN2 5QY

Tel 01522 512512
Minicom for the deaf 01522 573618
www.ulh.nhs.uk

Professor Davina Porock
Professor of Nursing Practice
A Floor, School of Nursing
University of Nottingham
Queens Medical Centre
Nottingham NH7 2HA

Our ref:290807Porock
REC ref:07/H0407/41
3 October 2007

Dear Professor Porock

Re: Neonatal Nurses' attitudes towards borderline viability

Thank you for submitting the R & D Registration form and supporting documents for consideration by the R & D Department.

The R & D Department has reviewed your application and is pleased to inform you that you have approval from this department, subject to the approval of the Ethics Committee.

Please send a copy of the revised version if any changes are made as requested by the Ethics Committee.

The ULH NHS Trust has contractual obligations to the Department of Health to ensure that all research is carried out in accordance with the Department of Health Research Governance Framework. The Trust manages all research in accordance with the requirements of the Research Governance Framework. Could you please ensure that your project conforms with the standards set out in the Department of Health, Research Governance Framework.
.(http://www.dh.gov.uk/PolicyAndGuidance/ResearchAndDevelopment/ResearchAndDevelopmentAZ/ResearchGovernance/fs/en)

I look forward to receiving a summary of the results of the study once completed, and wish you well in this project.

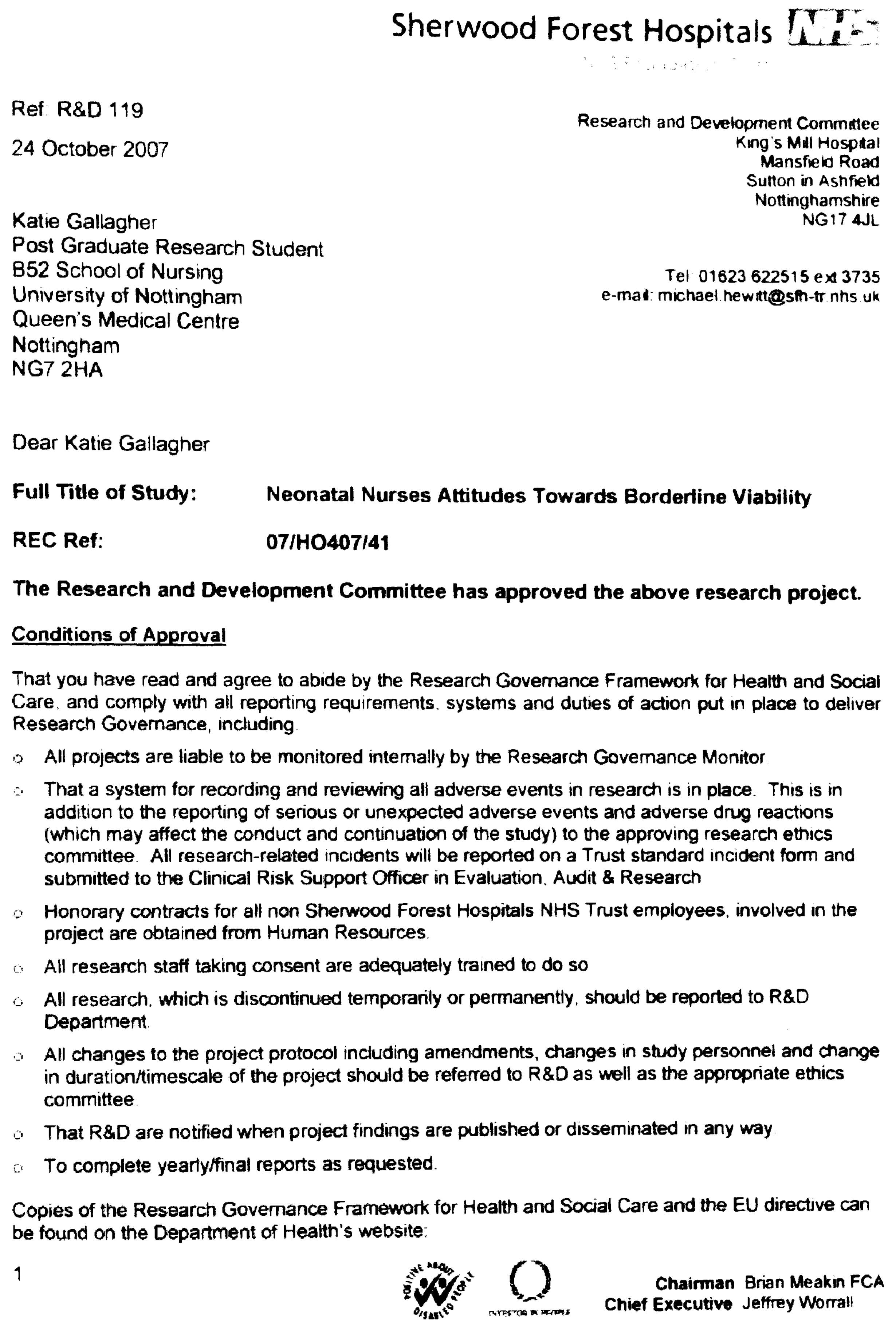
Please feel free to contact the Department for any further information or help.

Kind regards

Yours sincerely

Professor O. Eremin
Director of Research & Development

cc Mrs Katie Gallagher



Sherwood Forest Hospitals

Research and Development Committee
King's Mill Hospital
Mansfield Road
Sutton in Ashfield
Nottinghamshire
NG17 4JL

Tel 01623 622515 ext 3735
e-mail: michael.hewitt@sfh-tr.nhs.uk

Ref R&D 119

24 October 2007

Katie Gallagher
Post Graduate Research Student
B52 School of Nursing
University of Nottingham
Queen's Medical Centre
Nottingham
NG7 2HA

Dear Katie Gallagher

Full Title of Study: **Neonatal Nurses Attitudes Towards Borderline Viability**

REC Ref: **07/HO407/41**

The Research and Development Committee has approved the above research project.

Conditions of Approval

That you have read and agree to abide by the Research Governance Framework for Health and Social Care, and comply with all reporting requirements, systems and duties of action put in place to deliver Research Governance, including

- All projects are liable to be monitored internally by the Research Governance Monitor
- That a system for recording and reviewing all adverse events in research is in place. This is in addition to the reporting of serious or unexpected adverse events and adverse drug reactions (which may affect the conduct and continuation of the study) to the approving research ethics committee. All research-related incidents will be reported on a Trust standard incident form and submitted to the Clinical Risk Support Officer in Evaluation, Audit & Research
- Honorary contracts for all non Sherwood Forest Hospitals NHS Trust employees, involved in the project are obtained from Human Resources.
- All research staff taking consent are adequately trained to do so
- All research, which is discontinued temporarily or permanently, should be reported to R&D Department.
- All changes to the project protocol including amendments, changes in study personnel and change in duration/timescale of the project should be referred to R&D as well as the appropriate ethics committee.
- That R&D are notified when project findings are published or disseminated in any way
- To complete yearly/final reports as requested.

Copies of the Research Governance Framework for Health and Social Care and the EU directive can be found on the Department of Health's website:

Chairman Brian Meakin FCA
Chief Executive Jeffrey Worrall

http://www.dh.gov.uk/en/PolicyAndGuidance/ResearchAndDevelopment/A-Z/ResearchGovernance/index.htm

National Research Register

The National Research Register (NRR) is a database of research projects that are taking place throughout the country. Information is kept on the Department of Health's website, which is freely available to the general public. As the Trust is in receipt of NHS R&D Support funding, it is required to submit quarterly to the National Research Register (NRR) all active projects in receipt of NHS, public or charitable funding or any project, which is of primary benefit to the NHS or the health of the nation. From the information submitted this project qualifies for submission.

The NRR can be accessed via the internet on http://www.update-software.com/[illegible]

Acceptance of conditions of approval

Commencement of the research project is taken as acceptance of the conditions of Research and Development approval, and your willingness to release details of the project to the National Research Register.

Any queries regarding the Research Governance Framework for Health and Social Care should be directed to Michael Hewitt.

Yours sincerely,

Dr Richard Scott
Chair
Research and Development Committee

c.c.
Michael Hewitt
Evaluation, Audit and Research Department
Sherwood Forest Hospitals NHS Foundation Trust
King's Mill Hospital
Mansfield Road
Sutton in Ashfield
Nottinghamshire
NG17 4JL

Appendix 4: Participant Information Sheet

University of Nottingham, School of Nursing
c/o B53 School of Nursing
Queen's Medical Centre
Nottingham
NG7 2UH
0115 82 30996

The University of
Nottingham

Neonatal Health Care Professionals Attitudes towards Viability

Name of Researcher: Katie Gallagher

Research Supervisors: Professor Davina Porock, Professor Neil Marlow & Dr Alison Edgley

Healthy Volunteer's Information Sheet – The Q Sort & Interview

Invitation paragraph

You have been invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish to. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part or not. If you decide to take part you may keep this leaflet. Thank you for reading this.

Background

The purpose of the study is to explore neonatal nurses' attitudes towards viability. It will test a theoretical framework which incorporates attitudes towards disability, technology, and fertility. The study involves a Q Sort along with a follow up interview. The study has been reviewed and approved by the National Research Ethics Service (NRES).

What does the study involve?

You will be invited to complete a Q Sort and a follow up interview. A Q Sort involves taking statements about viability and arranging them in order of agreement from 'disagree' to 'agree' on a grid. You will then be asked to record where you have placed each item. The time required for the Q Sort is between 1 to 1.5 hours, and is to be performed outside of work time. Following the Q Sort, you will be invited to participate in an interview. The interview will consist of two parts. In the first part, you will be invited to discuss your sorting of the statements in more detail. After this, you will be asked to discuss a pre-prepared scenario based on a typical example from the neonatal unit. The interview will be digitally recorded and will take up to 45 minutes. Interview recordings and transcripts of the interviews will be stored on a password protected University archive for 7 years and will only be accessible to the researcher (Katie Gallagher). You can undertake the Q sort without having to participate in the interview.

Two neonatal nurses from each nursing band (5,6,7 & 8) will be required to fulfil the aims of the study. If more than two nurses from each nursing band volunteer for the study, two nurses will be randomly selected from all those interested to participate.

If members of staff become upset about any issues raised by the study, during any time of the investigation, a staff counsellor can be arranged by the researcher to discuss these feelings further.

Why have you been chosen?

As a nurse who works on a neonatal unit within the Trent Perinatal Network, who has at least three months experience on the Neonatal Unit, you have been invited to participate in this study. We are interested in your views and opinions on the viability of premature infants.

Do you have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What do I have to do?

If you are interested in taking part in the study, we would like to find out your attitudes towards abortion and viability. A consent form will be given to you to fill in, and please feel free to keep this information for your records.

What if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. Please contact either Professor Porock on 0115 8230813, or Katie Gallagher on 0115 8230996. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Please contact the Patient Advise and Liaison Service on 0800 183 0204 for guidance on how to do so.

Will my taking part in this study be kept confidential?

Participants are ensured of their confidentiality, and will remain anonymous throughout the study. Interviews will be linked to the Q Sorts through individual codes, and will be confidential to the researcher, Katie Gallagher.

All data will remain completely confidential. Participants will not be identifiable from any of the data gathered from the Q Sorts or interviews.

The supervisor of the investigation (Professor Porock) will be informed of the addresses of participants who chose to be interviewed at home, for the safety of the researcher (Katie Gallagher). This information will remain confidential and will be discarded after the interview has taken place.

All information which is collected during the course of the research will be kept on a password protected database and is strictly confidential. All information will be confidentially archived by the University of Nottingham for 7 years.

What will happen to the results of the research study?

The results of the study will contribute to the researchers (Katie Gallagher) PhD in Nursing Studies. The results will be presented on the neonatal unit following completion of the investigation. The results may contribute towards publication in academic journals. If you wish to see a copy of the results, please contact Katie Gallagher.

Who has reviewed the study?

This study has been reviewed and approved by the National Research Ethics Service (NRES).

What do I do now?

If you are interested in taking part in the study, we would like to find out your attitudes viability. A consent form will be given to you to fill in, and please feel free to keep this information for your records.

Should you require any further information, either prior to your participation or following your participation, please contact either the investigator or supervisor:

Katie Gallagher RN (Child) MN MARM
c/o B53
of Nursing
Queens Medical Centre
Nottingham
NG7 2HA

Telephone: 0115 82 30996

Davina Porock PhD RN
Professor of Nursing Practice School
University of Nottingham
A floor Queens Medical Centre
Nottingham
NG7 2HA

Telephone: 0115 82 30813

Thank you for your time and considering taking part in the study.

Appendix 5: Consent Form Q Sort & Follow up Interview

The University of
Nottingham

Title of Project: Neonatal Health Care Professionals Attitudes towards Viability

Name of Researcher / Supervisor: Katie Gallagher / Davina Porock

1. I have been informed of and understand the purposes of the study.. ☐

2. I have read and understood the Patient Information Sheet version 2 dated 2/7/2007.. ☐

3. I have been given the opportunity to ask questions.................. ☐

4. I agree to participate in the both the Q Sort and follow up interview, however understand that I can withdraw from the study at any time for no reason.. ☐

5. I understand I can withdraw from the study at any time for no reason.. ☐

6. Any information which might potentially identify me will not be used in published material.. ☐

7. I agree for the interview to be digitally recorded..................... ☐

8. I agree to participate in the study as outlined to me.............. ☐

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

1 copy for the participant and 1 copy for the researcher

Appendix 6: Q Sort Instruction Sheet

Instructions for Completing your Q Sort

Thank you for agreeing to take part in this study. Your time and responses are greatly appreciated. The following set of instructions will guide you through completing the Q Sort as easily as possible. If, after reading these instructions, you are still unsure of how to complete the Q Sort, please do not hesitate to contact the researcher, Katie Gallagher, who will be happy to further explain the Q Sort. Please remain assured that your responses will remain completely confidential.

Please read the following instructions prior to starting your Q Sort.

1. The Q statements which you see before you have been created from literature searches, media statements and interviews, to represent various debates surrounding borderline viability of premature infants. Please take your time to read through these statements, and think about how each statement reflects your personal attitudes towards borderline viability.

2. Once you have familiarised yourself with the statements, sort the statements into 3 piles:

    a. Statements which **most** reflect your personal attitudes towards viability
    b. Statements which **least** reflect your personal attitudes towards viability
    c. Statements which you feel **uncertain**, or **neutral**, about

3. From pile a, select the **one** statement which **most** reflects your attitudes towards viability. Place this statement on the right hand side of the distribution grid, under the heading 'most like my point of view' (+6). **The specific order of the statements under the headings does not matter for each of the headings.**

4. From pile b, select the **one** statement which **least** reflects your attitude towards viability. Place this statement on the left hand side of the distribution grid, under the heading 'most unlike my point of view' (-6).

5. Return to pile a, and select three statements which reflect your attitudes towards viability, however not as strongly as the three previously selected. Place these 3 items under the '+5' section.

6. Return to pile b, and select three statements which do not reflect your attitudes towards viability, however not as strongly as the three previously selected. Place these 3 items under the '-5' section.

7. Repeat steps 5 and 6 with all statements, with the statements working towards 'neutral' in the middle positions ('0'). Do this until all statements have been positioned in the grid. Once completed, review your Q Sort to ensure that you are happy with the position of your statements, and that the grid accurately reflects your opinions towards borderline viability.

8. Finally, write down the item number of each statement on the response sheet included in this pack, so that your responses can be easily identified.

You have now successfully completed the Q Sort. I hope you have enjoyed the experience and thank you for your time.

Appendix 7: Q Sort Response Sheet

Please write the number of each statement from the corresponding grid in the table below:

-6	-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5	+6
(1)	(3)	(3)	(4)	(5)	(7)	(7)	(7)	(5)	(4)	(3)	(3)	(1)

Version 1: 13/06/2007