UNIVERSITY OF SOUTHAMPTON

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES

School of Nursing and Midwifery

Mothers' experiences of their babies' transfer to a regional neonatal unit

By

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ABSTRACT

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES

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Doctorate in Clinical Practice

MOTHERS' EXPERIENCES OF THEIR BABIES' TRANSFER TO A REGIONAL NEONATAL UNIT

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The transfer of babies between hospitals is a common feature of neonatal intensive care in the United Kingdom (UK) (Steeper 2002, DOH 2003, Parmanum 2000).However; there are relatively few studies that investigate mothers' experiences when their babies are transferred from their local neonatal unit to a Level 3 neonatal unit (Steeper 2002).

This qualitative study was designed to describe and interpret the meaning mothers attributed to their experience of having their newborn babies transferred from a local neonatal unit to a regional unit. The approach used was influenced by hermeneutics phenomenology and van Manen's human science approach (1990).

A purposively selected sample of 15 English-speaking mothers in one designated regional unit in the south east United Kingdom (UK) following the transfer of their newborn babies from their local neonatal unit were interviewed face to face about their experience of their babies' transfer. Interviews took place over a seven month period in 2004. The tape-recorded interviews were transcribed into verbatim text. Data analysis was guided by the works of van Manen (1990) and Moustakas (1994).

The concept of 'distance mothering' is suggested to conceptualise how the mothers' emotional responses, information issues and adjustment were interrelated to the perceived geographical distance and their maternal role to their transferred baby and other siblings or other family members at home.

The findings indicated that ideologies of motherhood or the discourses that contribute to their (re)production need to take into account the variety of different circumstances mothers faced. Rather than concentrating only on the ill transferred baby, the focus of professional care should be extended to understanding and addressing women's individual emotional responses, and need for information and adjustment in ways that would help them to meet their perceived obligations to function in other roles, including their role as mothers of their other children. Quality of information, information provision and relationships with staff were seen as playing a crucial role in helping them as they fulfilled their maternal and caring obligations.

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Definitions .

Back neonatal transfer – the transfer of the convalescing neonate from a level 3 Neonatal unit to their local neonatal unit (Klawitter 1999)

Ex utero transfer - the transfer of a baby to another hospital for further care

Initial neonatal transfer – the transfer of the neonate from a local neonatal unit to a level 3 Neonatal unit. (Leslie 1995)

In utero transfer – the transfer of a mother to another hospital for maternal care or predicted neonatal care for her newborn(s)

Level 1 Neonatal Unit or Special Care Baby Unit (SCBU) – a neonatal unit providing special care but do not aim to provide any continuing high dependency or intensive care (BAPM 2001)

Level 2 Neonatal unit or High Dependency Care Unit (HDCU) – a neonatal unit providing high dependency care and some short term intensive care. (BAPM 2001)

Level 3 Neonatal unit or Neonatal Intensive Care Unit (NICU) – a neonatal unit providing the whole range of medical neonatal care but not necessarily all specialist services such as neonatal surgery (BAPM 2001).

Local neonatal unit – the neonatal unit where the newborn baby are referred from.

Mother – the person giving birth to the newborn baby.(Boxwell 2000)

Neonates – a baby less than 28 days old.(Boxwell 2000)

Newborn baby – an infant who after complete separation from its mother shows signs of life regardless of its gestation or its birth weight (Boxwell 2000)

Regional neonatal unit – a neonatal unit providing the whole range of medical and specialist services such as neonatal surgery.

Chapter 1: Introduction, rationale and background information to the study

1.1 Introduction

The research problem that this study sets out to address is concerned with mothers' experiences of their babies' transfer to a regional neonatal unit.

It has been reported that most major perinatal centres in the United Kingdom (UK) are regularly unable to meet in-house demands (Parmanum et al 2000). An equivalent of 2510 transfers over a year was identified in a recent detailed analysis of all transfers to or from neonatal units involving the whole of London and South East England over a period of three months (90 days) from 1st January to 31st March 2001 (Kempley & Sinha 2004). Information is not widely available on transfers per number of births in other regions of the UK, but data supplied from a regionalised team in the Northern Neonatal Network also reported considerable numbers of transfers (the equivalent of over 13 transfers for each 1000 births) within the Yorkshire regions of the UK (Gill et al 2004). The need for neonatal surgery and neonatal intensive care that are not available locally was the most common clinical reason for transfer (Kempley & Sinha 2004).

What is it like for the parents when they are told of the need to transfer the newborn baby to another neonatal unit? There is very little in the literature which attempts to understand the experience of having your newborn baby transferred to an unknown neonatal unit. What is the experience of mothers with transferred babies? This is the question that will be posed again and again by the text in an attempt to understand how this experience unfolds.

1.2 Organisation of the thesis

In order to structure the thesis in a way that has meaning and provides relevance and background to the study, it was necessary to divide the thesis into a number of chapters.

There are five chapters in this report. In this chapter, the rationale and background information to the study are provided. My interest in the topic is presented to provide an insight into my social context and as an invitation to share the lived –world of the researcher. Views and opinions were sought from key people involved with the care of the babies and mothers in one of the regional neonatal units in the UK. Thus influences from clinical practice are identified to confirm its

relevance. The chapter concludes with the purpose of the study and a brief summary of the study design.

In Chapter Two, a detailed review of neonatal transfer is undertaken to identify gaps in the current literature and to refine the aims of the study. Since the need for neonatal transfer arises in response either to the needs of the ill newborn or to the centralisation of specialised facilities, studies looking at parents' experiences with critically ill and or premature babies are also discussed. This is to give the reader a background understanding of the context of parents' experiences, to enable a more comprehensive interpretation of the data later. While these studies have identified, through a variety of research approaches, significant factors relating to parents' experiences, they have failed adequately to explore the experiences of parents with transferred babies. This present research study aims to address this topic, fill the gap in the literature and provide an extra dimension in the research on neonatal transfer. This chapter concludes with the implications for the research study.

Chapter Three provides a description of hermeneutics phenomenology, which is the methodological approach chosen for this study. This chapter begins by locating the methodology within the paradigm of inquiry and provides a rationale for using this particular approach. Following this, an overview of the various types of phenomenology and the historical development of this particular methodology are then discussed. Some of the philosophical tenets underpinning hermeneutics phenomenology that are pertinent to this study are described. This is followed by details of the research process and methods utilised in this study to explore the study's research question. Procedures for the selection and recruitment of the study participants, collection and analysis of data, and ethical considerations are then outlined. In particular, the way in which van Manen's (1990) six activities for phenomenological data analysis are congruent with the chosen methodological approach is described and demonstrated. It will be shown that this method was most suited to this study, as it reflects the philosophical underpinnings of the methodology, and enabled me to draw on my experiences whilst closely interacting with the text. The issue of rigour is described to highlight the importance of ensuring methodological consistency with the chosen approach throughout the entire process. Ethical issues and findings for the pilot study conclude the chapter.

Chapter Four reports the major themes that were revealed from the data analysis. Four major themes emerged from the data: emotional responses, information, adjustment and geographical distance.

The final chapter, Chapter 5, summarises and discusses the overall findings and compares and contrasts these with the extant literature. A number of recommendations for changes in clinical practice are outlined, and areas for further research are suggested. The limitations of the study are then discussed and a conclusion to the study is provided.

1.3 Rationale for the study

Technology continues to advance rapidly, providing premature and critically ill babies with greater opportunities for survival (ONS 2001). Current neonatal services in the UK cope with demand by running at high levels of cot occupancy and, when necessary, transferring mothers and babies to wherever a cot is available, often at short notice and often a long distance from their homes (DOH 2003, Parmanum 2000). As a result, the number of babies being transferred from smaller units to regional Neonatal Intensive Care Units (NICU) has increased substantially (CESDI 2003).

The Project 27/28 report by CESDI (2003) reviewed the survival rates of babies born in England and Wales between the years 1998 and 2000 at 27-28 weeks gestation. It found that 7% had to be transferred to a more specialist facility within 24 hours after birth and 24.2% within the first 28 days of life. Although the report was critical of deficiencies in care, especially in the transfer of mothers and babies which was highlighted as an area of particular concern and called 'ad hoc and precarious', the needs of these parents were not mentioned in the summary of the main recommendations of the report. Newborn babies are still being shuttled around the country because of a shortage of neonatal intensive care cots, as demonstrated in recent reports in the media (The Guardian 2005, Times Online 2005, The Observer 2002).

The recent Neonatal Intensive Care Review Services Report (DOH 2003) acknowledges publicly that there are high levels of inappropriate transfer of mothers and babies across units due to the limited capacity of neonatal services in the National Health Service (NHS) in the UK. However, there are relatively few studies that investigate mothers' experiences when their newborn babies are transferred from their local neonatal unit to a level 3 neonatal unit (Steeper 2002).

While much has been written about the stress and anxiety experienced by parents of babies requiring NICU, an understanding of the experiences of mothers when their newborn babies are transferred from their local neonatal unit to a level 3 neonatal unit remains undeveloped (Wilman 1997, Steeper 2002). The literature provides very little information and few guidelines regarding the emotional state of these mothers (Steeper 2002). The experience of these parents may be dramatically different from those of parents of critically ill and/or premature infants hospitalised in a neonatal unit that is locally situated. We need to find out from these parents how these experiences alter their lives in order to better prepare parents and institutions to cope effectively with the problems attendant to these experiences.

The need to study health consumer experience has been highlighted in the government's health strategy documents 'A First Class Service' (DOH 1998) and 'Patient and Public Involvement in the New NHS' (DOH 1999). The report 'Consumers and Research in the NHS' (DOH 1996) emphasised the need for research into lay perspectives along with the importance of 'sociological and qualitative' approaches (Blaxter 1995). Considering mothers' perspectives of the care they receive is appropriate in a modern health service, from the point of view that they are stakeholders in the service and yet may have little influence on the services that are purchased on their behalf. Therefore the study seeks to add to the existing knowledge about neonatal transfer and parental reaction to such an event from the mothers' perspectives.

1.4 Situating the study

Outlining the researcher's rationale for the choice of research topic provides an insight into the stance and situation of the researcher which, in turn, assists the reader to appreciate the interpretation. This requires illumination of the history and 'prejudices' of the researcher, which is the justification for this section where I, as the researcher, offer 'my story'. It is also an acknowledgement that whilst we exist in ourselves, we also exist and impact upon and influence the lives of others (van Manen 1990).

1.4.1 A personal context

My story concerns a journey, embarked upon 15 years ago, which in some ways parallels the upheaval experienced by parents whose newborn babies are transferred to another neonatal unit,

which is unknown and perhaps some distance from their own homes. There are differences: I had choices in the path I undertook. I did, however, undergo enormous crises and adjustments due to my experiences of being in another country as my views of the world began to change.

I first came to the UK in the early 1990s to undertake my undergraduate and post graduate nursing degrees. The unfamiliarity of the culture struck me immediately. I found that the void left by family and friends made me appreciate what I had left behind. I felt very much on my own and homesick for the first few months. I gradually accepted it as 'home' as I adapted to the new place and lifestyle. I learned to fend for myself in unfamiliar territory, to adjust and adapt to new circumstances.

Following my neonatal nursing training, I started working as a neonatal nurse for various neonatal intensive care units in the UK. Some of the babies in these units were transferred from various parts of the UK. I often reflected on the impact on the family of an unexpected transfer of a newborn baby into a level 3 neonatal unit, and how best to support and empower parents in this situation. Unfortunately I left the UK in the late 1990s to get married before I could investigate it any further. Becoming a mother was a profound experience for me that completely changed my life. Despite my familiarity with babies' care based on my 15 years experiences in neonatal nursing and my experiences as a mother of another child, I encountered unexpected emotions when my second child needed to be transferred to a neonatal unit for further management. I found that it was very difficult having to be a mother to both my children at the same time, as one has to be left at home and another has to be in the hospital. The decision to stay with my second one in the hospital was not made any easier as I was still breastfeeding my first one. On reflection I was very fortunate as I had the full support not only of my husband but also my parents-in-laws, who took over the care of my first child thus helping to alleviate some of my worries about her well being. I remember how hard it was to stay in the hospital accommodation which, although convenient, was also very 'un homely' with its functional furniture.

Professionally, I was struck by the mothers' emotions when their newborn babies were transferred to another neonatal unit. Although on a cognitive level most parents seemed to understand the need for the transfer, they quite eloquently expressed their distress at leaving the security of a known and trusted unit – i.e. their local neonatal unit – to go to one which is unknown, the regional neonatal unit.

Had my colleagues or I not provided the appropriate care or was there something in the new environment that influenced their experiences? I wondered what we as neonatal nurses could do differently to enhance the mothers' experiences when their newborn babies were transferred from their local neonatal unit to another neonatal unit. These questions continually concerned me as I observed these parents having to cope not only with having a critically ill newborn baby but also with the differences between units, such as staff ratios and differences in practices. A personal view arising from my personal experiences is that an assessment of the needs of the mothers is rarely considered and the major focus (rightly or wrongly) is to stabilise and treat the baby. Many of the interactions with mothers appeared to be relatively brief and focused on the newborn babies' needs.

There are occasions when I have admitted the newborn baby from another unit with the mother still in the referring hospital due to postpartum complications that prevent her transfer. To me it appears that the transfer had physically divided the family and brought the family under the care of two completely different health care organisations. How could I best address the concerns I had regarding the experiences of these parents? My questions demanded responses which led me into wanting to know and understand the meaning of the experience from these mothers' perspectives. I surmised that this knowledge would improve collaboration between nurses and parents and the overall care provided.

Thus this study has been influenced by my own significant professional experiences with mothers in neonatal intensive care units and as a mother whose second child was transferred to another neonatal unit when he was born: to me, one of the most traumatic events that any mother could experience. I felt that understanding mothers' experiences would offer insights of value to care professionals and influence professional care education and practice for the benefit of mothers.

This section has considered the notion of self and has examined this notion in the context of this research. The next section considers other influences on the research study development.

1.5 Other influences on study development

1.5.1 Preliminary clinical meetings

In the early stages of the study, alongside the literature review, views and opinions were sought from key people, some involved with the care of the babies and mothers and others with no involvement but an interest in neonatal transfer in one of the regional neonatal units in the UK. The purpose was to ascertain whether the topic area had currency in the locality, and whether it was perceived as a useful line of inquiry.

Based on meetings with clinicians and senior nursing staff in a level 3 neonatal unit, which also serves as the regional neonatal surgical unit, there was a recognition of the need to understand mothers' experiences with transferred babies, as there had been a 50% increase in babies being transferred from other referring units in 2002 compared to 2000 and 2001. A recent three-month survey (May-July 2002) carried out in the region where the unit is situated demonstrates that three transfers are made each weekday and two transfers each weekend day within the geographic network (Central South Coast Specialist Confederation 2003, unpublished data). This geographical network covers the Central South Coast of the UK, which provides a total of 30 intensive care cots, 24 high dependency cots and 93 special care cots.

1.5.2 Clinical Research Advisory Group (CRAG)

Following these meetings, a Clinical Research Advisory Group (CRAG) was formed in order to guide and support the researcher. The Group met quarterly and consisted of voluntary representatives from the clinicians (neonatologist, neonatal surgeon), nurses, social worker, supervisors and parents who had previous experience of having their babies transferred to another unit. Terms of reference and membership of the group are found in appendix 1.

Initial meetings discussed the focus of the study and agreement on the line of inquiry. Since parental perceptions associated with the initial transfers are more immediate and less negotiable, due to the baby's condition, in comparison to back transfer which could be pre scheduled, the members agreed that it is in the former case that clear, flexible and responsive guidance is most required.

Considerations were given to whether or not to include fathers and mothers together in one study. It was recognised that the mother and father each have their own experiences that may be uniquely different from each other. It was agreed that to represent the mothers and fathers together in one study findings may not do justice to their unique experiences as mother and father of a transferred baby. Thus it was decided that this study will only focus on the mother experiences when her baby was transferred from the local neonatal unit to the regional neonatal unit.

Subsequent meetings took place three monthly and served to address related ethical issues and the conduct of the study in the clinical area. The criteria for participants' eligibility in the study, the recruitment strategy and the interview questions were developed with input from CRAG members and supervisors.

On a personal level as a researcher, the conduct of the research was important. It was necessary to obtain the views of other people so as to maintain the direction of the research and its objectivity. Feedback from the group facilitated opportunities for reflection and consideration. Some of the members were familiar with the subject matter of the research whilst others were not. It was important to elicit feedback not only from health professionals but also from health care users, in this case the parents. Their perspectives provided an invaluable opportunity to consider different approaches to data collection and investigation of the subject matter.

The next section attempts to give some of the background of neonatal care management in order to provide some understanding of neonatal transfer in the UK.

1.6 Background information to the study

It is important to know some of the historical background of neonatal care and the rationale for the current management of the provision of neonatal services in order to understand why babies are moved in the current organisation.

This section begins by setting out the focus of this investigation, with an explanation of the different categories of neonatal transfer that can occur during the neonatal period to provide an overall understanding of the procedure. This is followed by an overview and description of the

history of neonatal care and neonatal transfer, mainly within a UK context, to provide the reader with a background understanding of the context of the study.

1.6.1 Categories of neonatal transfer

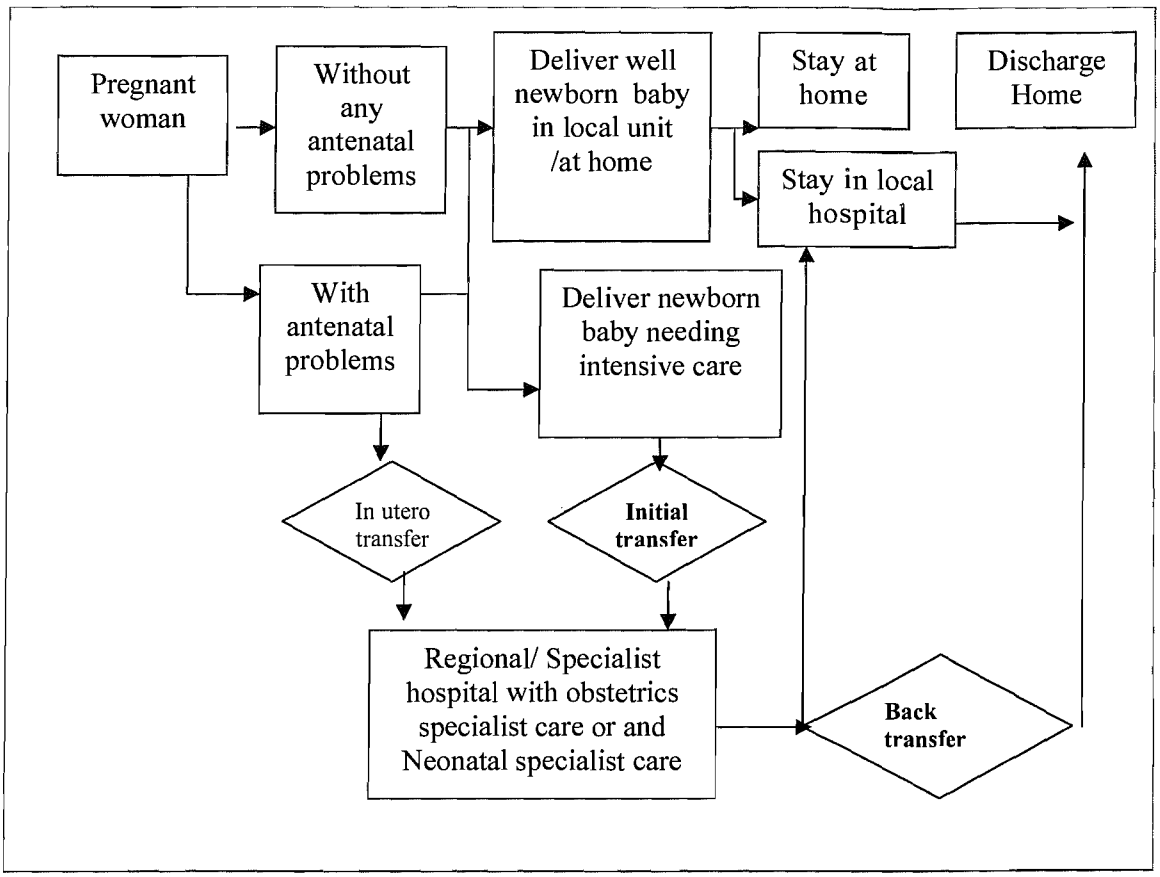
1.6.1.1 Initial transfer

Babies who are born at hospitals which offer intensive care but who subsequently require care such as specialist respiratory support or surgery may be transferred to a regional neonatal unit (Middleton & Leslie 1995). This is called initial transfer. Thus the mothers' experiences of the transfer may be traumatic because of its unexpected nature.

1.6.1.2 Back transfer

When a newborn is past the critical stage, it may become necessary and desirable to transfer the newborn back to the local neonatal unit near the residence of their parents (Klawitter 1999). This is called back transfer. Back transfer is usually planned to take place when the infant is stable, allowing time for parents to question and plan ahead and thus possibly be better prepared (Klawitter 1999, Chester 1994). Figure 1 provides an overview of the potential pathways of a pregnant woman in labour and the different categories of transfer.

Figure 1.1: Overview of the potential pathways of a pregnant woman in labour.



1.6.2 Brief historical perspective

The emergence of skills to care for ill or premature newborns is often traced to exhibits of premature infant care at public exhibitions, such as the 1933 World's Fair in Chicago. These exhibits preceded the emergence of neonatal intensive care units and the transport of ill infants. The most rapid developments in neonatal medicine occurred after the Second World War but it was in the 1970s that subsequent developments of pressure-limited ventilation, neonatal surfactant therapy and antenatal corticosteroids considerably improved survival rate (Blackburn 2003).

After establishment of centres to care for ill neonates, attention shifted to transportation of sick neonates. Butterfield (1993) has written an excellent and personal review of the beginnings of neonatal transportation which indicated that the first dedicated neonatal transport vehicle was in 1934 in the United States of America (USA). The next evolution in transport developed from the

lessons in aero medical transport of the wounded in World War II, Korea and Vietnam. The first reported use of air transport of the newborn was in 1958 in Colorado using a DC3 airplane and, in 1967, the use of a helicopter (Butterfield 1993).

Although the role of nurses in neonatal transport was mentioned in Butterfield's account of its historical development, their role was described as being functional, with training in medical stabilisation procedures. No mention was made of the parents at any stage of the neonatal transfer. Similarly, recommendations by the Transport of Neonates in Ambulances (TINA) document (DOH 1995) did not address any parental needs or preparation. A National Paediatric and Neonatal Interfacility Transport Medicine Leadership Conference held in Chicago (2000) only addressed issues related to accreditation, team configuration, economics of transport medicine in health care delivery and international transport opportunities (Woodward et al 2002).

It would appear that, despite the increased awareness of neonatal transfer, an understanding of the psychological and emotional impacts on the family of these transferred babies remains undeveloped (Frischer & Gutterman 1992, Steeper 2003).

1.6.3 Neonatal care and transport services in the UK

Organization and management of neonatal care has undergone many changes under the influence of British NHS policy developments, which have led to a degree of variation within regional service provision. In examining the factors which impact on the current provision of neonatal intensive care (NIC), both historically and politically, the issue of availability and access to NICU may be more clearly understood. This understanding will help to clarify the current situation as this has implications for the neonatal transfer services as a whole.

The provision of NIC in the UK has evolved through a series of local initiatives (Milligan et al 1997). The 'Care of Premature Infants' Health Circular in 1944 recommended the care of premature babies under the supervision of a pediatrician rather than an obstetrician as was previously the case. The importance of preserving links between mother and baby was reiterated in the 'The Report of the Expert Group on Special Care for Babies' in 1971, especially when the baby had been transferred in from a peripheral hospital (paragraph 5.17). Although the report recommended single rooms and day room facilities for resident mothers (paragraph 8.16), none of

these recommendations were given enough status to be included in the summary of the main recommendations of the report (DOH 1971).

It should be noted that provision of accommodation for mothers following the transfer of the baby to another hospital was first recommended in 1949 in the Neonatal Mortality and Morbidity Report. This was followed in 1959 by the introduction of unrestricted or open visiting for parents in 'The Welfare of Children in Hospital' report. Fortunately the role and status of parents, particularly mothers, was recognized and given a much higher profile five years later in the report 'Fit For the Future' (DOH 1976).This may be because, around this time, the detrimental effects of maternal and infant separation were being universally acknowledged and recognized.

With the NHS reforms of the late 1980s and early 1990s, particularly the White Paper Working for Patients (DOH 1989) and the NHS and Community Care Act (DOH 1990), came decentralization of all health care, with the control of neonatal services being devolved from region to district, leaving district health authorities with the duty to determine need and purchase services based on that need (Pope & Wild 1992). The Clinical Standards Advisory Group (CSAG) identified two types of transfer that were unequivocally substandard practice (1993). They stated that mothers and infants should not be forced to travel beyond their nearest referral centre and that tertiary centres should not transfer out their own high risk mothers and infants. A survey of neonatal transfers carried out in 1986-1987 found that intensive care cot provision had doubled since 1980 but that problems remained with regard to availability of cots in tertiary units, especially for the smallest babies (BAPM 1989).

Within a climate of limited resources, the demands of neonatal intensive care are enormous in terms of personnel, equipment and support services. This situation results in regional and cross-regional transfers just to find an available cot space (Turrill 2000). A study of 37 of the largest NICU in the UK indicated that 1 in 12 of all babies requiring NIC were subject to transfers which were largely unplanned (Parmanum et al 2000).

With the recent Neonatal Care Services Review (DOH 2003) with its recommendations of the establishment of managed clinical networks with good referral and transport arrangements, new approaches are emerging. Increased cooperation between units and ambulance authorities is seen as a solution to prevent inappropriate transfers. However, there is no mention of the emotional impacts on the family of these transferred babies. Studies of parents' experiences with infant transfer are few and are mostly from Northern America (Steeper 2003). Although the current

report by CESDI (2003) highlighted deficiencies in care in neonatal transfer, which was described as 'ad hoc and precarious' (p 6), the impact of the transfer on the family was not mentioned in the report. There is an urgent need to explore and understand parental reactions to such an event from their perspectives.

1.7 Purpose of the study

This study seeks to describe and interpret the meaning mothers attribute to their experience of having their newborn babies transferred to a regional neonatal unit. To gain a greater understanding of what it means for mothers to have experienced this phenomenon is to make known what it means for mothers to live through this particular event in their lives.

This is an ontological question. It is from the experience of this event in their lives that the question arises and was posed to the study participants: W*hat does it mean to have your newborn baby transferred from the local neonatal unit to a regional neonatal unit?* To reach an understanding of this question it was essential to turn to those who have lived through such an experience, and utilise an appropriate research approach that can assist in providing an answer to the research question.

1.8 Brief summary of study design

To understand the experience of mothers when their newborn babies are transferred from their local neonatal unit to a Level 3 neonatal unit required a methodology that could accommodate the complexity of personal experience. I am interested in what these mothers have made of their experience. Therefore a qualitative inquiry, using the hermeneutics phenomenological approach was most appropriate. Further details are found in Chapter 3. Data was secured in this report through a face to face semi structured interview with the mothers at 7-10 days after the transfer of their babies. Data was transcribed verbatim by the researcher and analysed using van Manen's (1990) procedural steps. Further details of the research methods are found in Chapter 3.

1.9 Chapter summary

In this first chapter, I have introduced the study and made known my interest in pursuing this topic of research. I have described the background of the study in the UK context and clearly identified the need for this research. Following this, I have outlined the purpose of the study and posed the ontological question. A brief summary of the study design concluded this chapter. The following chapter reviews the literature that is relevant to the research question.

Chapter 2: Literature review

2.1 Introduction

This chapter provides an overview of the literature surrounding neonatal transfer and the experience of mothers and/or parents in order to highlight what is already known about the subject and also to identify existing gaps in our understanding. Experiences of mothers and/or parents were explored because it was found that in some studies the term parent was used to encompass mother and /or father experiences.

The chapter begins by detailing the systematic approach applied to the identification of published literature. The need for neonatal transfer arises in response to the sudden needs of the ill newborn or to the lack of specialist facilities. Therefore it is important to consider the experiences of mothers and/or parents with premature and/or critically ill infants. This will give context to the physical, emotional and psychological impact of the experience and help, collectively, to provide an overall picture of any existing problems faced by these parents prior to the neonatal transfer. It will also provide a sense of the context within which parents' experiences occur and thus enable a more specific and comprehensive interpretation of the data. A consideration of the magnitude and complexity of neonatal transfer experiences as a research and clinical problem is illustrated, and the paucity of literature focussing on experiences in initial transfer is demonstrated.

The chapter identifies limitations in the current literature and concludes with the implications for the current research study.

2.2 Search strategy

An extensive literature review was undertaken to consider current evidence relevant to neonatal transfer. The search strategy used Boolean logic to identify specific words in search fields which were linked by operators. Preliminary searches demonstrated that it was necessary to use the combined term neonatal intensive care/special baby care unit (SBCU) to retrieve information about parents' experiences in a NICU, since in the past decade the SBCU has also become more technically orientated, thus making it possible to provide more advanced care for smaller and sicker infants than was previously possible (Lau & Morse 1998). The term parent or mother or father was used as it was found that in some studies the term parent was used to encompass

mother and/or father experiences. Similarly the term 'transport' was used in addition to 'transfer' as either of these terms were used in practice to indicate the movement of newborn babies between neonatal units.

Keywords used in the search thus included:

- parent /father/mother
- neonatal intensive care /special baby care unit
- premature/critically ill baby /critically ill newborn/critically ill infant
- transfer/transport

Inclusion and exclusion criteria were established (Table 2.1). Findings from the databases which included CINAHL, MEDLINE, BNI, and EMBASE were illustrated in Table 2.2. Broad inclusion and exclusion criteria were defined at the outset of the study to ensure that as many relevant papers as possible were identified for closer analysis.

Table 2.1: inclusion and exclusion criteria for inclusion of articles

Inclusion criteria	**Exclusion criteria**
1. Articles must be in English as translations of eligible non-English papers were not available.	1. Articles not in English
2. Articles relating to neonate as defined in the list of definitions.	2. Articles relating to adult
3. Articles relating to i) parental perceptions or experiences on having a critically ill and/or premature infant hospitalised in a NICU ii) neonatal transfer or transportation	3. Articles relating to i) management care of critically ill and/or premature infant ii) outcomes of critically ill and/or premature infant iii) staffing, equipment and training required in the transfer or transportation process or outcomes in neonatal transfer
4.Articles relating to i) impact of having a critically ill and/or premature infant hospitalised in a NICU ii) impact of transfer or transportation on the family or parents	4. Articles relating to the process of neonatal transfer or transportation or management of the transfer or transportation
5. Primary research articles and literature review	5. Articles that are not research based as these proliferate existing knowledge (the status quo), rather than contributing to advances in the evidence base for neonatal transfer.

Table 2.2: Findings from databases.

KEYWORDS	DATABASES				
	MEDINE	BNI	CINAHL	EMBASE	Total
Premature or critically ill infant combined with neonatal intensive care unit or special care baby unit combined with parent or mother or father	37	0	23	23	83
Premature or critically ill infant combined with transfer or transport combined with parent or mother or father	41	0	3	46	90

The thesis collection of the University of Southampton was also searched for related unpublished research studies. It was decided to use the most up-to-date information available, and chronologically the search was carried out from 1990 onwards.

Titles of items retrieved from databases were viewed on screen and abstracts of those that appeared to have some relevance were printed. The abstracts were studied and those items identified as pertinent were obtained. However, there are limitations to the method used, as only studies containing the keywords are likely to be identified. Thus, once literature had been obtained, it was scrutinised for other relevant references and, where possible, these were also obtained. A table of studies highlighted in this chapter is provided in appendix 2.

A modified data extraction strategy based on the NHS CRD (2001) was used to facilitate uniform descriptions of all selected articles and to enable where possible determination of the studies' relevance. The NHS CRD (2001) data extraction strategy which entails information about:

1. General information: date of data extraction, identification features of the study and identification of the reviewer was modified to one category of data as descriptive data such as title, author, year and country.
2. Specific information and methodological quality which include information about study characteristics such as population and study design characteristics were modified to one category of data which include details about the study design, sample and instrument

3. Interventions and outcome measures were not included due to the nature of most of the available studies under review
4. Analysis and results were modified into one category of data labelled as conclusions.
5. In addition, research aims and limitations were added to the data extraction form to enable possible determination of the studies relevance

The modified data extraction sheet allowed three main categories of data to be analysed in tabular form (appendix 2):

1. descriptive data such as country of origin, the setting , number and characteristics of the participants
2. study aim and design
3. study results and limitations

Experts in the field were consulted through personal communication (appendix 3) wherever possible and through internet neonatal network chat (appendix 4). It was recognised that using this strategy alone to determine the value of both qualitative and quantitative studies may not accurately reflect the validity or trustworthiness of the studies. Thus, in this review no attempt was made to grade papers according to level of evidence; rather, it reflects an attempt to catalogue the nature of research studies undertaken, their focus, methodological parameters, and study groups, rather than setting out to grade studies and assign quantity scores to them. Once retrieved, all papers were critically appraised.

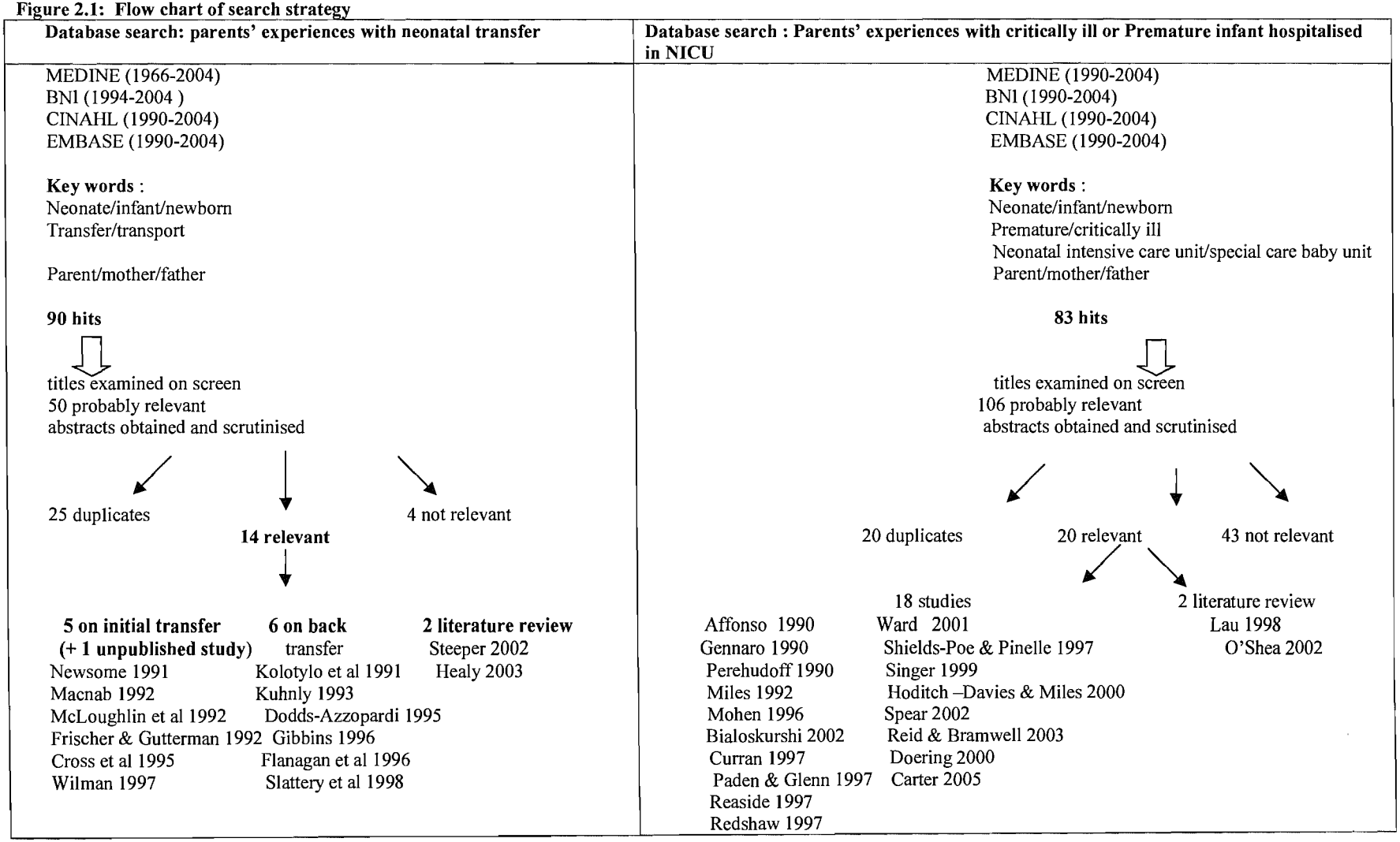
Quality of evidence

Although hierarchies of evidence are available for the assessment of quantitative health service research, for example that provided by the National Institute for Clinical Excellence (NICE, 2001), this is not appropriate for qualitative research due to the inappropriate criteria used. In the present review, the task was further complicated by the paucity of rigorous qualitative research on neonatal transfer; if published criteria were used to select studies of adequate quality, almost all work published on neonatal transfer would be excluded. For the purpose of this review, the screening questions developed by the National Critical Skills Programme (CASP 2003) in developing a screening strategy for qualitative methodologies were used to help in appraising the

quality of studies for inclusion, as the CASP approach helps to minimise the potential for error in judgement and it is easy to use and understand (see appendix 5 for an example).

A flow chart of the search strategy can be found on the next page (Figure 2.1)

Figure 2.1: Flow chart of search strategy



2.3. The experiences of parents with critically ill and/or premature infants hospitalised in NICUs.

2.3.1 Introduction

It has been postulated that neonatal transfer can intensify parental stress associated with having a sick newborn hospitalised in an intensive care environment (Wilman 1997, Fischer & Gutterman 1992). Understanding the experience of parents of preterm or critically ill newborn babies hospitalised in a NICU is an important first step towards gaining a perception of the typical problems faced by these mothers and their emotional status prior to having their newborn babies transferred. In this way it may be possible to distinguish aspects of the mothers' experiences relating to transfer from the wider and possibly overwhelmingly emotional experience of having a premature and/or critically ill infant hospitalised in a NICU generally. Thus it may assist the reader in placing in context the data analysed by this study.

2.3.2 Studies Reviewed

A total of 83 potentially relevant primary papers were identified. Each abstract of these papers was read carefully to assess whether the full paper should be retrieved. Studies relating to management /interventions/outcome of care (n=43) and duplicates (n=20) were discarded as irrelevant to this study.

A total of 18 research papers and two literature reviews were retrieved as they were considered relevant to the experiences of parents of premature or critically ill newborn babies hospitalized in a NICU. The majority of these (14 studies) were published between 1990 and 2000 with the remaining four in the last three years (year 2001-2004). Most of the findings were reported from the USA (12 studies). A variety of methodologies were employed in these studies: a qualitative approach was used in five studies, while quantitative scales were used either solely or in combination with other research methods (interviews) in the majority (10 studies). Most of these studies focused on the mothers' experiences (13 studies) or the joint experiences of parents (5 studies).

The findings of the studies are presented using two subheadings to illustrate possible parental experiences and reactions to having a critically ill or premature infant hospitalized in a NICU. These subheadings are: parents' experiences of having a critically ill premature infant, and the parents' experiences of the NICU. They do not provide an exhaustive account of the findings, but represent the major themes to emerge as I interpreted them.

2.3.2.1 The parents' experiences of having a critically ill premature infant

For almost all families, the birth of a premature infant and the associated perinatal problems are experienced as an acute emotional crisis which is characterized by anxiety, grief, denial, depression, stress and, for some parents, guilt, anger and blame (Affonso et al 1992, Padden & Glenn's 1997, Curran et al 1997, Reid & Bramwell 2003).

The study by Affonso et al (1992) on stressors of mothers with premature infants admitted to the NICU reported indices of emotional responses such as feelings of helplessness and anxiety across four time intervals: within the first 96 hours of the infant's admission to the NICU, during the second and third weeks of the infant's life, between the fifth and sixth weeks and during the week prior to the infant's discharge home

Similarly, Padden & Glenn's (1997) phenomenological study indicated that anxiety about their infants' survival and stress were described by 36 UK mothers of preterm infants admitted to the NICU throughout the period of their hospitalization. The data were collected during interviews that took place 4-9 days following birth, and were analysed independently by the two authors. 25% of the recordings which were selected at random for comparison demonstrated almost complete congruence in the categorizing responses.

Curran et al (1997) mailed questionnaires to 60 parents with preterm infants at three time periods: admission, during the stay and at the end of the stay in the NICU. They also found that the most common emotions included fear, anger, anxiety and depression. The extent of the emotional response has been reported to have been influenced by the nature of the NICU environment (Affonso 1992, Moehn & Rossetti 1996, Redshaw 1997, Padden & Glenn 1997, Holditch- Davies & Miles 2000, Reid & Bramwell 2003), and the infant's health status (Shields-Poe & Pinelli 1997, Miles et al 1991, Gennaro et al 1990).

In an attempt to look into mothers' experiences in the UK, Reid & Bramwell's study (2003) on mothers (n=230) from 23 British NICUs which varied in size used a two-adjective checklist.They reported that the majority of the mothers focused mainly on their emotional response to the situation and on their baby. Interestingly, there were few significant differences reported between NICUs of different sizes, although monitoring equipment was reported to cause anxiety to 50% of mothers.

Although a recent comparative study by Carter et al (2005) of 447 parents with an infant admitted to a regional NICU and 189 parents with infants not requiring NICU admission indicated that a higher proportion of NICU parents suffered from anxiety, it was concluded that the overall levels of anxiety were relatively low in both groups of parents in relation to the environment. The study used self-report questionnaires assessing depression and anxiety symptoms based on the Edinburgh postnatal depression scale (Cox et al 1987) and the hospital anxiety and depression rating scale (Spanier 1976), to make direct comparison between the NICU parents and non NICU parents. However, there are methodological difficulties in making comparative studies on this topic: these include the selected use of subscales, and differences in the timing of when the questionnaire was administered from three days to 12 months after birth. This is critical in relation to this study, which included data collected on one occasion very early in the postpartum period. The time course for symptoms of anxiety and depression consequent on the birth of a normal baby is not necessarily the same for every mother, nor can it be assumed to be the same for parents whose baby is born preterm or with a medical condition necessitating admission to a NICU. The importance of assessing parental psychological status more than once at various points in time has been emphasised by some authors (Pederson et al 1987).

According to Shields-Poe & Pinelli (1997), parental anxiety and stress is significantly related to the degree of neonatal illness. In their co-relational study aiming to identify sources of stress in 212 mothers in the USA, it was demonstrated that the parents perceived the severity of their infants' illness as the most powerful variable associated with the stress scores. Data were collected by means of an interview and four questionnaires completed within three weeks of the baby's admission. These questionnaires included the Parental Stressor Scale : NICU (Miles et al 1992) which measures self-rated parental stress, Spielberger State Anxiety Inventory (Spielberger 1983), which measures the trait and state of anxiety, Life Events Scale (Holmes & Rahe 1967), which asks which events had been experienced in the past year and a parental questionnaire that collects demographic data.

One of the scales used, the Life Events Scale to measure trait and state anxiety in the study was developed in the 1960's. Since then many technological advances have been made that have changed the nature of NICUs and the life expectancy of ill babies. It is possible that stresses experienced by parents in the 1960s were different from those a parent may experience today, and therapeutic nursing may also have changed with the implementation of family centred care and parental participation in care (Heuer 1993). However, similar findings were also reported by Pederson (1987) using a structured interview on 144 parents of preterm infants prior to their discharge from NICU. Sixty eight of the mothers reported being emotionally upset. A considerable percentage worried about their infants' survival (24%). Although difficulties in arranging transportation and the financial burden imposed by the expense of travelling to the hospital were mentioned, there was no obvious data to suggest the significance of these factors This may be because the hospitalisation costs are covered by the provincial health plan which may have included hospital transportation expenses.

However, in other studies, mothers appeared equally anxious and stressed regardless of how ill their infant was (Redshaw 1997, Reid & Bramwell 2003). Reid & Bramwell's study (2003) of 40 mothers with moderate-risk preterm infants in a NICU in the UK did not show a significant correlation with any of the subscales relating to the infant's illness. Similarly the study by Spear at al (2002) using SNASP (Score for Acute Neonatal Physiology) which examined family reactions to sick premature infants in NICUs also found no relationship between infant morbidity and the overall level of stress and anxiety in families. This is an unexpected finding as it conflicts with other studies that sicker infants will provoke higher anxiety and stress levels in parents (Sheilds-Poe & Pinelle 1997, Miles et al 1992).

These conflicting findings may be because the complexity of the parental response that is rooted in a rich social domain may be lost in the simplistic process of quantification. Questions also arise about the analysis and interpretation of mean scores from the Parental Stressor Scale (Miles 1979) used in both Reid & Bramwell's (2003) and Holditch-Davies & Miles's (2000) studies. For example, Miles reported the highest mean score for mothers' perceived most stressful experience as being 2.87 (parental role alteration) derived from a 5-point Likert-type scale, with five being the most stressful. From this score it is inferred that parental role alterations were sources of high stress for mothers. It is surprising that the highest mean score recorded is only marginally above

midpoint of the scale and this raises questions of sensitivity and the discriminatory power of the tool.

Two common psychological stress responses, anxiety and depression, were studied by Gennaro et al (1990) from the time of birth until the infants reached 5 months adjusted gestation age. The Multiple Affect Adjective Checklist-Revised-State Form (Zuckerman & Lubin 1988) was used to measure maternal anxiety and depression. The time of greatest anxiety, for both mothers with very low birth weight and low birth weight premature infants, was the week after delivery until at least to their adjusted gestation age .This differences in anxiety may be because of the chronological time it takes the infants to reach their adjusted gestation age where they are becoming more responsive and may also be perceived to be out of danger of death. Another more recent study by Singer et al (1999), using four standardized self reports, also indicated that the psychosocial impact varies depending on the medical condition, age and developmental outcome of the infant. However, the use of the checklist and scales in both these studies may have resulted in an inaccurate reflection of the parental response, as data elicited may be subjected to predetermined issues from clinical perspectives.

In summary, all the identified published studies consistently reported parents' experiences as being emotional events which may be affected by the NICU environment (Affonso 1992, Moehn & Rossetti 1996, Redshaw1977, Padden & Glenn 1997, Reid & Bramwell 2003), and infant's health status (Gennaro et al 1990,Shields-Poe & Pinelli 1997, Redshaw 1997, Singer et al 1999,Spear et al 2002) . A variety of negative emotional responses such as anxiety, depression, helplessness, fear and anger were reported in these studies. Although issues relating to separation and parental role alteration were reported, it was not clear whether these were related to being unable to be with the baby because of the NICU admission or because of the physical distance from home to the neonatal unit (Redshaw 1997, Padden & Glenn 1997, Reid & Bramwell 2003). There is very little detail regarding whether the babies are locally born (inborn) or born in other units and then transferred to the NICU: factors which may have affected the parents and/or mothers' overall experiences. Only one study reported the inconvenience of visiting infant due to difficulties in arranging and financing transportation to hospital (Pederson 1987). Thus there is a need to explore the mother experiences with transferred babies in order to better understand the mother and provide appropriate care.

The majority of these studies were reliant on measurement tools or checklists to investigate parents' experiences of hospitalized infants in NICUs (Gennaro et al 1990, Curran 1997, Redshaw 1997, Sheilds-Poe & Pinelli 1997, Singer 1999, Spear et al 2002, Reid & Bramwell 2003). The complexity of the parental response that is rooted in a rich social domain may be lost in the simplistic process of quantification. Parental feelings are also likely to change as the baby's condition fluctuates on a day-to-day basis. The one-off score cannot take the dynamic nature of an illness experience into account. Comparison between studies is also difficult because of the use of different dependent variables which have included anxiety and depression. In much of the literature there is confusion in the definition of the term 'stress' and it is often used interchangeably with the terms referring to the affective response to perceived stressors such as 'anxiety' 'depression' 'fear' etc. Moreover all the studies do not focus on the mothers with transferred babies. In the light of these issues, and increased incidences of hospital transfers for critically ill babies, rigorous well-designed studies from the mother's perspectives are needed to provide a deeper understanding of mothers' experiences of having a critically ill, hospitalized infant transferred to a another regional neonatal unit.

2.3.2.2 The parents' experiences of the NICU.

Advances in medical technology have meant that smaller sicker preterm infants are being assisted to survive. Whilst this is a major achievement, it can mean increased family stress. Researchers have emphasized that understanding the nature of this stress, the coping abilities or resilience of families, and how best to support families, is crucial for professionals providing care to these infants and their families (Affleck et al 1991; Reid & Bramwell 2003).

Parents can experience many difficulties when trying to establish meaningful and positive interactions with their premature infants during hospitalization (Moehn & Rossetti 1996). In the following discussion these difficulties have been thematically organized and relate to the medical setting of the NICU, information needs and sources of stress.

2.3.2.2.1 The medical setting of the NICU

A study comparing the experiences of mothers (n=420) from 23 NICUs of varied size in the UK, using mailed questionnaires based on an adjective checklist two months after the baby had been discharged, found that mothers reported the NICU as 'frightening' while district units were

'relaxed'. One reason given for this was that the incubators used in the NICU were viewed as a 'barrier' to normal contact (Redshaw1997). Similar findings were reported by the majority of the 36 mothers (75% of the comments) in Padden & Glenn's phenomenological study (1997) in the UK who referred to the technological environment of the NICU as being frightening and daunting. Holditch-Davies & Miles (2000) retrospective study of 31 mothers using the Preterm Parental Distress Model (Miles et al 1992) for data analysis also verified the NICU environment as one of the concerns reported by the mothers.

This contrasts with the previous findings of Perehudoff (1990) which found that the mothers did not report concerns about the physical setting of the neonatal unit. However, this may be attributed to the fact that both the studies were carried out in 1990. Since then, many technological advances have been made that have changed the nature of NICUs. It is likely that the mother experiences of the NICU are affected by these advances. No details were given as to whether the units in most of the studies were local based units or not, which may have influenced the parents/mothers' experiences and interactions in the neonatal unit, as unfamiliarity with a regional unit may affect their overall perception of their hospital experience.

In conclusion, the NICU environment was found to be frightening and unfamiliar to parents (Redshaw 1997, Padden &Glenn 1997, Holditch-Davies & Miles 2000) although Redshaw (1997) indicated a difference in the way the parent viewed the NICU as ' frightening' and district units (local units) as 'relaxing'. This is an important finding, as although most premature infants are born in hospitals with NICUs, there are many premature infants born in hospitals without such units. Lack of a NICU requires the transfer of the infant from a local unit to a hospital with intensive care facilities. Many of these NICUs function within an acute medical model, with priority given to the immediate demands of direct patient care and little time identified to assist parents in coping with the crisis of having a sick infant (Reid & Bramwell 2003). It is, therefore, important to investigate the experiences of mothers with critically ill and/or premature baby that were transferred to a regional unit. This will add to existing knowledge about parents' experiences with a critically ill and/or premature baby.

2.3.2.2.2 Information needs of parents

The ease and the ability with which parents can obtain and understand information about medical procedures, their own feelings and responses is a source of situational stress and anxiety for many

parents (Bialoskurski et al 1999, Redshaw et al 1996). Throughout the infant's hospitalization, parents need accurate and timely information about their infant's condition (Ward 2001, Affleck et al 1991, Redshaw et al 1996).

Ward (2001) reported information-related needs as the most important in her study using the NICU Family Needs Inventory on a convenience sample of 52 parents of NICU infants. Similar findings were reported by McKim 's study (1993) of 56 mothers, using 30 closed questions to assess the kinds of information the parents received and 32 open ended and closed questions to assess information needs. The study suggested that mothers who reported that they needed more information and then did not receive it, were more anxious.

The capacity of parents to retain information, however, may depend on how this is provided by staff (Redshaw & Harris 1995). Most people can only absorb so much information during times of stress and therefore the delivery of information needs to be paced, relevant and timely (Redshaw 1996, Reid & Bramwell 2003). Parents have reported feeling overwhelmed by the noise, exposure to other sick infants, the crowd of health care personnel. Curran et al's study (1997) found that the seemingly relentless medical procedures involving the infants affected the ability to process any information given to the parents. Similarly, other studies have also reported parents feeling disorganized, distraught and unable to concentrate or process much information when this is given in the NICU (Affleck et al 1991, Redshaw et al 1996).

It is clearly important to ensure that repeated opportunities are provided for information to be discussed and talked through more frequently so that parents can extract information and clarify misunderstandings when they are ready to hear and understand. In one study where mothers were interviewed at six weeks, 30% of mothers of very preterm infants had little or no understanding of the information they had been given during the period of neonatal intensive care (Curran 1997). It was found that, even in the presence of a good explanation, some mothers used cognitive strategies to protect themselves from any bad news regarding their infant's condition in addition to the difficulty of grasping medical information (Curran 1997). It has been reported that parents should be told as much as possible using a caring and empathetic approach (Redshaw 1997). However, there is a question about who is authorized to give information to parents. In Redshaw's study (1997) of 230 mothers from 23 NICUs in the UK, doctors were generally seen as the appropriate experts in this role and that nurses were perceived generally as tending to avoid answering questions. Padden & Glenn's (1997) study of 36 mothers who were interviewed

between four and nine days following birth also reported that the parents needed to have more discussion with the doctors who monitored their infants' progress even though communication with staff (nurse and doctor) was positively regarded. Although this supports findings by Curran et al (1997), who found contacts with doctors to be inadequate, the researcher speculated that the reason for this finding regarding limited contacts with the medical staff may have been due to the generally healthy condition of infants in Padden & Glenn's study (1997).

Another obstacle to parents receiving information about their infants is that many NICUs do not have a well developed system of primary care nursing, so that any number of health care staff can be responsible for the same infant during the course of hospitalization. Parents may have to tell their story again to each new nurse assigned to the infant's care. The presence of multiple information and care givers can result in parents receiving conflicting and inconsistent information about the infant's current condition, changes in condition and long-term outcomes (Bialoskurski et al 2002). There may also be incongruence between professional expectations and parental reactions to infant-related information (Affleck & Tennen 1993). The professionals may feel that they have provided good information in an appropriate manner, while the parents may recall little of what has been said, and express anger about the professional involved (Curran et al 1997).

Technical information and jargon can also constitute a barrier to the passing of information between staff and parents (Moehn & Rossetti 1996). Thirty parents in Moehn & Rossetti's study (1996), using interview and questionnaire two weeks following discharge, identified communication with staff as a stressor encountered while their infants were inpatients in the NICU. In another study, analysis of observer comments showed that, while engaged in information exchanges with mothers, nurses failed adequately to assess the mother's current level of knowledge (Fenwick et al 1999). Other research findings have indicated that some nurses tend to deliver information in a didactic fashion, telling parents rather than communicating with them (Singer 1999). These patterns of communication do not result in relationship building, where sharing and negotiation are important elements (Fenwick et al 1999). The NICU staff members are a key resource for parents who need information and support and while, in many instances, they provide a great deal of help, they are also often busy. Mothers who have more negative experiences in NICUs have reported problems with the nursing staff, arising from inconsistencies and conflicting information and leading to uncertainty, anxiety and increased stress (Redshaw &

Harris 1995). Conflicting instructions and information, differences between stated policy and actual practice have created barriers to effective parental involvement in the infant's care (Fenwick et al 1999).

A recent study (Bialoskurski et al 2002) asked 209 mothers of premature infants cared for in a NICU to indicate their needs and priorities by completing a questionnaire. Two self-ssessment schedules were used: critical care maternal inventory needs and a ranking scale. Mothers indicated their need for accurate, reliable and topical information regarding their infants' status, the importance of having their questions answered and the need for regular communication. Mothers identified their need to talk to the same nurse regularly and with the doctor every day as very important to satisfy their needs (Bialoskurski et al 2002). The level of consistency in explanations regarding care was reported in a survey of 171 parents after their infants had received neonatal care (Steward 1991). Of respondents, 9% described inconsistencies among staff in instructions regarding maternal involvement in care and 26% reported inconsistencies about breastfeeding advice.

In summary, the need for accurate and timely information is consistently highlighted in most of the studies. Collectively, they provide an overall picture that many parents are dissatisfied and /or feel the information is inadequate. The data suggest that communication and information surrounding the infant is of paramount importance to parents.

However, most of the studies are based on survey data (Bialoskurski et al 2002, Redshaw & Harris 1995). The problem with survey data is that the questions are often predetermined by the clinical beliefs and priorities of the designer of the study. These priorities and beliefs may not be shared by the lay population and therefore may give a jaundiced view of the lay world as defined by a particular perspective. Moreover, individual differences arising from a mother's situation and personal characteristics are not elicited and this may affect the findings. Some of the studies did not examine any particular area in depth; rather it was measured in one or two quantitative statements within questionnaires. Further research is required to explore parents' experiences of communication and information-giving within the NICU and in relation to information needs about transfer from the parents' perspectives.

2.3.2.2.3 Sources of stress

Although studies have investigated parental stress related to the sights and sounds within the NICU, environmental stress has been reported as one of the areas of least stress to parents (Miles et al 1991). Miles et al study (1991) found that the physical aspects of the NICU were not highly stressful, possibly due to the fact that parents are too focused on their infant to be concerned with the physical environmental aspects. Lower stress levels may be attributed to the familiarity of the parents with the NICU or to parents' sense of reassurance that their small and sick infants were being cared for in a NICU (Perehudoff 1990) where responsibility and care were shared with the medical staff. There is lack of details on whether these are magnified by distance or by strange surroundings if the babies were transferred from their local neonatal unit to a regional neonatal unit.

The loss of the normal parental role may be compounded by a struggle to negotiate a care-giving role with neonatal nurses caring for their infant (Miles et al 1999). Relationships with staff can become a source of stress when discrepancies occur between perceptions and expectations (Perehudoff 1990, Miles et al 1993, Curran et al 1997).

Staff communication and behaviours have been found to have a negative influence on parents' stress levels in some studies (Moehn & Rossetti 1996, Padden & Glenn 1997, Curran et al 1997, Holditch-Davies & Miles 2000, O'Shea & Timmins 2002,) but not in others (Perehudoff 1990, Miles et al 1991). Both Padden & Glenn's (1997) and Curran et al's (1997) studies found that communication with doctors was inadequate and unsatisfactory. However there were no details whether the mothers or babies were actually transferred from another hospital which could have affected their opportunities for communication with doctors due to the distance.

Reaside (1997) highlighted that mothers may also have to deal with extraneous stressors from numerous sources outside the acute health care situation. Many of the parents in the study commented on the more immediate stressors such as arranging child-care for siblings, which in turn prevented them from visiting their sick infant. There were however no details whether it was related to having their babies transferred to another perhaps distance neonatal unit or from having their babies admitted to a neonatal unit.

In summary, the studies indicated that changes in the parental role and difficulties in communication with staff have been found to have a negative influence on parents' stress levels. The relationship with staff was reported as a possible source of stress when discrepancies occur due to different expectations or miscommunication between staff and parents. In comparison, the physical aspects of the NICU were not reported to be highly stressful. Child care arrangement as a stressor was only highlighted by very few studies. This may be because the parents in the studies reviewed have no other children although this is a personal speculation as there is inadequate sampling data in most of the studies.

There are, however, limitations to the studies reviewed to date. There is a wide range of timing of investigations into parental stress with many studies having only vague reference to the actual timing. Timing of data collection is an important factor in investigating the experiences of these mothers, as highlighted in Affonso et al's study (1992). Different stressors may be more relevant at different stages of the mother's experience. Some of the data may have been based on retrospective memory of a potential lengthy NICU hospitalisation and the accuracy of these remembrances is unknown (Sheilds-Poe & Pinelle 1997, Redshaw 1997).

2.3.3 Summary of studies reviewed

One can make only tentative generalisations about parents' experiences and interpretations during their premature babies' hospitalisation because the specific focus differed for each of these studies. The extent to which differences in health care systems (Canada versus the United States versus the UK) affect parental experience also needs further investigation. The differences in health costs may have influenced the experiences of the parents as it may have increased their anxieties in relation financial implications in some of the studies.

Differences in medical and nursing practice and technology also preclude comparisons of studies across the last few decades. Changes in care-giving practices in the NICU, such as unrestricted parental visitation, were not common practices as recently as 20 years ago (Sammons & Lewis 1985). The experiences of the parents may change with opportunities to visit the infant other than during predetermined visiting hours, as there may be more opportunities for establishing parental role. Similarly the acceptance of family-centred care as an ethos in neonatal care is believed to encourage parental participation and involvement in their infants' care (Darbyshire 1994).

As a group, however, these findings indicate that having a premature and /or critically ill infant hospitalised in a NICU is a stressful and emotional event for parents, evoking a mixture of feelings: anxiety, stress, fear, uncertainty and worry (Affonso et al 1992, Padden & Glenn1997, Redshaw 1997, Curran et al 1997, Reid & Bramwell 2003). Although study findings vary as to which aspects of the NICU generated the greatest degree of stress, a number of studies identified the premature baby's condition as well as conditions within the NICU, such as the sights and sounds of the unit, and staff communications, as high intensity stressors (Bialoskurski et al 2002, Redshaw et al 1996 Affonso et al 1992, Miles et al 1992). Information needs across all the studies were consistently reported.

The research reviewed gives compelling evidence that the experience of having a hospitalised premature baby poses significant threats to mothers' psychological well-being. Most premature babies are born in hospitals with NICUs, but there are many premature babies born in hospitals without such units. None of the literature reviewed considered the experiences of parents when their babies' condition necessitates transfer to another unit shortly after birth. What are the experiences of mothers whose infants were critically ill babies, who must also contend with having their babies transferred? Not only are there segments of the population of mothers with transferred babies about whom we know very little, but the studies we do have are rather limited in scope – as illustrated in the following section (Steeper 2003). Further research is necessary to explore this aspect in view of the increased level of neonatal transfers across units in the UK (CESDI 2002, DOH 2003).

2.4 The impact of neonatal transfer on the parents' experiences

2.4.1 Introduction

Although there is an abundance of research available on a range of issues related to neonatal transfer (794 hits found), most of the studies are evaluations of equipment (Miller and Nacrae 1994, Scot et al 1994), factors affecting the outcome of transfer in terms of morbidity and mortality (Nicholls et al 1993), composition of transport personnel (Aylott 1997 Healy 2003) and studies of neonatal transport practice, particularly comparing modes of transportation (McKay et al 2003). Thus hits relating to the mechanism/equipment/team composition/outcome of transport or transfer in terms of mortality or morbidity were discarded as irrelevant to this study. Duplicate references within and across search domains were removed.

2.4.2 Studies reviewed

Eleven published studies that addressed the needs of parents with neonatal transfer were identified. Five of the studies looked at the effect of initial neonatal transfer on the parents, while the remaining six focused on the effect of back transfer. One unpublished thesis is retrieved as relevant, as indicated by the inclusion of mothers who had experienced neonatal transfer.

Although this study is about initial transfer, studies of initial and back transfer will be discussed separately to identify issues arising from each type of transfer. This is to identify existing gaps in the research and provide a rationale for this study.

2.4.2.1 Parents' experiences with initial transfer

Frischer and Gutterman (1992) in the USA attempted to provide a theoretical framework from which to understand parental experiences during the transport of a newborn. They devised a series of interviews conducted with transport teams from two NICUs and parents involved in the transport. The interviews explored emotional issues involved from the perspective of both the transport team and the parents. The transport team members identified emotional demands as being far greater than the physical demands. The transport team indicated that, with better preparation for the parents, their capacity for coping with the process is much improved. The six parents' anecdotal accounts of their experiences showed that they felt helpless because of their inability to be with their babies, worried and uncertain about their babies. The mothers related their feeling of guilt to the feeling of neglect they felt due to the perceived lack of the husband's attention because he was visiting the new baby rather than spending time with the mother in the local hospital. The need for ongoing support and information was highlighted. Travelling to visit the baby in the regional neonatal unit was identified as a handicap because it was time-consuming and costly.

Wilman's (1997) UK study produced similar findings. A variety of emotions were reported, including feelings of guilt, grief and shock. Wilman (1997) also reported that parents not only suffer from all the conventional problems that accompany any NICU admission, but these are magnified by distance, by strange surroundings and by extended lines of communication. He

concluded in his study that the emotional and financial factors as well as problems with communication can increase the stress for these parents.

However, there is a lack of supporting information on the methodological approach, making it very difficult to establish the questioning approach adopted in both the studies. As a consequence, interpretation and comparison of the findings are difficult. No details of how the survey was done were reported in Wilman's study, thus making it difficult to establish the research approach adopted and how this may have influenced an individual's response. Personal communication with Wilman failed to retrieve details about the study (appendix 3). In both the studies, there is lack of detail about the participants, making it difficult to judge the credibility of the studies. The thought processes used in determining themes are not described (Frischer and Gutterman 1992, Wilman 1997).The sample size is not alluded to in Wilman's study nor the sampling criteria in Frischer & Gutterman 's study. These factors make it difficult to extrapolate the findings and apply them to the wider population. Rigorous, well-designed research from a qualitative approach in the proposed study may begin to provide a deeper understanding than that which can be provided through quantitative methodology (Polit & Hungler 2001).

An evaluation of the effectiveness of an information pack by Cross et al (1995) using a questionnaire about satisfaction levels of 19 mothers in the UK demonstrated high levels of appreciation of the specially designed information given during the transfer of their babies. Although this survey predominately looks into evaluating the effectiveness of an existing information pack and only applies to 19 mothers in the author's place of work, it has implications for the role of information in meeting the needs of these mothers.

Other major problems highlighted both in a Canadian study of 54 parents by Macnab (1992) and in McLoughlin's et al (1992) study of 93 mothers in the UK were related to finances and the logistics of the journey to visit the baby. Financial problems were placed first on a list of stressors in Macnab's retrospective study, using telephone interviews with 54 mothers to elicit problems associated with the transfer. Although, in comparison to North America, the geography of the UK, with relatively short distances between hospitals, may lessen any financial stresses on parents, McLoughlin's study in a British NICU concluded that there was a need for financial help for parents on low incomes to facilitate visiting and increase family contacts. However, the semi-structured interviews in McLaughlin's study were focussed on pre-determined topics related to parental visiting practice only. There were no details about whether the questions asked in their

54 retrospective telephone interviews were preset or whether these problems emerged simply from the parents' recollections of their overall experiences during the one year the study was conducted. Both the studies were done in the early 1990s. Current sources of financial assistance or support for parents in the UK need to be considered, together with the subsequent effect on the parents with transferred babies. Further research should be conducted to clarify the nature of current problems encountered by mothers of transferred babies from the mothers' perspectives, rather than from predetermined clinical perspectives, as; otherwise, data elicited may be related only to those predetermined issues.

Although Newsome's unpublished study (1991) was on maternal needs when their premature babies were admitted to the NICU, it will be discussed here because, of the 21 mothers interviewed, 17(91%) had experienced more than one neonatal unit before their babies were discharged home. The study indicated that, for these mothers, there was increased anxiety and isolation due to maternal separation from family, friends and the social support network. Future research pertaining to problems associated with transfer to and from the NICU was indicated to address the gap in this area. However, these mothers were interviewed 18 months after the birth of their baby. The intensity of initial emotions and needs may have altered during the intervening period, whilst others may have changed by repeatedly reworking events.

In summary, the initial neonatal transfer studies suggest that having a newborn baby transferred to a regional neonatal unit is a significant emotional event with reported feelings of guilt, anxiety and isolation (Newsome 1991, Frischer & Gutterman 1992, Wilman 1995). The importance of good communication (Cross et al's 1995) and the need for ongoing information and support for the parents was highlighted as a constant theme running through most of the studies. (Newsome 1991, Frischer & Gutterman 1992, Macnab 1992, McLoughlin et al 1992, Wilman 1995).

However, most of the studies were conducted over the last ten years (Newsome 1991, Macnab 1992, McLoughlin 1992, Frischer & Gutterman 1992, Cross et al 1995) and, since then, many technological advances have been made that may have changed the nature of NICUs. Today parents have greater expectations of infant mortality as medicine and technology continue to progress. It seems likely that the needs of parents will evolve as these advances continue to be surpassed.

Some of the studies done were carried out in North America (Macnab1992, Frischer and Gutterman 1992). Whilst this does not negate the findings, there are some fundamental differences between the cultures and health care systems of these countries as well as the greater availability of public transportation and shorter distances in the UK than would be typical of much of North America. This may affect the logistic of parental travelling in visiting the infant in the USA in comparison to the UK. The USA system of health care is fundamentally financed by patient and family contributions, which may evoke a unique set of stressors and financial implications for parents with transferred babies.

The point of time after transfer at which different researchers initiate data collection has been subject to variation. Neither Frischer & Gutterman (1992) nor Wilman (1997) indicated when the data were collected. Other surveys indicate that most of the data were collected retrospectively twelve to eighteen months after transfer, causing some concerns as reported feelings and recall of events may be altered over time (Newsome 1991, Macnab 1992, McLoughlin 1992). Conducting interviews in relation to past events carries with it the potential for memory decay (Ely et al 2000, Smith 1992). Participant recall might be affected by the perceived importance of the event or the possibilities of the participant repressing threatening, unpleasant or embarrassing events.

Half of the existing studies focus on predetermined topics (Macnab 1992, McLoughlin 1992, Cross et al 1995) which might have a bearing on the reported findings. Such a study may not reflect accurately the parents' perceptions of the transfer because it was based on health care providers' perceptions of the parents' perceptions and did not attempt to elicit parents' experiences concerning the transfer inductively. It is likely that the results represent an incomplete picture of these mothers' experiences in the UK. Since the mothers are the stakeholders in the neonatal care services, it is appropriate to consider mothers' experiences of the care they receive. This approach is supported by the Patient Charter (DOH 1996) that engenders the concept of parental empowerment. In the light of these issues, current and prospective studies from the mothers' perspectives are needed. Good quality evidence about this would make a significant contribution to improving care for these families.

2.4.2.2. Parents' experiences with back transfer

Although back transferring a baby to a hospital closer to home has many potential advantages, the six studies of neonatal back transfer indicated that it can be stressful to parents. They were

adversely affected by incomplete or inconsistent information and differences in care practices (Kolotylo 1991, Kuhnly & Freston 1993, Dodds-Azzopardi &Chapman 1994, Gibbins & Chapman 1996, Flanagan et al 1996 and Slattery et al 1998). Three of the studies used an exploratory approach while survey was used in the remaining three studies.

Kolotylo et al (1991) in USA, Kuhnly & Freston (1993) in USA and Gibbins & Chapman (1996) in Canada used an exploratory inductive approach to ascertain parental reactions to their babies' back transfer. Both Kuhnly & Freston (1993) and Gibbins and Chapman (1996) interviewed 7 couples and 15 couples respectively a week after transfer whilst Kolotylo (1991) interviewed 15 mothers within a week post transfer.

Gibbins & Chapman (1996) attempted to describe the parents' feelings before and after their infants' transfer to a NICU. Helplessness and lack of control were initially reported by the parents, followed by mixed feelings of relief, anxiety and uncertainty. Similar feelings were also reported in Kolotylo's study (1991) which found these to be influenced by the communication of information and differences in care practices (Kuhnly & Freston 1993, Gibbins & Chapman 1996). Dependence on familiar things and people were reported as an issue in Kolotylo's study (1991). Verification of the data was done by either independent or simultaneous data analysis by the two authors in Gibbins & Chapman study (1996) or using an expert validator in the Kuhnly & Freston study (1993). However, although Gibbins & Chapman (1996) reported their study approach as using grounded theory, there were minimal explanations as to how the theory of 'holding on' evolved. All three studies reported the transfer event as being stressful and emotional which are affected by incomplete information and perceived differences in care giving practices in the two units.

Similarly, Dodds-Azzopardi and Chapman's (1994) retrospective descriptive study of 44 parents by means of a questionnaire conducted between four and seven days after the transfer concluded that a lack of communication between health professionals and parents was related to parental stress. In 1996, Flanagan and colleagues conducted a pilot study to test an instrument designed to measure mothers' perceptions of the back transfer experience. Forty one mothers completed the 24 item NICU/Community Hospital Transfer Quality Scale. The study found that communication with health care providers is an important component of the transport experience and that poor communication produces stress.

This descriptive correlation study was repeated by Slattery and colleagues in 1998. One hundred forty three mothers whose babies were transferred from a Level 3 NICU to a community hospital completed the same instrument. Overall stress was reported as moderate which was influenced by three factors: pre transfer preparation by health professions , perceived differences in care practices and the degree of the baby's medical problems. They found that, on the whole, mothers reported relatively positive experiences with back transfer.

In conclusion, studies related to back transfer indicated that parental experiences were affected by lack of information as well as differences in care practices between units (Kolotylo 1991, Kuhnly & Freston 1993, Dodds-Azzopardi & Chapman 1994, Flanagan et al 1996, Slattery 1998). Mixed feelings were reported indicating that, for some parents, the experience was relatively positive (Gibbins & Chapman 1996, Slattery et al 1998). However, the majority of the studies reported the event as being stressful and emotional, affected by inadequate information and perceived differences in care giving practices. Based on the consistency of the findings, communication is clearly an issue for these mothers – one that affects their perceptions of undisclosed differences in care practices between units as a result of incomplete information.

However, the tools used in three of the remaining studies are designed from the health care professionals' perspectives and did not seek to elicit parental experiences concerning the back transfer spontaneously (Dodds-Azzopardi &Chapman 1994, Flanagan et al 1996 and Slattery et al 1998). Both Flanagan et al 1996 and Slattery et al (1998) mentioned the use of a tool based on data obtained from an earlier pilot study. However, there were no details of this earlier pilot from which the tool was derived, nor of how it was conducted to justify its relevance to both studies. The three studies using the inductive approach included sufficient details about methodology (Kolotylo 1991, Kuhnly & Freston 1993, Gibbins & Chapman 1996). However, all these studies (Kolotylo 1991, Kuhnly & Freston 1993, Gibbins & Chapman 1996) were done in North America. Thus the findings will have to be considered in the light of this as facilities, procedures and structures differ from those in UK. The regionalised perinatal care in the health system in both United States and Canada may have affected the parents' response due to its implications for hospital costs.

2.4.3 Neonatal transfer studies summary

Emotional and information needs were reported in both types of transfer studies. Although both initial and back transfers were reported as being an anxiety-provoking event, there are some differences in the emotions reported. Feelings of guilt and anxiety were reported by mothers in initial transfer (Newson 1991, Frischer & Gutterman 1992, Wilman 1997) while mixed feelings were reported by some of the back transfer studies (Kuhnly's 1993, Gibbins & Chapman 1996, Slattery et al 1998). This may be because back transfer moves a convalescent baby and the mother closer to her social support system, while in initial transfer the transferring of the critically ill newborn baby to a regional NICU means the baby is not well and is geographically separated from its parents (Sherwin & Weingarten 1988). However information needs across both initial and back transfer studies were consistently reported

2.5 Implications for the current research study

There is an abundance of research available on the crisis effect on parents of having a premature and/or critically ill newborn hospitalised in a NICU. Since parents of ill newborn babies already have to cope with the initial family disruption created by the high risk birth, any change in conditions or perceived threats to the high risk baby, such as those associated with transfer, may intensify existing anxiety levels and initiate the need for further adjustment.

A review of the literature indicated a paucity of research about parents' perceptions of their infants' transfer between NICUs, especially the initial neonatal transfer. Major knowledge deficits remain concerning how these mothers conceptualise their experiences of not only having a critically ill and/or premature infant but also having the infant transferred to an unknown and perhaps distant neonatal unit. In view of the current report by CESDI (2003) and the recent neonatal services review (DOH 2003), which highlighted the deficiencies in care in neonatal transfer, there is an urgent need to gather data about the mothers' experiences when their newborn babies are transferred from their local neonatal unit to a level 3 neonatal unit.

Moreover, most of the research on initial neonatal transfer has been conducted from the healthcare and clinician professional perspective (Cross et al 1995, Macnab 1992, McLoughlin et al 1992). To support these mothers effectively, nurses need to understand their experiences as they adapt to an ill newborn baby who needs transfer to another unit. Because the real experts on

mothers' needs are mothers, one way to gain understanding is to listen to what these mothers say about their experiences and feelings. There is a need to understand the mother's experiences and needs from her perspective, rather than re-stating a healthcare perception of what her needs are/should be.

Since initial and back transfer are qualitatively different in purpose and outcome, a deeper understanding of the mother's experiences in initial transfer might enable nurses to devise interventions that better meet the concerns of these mothers and facilitate a positive transfer experience. It is the development of a deeper, more meaningful understanding of the mother's experiences of initial transfer which ultimately is a crucial factor in the nurse's engagement with her concerns and, perhaps more fundamentally, in the development of the empathetic understanding which is essential for the development of the best possible standards of care.

2.6 Chapter summary

This chapter has provided an introduction to the study and an overview of the literature that relates to parents' experiences in neonatal transfer. An overall picture of any existing problems faced by parents prior to the neonatal transfer was provided in the literature review to provide a fundamental understanding of the emotional situation these parents face.

The literature review and findings from preliminary meetings with the clinical staff are offered as evidence that there is a requirement for greater knowledge and exploration of the mothers' experiences. The increasing inter-hospital transfer of babies reported in Project 27/28 also served as an impetus for the study (CESDI 2003). Better knowledge about how mothers experience the events that occur during transfer would be key to understanding their reality during the initial neonatal transfer process. As it has been highlighted in the literature, the experience of these mothers has been under researched. It appears appropriate to use qualitative approaches which lend themselves to exploration, interpretation and explanation. In the next chapter, a detailed description and justification of the research design and methods is provided.

Chapter 3: Research design and methods

3.1 Introduction

The literature review in the previous chapter has established that exploring mothers' experiences of their babies' transfer to a regional neonatal unit was a valuable area for research. Such an investigation required a methodology sensitive to uncovering detail.

The importance of making clear the philosophical, theoretical and methodological underpinnings of a research study is to allow the reader to understand the perspective of the researcher conducting the study and the interpretation to be viewed from that perspective.

This chapter comprises three sections. **Section one** describes the research design and provides a rationale for using ontological-hermeneutics informed by the ideas of Martin Heidegger (1889-1976). An overview of hermeneutics with reference to the work of several philosophers including Heidegger (1927/1962) and Gadamer (1975) are provided. Following this, I reiterate how the philosophical tenets of Heidegger are relevant to the research question and will be incorporated into the research process. A brief discussion of the limitations of using ontological hermeneutics is included to demonstrate my understanding of the issues of using this particular qualitative approach.

Section two presents the necessary procedural activities and documents how data were collected, handled and interpreted in order that the ethics, trustworthiness and rigour of the study may be evaluated. A description of van Manen's (1990) six research activities for phenomenological data analysis is also included to provide an auditing of the interview accounts into themes.

Section three concludes with the findings of the pilot study.

Section 1: Research design

3.2 Methodological considerations

The responsibility of selecting an appropriate research approach is largely influenced by the research question and intended purpose (Denzin & Lincoln 1994, Robson 1993). The choice of research method could equally be influenced by the interplay between research purpose, intended outcome and researcher preference (Creswell 1998, Robson 1993).

As the main aim of the study is to explore the experiences of mothers when their newborn babies are transferred from their local neonatal unit to a Level 3 neonatal unit, the chosen methodology needs to facilitate the capture and exploration of these mothers' lived experiences.

As a neonatal nurse I wanted to find answers to clinical questions; I wished to access knowledge, derived from mothers to inform and direct care. Furthermore I did not want my research to be too tightly bound by the framework of scientific methodology, which would have resulted in my missing much of the texture and nuances in social relationship, because, like Marshall (1981), I believed that 'research is a social process negotiated and pursued in relationship with others' (p. 2).

I was interested in methodological practices that supported the need for rapport in establishing good research relations. I sought from the outset a methodology that would not be advocating a 'value free stance'. I also believe that research is not something separate from the researcher's life, especially when the research is in an area that matters to the researcher. These beliefs played a part in my search for appropriate methodologies. The search took me towards looking at paradigms of research that would reflect these views and more importantly would achieve the aim of this study.

A good research undertaking starts with the selection of the topic, problem or area of interest as well as the paradigm (Creswell 1998). Denzin and Lincoln (2000 p. 157) define paradigm as *'a basic set of beliefs that guide action' and informs a researcher as to what is important and legitimate, when undertaking systematic inquiry'.*

In the literature, there is a variety of classifications of research paradigms. One of the classifications is offered by Wilkes (1991): positivist, critical theory and interpretative approaches.

In positivism, there is an understanding that reality has existence 'outside' and independent of the individual (Patton 1990). Natural science relates to the study of reality through objective measurement, and the aim is generalisability via a search for patterns, regularities, and universal laws of human actions to describe probability and suggest cause and effect. In the positivist view objective reality exists; it is 'out there'. The research aim in this study does not claim a known hypothesis, nor is it attempting to test a hypothesis. Rather it aims to unravel the meanings that mothers make of their experiences within a specific context, to gain understanding about the mothers' ways of being. The positivist paradigm therefore is not congruent with the study.

Critical theory seeks to criticise incongruities and contradictions in people's lives through focusing on critical self-reflection, coupled with action and change (Wilkes 1991). It seeks not just to study and understand society but rather to critique and change society. However, an understanding of the particular world is required before it can be deconstructed and criticised. An understanding of the mothers' experiences on newborn baby transfer needs to be established before it can be critiqued. Moreover it is not the intention of this study to critique or change, but to understand the mother's world in this instance.

Interpretivism is concerned with interpretation and gaining meaning from humans and human interaction with the social world, to understand a view of their constructed, subjective reality. The aim is to understand complex and multifaceted human experience. This socially constructed world is intricately woven between all the individuals involved in the research situation and therefore multiple realities exist (Grbich 1999). It is emphasised that the researcher is part of the research and that the impact of the role is an integral part of the investigation.

In my research I was interested in the mothers' experiences when their newborn babies were transferred and I wanted to examine especially 'newborn transfer', a phenomenon I had noticed in my own practice. The most appropriate research approach for the study therefore lies in the interpretative paradigm. However, there are different approaches to be considered. Prior to deciding on a phenomenological approach, I spent some time considering the potential of ethnography, ground theory and case study as alternative approaches. Below, the key tenets of

each of these methods or philosophies are presented with an outline of the reasons why they were not adopted as the most appropriate means of achieving the stated study aims.

Ethnography has its roots in cultural anthropology (Spradley 1979). Its focus is to develop in-depth understanding of the meanings people hold of actions and events within the context of a specific culture or environment (Aamodt 1991), through participant observation, becoming involved in the everyday lives of people, and in-depth interviews. The primary focus is to interpret the process and product of cultural behaviour which is not the aim of this study.

Ground theory is a research approach with its origins in the interpretative tradition of symbolic interactionism (Benoliel 1996), which focuses on the meanings of events to people and the symbols they use to covey that meaning (Baker et al. 1992). It generates inductively based theoretical explanations of social and psychological processes based on observations of social interactions, listening to informants, and reading what others have written and inferred from thinking about one's past experiences (Baker et al. 1992). However, this study is not concerned with theory generation but with understanding the mother's world when their newborn babies are transferred.

Case study originates from the human social sciences and evaluation research (Creswell 1998). Yin (1993) reinforces the case study as an ideal research methodology when the 'how' or 'why' questions are being asked and where the focus is the real-life context. Understanding the mothers' experiences of their babies transfers was the main focus of this study and not the how or why of the babies' transfer.

Phenomenology, which appears to deal with the assumptions of getting to know about a particular phenomenon, seemed to be an appropriate approach. Phenomenology offers a stance for describing and examining human experiences, and hermeneutics contributes to the idea of interpretation from different perspectives (Grbich 1999). Instead of pinpointing a minute segment of experience as in quantitative research, a phenomenological view enlarges the experience and attempts to understand it in the complexity of its context. From listening and interpreting the mothers' experiences, the researcher is open to new understandings, which I believe can enhance the understanding of these mothers' experiences, which is the aim of this study.

This decision was supported in the pilot study (refer to Section 3). I found that in order to make

sense of the data collected, I had to immerse myself in the mothers' world and draw on my own experience. During these interviews, my personal reactions allowed me to appreciate how my experiences of being a mother myself were influential on my understanding and interpretation.

The commitment to undertake a project with clear practical relevance and application was apparent from field notes kept throughout the study. The following entry was recorded early on in my field notes in the initial stage of the study:

'I've been thinking about what I want this work to be about...my main interest and feeling is that I need to ask mothers to talk about their experiences in order to really get at what it is like...to really understand them as mothers with transferred babies...I am not trying to find an explanation for the transfer...what I want is to understand what it feels like...'

(Field notes 1, p. 2)

A researcher's epistemology according to Holloway (1997) and Creswell (1998) is literally her theory of knowledge, which serves to decide how the social phenomena will be studied. My epistemological position regarding this study can be formulated as follows: a) data are contained within the perspectives of people that are involved with the phenomenon; and b) because of this I engaged with the participants in collecting the data.

Phenomenologists, in contrast to positivists, believe that the researcher cannot be detached from his or her own presuppositions, and that the researcher should not pretend otherwise (Hammersley 1992). The intention of this study at the outset was to gather data regarding the perspectives of research participants about the phenomenon of having their newborn babies transferred to another neonatal unit from their local neonatal unit. Thus the methodology used in this study was largely informed by Heideggerian phenomenology whilst hermeneutics (interpretation) provided the framework used to develop understanding of the parents' experience in a disciplined fashion (van Manen 1990).

3.3 Phenomenology

In this section, frameworks that support the study are discussed to illustrate their application to the context of the study and how the methodology evolved in response to understandings gathered across the course of the study.

Phenomenology has its roots in philosophy and was conceived by Husserl at the beginning of the twentieth century (Baker et al. 1992). Phenomenological research sets out to make explicit common meanings of lived experience (Cohen 1987), through engaging with individuals to uncover the fundamental features of a given phenomenon (Oiler 1982).

Philosophy may be affected by culture and language, thus the different types of phenomenology will often be affected by culture and language. The different types of phenomenology will often reflect the cultural background and tradition of the philosopher. Hence German phenomenology differs from French phenomenology, and the phenomenology of North America is, according to Crotty (1996), much more reflective of American intellectual tradition than its European origins. Lyotard (1991) perceives that phenomenology is an ongoing process that has many different accents, but retains a common phenomenological style.

Overall, there are two main phenomenological approaches that researchers may take in order to gain knowledge and understanding: Husserlian and Heideggerian. The Husserlian tradition is epistemological and has as its focus the description of the life world from the viewpoint of an observer. In contrast, the phenomenological tradition of Heidegger is based on an existential, ontological perspective, which considers that the observer cannot separate himself or herself from the world.

The methodology for this study is informed by the ideas of Martin Heidegger. As it is essential to demonstrate congruence between the philosophical underpinnings and the research approach taken, it is necessary to review the origins and historical development of phenomenology. This will help to make clear the distinction between Husserlian and Heideggerian phenomenological traditions and to demonstrate why Heideggerian phenomenology is appropriate for this study.

3.3.1 History of phenomenology

The birth of phenomenological philosophy as a school of thought and as a research method occurred in Germany in the late nineteenth century. It emerged as a result of a growing dissatisfaction with positivism being unable to provide an appropriate means of discovering and supplying answers to human concerns (Cohen 1987). The positivist perspective encompasses the Enlightenment, which is generally referred to as the self-proclaimed 'Age of Reason' that began

in England in the seventeenth century and became widespread in France in the following century (Crotty 1996). The term 'positivism' was popularised by Auguste Comte (1798–1857), a French philosopher and self-proclaimed scientist who believed that the human mind could only function at its best if all people embraced one scientific method society (Crotty 1996). To this end, Comte founded the Societé Positiviste in 1848, whose purpose was to encourage all people to become positivists as a means to establishing a stable and equitable society. Positivism takes the stance that the only true and valid form of knowledge is that derived through the application of the scientific methods of direct observation, experimentation and comparison. Positivism seeks to scientifically establish laws that can be used to explain, predict and control society.

As discussed above, phenomenology emerged as a reaction to the deprecation of philosophical knowledge and the objectification of humans by the natural scientists. Thus, phenomenology strives to understand human phenomena through interpretation of human beings in their social, historical and political contexts rather than employing the methods of external observation and explanation as used in the natural sciences (Ray 1990).

In order to trace the development and increasing usage of phenomenology, Spiegelberg (1982) wrote a comprehensive history of what he referred to as the 'phenomenological movement'. He used the term 'movement' to signify that phenomenology is not a stationary philosophy, but one that changes across, and within philosophers. He divided the movement into three phases: the preparatory phase, the German phase and the French phase. For the purpose of this study, which uses an approach informed by the ideas of the German philosopher Heidegger, only the German phase will be discussed.

A brief overview of the work of Husserl is included in this discussion, acknowledging the important contribution he made to the development of the phenomenological movement. The ideas of Heidegger relevant to this study are then discussed, followed by a description of Heideggerian hermeneutics, with reference to the work of the philosophers Schleiermacher, Dilthey and Gadamer.

3.3.2 German Phase

3.3.2.1 Husserlian phenomenology

The German phase of the phenomenological movement was dominated by the work of two philosophers: Edmund Husserl (1859–1938) and Martin Heidegger (1889–1976). However, Husserl is generally acknowledged to be the central figure of the phenomenological movement. Husserl was also a mathematician who strove to incorporate mathematical rigour in his method. This is reflected in the main tenets of his phenomenological philosophy, which is underpinned by objectivity, researcher detachment, and the suspension and bracketing of researcher assumptions and biases (preconceptions or pre-understandings).

Husserl based his philosophy on a critique of positivism, which remained the dominant worldview of knowledge inherent in the physical and social sciences at that time. This view ignored phenomena that could not be directly observed or measured. He believed that science needed a philosophy that could come in contact with deeper human concerns. His mission was to reinstate the discipline of philosophy to its former importance through the search for absolute knowledge (Cohen 1987). Husserl believed that pure truth and a clear understanding of the essential nature of reality could only be discovered through the study of lived experience and systematic descriptions of the phenomena encountered by humans in their everyday lives.

Husserl sought to establish a science of phenomena as a science of recognition of essences or structures rather than of matters of fact proven by methods more accustomed to positivism. Thus, Husserl was concerned with essence, which has been defined as 'a fact or entity that is universal, eternally unchanging over time and absolute' (Jennings 1986, p. 1232). He classified his phenomenology as transcendent, one whose purpose was to transcend or overcome the traditional scientific notion that only that which can be observed and measured using empirical methods is valid knowledge. The process of transcendental subjectivity is achieved through seeking to research the genuine and true form of things themselves. Therefore, Husserlian phenomenology attempts to describe the way the world reveals itself to consciousness without using theoretical constructs derived from philosophy and science (Palmer 1969).

Husserl was concerned with 'how do humans know what they know?', thus his concerns were epistemological in nature. He believed that meaning and understanding could only be gained through direct experience of a phenomenon and avoidance of theories and preconceptions. This stance reflects a Cartesian notion of subjects experiencing, and knowing, objects in their world.

Husserl, like Descartes, placed consciousness at the centre of this philosophy (Palmer 1969) and saw it as the foundation of knowledge. However, Husserl's notion of consciousness differed from Descartes' in that he claimed that we are always conscious 'of' something. For example, one cannot just be frightened, or upset; one is frightened of something, or upset about something. Husserl names this intentionality, which he sees as being unique to the human mind and distinguishing it from all other things (Palmer 1969). In response to situating human consciousness at the centre of his philosophy, Husserlian phenomenology sought to illuminate both the content and the method of the mind (Palmer 1969).

Phenomenological reduction, which is also referred to as eidetic reduction or bracketing, is an important concept in Husserl's phenomenological philosophy (Cohen 1987). Husserl formulated the notion of the life world, or Lebenswelt, which he saw as the everyday world in which we live, the natural taken-for-granted attitude (Ray 1990). Taking as his starting point this life world, Husserlian phenomenology suspends and holds in abeyance the usual assumptions and presuppositions to get behind the 'natural standpoint' to find the underlying structure. Thus the researcher takes a detached view, in order to see the phenomenon from an objective stance. He saw this as the only means by which the phenomenon in question can be revealed in pure, uncontaminated consciousness. Husserl was committed to seeking absolute knowledge by peeling away the non-essential features of objects and revealing the underlying essence (Jennings 1986). Thus, Husserl's phenomenological method went to the things themselves, bypassing previous knowledge and theoretical understandings in order to reveal the essence of a phenomenon.

Annells (1999) situates Husserlian phenomenology within the positivist research paradigm being as it is concerned with researcher objectivity and bracketing of the natural world. Thus Husserl's philosophical stance is not appropriate for this study, which seeks to understand the meaning for mothers of having their newborn babies transferred. This particular question is an ontological question: it is concerned with what it means to be a mother and experience a particular phenomenon in a particular context – in this case having their newborn babies transferred from their local neonatal unit to a regional neonatal unit. As this study asks an ontological question, it requires an approach that reflects an ontological perspective.

I clearly identified in Chapter 1 that my interest in pursuing this line of inquiry arose from my own interest and background as a neonatal nurse who has cared for many mothers whose babies are transferred and as a mother who had experienced neonatal transport. My experience as a nurse and as a mother with a transferred baby meant that I did not feel I could genuinely enter the world

of the study participants devoid of professional knowledge, beliefs and values regarding the problem under investigation. Therefore I chose to adopt the perspective of Heideggerian phenomenology, which also derives from the German phase but whose philosophical underpinnings differ from those of Husserl's.

3.3.2.2. Heideggerian phenomenology

Martin Heidegger was born in Messkirk, Baden-Wortemburg, in Germany in 1889. He commenced study at the University of Freiburg in 1909, where initially he was a student of theology, later switching to mathematics and philosophy. He was also a student and colleague of Husserl for a period of time. Although Husserl's ideas initially impacted on and influenced Heidegger's ideas, it soon became apparent that his philosophical concerns differed markedly from Husserl's (Palmer 1969). Whilst Husserlian phenomenology was epistemological and primarily concerned with revealing the essence of phenomenon, Heidegger was more interested in applying phenomenological method to a much deeper question – that of being itself (Palmer 1969). Heidegger used the term Being with a capital B, to denote the being of human beings.

Heidegger believed that the ontological question of 'what it means to be' was primordial and should come prior to seeking epistemological answers or questions of knowing. That is, he turned the phenomenological focus from the Husserlian stance that ought to ask the epistemological question 'how do we know what we know?' to an ontological perspective that asks 'what does it mean to be a person?' (Leonard 1989, p. 42). This shift by Heidegger from the epistemological stance of Husserl to an emphasis on ontological questions resulted in the development of a second branch of phenomenology known as hermeneutic phenomenology.

Heidegger's quest was to illuminate Being, and make it the central question of concern to philosophers. He did not seek to question Being itself: instead he questioned the meaning of Being. In the first part of Being and Time, Heidegger considers the reasons why the question of Being has been overlooked and attributes this to the view that Being was so universal and taken for granted, that philosophers did not see any reason or need to discuss it. He disagreed with this viewpoint and instead saw Being as *'the darkest concept of all'* (1927/1962, p. 230) which could only come to light and be revealed through an examination of human ways of being. In so doing, he noted that since what things are (their Being) is accessible only when they are shown to us as relevant in some way, we need a 'fundamental ontology' that clarifies the meaning of things in

general. Heidegger saw that the first task of fundamental ontology was to clarify the possibility of having any understanding of Being at all.

Heidegger considered phenomenology as one way of bringing to light the ontological foundations of understanding *Being*. Like Husserl, Heidegger also refers to the lived world, and believed that an understanding of being can be reached through 'being-in-the world', and to what he sees as the pivotal notion of human everyday existence: *Dasein* (Annells 1996). Heidegger uses the term *'Dasein'* to depict human Being. That is, the Being that belongs to persons, the nature of *Being* that gives rise to an awareness of the existence of Being. The word *Dasein* literally means *being there* (Annells 1996). Heidegger uses it to denote the being there of human beings, the place where Being is and manifests itself. Heidegger saw *Dasein* as the locus of human existence. Thus *Dasein* in a Heideggerian sense is the basic structure of humans, where each human's own way of being is an issue for it (Giugnon 1993).

In contrast to Husserl's view of reduction and bracketing of pre-understandings, Heidegger considered that there was no 'I' separate from the world. Rather there is *Dasein* which is the *'entity which each of us is himself'* (1927/1962, pp. 27-28). Being-in-the-world is therefore an essential part of the structure of *Dasein*, and inseparable from it (1927/1962, pp. 78-90). There is no pure vantage point to which we can retreat that will enable us to see the world from a disinterested and supposition free stance (Giugnon 1993) and Heidegger repeatedly emphasises that the world and *Dasein* are not separate. Thus *Dasein* cannot be comprehended without considering the world, since the world is an essential characteristic of *Dasein* itself (1927/1962, p. 92). As the world and *Dasein* are inseparable and since this being-in-the-world as human existence is the only position possible, there is no subject-object dichotomy of the world and *Dasein*. Phenomenology from a Heideggerian perspective renders no possibility of separating the self from the world and so it is impossible to bracket one's assumptions and be separated in any way.

Heidegger's fundamental ontology begins with a description of the phenomena that shows itself for us in relation to our being-in-the-world and our pre-understandings of what things are all about (Giugnon 1993). From being participants in a shared world we are able to grasp the being of entities such that the hidden meanings of these emerge and come to light. In Heidegger's view, the hidden meaning of phenomena is revealed firstly through a description of everyday existence, a phenomenology of everydayness which, when coupled with a hermeneutic (interpretation), brings to light the hidden meaning of the practical life world (Giugnon 1993). That is, by

examining human ways of being-in-the-world, we are able to bring to light the meaning of *Being*. In this way, Heidegger sees that there is a 'clearing' in which specific forms of human existence are revealed (1927/1962, p. 171). This clearing allows that which is hidden to become accessible and show up as what it is. *Dasein* is said to be a clearing through which entities can stand forth and be revealed.

However, neither Husserlian nor Heideggerian philosophy seemed to offer me a satisfactory set of beliefs and assumptions to support my study. Husserlian phenomenology does not draw solely on the experience of the 'other' under the auspices of a single point of view. In this study neither the mother nor the researcher can assume a privileged position in interpretation. I felt that my preconceived ideas, values and experiences were important to me and I did not want to 'bracket them', even if it were possible, and it has been widely acknowledged to be impossible (van Manen 1994). The very fact that I am a practising neonatal nurse and am the product of my previous experience led to my desire to undertake the study, further supporting my reluctance to 'bracket' my beliefs. Conversely Heideggerian thinking seemed to accept without challenge pre-existing ideology and prejudice as an unavoidable characteristic of human understanding; yet these may deform new understandings of lived experience (Warnke 1987).

The limitations of these two phenomenological approaches have led to further streams of thought. A completely unobstructed view of reality is assumed to be impossible, but movement towards it by uncovering previously obscured essences that can support new understandings is considered a worthy activity (Warnke 1987). Further readings led me to approaches supported by this thinking: Gadamer's (1988) hermeneutics and van Manen's (1994) method of exploring lived experience.

3.3.3 Hermeneutics

The term hermeneutics means interpretation. It is derived from the Greek word *hermeneuin*, which means to interpret, and is thought to have originated from the Greek God Hermes who apparently discovered languages and writings and conveyed messages to human beings so they could in turn convey them to others (Thompson 1990). According to Palmer (1969), hermeneutics involves both interpreting and understanding texts particularly where the process involves language. The underlying assumption of hermeneutics is that humans experience the world through language that provides understanding and knowledge. Thus language enables humans to derive understanding of the world in which they live. Hermeneutic interpretation, therefore,

enables meanings in human understanding of being–in-the-world to be revealed in a meaningful way.

Traditionally, hermeneutics referred to the process involved in interpreting biblical texts. Later it became an accepted means to interpret other secular texts such as in law and literature. In the nineteenth century hermeneutics took a practical turn, and formed the basis for all human science (Palmer 1969). This was due mainly to the influence of two scholars. Schleiermacher and Dilthey, who both sought to extend hermeneutics beyond its traditional, specific role.

3.3.3.1 Schleiermacher

Frederich Schleiermacher (1768–1834) was a Platonic scholar who first proposed a general hermeneutics, thus moving away from a specific theological, legal or literary meaning (Palmer 1969). He asserted that the principles underpinning traditional hermeneutics could be generalised into a set of laws by which meaning operates, which could be used to guide the process of extracting meaning from a text (Palmer 1969). Schleiermacher proposed that such a science of understanding comprised two distinct parts that were both essential in the process of reaching meaning: understanding language and understanding and re-visioning the thoughts of the author of the text. His contribution marked an important turning point in the development of hermeneutics as it became to be seen as the art of understanding language in any context.

3.3.3.2 Dilthey

Wilhelm Dilthey (1833–1911) continued to develop hermeneutics, seeing it as the only means by which human expression could be revealed meaningfully. At this time, reductionist thinking inherent in natural sciences was also being extended into the domain of the human and social sciences. That is, there was a prevalent belief that valid knowledge could only be derived from research that took an objective, atemporal stance. However, Dilthey asserted that human understandings could not be reached through such methods, but instead could only be gained from studying the experiences of life itself. (Palmer 1969). Life experience, according to Dilthey (1985, cited in van Manen 1990, p. 35) involves our immediate, pre-reflective consciousness of life.

A lived experience does not confront me as something perceived or represented; it is not given to me, but the reality of lived experience is therefore – me because I have a reflexive awareness of it because I possess it immediately as belonging in some sense.

Dilthey believed that the task of human science, then, was to reveal the underlying structures that give meaning to an experience. A key feature of his work was the assertion that interpretation can only occur from within an historical perspective. That is, in order to understand the present, we need to be aware of and acknowledge the past. Dilthey believed that both the past and the future constitute the horizon and it is only within this horizon that the present can be interpreted. Following on from the earlier work by Schleiermacher, Dilthey further developed the concept of the hermeneutic circle (Palmer 1969) which involves the continuous circular movement between the background of shared meaning (the whole) and the individual experiences (the part) of the participants (Leonard 1989).

Dilthey extended the concept to place the person within the circle, a move that effectively shifted the focus of interpretation from the author, as in Schleiermacher's work, to the expression of lived experience. This focus was clearly phenomenological in nature, and was influential in the development of Heidegger's later work.

3.3.3.3. Heideggerian hermeneutics

Heidegger is considered the prime instigator of modern hermeneutics (Annells 1996). His work, starting as it did with a rethinking of Husserl's phenomenology, also extended the work of Dilthey by further extending the concept of the hermeneutic circle. Rather than seeing it as part of the method for researching within the human sciences, Heidegger took the stance that it was central to all human knowing and understanding. Heidegger (1927/1962) believed that everyone exists hermeneutically through interpreting and finding meaning in their lived world, and he saw that hermeneutical inquiry could be applied to search for the meaning of Being. He, therefore, goes beyond Dilthey's life experience view to situate hermeneutics ontologically.

Essential to understanding are three considerations that Heidegger termed the structure of understanding, or fore-structure. There are three considerations he sees as integral to human interpretation and understanding that takes place within the hermeneutic circle (Gelven 1989). Firstly, the fore-having relates to the taken-for-granted, background practices that are already understood and allow for interpretation to occur. The next part, known as fore-sight, relates to the particular point of view for which we make an interpretation that is the awareness and background of the interpreter that directs him or her in a specific way towards phenomena. The third part, the fore conception, is concerned with our expectations, and is linked to the previous considerations. As a result of our fore-having and fore-sight, we anticipate a range of possibilities

in an interpretation. The fore-structure of understanding, then, is an essential component of Heidegger's hermeneutics.

Heidegger believed that the way meaning is uncovered is through language, that is, language sets up the conditions for human understanding in our everyday life. Language makes meanings, which are disclosed to us through language (Thompson 1990).

Heidegger's perspective on hermeneutics is important for this study as it positions the researcher within the research process. That is, the researcher is with the participants and incorporates his or her own perspectives throughout the interpretative process to reach a fusion of horizon of understanding. This position reflects my own position as nurse and nurse researcher. I have always aimed to be with patients and not distance myself. The way in which I incorporate a Heideggerian hermeneutical perspective in data analysis is explained in the next section.

Following on from the work of Heidegger was another German philosopher, Hans Georg Gadamer. Gadamer built on the work of Heidegger and extended discussion on many of the concepts underpinning hermeneutics. Although coming after Heidegger, a brief discussion of his ideas will now be provided as they assisted me in finding my understanding of hermeneutics.

3.3.3.4 Gadamer's hermeneutics

Gadamer is the crucial figure in philosophical hermeneutics, and as a student of Heidegger his philosophy extends Heidegger's existential ontological exploration of understanding. Knowledge is developed through a 'hermeneutic circle' and 'the fusion of horizons' where pre-understanding is merged with meanings in the text to become the pre-understanding of the future (Koch 1994b).

The hermeneutic circle is a metaphor for describing the analytical movement between the whole and the part, in which each gives the other meaning (Heidegger 1962). Based on this assumption, all participate in evidence generation, and lead to a 'fusion of horizons' whereby the perspectives of the researcher and participants are brought to bear on the project via this fusion. A related concept of Gadamer is that of 'prejudice', that the horizon incorporates the background meanings and frame of reference.

The Heideggerian–Gadamerian position is that interpreters participate in making data precisely because the hermeneutic circle cannot be avoided (Grondin 1994). Co-constitution demands that

primary data be regarded as contextualised life events, with the person's and the researcher's perspectives specified via the 'fusion of horizon'. The following section provides a brief explanation of Gadamer's concepts.

a. Fusion of horizons

Gadamer extended and drew on Husserl's concept of the horizon, and described how a fusing of horizons occurs through a process of understanding when researchers immerse themselves in the analysis of the text, allowing the horizon of the text to fuse with the horizon of their own meanings. This continuous interaction between the interpreter and the text introduces Gadamer's notion of effective historical consciousness (1975), which refers to the conscious task of trying to understand the text by comprehending its historical and present contexts. Through this fusion of horizons, this joining of one's own historical concepts and meanings with those of the text, a greater understanding can be achieved.

For Gadamer, hermeneutic interpretation involves a conversation between the interpreter and the text that is reciprocal in nature. The interpreter enters a thinking dialogue with the text in order to arrive at a more complete understanding. Like Heidegger, Gadamer considers it essential that the historical, social and biographical location of both the text and its interpreter (the pre-understandings) are made explicit in the interpretation process. My interest and background can be found in the section 1.4.1 of this work and throughout the work. I believe this helps to make explicit my understanding and interpretation of the text.

b. The hermeneutic circle

The concept of the hermeneutic circle involves a continuous, circular process whereby the interpreter moves between the whole and the part of the text derived from participants.

Polkinghorne (1983, p. 227) describes the hermeneutic circle as:

> *The process of understanding is a movement of the first pre judgemental notion of the meaning of the whole, in which parts are understood, to a change in the sense of the meaning of the whole because of the confrontation with the detailed parts of the whole.*

According to Leonard (1989), through the process of systematically analysing the whole, we gain perspectives and an increased depth of understanding. This in turn is used to examine the parts of the whole, and then re-examine the whole in light of the insights gained from the parts. Moving back and forth within the hermeneutic circle gives rise to an increased awareness and understanding, and can also reveal meaning that may have previously been hidden or undisclosed.

The hermeneutic circle includes both the participants and researcher. The participants tell their study from their own interpretation, and the researcher interprets this from his or her own background and experience as well as the participants. Thus there is a moving back and forth.

c. Prejudice

Gadamer defines the concept of prejudice as preconceived ideas or notions that are derived from one's background and past history. Gadamer's (1975) concept of prejudice is linked to Heidegger's ideas of the three-fold structure of understanding, or fore-structure. Grasping this fore-structure of shared understanding, or prejudices, becomes the starting point of interpretation. A description of where I am situated in the study, reflecting Heidegger's stance of the researcher being involved in, and not separated from, the research was presented in the previous chapter.

d. Dialogue with the text

Hermeneutical interpretation requires the researcher to continually engage with the text. In effect, the researcher is involved in a conversation or dialogue with the text that continues throughout the entire analytic process. Engaging in a dialogue with the text opens up new ways of looking at the world, as the researcher questions the text and reflects on the questions derived from the text. Dialoguing with the text enables the researcher to reach a greater understanding of the meaning of the participants.

e. Language

Hermeneutics emphasised the primacy of language. Gadamer (1975) sees the goal of hermeneutics as to examine the nature of human understanding, a goal that can only be achieved through a thorough and rigorous examining of language itself. For Heidegger and Gadamer, language is the medium of interpretation, and the product of human culture. Language is created and reproduced socially and historically, existing in our everyday lives and forming the background of shared understandings that form our prejudices and preconceived ideas. Thus, language is a way of being in one's world.

Like Heidegger, Gadamer believed that understanding is derived from an historical and cultural perspective that is dynamic and changes over time. Thus he believed it was not possible to develop a systematic method for the human sciences, as this requires a static, detached and objective stance that will only abstract from the truth.

The importance of silence, listening, hearing and talking is an integral part of this study. It is the tool by which the data are collected and experienced.

3.3.4 van Manen's human science approach

van Manen (1994) is an educationalist who was concerned with devising a method of exploring issues of relevance to the practice of teaching. He claims his method for exploring human experience to be both phenomenological and hermeneutic. He believes that complete reduction is unobtainable but reflection on goals and methods plus the use of 'free imaginative variation' are seen as part of the process of the structural analysis of the 'taken for granted'.

van Manen offered an alternative phenomenological approach which has elements of both Husserl's and Heidegger's philosophies. This is evident in his six research activities, which serve to partly influence the methodological structure of this study, as I see this as having utility for improving thoughtfulness, and practice action. It does not describe actual states of affairs but aims to make explicit the structure in the taken-for-granted, enabling 'action-sensitive' knowledge that facilitates more thoughtful action.

3.4 The philosophical underpinning

The struggle to apply Husserl's philosophy to the practical process of knowledge generation has spawned a diverse range of research methods and methodologies, of which I have presented just a few that follow a particular direction.

If all phenomenology has its origins in Husserl's thinking, then this study is phenomenological. In the absence of any clear and consensual definition of phenomenology, I made no presumption that this study is an example of phenomenology. However, it has been influenced by Husserlian and Heideggerian philosophies and in particular the ways in which these have been translated into method by van Manen (1990). The importance of the acknowledgement of the researcher's background, expectations and frames of meanings in the act of understanding caused me to favour its adoption for this study, as previous experience had led me to believe that these factors were important not only to understand better, but also to understand differently. Understanding like conversation is always a reciprocal relationship (Hekamn 1983). This hermeneutic inquiry is

inevitably influenced by my values (Gadamer's notion of prejudice). I take the position that my values or prejudices, rather than getting in the way, make the research meaningful to its readers.

Thus the philosophical assumptions underpinning the study were selected for their consistency with each other and their ability to provide a coherent justification of the decisions and actions throughout the research process.

3.4.1 Limitations of ontological hermeneutics

There are limitations associated with all research methodologies, and it is important that researchers acknowledge the specific limitations associated with their chosen approach. When using phenomenology, the researcher needs to be aware of the philosophical and methodological concerns surrounding this means of inquiry.

Throughout this chapter I have identified that those undertaking a phenomenological study must articulate and incorporate the philosophical underpinnings relevant to the type of phenomenology used. To do otherwise would invalidate a study's credibility. As a qualitative approach to research, it is acknowledged that phenomenology does not attempt to predict, generalise or generate theories.

Instead phenomenology aims to increase our understanding of certain phenomena, and the meaning individuals attribute to these. This is of value for those interested in human experience, and contributes to nurses' understanding of patients' perspectives. Moreover, this form of interpretative research can heighten our sense of awareness and appreciation of the human condition, and may provide possibilities for future research. It is therefore important that the methodological approach chosen reflects the aims and purpose of the research question. This has been clearly demonstrated in the present study.

3.5 Section one summary

The above discussions have shown that phenomenology is an approach that is important in the study and meaning of human experience. The review of the historical development of the phenomenological tradition highlighted the two types of phenomenology, and identifies that Husserl's work provided a basis on which others could build, including Heidegger. It has also shown that the ontological hermeneutic phenomenology of Heidegger was most appropriate to answer the research question, as it provided direction to allow me to uncover the meaning

mothers attribute to their experience of having their newborn babies transferred to a regional neonatal unit. Relevant concepts within the hermeneutic phenomenology were explained to provide the context for the study. Limitations inherent in adopting this approach have been identified. The following section will outline the processes that enabled me to gain an understanding of the research question.

Section 2: Methods

3.6 Introduction

In the previous section, the research design used in this study was discussed, and its relevance for this particular study was demonstrated. To advance this study and reach an understanding of the phenomenon of interest requires that the research method chosen is consistent with and reflects the philosophical tenets underpinning the methodology.

This section describes the method utilised in this study to explore the phenomenon. A description of van Manen's (1990) six activities for phenomenological analysis is presented and the justification for choosing this particular approach to analysis is provided. Included is the procedure for the selection and recruitment of the study participants. The procedures for collection and analysis of data are described in detail, and ethical considerations are outlined. I conclude with a discussion on rigour when using this type of research approach to demonstrate my understanding of the issues involved in using Heideggerian ontological hermeneutics and to make clear how I ensured rigour throughout the entire research process.

3.7 Sampling

In qualitative research, the purpose of sampling is not to generalize but rather to maximize the scope and depth of information regarding the phenomenon under study from those whose perspective is desired (Field & Morse 1996). According to Hycner (1999, p. 156), *'the phenomenon dictates the method (not vice-versa) including even the type of participants'*. In order to develop greater understanding of the phenomenon of being a mother with a transferred baby and to identify issues of importance to mothers, it was decided that mothers would be selected purposively (Patton 1990). Theoretical saturation is not sought in hermeneutic studies as the temporality of truth is recognized (Moustakas 1990). Furthermore the research question was

developed broadly and a progressively intense focus on specific aspects of the lived experiences was not sought.

An adequate sample size is ultimately justified by evaluating the quality of information collected to see whether the information was adequate to support the particular study (Sandelowski 1995). It is therefore not possible to know in advance how many interviews will be sufficient. The sample size for the study is potentially infinite in that any account of the mother's experiences in initial neonatal transfer might be able to further advance knowledge and understanding of this phenomenon. This is based on the principle that as long as all of the participants have experienced the research phenomenon, a large number of participants is not needed to reveal the phenomenon's basic essences, which remain immutable (Polit & Beck 2004). However, constraints of time and resources had to be taken into account and a sample size of 15 mothers was recruited.

3.7.1 Sampling criteria

Sampling criteria were formulated after advice and discussion with the CRAG members based on my judgment, the purpose of the research, and their experience of the subject matter and the clinical area.

A mother was included if:

- Her baby has been transferred from their local neonatal unit to the unit in which the research was being conducted.
- Her baby's condition was considered non-life-threatening at the time of her recruitment to the study by the neonatalogist in charge.
- She was in a satisfactory physical and emotional state as judged by the consultant or nursing staff in the neonatal unit.
- Her baby's stay was three days or more, from the day of transfer into the neonatal unit in which the research is being conducted.

These criteria sought to ensure that only mothers who had had the experience of having their newborn babies transferred from a local neonatal unit to a Level 3 neonatal unit and would be able to share the experience were recruited. A period of three post transfer days should allow the

mother to experience the new setting, form personal impressions about the new environment and for the baby's condition to be stabilized by then (Boxwell 2000).

A mother was excluded if:

- Her baby was born in the unit where the research was being conducted.
- Her baby was electively admitted to NICU for any elective procedure.
- Her baby was critically ill or dying at the time of potential recruitment to the study.
- Her baby had been transferred more than once into the neonatal unit in which the research was being conducted.
- She was not comfortable conducting the study interview in English.
- She did not consent to participate in the study.

These criteria sought to exclude mothers who had not had the experience of having their newborn babies transferred from a local neonatal unit to a Level 3 neonatal unit or who had experienced transfer of their baby before, thus may have particular experience of transfer. Any elective transfer may entail preparation being given to the mother and thus may influence how the experience is being viewed. To avoid any possibilities of the mother experiencing acute crisis and emotional turmoil when her baby is critically ill, the mothers of such babies were excluded from the study. Consideration was given to whether or not to include mothers who were not comfortable to participate in an interview in English. Clearly, there may be very particular issues to be addressed here, as these mothers are likely to have additional difficulties and may also be less likely to have supportive family close by. However, in view of the time and budget constraints, this study will be restricted to mothers who are comfortable speaking English.

All the participants were mothers. This does not imply that I am uninterested in the father's experiences or that the fathers are uninterested in their child's health care or in research, but reflected the CRAG recognition that the mother and father each have their own experiences that may be uniquely different from each other. Moreover, the current prevalent pattern of parent most likely to stay with the child during hospitalisation was the mother, being the predominant carer (Darbyshire 1994). A clear implication of recruiting mothers only is reflected in this study's title. In the limitations section in the discussion chapter, it is emphasised that a study involving mothers (or indeed fathers) cannot be presented as an account of the experiences of parents in general.

3.8 Gaining access

3.8.1 Site selection and location

The implementation of the study relied on gaining access to mothers who had experienced having their newborn babies transferred to another neonatal unit.

Due to time constraints and practicalities, the nearest Level 3 neonatal unit where the researcher had not worked and which offered both medical and surgical neonatal care in the South East of England region was selected. Initial transfer into this unit is therefore relatively common.

The unit

This unit was opened in 1981 and offers modern facilities for both staff and parents. Within the maternity unit there are about 5000 to 6000 deliveries annually and approximately 9% of these are admitted to the neonatal unit. It was recognised as one of the Regional Centres for neonatal medicine in 1988 and the Regional Centre for surgical neonatal services in 2000 in the Wessex Region of the UK by the Regional Health Authority.

The unit is officially funded for twenty-two cots, six of which are designated intensive care cots. The total number of admissions in 2002 was 602, of which 118 (19.6%) were babies transferred from other neonatal units (unpublished data 2002).

The unit is divided into three open plan rooms, one for babies requiring intensive care, one for babies requiring high dependency care, and one for babies requiring special care. The intensive and high dependency rooms are relatively small and cramped due to an ever- increasing amount of hi-tech equipment, not envisaged when the unit was designed, and intermittently by overcrowding of babies.

Parents, siblings and grandparents are allowed to visit the babies in all the three rooms. It has an open visiting policy and toys are available for young children to relieve the boredom of hospital visits. Facilities for parents include a coffee room, single and double accommodation, and a two-bedded mother and baby room for 'rooming in' prior to discharge or for establishment of breast feeding. Parents are invited to a support group, which meets weekly on the unit. by one of the two Family Support Sisters. An explanatory booklet introducing the unit and giving brief details of

the facilities, staff and support is given to all the parents when their babies are admitted to the unit. The multidisciplinary team, consisting of nurses, doctors, social worker and a liaison health visitor, meets weekly to discuss admissions, progress, social problems and discharge plans.

3.8.2 Negotiating access

Approaching participants in person, researching a topic they are interested in, and visiting at their convenience help to increase their confidence in the study and reduce non-response (Barriball and While 1994). These factors were therefore taken into account when planning to approach both gatekeepers and participants. Gatekeepers can be crucial in providing access to participants where there is difficulty in accessing participants as in this study.

In health care settings, access may involve a lengthy process of negotiation between several sets of professionals – managers, nurses, doctors – quite apart from the formal approval of the ethics community (Mays & Pope 1995). Waddington (1994) discusses how gaining access involves a process of managing your identity, projecting an image and convincing gatekeepers that you are non-threatening. Personal and psychological issues on the part of the researcher may also contribute to facilitate or impede access. I found that it involves considerable time and effort and constant endeavour to strive for 'cultural acceptability' with the gatekeepers in the site. It is not a straightforward process of speaking to the person in charge and obtaining an honorary contract from the hospital in which the study is being conducted for legal and ethical requirements.

Appointments were made and a series of meetings were held during the year 2003 with senior medical and nursing staff in the unit to discuss the possibility of carrying out this research. These meetings gave me the opportunity to meet each of the senior staff in person and win their support for the study. I felt this was especially important as the study had implications for patient care in taking nurses' time to introduce and give the information sheet to potentially eligible mothers.

3.9 Recruitment

Participants were recruited over a seven-month period (April to October 2004 inclusive) in one designated regional neonatal unit in the UK.

Full orientation to the research study was provided for the nurses working in the neonatal unit. An information sheet about the study was given to the nurses in the unit (Appendix 6) by the researcher and the researcher had group and one-to-one sessions to discuss the study fully with the staff.

All potentially eligible mothers were identified by the researcher from the routine information about admissions held in the NICU. The nurse looking after the baby was approached on the fourth day after the baby's transfer to ascertain any concerns for the baby and the mother. If there were no concerns, the introduction letter and information sheet about the study were given by the nurse to the mothers (Appendix 7). If there were any concerns from the nurse, the situation was assessed daily. The information sheet was only given when there were no expressed concerns from the nurse.

The mother was given a pre-addressed return envelope to insert a reply slip indicating whether or not she was willing to be contacted by the researcher to explain about the study. A sealed box had been placed in the main nurses' station in the unit for the mothers to return the reply slip. The box was checked daily to monitor return slips and thereby identify mothers who wished to find out more about the study.

Once a mother had returned the reply slip indicating her willingness to consider participation in the study, I arranged to explain the research study in more detail and answer any questions that arose. Written consent was obtained after the mother had enough time to consider her participation in the study (Appendix 8). Arrangements were made to interview the mother within the tenth post-transfer day of the baby to the unit. A flowchart detailing the research protocol is found in Appendix 9.

3.10 Data collection

In qualitative inquiry, data collection usually involves collecting some form of conversation with the focus on language. It is argued by Silverman (1993) that whilst conversation is often seen as trivial, it is increasingly recognised as the primary medium for social interaction to take place. The most common method of getting participants to talk in a research setting is by interview. Allowing participants to tell their stories is a primary way of understanding events and discovering the meaning of their experience (Rubin & Rubin 1995, Ely et al. 2000).

The vital aspect of this study was to talk to mothers about their experiences when their newborn babies were transferred. Therefore the appropriate data collection was to engage the mothers in dialogue about this issue. One-to-one interview was selected as the most appropriate research method to allow for more sensitive questioning than could be used, for example, via self-completed questionnaires. It also offers the opportunity to pursue and clarify issues that participants may raise (Polit et al. 2001, Denzin & Lincoln 1994, Robson 1993).

3.10.1 Research interviews

Interviewing is a learned skill. It is important that the interviewer learns to see the experience from the perspective of the participants, to understand the meaning of the words by probing and clarification, yet not to lead (Ely et al. 2000, Rubin & Rubin 1995, Morse 1991).

The interviews in this study were guided by approaches that emphasise the interactional nature of the social encounter taking place when two people come together for the purpose of a research interview (Kvale 1996). The purpose of the interviews conducted for this study was to capture the subjective perceptions of the study participants. An open non-directive interview is commonly thought to be the best tool for this purpose (Kvale 1996). Kvale (1996) remarks that qualitative interview is 'literally an inter view, an interchange of views between two persons conversing about a theme of mutual interest,' where the researcher attempts to 'understand the world from the subjects' point of view, to unfold meaning of peoples' experiences' (pp. 1-2). At the root of phenomenology, 'the intent is to understand the phenomena in their own terms – to provide a description of human experience as it is experienced by the person herself' (Bentz & Shapiro 1998, p. 96) thus allowing the essence to emerge (Cameron et al. 2001).

The underlying rationale of this approach is that we need to know how the mothers construct meaning in order to understand how that meaning is embodied in their actions and interactions with others. Implicit in this is the belief that people act in accordance with the way they define a particular interaction (Rose 1996).

The approach of the researcher can reduce his or her impact on the data generated (Rew et al. 1993). The adoption of a reciprocal and equitable relationship with participants is advocated by Rose (1996). I tried to establish trust by finding a role that was acceptable to the participants – as a nurse studying a topic relevant to the participants. I also developed contacts with the

participants by explaining the purpose and need for the research through the introductory meeting and use of the consent form (Moustakas 1990).

I was concerned throughout the process of interviewing that the participants should be influenced as little as possible by my own perspectives. The outcome of this concern was interviews that shared the following characteristics. Firstly, they followed no set procedure or prescription (Kvale 1996). Secondly, they were all directed by concern to respond to the research question (van Manen 1994). Thirdly, I always initiated the dialogue with a single opening question:

> *Please tell me what it is like to have your baby transferred from the neonatal unit she/he was first admitted to the present neonatal unit.*

This question was intended to generate description, examples, anecdotes and analogies (van Manen 1994, Crotty 1996). The remaining dialogue was then built onto the response to this first question, rather than an interview following any pre-planned structure. At times it was necessary to ask for clarification by asking open-ended prompts. The sort of prompts used was:

> *Could you tell me a bit more about...please?*
> *How did that make you feel?*
> *Go on ...*
> *Is there anything else?*

3.10.1.1 Advantages and disadvantages

Interviews might be time consuming (Hutchinson et al. 1994), and there may be an assumption that the interviewee is being truthful (Wengraf 2001). Participant recall might be affected by the perceived importance of the event or the possibility of the participant repressing unpleasant events (Wengraf 2001). However, large volumes of rich contextual data may be obtained. Clarification of certain statements or interpretations is possible and non-verbal cues can be observed. Some of the positive outcomes for participants include catharsis, validation, empowerment and healing (Hutchinson et al. 1994 Morse 1991).

The potential of unstructured interviews as a medium for accessing experience has been challenged, as they can collect retrospective data and thus may not be trustworthy (Patton 1999).

However, for the purpose of studying experiences it is not important that the interview is an accurate account of exactly what happened to the participant, only that it is a representation of the phenomena under study (Speigelberg 1971).

3.10.1.2 Arranging and conducting the interviews

I negotiated with each of the mothers a suitable time and place for the interview. A quiet room was negotiated with the Clinical Nurse Manager. On arranging an interview I asked participants if they would like me to contact them the day before to confirm that the arrangements were still convenient.

The interviews were all tape-recorded and were between 45 and 90 minutes in length. The time spent in conversation before and after the interview varied considerably between a few minutes to half an hour.

The sensitivity of the subject made the development of rapport and a trusting relationship imperative. Initially my acceptance by staff and my clinical background in neonatal nursing provided me with some degree of credibility in the eyes of the mothers and assisted in the establishment of rapport. I was not directly involved in their baby's care yet I had an understanding of the world of neonatal care that they had entered. I was always careful not to align myself too closely with staff or become involved in the baby's care for fear that doing so would jeopardise my perceived impartiality. I was aware of the demands on mothers' time and that agreeing to be interviewed was one more task to be added to an already long list of things to do. Accommodating mothers' preferences regarding the timing and location of the interview and being sensitive to their baby's condition was an important part of maintaining rapport.

During the interview, sometimes I refocused the interview when it appeared to be heading off on a tangent of no real value. For example, in one of the interviews in the pilot study, the mother started talking about her premature labour; I tried to redirect her back to the focus of the study by asking questions like:

You mentioned earlier that...can you tell me more about this and how it made you feel.

Let's explore a bit deeper on your comment about....

Before leaving the interview I reconfirmed the consent given to use the data gained during the interview. During each interview I always carried with me a list of support agencies in case issues rose during the interview that caused distress to the participants (Appendix 10).

Immediately following each of the interviews I returned to an empty room to check the standard recording, and make notes relating to the interview in my study journal. The content of the notes included details of the interview that occurred before and after the tape recorder was activated, observations relating to body language, non-verbal communication, contextual events, thoughts and observations associated with the interview (Appendix 11).

After each interview a letter of thanks, an interview comment sheet and a stamped addressed envelope was sent to each mother (Appendix 12). Any responses were treated as data and incorporated into data analysis.

3.10.1.3 Equipment used

A small tape recorder and a boundary microphone designed for use in the interview setting were used. Before leaving for each interview the tape recorder was checked to ensure it was in working order. A spare tape recorder and a supply of batteries and blank tapes were taken to the interview. During the interview the tape recorder and the microphone was placed as close to the participant as possible, but out of the direct view of the participant. The words of caution by Easton et al. (2000), that equipment failure and environmental conditions might seriously threaten the research undertaken, were borne in mind. They advise that the researcher must at all times ensure that recording equipment functions well and that spare batteries, tapes and so on are available. I used a checklist each time prior to any interviews (Appendix 13) to ensure that there was minimal disruption.

3.10.1.4 Medical records

Accounts of the ongoing management and treatment of the baby were gathered from the baby's medical record and nursing notes. This provided a sense of the context within which the mothers' experiences were occurring and thus enabled a more comprehensive interpretation of the interview data.

3.10.1.5 Study journal (field notes)

A journal was kept to provide an ongoing record of the study development and process. It also provided me with the opportunity to explore what was happening in the study as it allowed me to take further actions in relation to the process and direction of the investigation (Ely et al. 2000). According to Ely et al. (2000), the journal may contain *'feelings, insights, assumptions, biases and ongoing ideas'* (p. 69).

The following list describes its functions:

- Record thoughts and decisions regarding the progress of the study
- Record personal thoughts and feelings concerning the study and personal progress
- Record personal reflections before and after each interview
- Record any brainstorms or ideas or thoughts whilst transcribing / reading interview data
- Record any ideas and connections during data analysis

Researchers have given more prominence to the textual nature of phenomenological inquiry while not addressing the phenomenological reflection or the relation between phenomenological reflection and the writing process. I found that in order to engage with the text, it helped to reflect on how my history shaped my ideology and vice versa in order to develop deeper analysis of the social situations that framed my actions and my subsequent interpretation of the data. It is recognised that the themes thus identified are arguably related to the researcher's context of engagement with the text and may be accepted as simply one amongst many ways of understanding these experience(s). However, writing and keeping a study journal allowed me to re-enter the experience and re-capture the conversation.

3.11 Data management

3.11.1 Data storage

All data, transcripts and tapes relating to the study were stored in a locked filing cabinet to which only I had access. Field notes, transcribed interviews and flow diagrams were dated and numbered ID codes were assigned to each set of notes to identify relevant interviews and cases. Each piece of information gathered for each participant was stored in an A4 file. Prefacing each

file was a summary sheet containing a summary of each participant's social situation, along with key codes or themes to emerge from their unique data set.

I opened a file with divisions for the various interviews and filed the following hard copy documentation:

- The informed consent
- The field notes that I made subsequent to each interview
- The transcript interview
- Any additional information about the circumstances
- Any notes made during the 'data analysis' process, e.g. grouping of meanings into themes

3.11.2 Data analysis

van Manen's six stages

The desire to be true to the mothers' experiences of their situation was perhaps the biggest challenge of the study. van Manen (1990) himself cautions against using these steps mechanistically and acknowledges the somewhat artificial nature of the divisions.

Table 3.1 van Manen's (1990, p. 31) six stages

i)	Turning to the nature of lived experience
ii)	Investigating experience as we live it rather than as we conceptualise it
iii)	Reflecting on the essential themes which characterize the phenomenon
iv)	Describing the phenomenon through the art of writing and rewriting
v)	Maintaining a strong and orientated relation to the phenomenon
vi)	Balancing the research context by considering parts and wholes

These six stages are explained below.

i) **Turning to the nature of lived experience**

van Manen (1990) notes that a phenomenological study is the project of someone, a real person, within the context of that particular individual. Thus all experience is context bound. In choosing to focus upon the lived experience of mothers whose newborn babies were being transferred from their local neonatal unit to a Level 3 neonatal unit, I selected a topic that interested me deeply because of my professional experience in caring for such babies and their families. This in turn met van Manen's requirement for turning to a phenomenon that seriously interests me, the researcher.

ii) **Investigating experience as we live it**

This aspect reinforces the value of seeking a greater understanding of a human experience by treating the people who are actually living the experience as expert. To me this stage highlighted the importance of selecting participants who had the experience. The CRAG proved invaluable in helping to set the inclusion and exclusion sample criteria (see section 3.7.1). It is believed that through the utilization of clear criteria of selection, the mothers who participated in the study had lived the experience of having their newborn babies transferred to a Level 3 neonatal unit and therefore could be regarded as experts from whom to acquire a greater understanding of this lived experience. By listening to them one can arguably gain a better understanding of the transfer experience. This was evidenced by the rich data gathered from the interviews.

This aspect of van Manen's method supports my beliefs that rather than just trying to conceptualise and theorise about what it would be like to have a newborn baby, a greater understanding is achieved by asking those who experienced the phenomenon themselves.

However, in order to locate and recruit participants it was necessary to gain the support of the staff in the unit I had planned to access. Prior to commencing the study, I met with the respective staff to discuss my proposed research. I described the aim of the study and answered any questions that arose. This was an extremely important activity, as gaining access to participants relied heavily on gaining the support and assistance of the nurses.

iii) **Reflecting on the essential themes which characterize the phenomenon**

The purpose of phenomenological reflection is to try to grasp the essential meaning of something. van Manen does not consider essential themes as objects or generalisations but more like *'the stars that make up the universes of meaning we live through'* (p. 90).

In attempting to understand how to operationalise this stage, the following points were used to help me to understand what constituted a theme in a phenomenological study:

a. Theme is the experience of focus.
b. Theme is the form of capturing the phenomenon one tries to understand.
c. Theme is the sense we are able to make of something.
d. Themes are not objects one encounters at certain points or moments in a text.
(van Manen 1990 pp. 87 and 88).

The search for meaning within the themes involves both the researcher and each participant giving shape to previously unclear constructs by discriminating between incidental and important themes. This is achieved by determining the important quality of a theme, which leads to discovery of the qualities without the phenomenon losing its fundamental meaning (van Manen 1990). The process of achieving this requires a decision on whether the phenomenon would still be the same if the theme were deleted from it. The following section illustrates the process of reflecting and identifying the themes. And example will be given to illustrate the process.

The process of reflecting and identifying themes:

Reflecting on essential themes

In order to reveal the multi-dimensional structure of the meaning of a phenomenon, the phenomenon (or its textual representation) is approached in terms of meaning units or themes. Thus, it becomes possible to reflect upon lived experience through analysis of the thematic qualities of that experience.

In his description of hermeneutic phenomenological reflection, van Manen (1994) reveals the concept of theme to be little more than a means to reach the notion we desire to understand.

Thematic formulation, he argues, represents a free act of seeing meaning, not a pre-determined method; it is *'a process of insightful invention, discovery or disclosure.'* (p. 79).

Phenomenological themes portray experiential structures which describe the experience rather than conceptual formulations.

In searching for themes within the transcripts, it is essential to maintain a strong orientation to the phenomenon and not to surrender to the many temptations to distraction which divert one's attention away from the fundamental question being asked. In particular, the temptation to resume a scientific distancing from the texts and to engage in the abstraction of theory can become almost compulsive. In an attempt to secure the phenomenological essence as opposed to the scientific appearance of the phenomenon, the construction of thematic statements was aided by constant referral to two questions which always remained within sight during data analysis and which served as a continual reminder of the purpose of the enquiry.

The two questions which helped to maintain orientation to the focus of study were as follows:

1. *What point is made by the mother about the meaning of having a newborn baby transferred to another neonatal unit?*

Throughout the process of transcription analysis, this prompt helped in maintaining appropriate focus upon the text.

2. *Does the theme describe an aspect of the meaning of having a newborn baby transferred to another neonatal unit?*

This prompt facilitated the writing of each theme in order to preserve the essence of its meaning. Predominantly, participants' own expressions were adopted in formulating thematic statements.

As stated by van Manen (1990, p. 31), phenomenological inquiry is a project arising from a person's individual historical and social background that sets them on a quest to make sense of a specific aspect of human existence. My own unexpected experience of having my second child transferred when he was two days old indirectly influenced my decision to find out more about neonatal transfer. Thus the circumstances leading to the formal exploration of this research question was a culmination of my professional and personal interest.

My pre-understandings

Gadamer (1987) suggests that understanding always involves the interpreter bringing pre-understandings to the interpretative process. Interpretation involves a confrontation between the horizons of the interpreter and text since textual interpretation sets something new, the horizon of the text, against something old, the horizon (or pre-understandings) of the interpreter. Thus all *'textual interpretation must begin then with the interpreter's reflection on the pre-understandings which result from the situation in which he or she finds him (or her) self'* (Gadamer 1987, p. 130).

My experiences, derived from clinical practice and my experiences as a mother whose son had been transferred to a neonatal unit, and my opinions, derived from existing bodies of scientific knowledge, constitute my pre-understandings of the given phenomenon. In this respect, my pre-understandings and my personal experience as a mother have influenced both direction and my interpretation of it.

I recognise it is not possible to bring all my pre-understandings to consciousness and that some will inevitably remain unknown. However bringing pre-understandings to consciousness is not an attempt to eradicate them, but rather an attempt to enter the hermeneutic circle in a way that enhances the interpretative endeavour. I am also aware that my current convictions are based often on little more than rather narrow experience on my part, and hunches about the way things should be.

My field notes/study journal

Although others (Strauss & Cobin 1990) suggest the use of a separate diary to include emotions and private prejudices, I wrote about them in my field notes. In this way they became part of the talk I was hearing and they helped me to reconstruct particular past events. I also used the diary to reveal my underlying personal assumptions and preconceived ideas and changes in thoughts during the study period, as although by themselves they may have limited significance, when

related to other evidence they have much to offer (Koch 1994a). I found that by keeping this diary as a file on my computer, and writing entries, pre- and post- interview, as well as when I reread the units of data during analysis, I was able to bring my personal views into consciousness and record them (Appendix 11). Thus the presence of pre- understandings could be considered during textual interpretation in an attempt to prevent premature interpretative closure. In these ways, I brought my pre-understandings to consciousness, reflected on them, questioned their origins, adequacy and legitimacy, and thereby took account of their influence on myself and research.

For example, prior to interviewing Elaine (interview number one), I note down that she has two other children, a five-year-old daughter and a fourteen-month-old son.

I wonder how she manages...putting myself in her situation and knowing how it takes time to get used to a new environment from my experience of having to move to England...I think it must be horrendous and stressful....I remember being on my own here while the kids are in Malaysia waiting for their papers to be processed...the feeling of being alone and helplessness...I guess I already feel empathy and sympathy for Elaine. Although it is not such a bad thing to feel as it makes me feel I can understand what she is going through. It is a perspective that I think will make me particularly more sensitive to certain issues in relation to transfer, and that I needed some awareness of in attempting to hear Elaine's story.

During the process of interviews I made field notes and wrote in my journal. The field notes were brief reconstructions of events, observations and conversations that took place when I went to conduct an interview. To do this, I wrote them up immediately after each interview. The field notes described the concrete particulars of the interview and the relationship between participants and myself.

In fact the notes represented my 'learning curve' at the time. For although I did know something from my experience, the information presented by the participants was so unique that it was, for me, like a different discipline of study. It was in the notes that I asked myself questions such as:

What is going on here? Is this a significant incident or event? Why do I think this is important? Is it important to ME only or to the Participant?? What part did my pre- understanding play?

Critically reflecting on these questions helped me to identify areas of avoidance or any inability to hear certain concerns or meanings (Benner 1994). It also served to reveal some of my pre-understandings. I was prompted to question their origin, adequacy and legitimacy, and I was alerted to look beyond them to other interpretations, which were not foremost in my thinking.

Process of isolating themes

Having brought my pre-understandings to consciousness I considered their presence during textual interpretation. Initially, each transcribed conversation was read in its entirety to obtain overall understanding of the phenomenon under study. This initial overview required several hearings of the tape recordings in order to capture the style of the participant's conversation. The combined process of listening and transcribing was the beginning of familiarising myself with the *Dasein* of each participant. The depth and detail of the data felt rewarding, indicating that there was good communication between me and the participants. The general sentiments of each transcript were then preserved through the formulation of a brief summary, which summarised the main significance of the whole text. I found that writing out the story in one's own words encouraged close engagement with the story and the context, as it deepened familiarity and understanding of the text. It also aided me to enter 'into the hermeneutic circle' (Bleischer 1980, p. 103). This writing of each participant's story also included personal aspects of my engagement taken from the field notes and reflective journal. It allowed me to re-enter the experience and re-capture the conversation. Drawing on the text and reflective diary field notes helped in capturing the context, environment, actions, prejudices and feelings during the interview.

The text was searched for specific phrases or statements related to the phenomenon (composite theme). Phrases alone were insufficient to convey the true nature of the phenomenon. Therefore, paragraphs were included where deep feelings were evident. Headings were formulated that reflected the general nature of the words and phrases or paragraphs of each interview.

Whenever possible the participants' own words were used to convey the context of the conversation. Where the information was summarised, the interpretation of meanings was my own. This is Heideggerian phenomenology and the notion of bracketing does not apply because the researcher plays a part in the formulation of the data.

Once this approach had been exhausted, each statement was considered in terms of whether or not it supported the global perspective. Any discrepancy between statement and global view was

clarified by referring back to the original text and recording. The exposure of unsubstantiated meanings resulted in the elimination or modification of existing interpretations. In this way, meanings embedded within the text are discovered by moving back and forth between the parts of the text and the whole.

However not all composite theme encountered are unique to the phenomenon or experience as they can be historically and contextually determined or shaped. Thus I went through all of the composite themes and re-examined them by weighing the appropriateness of each them by asking:

What does this theme reveal about the experience being described? (van Manen 1990,pg 93)
Is this what the experience is really like? (van Manen, pg 99).

Confrontation with detail within the text can lead to a modification of one's interpretation of the whole and this helps to ensure that interpretation is grounded (van Manen 1990).

I also used Moustakas (1994) method of analysis step 2 (pg 120) whereby expressions not related to the experience being studied and vague expressions are eliminated. This process was continuously informed by my personal experience, also from reading the literature and from engaging in discussion with similarly experienced colleagues in neonatal care. It was Heidegger (1962) who identified that it is the researcher's preconceptions that guides the interpretation. The details of the discarded composite themes can be found in the appendix (Appendix 18).

In the following section I present an example of part of a participant's story (Elaine's) to help bring light to the process.

An example: Elaine's story

Elaine is the mother of a baby boy, born prematurely and transferred to a Level 3 neonatal unit for specialised care after he deteriorated and his condition gave cause for concern. The baby is the youngest of three, his most immediate sibling being 14 months. The eldest is a little girl aged six years old.

Matthew was born prematurely at 28 weeks and had been in a local neonatal unit for the past one month. Until the time of transfer, Matthew had been doing very well. He had been breathing on his own and was taking his milk via the naso-gastric tube the week before the transfer.

Elaine was the first person I interviewed for this study, and this particular situation provided me with a valuable learning experience that guided subsequent participant interviews and interactions. From my interactions with Elaine, I learnt the importance of first establishing rapport and trust with participants before asking them to share their personal feelings and thoughts with a relative stranger. After ensuring that consent has been taken and there were no further questions, I provided a rather (in retrospect) brief introduction and some preliminary discussion about the study, and then proceeded to switch on the audio-tape recorder. I invited her to talk about her experience of the phenomenon in question. After initial hesitation, Elaine started to relate her story in a relatively calm and matter-of-fact manner. At the end of her story, I was left feeling rather frustrated and dissatisfied with this particular interview. I felt that I had been unsuccessful in getting any real depth in our interview, despite my probing further, and seeking clarification when I thought necessary. I had a feeling of unfinished business. I was not sure whether it was because of my expectations or whether I had missed something.

After finishing the audio-tape recording, we arranged to have coffee after she went to do her baby's care. At this time I observed that Elaine seemed to relax. We talked about the baby's progress and shortly afterwards, she began to go back over, and revisit her story. She opened up to me, and recollected her experience with far more depth and richness than the rather stilted and shallow account she given only minutes previously. I then asked her if I could recommence audio-taping to which she agreed after confessing that she had felt awkward because she did not know if she had anything of interest I really wanted to hear. After reassurance, I resumed the audio-tape recording and this time there was no feeling of unfinished business. Indeed after finishing the interview some one-and-a-half hours later, Elaine confessed that, although she felt quite drained and exhausted and had no more words left to tell, she felt that she 'had told all' her experience.

Elaine's story described her experience of how she was first informed about the transfer of her newborn baby to another neonatal unit. Although her story did not follow an orderly sequence, and 'wandered all over the place' she provided a very rich and vivid account of her experience.

For example, she constantly referred to the perceived lack of information provided by the nurses in the local neonatal unit and the lack of coordination in the transfer process.

Elaine's story began with a recounting of how she was informed of her baby's transfer:

'I received a call on my mobile on the afternoon that he needs to be transferred... it was so unexpected...'

On further discussion we ascertained that Elaine had visited the baby the morning he was going to be transferred and there had not been any mention or concerns expressed by health professionals that he was not well and might need specialised care in another neonatal unit. Consequently she felt stunned and unprepared and she described difficulties in getting adequate information from the local unit.

'all they told me is that he has gone downhill...and that he needs to go to (regional neonatal unit) as he may need surgery....And that he needs to go now.'

Elaine felt that the staff (in the local unit) could have told her and her family more about what was happening:

'you know, it is really important to tell the family the truth, even if the answer is 'we don't know what is happening ...'the staff (neonatal staff) may see sick babies every day, but for me, this is a one off event .. I hope...they should tell us even if it may just be some thing small...as it is I was stunned when they told me...'

Elaine also described a lack of information-sharing by the two units and she appeared to be trying to work out the reasons for this. She wondered if this was due to the different units' policies or was due to poor coordination:

'when I first got there (the new unit) they asked me again my baby's details...I thought they could get most details from the other unit.'

And when she explained how she has to tell the nurse in the regional unit that Matthew was supposed to have his immunization soon:

' to be honest I don't think the right hand knows what the left hand is doing.'

Although the staff in the regional unit kept her up to date about the baby's progress, Elaine felt that the staff could have provided more personalised information:

'They (staff in regional unit) are very good in a way... they do tell what they have been doing for the baby...but that is as far as it goes...they don't ask you how you are doing.... You know how are you...your family sort of thing.'

Conflicting information was highlighted as a problem creating confusion and worries:

'they (local unit) told me (baby) needs an operation...but when we arrived here (regional unit)...the doctor said the baby may not need an operation. It is so confusing...and worrying really as I don't know what to believe now.'

My interpretation.

When Elaine had finished telling me her story, I felt I had been privileged to hear her account. She described how the lack of information about the transfer left her feeling unprepared and stunned. Elaine also indicated that she wanted more information specially related to the reason for the transfer and the baby's diagnosis. She identified the difficulties she faced trying to get information from the local unit. Although information was given in the regional unit by the nurses, Elaine felt that the information was impersonal and heavily focused on the baby only. It seemed important to her that the nurse understood her situation and cared for her as a person. Conflicting information given by the two units created confusion and anxiety.

Identifying themes

Significant statements were compared across the transcripts to identify composite themes that broadly reflected shared practices and common meanings.

These were considered in terms of whether they were unique to the phenomenon of having a newborn baby transferred to a neonatal unit other than the local neonatal unit (relational

incidental themes) or whether they could be common to having a newborn baby in a neonatal unit generally (recurrent themes).

For the purpose of establishing the nature of a theme, the following question was applied to each of the incidental themes:

> *If this theme is removed or ignored does the phenomenon of having a newborn baby transferred remain essentially unchanged?*

In the above example, I identified that there was a lack of information issue about the transfer from Elaine's interview. To test this theme I tried to conceive of the experience of having a baby's transfer such that the experience did not include information about the transfer. This seems impossible because it would be impossible to think that the extent of information and how it was given as not influencing the way parents viewed their baby's transfer. Elaine's transcribed interview emphasised that the lack of information had made her unprepared and stunned. Her vivid descriptions illustrated how important it was to know what had happened.

Having proposed one theme as being essential to the phenomenon, the possibility remained that this theme might be equally essential to the mother's experiences in a regional neonatal unit. In order to test for this eventuality the following two statements were considered in relation to the essential theme:

> The meaning of this theme is different for the mother having her newborn baby transferred to a regional neonatal unit than for having her newborn baby in a regional neonatal unit (this statement was supported).
>
> The removal of this theme renders the phenomenon meaningless (this statement was rejected).

This theme was thus determined a relational incident theme. (See Table 3.2)

Table 3.2: Composite, recurrent and relational incidental themes

Relational incidental theme	Recurrent theme	Composite theme (Significant statement)
Information issues	Inadequate information about reason for the transfer	*All they told me is that he has gone downhill* *That he needs to go to (regional unit)* *That he may need surgery* *Could have told more about what was happening*
Information issues	Lack of information sharing between the two units	*They asked me again my baby's details* *I don't think the right hand knows what the left hand is doing*
Information issues	Baby-focused information	*They (regional unit) do tell what they have been doing for the baby but that is as far as it goes*

A constitutive pattern or essential theme is one which is present in all texts and which represents the highest level of hermeneutic analysis (van Manen 1990). For this study, the constitutive pattern was determined according to a multi-dimensional perspective that encompassed van Manen's notion of essential theme.

Essences refer to patterns, structures, invariant features and what is necessary to the phenomenon. In hermeneutic phenomenology, free imaginative variation was often used to determine which of the themes is essential for and constitutive of, a fixed identity for the phenomenon under study (van Manen 1990 p107). The aim is to arrive at structural descriptions of an experience, the underlying and precipitating factors that account for what is being experienced; in other words the 'how' that speaks to conditions that illuminate the 'what' experience. However van Manen (1990) did not provide a clear guide as to how free imaginative variation in identifying essential theme. I found that Moustakas (1994 p 99) offered a way to make explicit the steps to 'free imaginative variation' which was not offered by van Manen (1990) (Table 3.3).

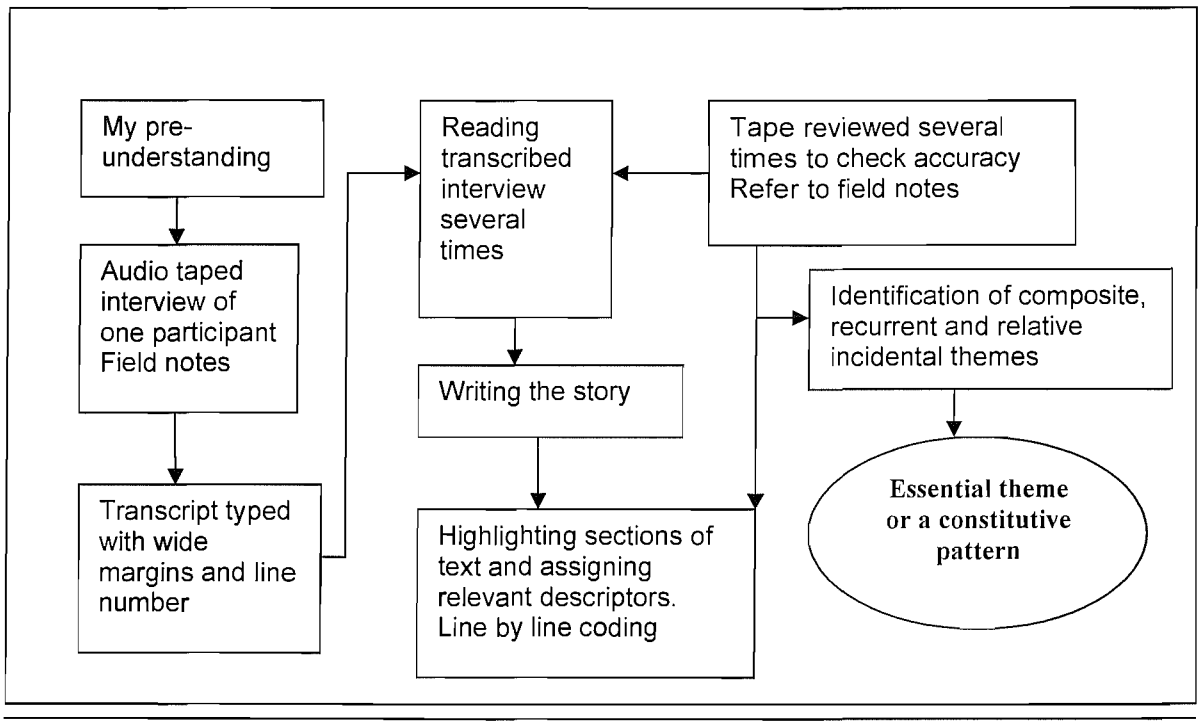
Table 3.3: Steps of imaginative variation for essential themes (Moustakas 1994 p99)

Step		Examples
1	systematic varying of the possible meanings that underlie the textural meanings	For each of the four themes, the following questions were asked: Is this phenomenon stills the same if I imaginatively change or delete this theme? Does the phenomenon without this theme lose its fundamental meaning?
2	recognizing the underlying themes or contexts that account for the mergence of the phenomenon	I try to conceive the experience of having a transferred baby such that the experience does not include each of the four themes for example I reflected and questioned myself on the theme about emotional responses. This seems impossible to think of having a transferred baby and not having the identified emotional responses. It seems to reflect what I found in my experiences as a neonatal nurse and as a mother with a son who was transferred when he was two days old.
3	considering the universal structures that precipitate feelings and thoughts with reference to the phenomenon, such as structure of time, space, bodily concerns, materiality, causality, relation to self or relation to others	For each of the theme, the following were done : I return to the raw data descriptions to justify the articulations of both underlying themes. I moved between the data, collected literature and my own understanding as a mother with a transferred baby until I reached a meaningful interpretation of the actual experience. I asked myself: How is the situation of mothers who have transferred babies to be conceptualised? Is there any discourse that shaped their concerns, and influenced the context they cared for their babies?
4	searching for exemplifications that vividly illustrate the invariant structural themes and facilitate the development of a structural description of the phenomenon	Here I compared each theme to each other and identify converges and divergences. The relationships between the themes were established through interpretations that identified patterns in the data which the study participants were not aware. I also checked my interpretations through discussion with peers, academics and clinicians and through alertness for further supporting or refuting evidence in my own clinical practice. Essential issues about normal 'mothering' were explored by reading discourses on motherhood. The essential meanings were identified by taking into considerations the circumstance the mother faced with a seriously ill infant that need to be transferred to another neonatal unit and how the mothers construct and relate to notions of being a mother to the transferred baby and their other perceived obligations to functions in other roles, be is as a mother to other siblings at home or as a wife. For example, the emotional responses reported by the mothers in this study appeared to be related to their perceived inability to assume responsibilities as a mother to both the sick infant in the distance regional unit and to other siblings at home. The transferred also caused information and adjustment issues related to the baby and for themselves as mothers. The impact of the geographical distance as a result of the transfer affected not only their family but also their role as mother to the transferred baby and their other siblings at home. All the four themes indicated the perceived need to maintain their maternal role despite the perceived geographical distance.

van Manen (1990) regards the process of differentiation between relational, incidental and essential themes to be the most difficult and the most controversial element of the phenomenological human science approach. Indeed, the determination of what constitutes the uniqueness of the phenomenon rests solely with the interpreter and, in this respect, relied unreservedly upon my own personal experience. This stage of analysis required complete textual immersion: reading and re-reading, listening and re-listening, and reference to relevant scholarly works, all of which informed the interpretative process. Inter-textual conflicts were clarified and resolved through re-examination of the original texts and recordings.

A summary of the process of thematic formulation is depicted in Figure 3.3.

Figure 3.3: Process of thematic formulation



iv. Describing the phenomenon through the art of writing and rewriting.

van Manen believed that one must be totally immersed in the text and bring significant relations to language into the text. In order to do this, the researcher must totally submerge herself in the text in order to identify the essential basis of the experience, thus seeking the essential meaning of

the experience. Ely et al. (2000) argue that we can reshape meaning through writing and this helps us to clarify our understanding.

Writing and rewriting according to van Manen (1994), 'separates us from what we know and yet it unites us more closely with what we know (p. 127). The act of writing and rewriting allowed the researcher to organise and objectify thoughts, and increased the researcher's understanding of the phenomenon. Free imaginative variation or the creation of a new images or abstractions in the imagination by synthesizing experiences and perceptions and varying concrete examples was also employed to increase understanding of the phenomenon being investigated as illustrated in Box 3.3.

Each participant's story was written and then rewritten after listening to the tape again.

Handwritten marginal notes were made on each interview in response to these questions and served as an aid to writing the summary description (see example below, Table 3.4, of an annotated extract from an interview transcript: the notes are typed rather than handwritten for the purpose of presentation)

Table 3.4: An annotated extract from an interview transcript

Nurse told me mother has just seen the doctor - baby's condition improving **mother appears relax – and happy ?? smiling (? good news about baby)**	*I have been to see him (baby) on Friday and he is fine...there was no indication at all that he is unwell.... So I told them (nurses in local neonatal unit) that I am going to visit friends in (place) and .. that I am on my mobile.... I didn't realise he is that poorly....obviously you weren't made aware of it ... there was no mention of it ..*	No indication Didn't realise he is that poorly Weren't made aware No mention

v. Maintaining a strong and orientated relation to the phenomenon

It is during this stage that a concerted effort was made to reflect critically on the derived thematic statements against the overall context of the story being told and deciding whether this interpretation fitted not only this particular section of the text but also as a whole.

I found it very challenging to apply it in practice as there is minimal guidance to accomplish this stage. I found that the following helped in this stage.

a) **Transcribing and reading**

I found that transcribing the interviews myself and repeatedly reading the text and listening to the tape helped me to gain a sense of the mother's story.

Simultaneously listening to the taped interviews from the participants while reading the transcript have enabled further contextualisation of the transcript. The revealing silences and laughter, gave access to more than just words. Thus the action encourages close engagement with the story, as advocated by van Manen (1994), and the context, as it deepens familiarity and understanding of the text and allows me to enter 'into the hermeneutic circle properly' (Bleischer 1980, p. 103). I found that a questioning process was paramount whilst reading the text in the study. Questions I found useful included:

What does she mean?
What is she trying to say?
What are my prejudices in my interpretations?
What is still puzzling me?

b) **Study journal and field notes**

I used the study journal to help me to articulate my thoughts and feelings more concretely. It enabled me to identify my own feelings associated with the study. Personal aspects of my engagement taken from the field notes and study journal also allowed me to re-enter the experience and re-capture the conversation (see Table 3.4 in highlighted font). Constant reference to the research question and aim was made in order to maintain strong orientation to the phenomenon.

vi. Balancing the research context by considering parts and wholes

There should be constant movement between the text and the overall study to get the total textual structure. The following process outlines how I reviewed the contextual given and how the reflection and perception are related to each other and to the whole.

a) **The whole stories**

I took several readings of each transcript whilst listening to the tape of the interview, to ascertain a sense of the whole. I considered that the frequency of listening to and reading the transcripts of the interviews would help to foster my interpretations of innuendo and emotion, which complemented each interview. My study journal and field notes were also used to provide an individual context for each participant. Throughout the initial recording of the interview, and then after listening to the tapes and re-reading the interview transcriptions, I was working with the whole story. That is, this initial part of the data analysis process involved trying to reach an initial understanding of the participant's overall experience. As I listened and read, I entered into a dialogue with the text to help me gain an understanding of this particular person's story, and situate it within their individual background. Entering into a dialogue with the text enabled me to ask questions as: what do I know about this person? What do I know about their babies? What does this person's experience reveal?

b) **Turning to the parts of stories**

After focusing on the whole stories, I then proceeded to turn to parts. After I had questioned and dialogued with the text, I proceeded to highlight any words or phrases that stood out as meaningful.

The parts are the more specific ideas and findings in each text. After I read through each transcript again, prepared handwritten notes, and highlighted individual sections, I attempted to do this activity in what is considered by some to be a more systematic way (Richards & Richards 1994). However, after my initial attempt using one of the qualitative data analysis software packages, NUD*IST, I did not feel comfortable or proficient at any time with this package. I had become accustomed to using hard copies of data and working with highlighter pens, and I believed that this method was suitable for my own needs. Moreover, the understanding of the meaning of phenomena *'cannot be computerised because it is not an algorithmic process'* (Keller

1995, p. 3). Therefore, after my initial attempt I did not use any software and instead returned to manual handling of data.

I sought to develop my own system of handling and manipulating data. Each line and page of the individual participant's text was numbered, as were the field notes pertaining to each individual. After I had numbered the text so that each transcript could be easily identified, and following on from the process of highlighting words and phrases from the whole stories, I proceeded to do the same at a more focused level. Thus I read each transcript individually, highlighted specific ideas and concepts, and began to group these together. Throughout the process of interpretation, I was fully immersed in the hermeneutic circle. I listened carefully on many occasions to the tapes, and read each transcription several times. I continued to analyse the data, reflected on at length and maintained a dialogue with the text. I also spoke to several of my peers about my interpretation during this process, including neonatal nurses and colleagues undertaking doctoral studies. This process was circular: as the meaning unfolded, I would return to the tapes and the transcriptions for further clarification and to reach a deeper understanding.

Although these activities are presented as stages one to six for illustrative purposes, there is overlapping and dynamic interplay among the six stages.

Before discussing ethical issues in the following section, it is timely to address the issue of rigour of this research study.

3.12 The question of rigour.

When using qualitative methodologies, the question of rigour or trustworthiness arises. Although there is a well-respected list of criteria for judging the quality and rigour of research (Mays & Pope 1995), it is important to recognise that the criteria for judging quality should be appropriate to the methodology of the study and not an uncritical application of a set of rules (Sandelowski 1993).

It is important to demonstrate that the research has accurately represented the social world under study (Grbich 1999) and to show that good research practice has been applied (Sandelowski 1993). With this in mind, several authors have offered ways of indicating rigour in qualitative

research, particularly when using a phenomenological approach (Koch 1994a, van Manen 1990, Walters 1995).

Making the research process as transparent as possible will allow systematic scrutiny at all stages of the research (Bailey 1996). Throughout this report there is an emphasis on clarifying the decision trail of the researcher so that the reader is able to audit my events, influences and actions in order to clearly establish the trustworthiness of the study. The strategies used in this study to achieve trustworthiness are listed in Table 3.5 and described in this section. Some strategies were used to establish more than one criterion and have been described under the criterion to which they most frequently applied.

Table 3.5: Process of maintaining rigour

Trustworthiness criteria	**Techniques**
Credibility	Prolonged engagement Peer debriefing Reflexive journal Negative case analysis
Transferability	Thick description Reflexive journal
Dependability Confirmability	Audit trail Reflexive journal

3.12.1 Credibility

Credibility is used to refer to the truth, value or believability of the findings through prolonged contact with participants (Guba & Lincoln 1985).

Credibility is achieved by ensuring the participants in the study are clearly identified and described (allowing for confidentiality). The process I used to make contact with the participants

is clearly described. Furthermore, the process of in-depth interviewing meant that I was in contact with each and every participant for a considerable amount of time. Prolonged contact has been suggested by Guba and Lincoln (1985) as one of the techniques that assist to establish the credibility of the study findings.

Another technique of establishing credibility was membership checking (Guba & Lincoln 1985). Member checking relies on the foundation assumption of a fixed truth or reality against which the account can be measured (Angen 200), but it is my belief that there is no fixed truth because understanding is inter-subjectively created within a historical and linguistic tradition. Moreover, a person's conception of truth (or understanding) is not static but changing constantly, through continual, partial and multiple interpretations, as is the nature of being human in the world. Thus in this study the process of integrating reflection information into the research process was used rather than member checking, due to my agreement with theoretical and ethical concerns raised by Sandelowski (1993). She sees stories as 'time bound interpretative, political moral acts' (p. 5) that cannot be corrected at a later time without complete re-analysis. The understanding of people is kaleidoscopic in nature and constantly undergoes metamorphosis because they are constantly interpreting and re- interpreting their experiences in the light of subsequent experiences.

Therefore I have not made any attempt to bring the analysed study data back to the informants for validation because the individual validation of the informants threatens rather than enhances interpretation of the study data. Sandelowski (1993) stated that this practice would undermine the meaning that is being constructed within the lived experience. To go back over the ground of an interview again with the mother is to reinterpret the interview with the participant and once this process begins it begs the question, 'when will it suffice to ask whether enough is enough?' Moreover, in this study, the participants are from all over the UK, making it rather impractical to check the interpretation with the mothers (Hammersley 1992).

A team approach to confirming the findings was also not used, as it is not truly reflective of the 'hermeneutic circle of understanding' explicated by Heidegger, wherein the interpretation is presupposed to be circular and dynamic in nature and can never be made completely explicit. Other individuals cannot verify interpretation because, as Gadamer's (1960/1989) hermeneutic holds, others bring their own foreknowledge, language, history and reasons to bear.

Negative case analysis is a powerful analytical tool. Given that the aim of qualitative research is to examine the range of experience rather than the average experience it is important that atypical experience be considered in the interpretation of the data and in the findings and discussion (Patton 1990). To this end I strove to adequately describe the range of experiences and give equal credibility to the constructions that mothers shared and those that diverged from the norm.

Conducting an inquiry can be a long and often solitary process. Peer debriefing provided me with the opportunity to discuss my work in a supportive environment and in doing so enabled me to develop and refine the various steps in the emerging design. While I received much support from my supervisors, the ability to discuss my work on a regular basis with a group of fellow research students was an invaluable source of support. The sharing of our developing ideas and interpretations and the giving and receiving of feedback kept me on track and assisted me in developing my study.

3.12.2 Transferability

The criterion of transferability is used instead of generalisation as the time- and context-bound nature of the inquiry mitigates against true generalisation of findings (Guba & Lincoln 1989). Transferability is concerned with the degree to which the findings are applicable to other settings, and is dependent on the degree of similarity between the two settings. It is the responsibility of the researcher to provide the 'thick description' necessary to enable those wishing to apply the findings to make a judgement on transferability (Guba & Lincoln 1989).

In this study, detailed descriptions of the setting, the parents involved, and the data collection and analytical processes used are provided so that the reader can experience the research process. Direct quotes have been used extensively in order to present the findings in the mothers' own words and to enable the reader to hear their 'voice', enter into their world, and interact with the data. This detail has been provided so that those wishing to utilise the findings within their clinical setting or practice can make credibility and similarity judgements. A study diary was kept throughout the study to provide an audit trail (Koch 1994a).

3.12.3 Dependability or confirmability

Dependability refers to the consistency of the data over time, that is, the extent to which findings can be replicated in the same or similar contexts with the same or similar participants (Guba & Lincoln 1989).

In this study the dependability and conformability of the research findings were addressed by faithfully recording all methodological decisions, the process of data collection and all interpretative comments and questions that arose during the analytic processes. These have been described throughout this chapter so that the reader can judge the conduct of the study and interpretations made.

3.13 Ethical considerations

Before commencing fieldwork it was necessary to seek and gain ethics approval from relevant bodies. The purpose of ethics committees is to ensure that research conducted on humans abides by ethical principles. Ethics is the study of standards of conduct and moral judgment, and ethical conduct by a researcher requires that ethical principles be taken into consideration throughout the entire research process. Thus it is essential that the research study is conducted without harming participants (principle of beneficence) and only after informed consent from participants, and that it follows a rigorous methodology and design (Polit & Hungler 1999).

Throughout the study, I was fully aware of and abided by these principles and requirements. I sought and obtained ethical approval from the local Research Ethics Committee and the Research Ethics Committee of the Research and Development Department in the participating hospital (Appendix 14).

After obtaining ethics approval, I commenced recruitment of participants and data collection. The process for this is outlined earlier in this chapter (Section 3.9). A number of ethical issues are apparent within this study and require consideration. The following section addresses these issues.

3.13.1 Informed consent

Informed consent was obtained after the potential participant had been fully and truthfully informed of the study's purpose and method. Traditionally consent is normally obtained at the beginning of the study but unforeseen events may require re-negotiation of consent (Munhall 1986). For example, if a baby's condition suddenly deteriorates, this may influence the mothers' willingness to participate. An update of the baby's condition from the neonatal nurse looking after the baby was obtained before approaching any mother to enrol in the study.

3.13.2 Confidentiality

Participants were informed of the process of consent and their right to confidentiality and anonymity. The data obtained were stored in a locked cabinet at the University of Southampton, School of Nursing and Midwifery, during the course of the study and will be archived for fifteen years before being destroyed, as recommended by the local data protection officer (personal communication June 2003). Details by which participants, families, health professionals or other health care staff could be identified were anonymised at the stage of transcript coding. Pseudonyms were used in this study and there is no clear identification of location beyond the study being focused in the south east of the UK. A mother's GP was only informed if she had given her permission for the researcher to inform the GP about her participation in the study (Appendix 15).

3.13.3 Protection from harm

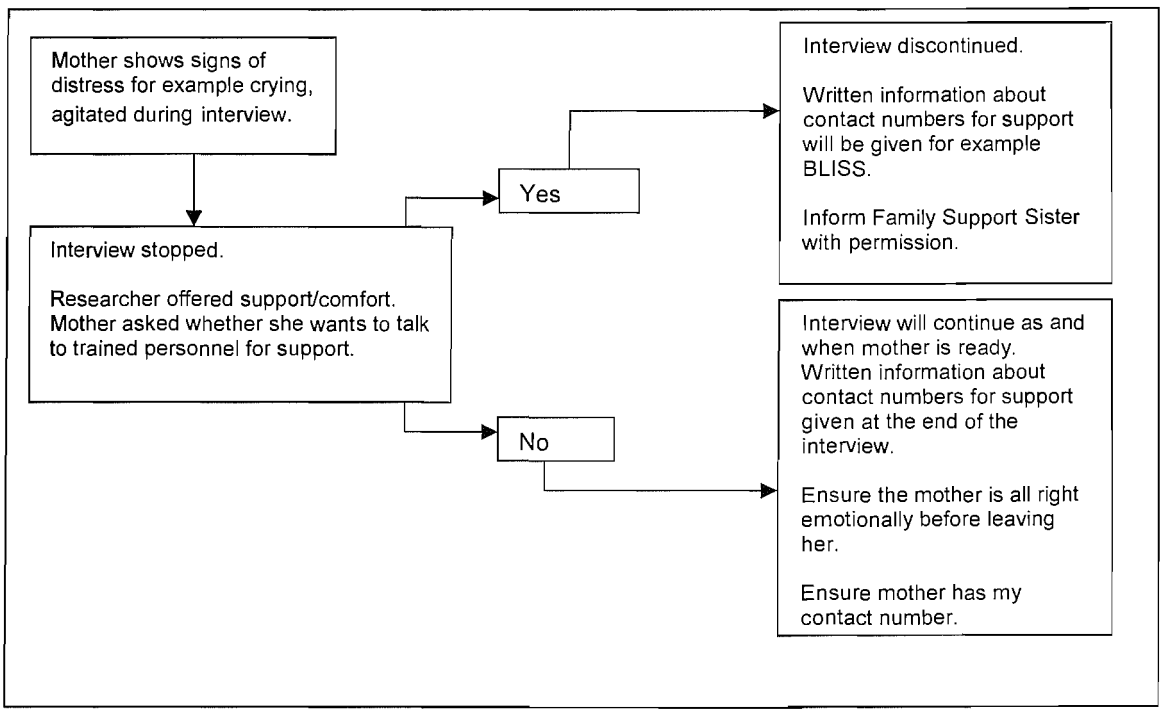
The process of being interviewed may be therapeutic, the interview being a catalyst allowing the interviewee to construct and give meaning to an entire sequence of events and actions (Morse 1991). This could potentially be empowering (Hutchinson & Wilson 1994). In a sense, it gave participants a voice and the rare opportunity to legitimately take some time out from their babies and reflect on their experiences in a non-threatening environment and with an impartial interested listener. Telling their story, and more importantly, being listened to, seemed to give participants a sense of mastery and control.

However, the opposite may be true, in that recounting an extremely painful process such as an emergency transfer of the baby could represent a point of crisis and reinforce feelings of

inadequacy and inability to cope. Therefore care was needed when approaching the mother. Sensitivity was necessary to the possibilities of causing distress to the mother. If there were instances where mothers became emotional or descriptions of their experiences indicated distress, a discussion concerning study continuation was instigated and the option of the participants' decision to curtail involvement in the study was reinforced. At the end of an interview, regardless of the level of distress exhibited by the mother, the mother would be asked if she required any additional support and I would organise this if requested. Written information about contact numbers and support groups was given to all the mothers (Appendix 10).

I was concerned about the limits of my personal abilities being tested on two levels. Initially, how would I cope with the emotions and reactions released from the participants? In addition, would I know when to stop if a person became distressed, which would require me to relinquish the research imperative? I reflected on these two issues and plans were made for these possibilities. From my personal coping perspective, I made sure that before each interview I found out as much as possible about the mother's and baby's general condition from the clinical staff in the unit. I prepared possibilities so that I would be receptive to their actual demeanour and able to adjust. I also tried to ensure that there was someone I could talk to after an interview to support me if need be. On the second question, the support protocol pathway (Figure 3.6) helped me to deal with the situation.

Figure 3.6: Pathway for maternal support for all participants in the study



3.13.4 Conflict of the researcher/clinical role

When conducting studies in the clinical area, nurse researchers may find role identity problematic, as the nurse may not be able to divorce himself or herself from the care and welfare of patients (Holloway & Wheeler 2002). This may not be an issue for the nurse only, as the patient may not understand this role and may expect nursing care from the nurse researcher (Holloway & Wheeler 2002).

Although there do need to be boundaries in the nurse researcher and participant relationships, there are few guides as to how to deal with emotive or emergency situations that may occur for the nurse researcher. Can I let go of my clinical skills to become a subjective reflexive nurse researcher?

I was keenly aware of the advice offered by many research books. Maintaining a friendly distance was prominently advised. Discussions with members of the CRAG and colleagues suggested that the researcher should not be drawn into venturing personal opinions but should gently steer the interviewee back to the subject by saying something to the effect of *'what I'm really interested in is your experiences on this matter.'*

However, I feel that it would be morally indefensible not to reassure a clearly anxious mother when it is within my capacity to do so. Oakley (1981) concurred with this view and argued that interviewing women was likely to be more successful when the interviewer was prepared to invest his or her identity in the relationship.

Finally, after a great deal of thought, reading and discussion, I decided to respond to the mothers as a researcher, a neonatal nurse, a woman and a mother: in fact, as a human being, with all the attendant complexities. My identity as a nurse and mother invests the relationships I share with participants with common understanding.

It seemed to work well. Frequently the mothers told me it was like talking to a friend, and invited me to contact them if I needed further information. I found that engaging in empathetic sharing made the interviews more honest and morally sound, a finding supported by Fontana and Fey (1998). According to Chesney (2001) and Wilde (1992), it is feasible to allow a degree of self-

disclosure as participants cannot be expected to give all the time. Thus for me partial solution came from reciprocity as the solution to the role conflict.

One of my colleagues suggested I read some work on reflexivity and explore my own perceptions of the interview setting. Thus the next section explores this concept in relation to role and identity.

3.13.5 Reflexivity

Research is a joint product of participants, the researcher and the relationship between the participant and researcher (Finlay 2002). The researcher can influence the research in multiple ways: choice of the topic, the focus and the methodology used in the research (Kleinmean & Copp 1993, Frank 1997, Finlay 2002, Hunter et al. 2002).

Thus the entire process should be made transparent for the reader and the researcher must be truly aware of, and take into account, the possible impact of self in all aspects of the research, although this may not be totally achievable. A concept commonly found throughout texts describing qualitative methodology is reflexivity or the need for the researcher to be reflective. However it is not an easy task comprehending the true meaning of the concept and embedding it as a continual aspect of a research study.

Although terms such as 'self-reflection' and 'reflection' yield an increasing volume of literature, the term 'reflexivity' remained elusive. It remains a very nebulous concept, seeming to defy precise definition, as found by Atkinson and Coffey (2002). Finally I came upon the following definition of reflexivity offered by Rice and Ezzy (1999), which greatly facilitated my understanding of the concept. They propose that there should be an acknowledgement of the role and influence of the researcher on the research project. The role of the researcher is subject to the same critical analysis and scrutiny as the research itself. I concluded, therefore, that reflexivity was really about how I, as researcher, impacted on the data I was gathering and the critical analysis of that role. It was suggested that reflexivity involves a more immediate, continuing, dynamic and subjective self-awareness in comparison with reflection, which may only involve thinking about an issue (Finlay 2002).

To me the most difficult aspect of reflexivity is how to achieve it, and when it can be said to have moved from reflection to a reflexive approach. In an attempt to achieve some understanding of the concept, I looked to texts written by researchers describing their research experience. Although gaining a definition and examples of how to achieve it are elusive, examples of real life research experiences provided some understanding and some degree of comprehension of how others achieved reflexivity. The importance of the researcher recognising and acknowledging personal prejudice is a way of attempting not to distort data but to explore the experience at different levels.

However, claiming to achieve emphatic understanding appears condescending and in some ways insulting to the participants and their complex individual experience. Realistically I am not sure I could acknowledge or be aware of all the values and prejudices that influence me as a researcher, and in turn the research. In order to consciously review the robustness of interpretation during the study, it would require great sensitivity and a degree of scepticism. This ability is only learnt through hard work, practice and seeking the critical opinions of peers and supervisors to test ones own thinking and re-focus attention (Ely et al. 2000).

Hertz (1997) feels that an acknowledgement of self and scrutiny of one's values and beliefs is fundamental to an understanding of reflexivity. Throughout the study, a study journal was kept to record personal experiences of interviews with the mothers and to assist in recognising the influence and personal biases and feelings on the research. This was done so that my personal interpretation of events could be more fully recognised. Extracts from the study journal is used concurrently with the participant's transcribed interview to aid in the interpretation of the data (see section 4.7.3 and section 4.7.4 for examples)

Creswell (1998), Ely et al. (2000) and Finlay (2002) all acknowledge the difficulty and continual self-awareness that reflexivity demands. Many attempts by researchers to be reflective result in just confessing or providing an explanation of how research has been achieved, and this does not necessarily equate to reflexive accounting (Ely et al. 2000). A reflexive approach is difficult to define and to achieve, and as with statistics the reflexive account has the ability to mask intentionally or subconsciously.

Reflection was undertaken throughout the process in order to understand my cultural view of the phenomenon and how I came to understand it in the way that I did. I am aware that my

background as a nurse and mother in a different country, together with my philosophical stance, values and feelings, has undeniably contributed to the interest I have developed in the experiences of mothers whose babies are transferred to another unit, and also to the way I view motherhood. I acknowledge that my particular stance is rather personal, but I also feel that motherhood is a difficult and onerous responsibility, without the added burden of having a sick baby that needed to be transferred to a new, unknown unit.

3.14 Section 2 Summary

This section detailed the methods of sampling, data collection and analysis. Issues concerning rigour and ethics were discussed. Formulating the right question in any research study is a necessary but not a sufficient condition for success. There is still the matter of translating the design into practice. At this stage, the entire endeavour was still quite vulnerable and tentative. What if the data were not available? What if the methodology used in the study is not appropriate? Either of these situations could call an entire study into question. The following section will discuss the pilot study and address these concerns.

SECTION 3: PILOT STUDY

3.15 Introduction

By conducting a pilot phase the initial assumptions about the study data and issues relating to the study design can be tested in the field. It is an important opportunity to correct aspects of the design that can determine the success or the failure of the overall study. Piloting of qualitative approaches can also be carried out if 'the researcher lacks the confidence or is a novice, particularly using interview technique' (Holloway 1997, p. 121).

However, completing a pilot study successfully is not a guarantee of the success of the full- scale study. It should be recognised that pilot studies may also have a number of limitations. These include the possibility of making inaccurate assumptions on the basis of pilot study and problems arising from contamination. The obvious concern is that if there were problems with the research tool and modifications had to be made in the light of the findings from the pilot study, data could be flawed or inaccurate. However, it could be argued that if the same research tool is used with no

modifications, the data may be of value. Some have argued that in qualitative approaches separate pilot studies are not necessary (e.g. Holloway 1997, p. 121).

The pilot study consisted of two interviews with mothers. The pilot interviews confirmed that mothers selected could provide insight into their experiences. As no changes were made to the data collection method following these two initial interviews, data from the pilot interviews was used in the study and the sample numbers include these two interviews.

3.15.1 Aims of the pilot study

The main aims of the pilot study were:

1. To assess the feasibility of accessing and recruiting mothers on the fourth day of their babies being transferred into the neonatal unit.
2. To assess the feasibility of interviewing the mothers within the tenth day of their babies being transferred into the neonatal unit.
3. To assess the relevance of the interview questions to the mothers and the aims and objectives of the study.
4. To assist in the refinement of plans with regard to techniques of data collection and data analysis.

3.15.2 Findings of the pilot study

To assess the feasibility of accessing and recruiting mothers on the fourth day of their babies being transferred into the neonatal unit.

The pilot study was planned for two months (March to April 2004) with the aim of recruiting two mothers. However, within a month two potentially eligible mothers were identified and successfully recruited by the fourth day of their babies being transferred into the unit.

The concerns that accessing and recruiting potentially eligible mothers by the fourth post- transfer day might be an unwelcome and emotional intrusion for some mothers appeared to be unfounded. The pilot study allayed these concerns with an adequate number easily recruited within the time frame. None of the potentially eligible mothers approached during the pilot study declined to participate in the pilot study.

However, recruitment in the precise way indicated by the initial protocol study may not always be possible in this study. The timing necessitated a flexible approach because of the baby's illness and the mother's other commitments. After discussion with my supervisors, clinical staff and CRAG, it was decided that if by the seventh post-transfer day, there were still concerns about the baby and / or mother's condition, and based on a mutual agreement between the nurse looking after the baby and the researcher, the potentially eligible mother would not be considered at all for the study.

To assess the feasibility of interviewing the mothers within the tenth day of their babies being transferred into the neonatal unit.

The timing of the interview for the mothers came into question due to concerns that mothers may still be experiencing emotional turmoil at that time. It became apparent that most of the mothers in the pilot study who agreed to participate in the study wanted to start telling me their experiences on the day I met them to explain the study. I felt that they really wished to begin there and then. In this pilot study, both the mothers were interviewed by the sixth and eighth day of the baby's transfer to the unit respectively.

Thus it was felt that this system appeared to work adequately during the course of the pilot study.

To assess the relevance of the interview question to the mothers and the aims and objectives of the study

The initial stem question, *'Please tell me what it is like to have your baby transferred from the neonatal unit she/he was first admitted to the present neonatal unit'*, allowed the mothers to recount their experiences. The interviews flowed freely and needed no active response from the researcher. The interviews were spontaneous, which was positive in that the participants chose the direction, but this resulted in challenging analysis of the transcripts. There was repetition throughout, although it can be argued that this reflects a typical conversation when one is relating one's story to another whilst emphasising certain points.

The presence of identifiable thematic statements encouraged me that the project was worthwhile and that an evidence-based study into mothers' experiences of their newborn babies' transfer was well received by the participants.

Seven days after the interview a thank you letter and an interview comment sheet with stamped addressed envelope was sent for feedback to the two mothers who were interviewed. None of the participants chose to contact me after their interview, so I assumed that they did not find being interviewed problematic. Notification of the mother's participation in the study to their GP (whenever written consent was given) did not elicit any comments or concerns post interview (Appendix 12).

To assist in the refinement of plans with regard to techniques of data collection and analysis.

A tape recorder was used for data collection. It was found that the boundary microphone used did not pick up sounds if the participants spoke quietly. Thus a body microphone was used for subsequent interviews with much better results. I also found that having a checklist to ensure that I had enough tapes and batteries and an extra tape recorder each time I went for an interview helped to ensure that I had not forgotten anything (Appendix 13). Talking to the nurse looking after the baby and checking the case notes prior to interviewing the mother had helped me to plan and adjust to the mother's actual demeanour.

Each interview took place at the mother's convenience. The two mothers chose to speak to me when they came to visit their babies, thereby minimising their travelling times for the parents. Disruption of care was minimised by negotiating the most appropriate time for both mother and baby. This worked reasonably well except for one occasion when one of the mothers chose to have the interview in the nursery beside her baby. The issue of confidentiality in such a public place left me very concerned and this was discussed in the CRAG meeting. It was decided that the mothers would be encouraged and advised to have their interviews away from the clinical area. A quiet room away from the unit was negotiated with the Clinical Nurse Manager.

Because of the nature of the interview and the fact that only two interviews were conducted in the pilot study, it was not possible to do justice to the data collected. However, preliminary analysis indicated the presence of identifiable statements.

3.15.3 Summary of pilot study

The one-month pilot enabled key issues related to timing for accessing and recruiting potentially eligible mothers, the research method used (unstructured interview), and the timing of the interview to be addressed and resolved. Accessing and recruiting potentially eligible mothers was extended to the seventh post-transfer day if there were concerns about the baby and / or mother's condition on the fourth post-transfer day.

3.16 Chapter summary

In section one of this chapter I have described the historical evolution from Husserlian to Heideggerian phenomenology to highlight the transformation in phenomenological thought from being purely descriptive to being interpretative. Heideggerian ideas of Being, the hermeneutic circle, and the Gadamarian idea of 'fusion of horizons' were discussed to emphasise that interpretation includes incorporating historical, cultural and social contexts in order to understand the lived experiences of people. The choice of a hermeneutic approach is clearly justified in the context of this study.

I have demonstrated that the method I utilised for collecting and interpreting the data was congruent with the philosophical underpinning of Heideggerian ontological hermeneutics in section two. The method presented allowed me to gather and interpret data in a way suited to both the philosophical underpinnings and my own personal orientation. The construction of the analysis process based on van Manen's approach (1990) was clarified. I also discussed the issues of rigour and ethics surrounding the use of this approach, demonstrating an understanding of the issues. The findings of the pilot study were provided in section three.

This chapter has been intentionally lengthy in order to describe the activities, decisions and procedures employed during the conduct of this study so that the reader can audit my 'decision trail'.

In the next two chapters, the findings and discussion of the findings are provided and the implications for nursing are identified, including recommendations for practice and research.

Chapter 4: Findings

4.1 Introduction

Phenomenological study aims to uncover the essences of lived human experience (van Manen 1990). This study concerns itself with understanding mothers' experiences when their newborn babies are transferred from their local neonatal unit to a regional neonatal unit.

This chapter begins by providing some details of the study participants to allow the reader to 'get to know' more closely the mothers involved in the study. An overview is provided before describing the findings of the analysis of the mothers' stories. The four themes found to underlie their experiences of the transfer of their newborn babies are 'emotional responses', 'adjustment', 'information issues' and 'geographical distance from baby'. Each theme is described and examples of how it manifests itself in the lived experience of the mothers studied are given.

4.2 Participant's profile

The characteristics of the 15 mothers involved in the study are summarised in table 4.1. The youngest mother interviewed was 17 years with the majority of mothers (eight) in the 31–40 age group and the remainder (six) in the 21–30 age group. Two mothers were single mothers while all the others were married or living with their partners. Nine mothers had between one or two other children ranging from 14 months to 7 years at the time of recruitment. Nearly half the mothers (eight) were employed either part time or full time prior to their delivery. All the mothers lived outside the regional neonatal unit area with more than half (nine) living about 20 or more miles away. The rest of the mothers (six) lived within a 20-mile radius of the regional unit. Five mothers chose to stay in the hospital accommodation at the time of interview while the rest (ten) chose to travel to and for to visit their babies in the regional unit. More details can be found in Appendix 17.

Table 4.1: Summary of characteristics of sample

Characteristics of mothers (n=15)	Numbers
Age	
15–20	1
21–30	6
31–40	8
41–50	0
Marital status	
Married/partner	13
Separated	2
Employment status	
Full time	1
Part time	7
Not employed	7
Distance from regional unit from home	
0-20 miles	6
20-40 miles	4
> 40 miles	5

Profile of baby

Demographic details and information regarding the babies' admission has been provided in order that the reader may know something of the babies and better understand the context in which these mothers are living.

Of the fifteen babies (eight boys and seven girls) of the mothers interviewed, only three were term babies; the rest (twelve) were premature babies, ranging in gestation from 24 to 33 weeks. Four of the babies were delivered by emergency caesarean section while the rest of the eleven babies were born by normal vaginal delivery. Two were transferred on the day they were born while the rest (thirteen) were in the local unit for at least two weeks prior to the transfer. Six of these thirteen babies were in their local unit for at least a month prior to the transfer (table 4.2).

Table 4.2: baby's profile

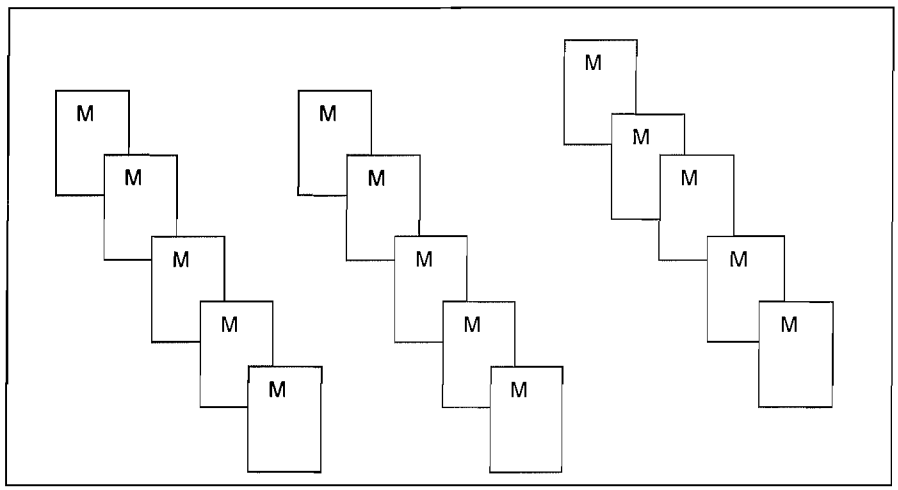
Characteristics of baby's	Numbers
Sex	
Male	8
Female	7
Gestation at birth	
Term (37 weeks to 40 weeks)	3
Less than 37 weeks	12
Duration in local unit before transfer	
1 day -6 days	4
7 -13 days	2
14 -20 days	2
21-27 days	3
28 -34 days	3
35 -41 days	1
Reason for transfer	
Surgery care	10
Medical care	5
No local neonatal cots	0

4.3 Overview

Thematic analysis revealed between eight and 12 composite themes within each transcript, producing 80 in total. Comparison of the texts revealed a number of composite themes (statements which are significant for phenomenological clustering into composite themes) (Moustakas 1994). These composite themes were then compared to identify recurrent themes. Details about the discarded composite themes can be found in appendix 16. Recurrent themes are themes with common elements shared between two or more transcripts, thus producing a total of 17 recurrent themes. Since the purpose of the study was to explore meanings that were common to the mothers, any remaining singular themes were discounted as irrelevant for further analysis (composite and recurrent themes are illustrated in figure 4.3). The 17 recurrent themes were then compared for similarity in meaning and this produced four relational incidental themes (figure 4.4). Using free imaginative variation (van Manen 1990, Moustakas 1994), the essential theme was then elicited (figure 4.5).

The findings represent extracts taken from all interview transcripts and also from my own diary, which provided an ongoing reflective account and which contributed actively to data generation. As a means of identification and as a means of protecting anonymity, each mother is identified by a pseudonym. Extracts annotated by the letter R (researcher) refer to my own comments that occurred within the interview dialogue, while the term 'field note' indicates transcription of my personal reflection account.

Figure 4.3: Composite to recurrent themes



Recurrent themes =17

Uncertainty	Information related to baby's condition	Environment	Burden of travel
Anxiety	Information about the transfer	Atmosphere	Burden on family and friends
Guilt	Transfer of information	Social relationships	Financial burden
	Baby-focused information	Living in accommodation	Lack of closeness
	Lack of empowering information		Impact on siblings

NB: M indicates the 15 mothers' transcribed interviews

Figure 4.4: Recurrent to relational incidental theme

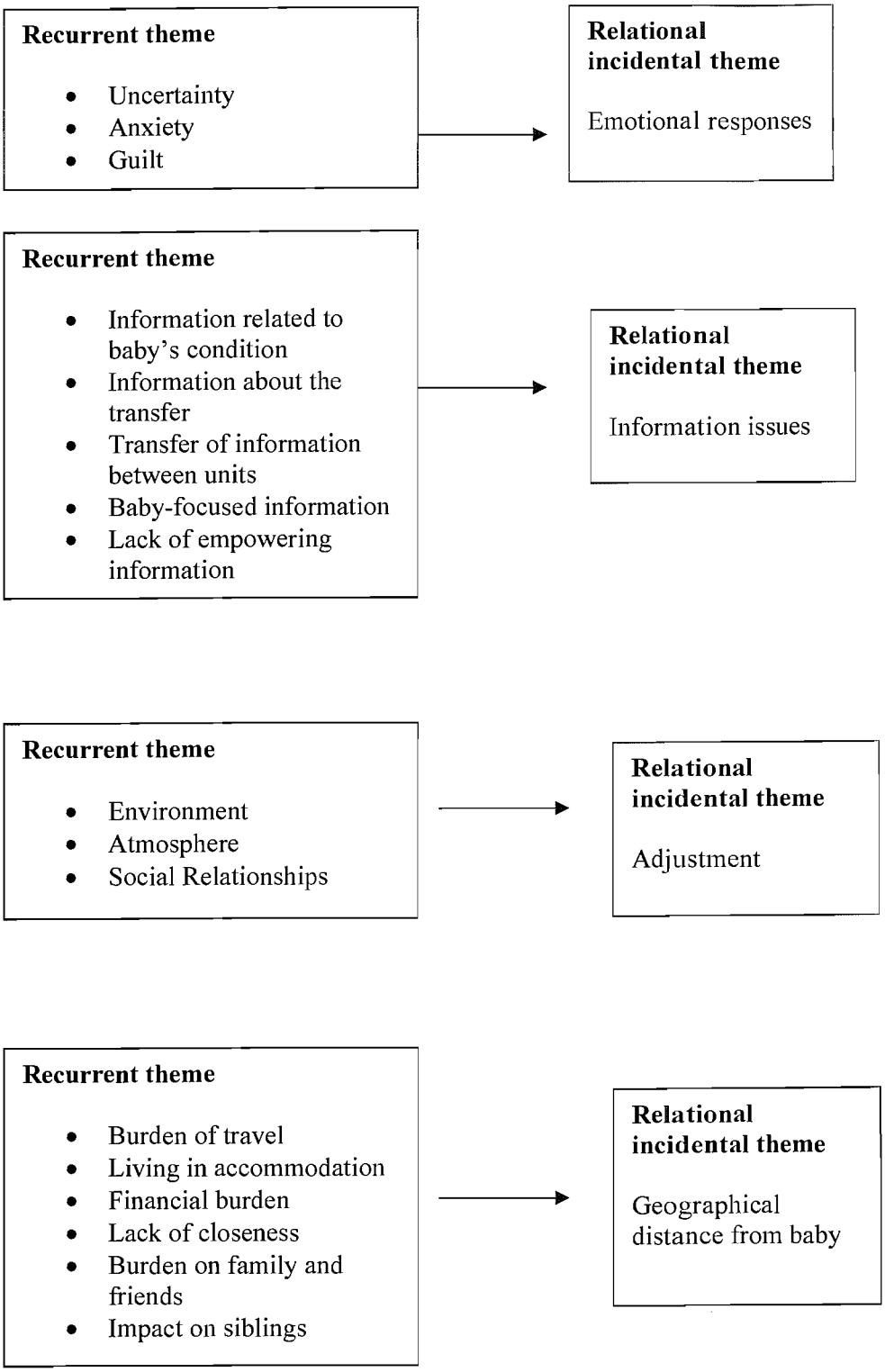
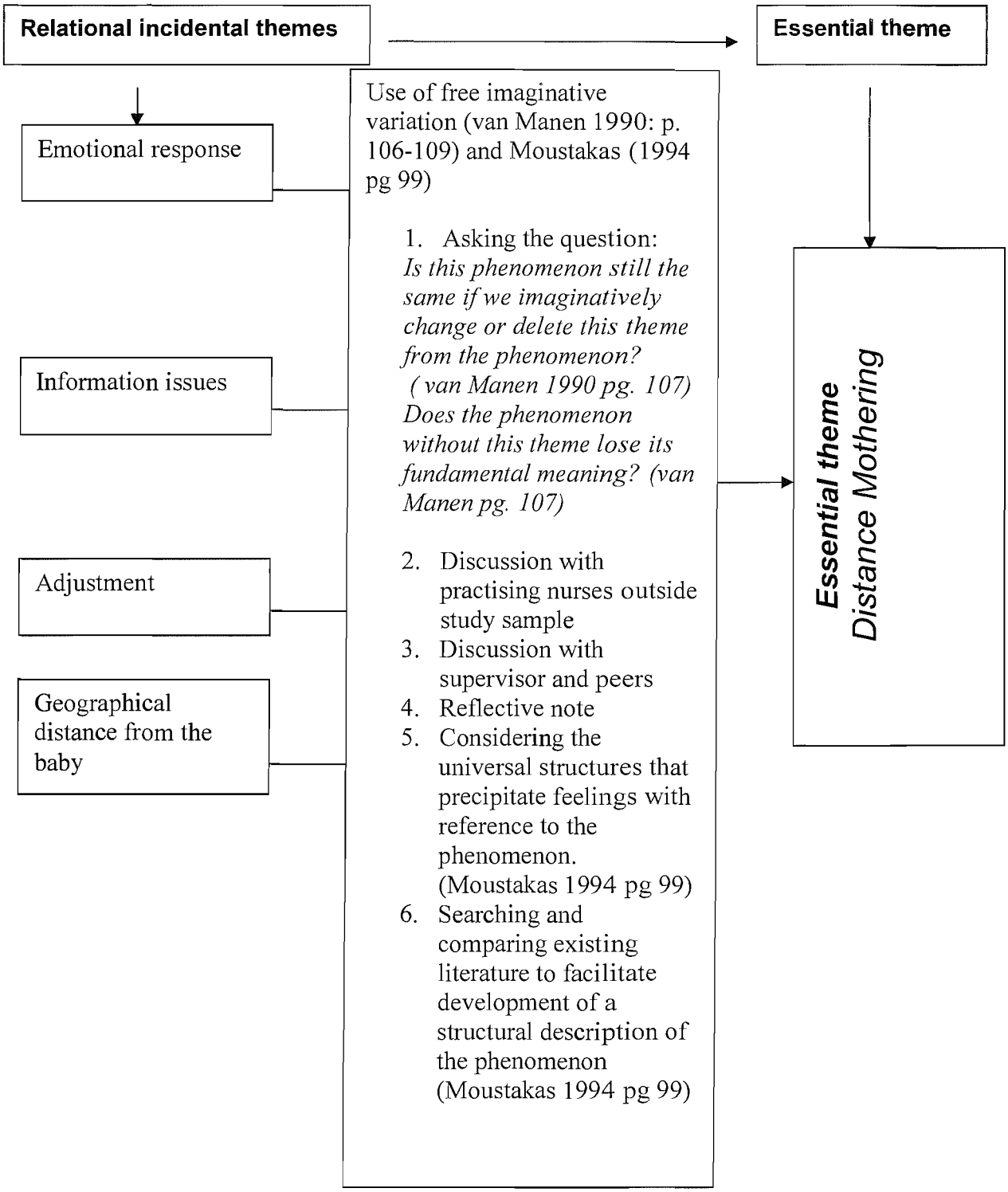


Figure 4.5: Relational incident theme to essential theme



4.4 Emotional responses

Although individuals varied greatly, a number of consistent themes were identified in the data that described features of emotional reaction to the transfer. The impact of their babies' transfer precipitated a range of emotional responses, with no apparent linear sequencing of responses over time.

4.4.1 Uncertainty

The unexpectedness of their babies' transfers precipitated feelings of immense uncertainty in study participants. Throughout the interviews, the mothers focused on their feelings of uncertainty about what was going to happen to their babies and to themselves. They talked of not knowing what to expect and stated that having their baby transferred was a new experience and could not be 'known' without experience.

No one told us....We were just in shock, terrified....We didn't know what to expect. (Carol)

It would be nice to at least tell us that they are considering transferring her (baby)...you don't know what's happening... suddenly they said she needs to go. (Alice)

I was just getting used to being in this unit ... you know doing most of her (baby) care and stuff.... I am not sure how the other unit will be like. (Irene)

All but one of the mothers expressed their feelings of not knowing what to expect. For example, one mother stated the following:

I was surprised at how traumatic an experience it was having a transfer...you just get a firm grasp of...what's happening (in local unit)...and then all of a sudden they're (the baby is) moving...there's always that uncertainty – will she (baby) be alright. (Fiona)

Not knowing what the future held contributed to their feelings of uncertainty:

It's hard when there are so many uncertainties…I guess it was because my son had just come in…they didn't know how he would react to the transfer…so they don't want to say much...and that was hard. (Nora)

There is so much I don't know….I don't know whether he (baby) will be alright after the surgery...I just don't know what the future holds for him. (Laura)

4.4.2 Anxiety

The mothers' emotional responses were experienced within a situation in which anxiety for their babies' survival was a constant and salient feature. They were quite explicit about their worst fear of not being able to be around the baby:

For all I knew she was dying and I wasn't allowed to be with her in the ambulance. (Elaine)

Well…he is obviously not well…that is why he needs to go to a bigger unit….I was so worried that he may not make it...you know the journey. (Mary)

It was probably one of the hardest days in my life watching them rush my baby to the ambulance…and not knowing how he is at the other end. (Gloria)

One mother described this worry about the infant's outcome as 'a roller-coaster ride from hell':

Extremely emotional, like one day up and the next day down…you never knew; we used to dread going…you know you have this fear that the next time you visited something is going to happen. (Heidi)

Mothers' comments also related to their anxieties at being separated from their ill babies at a time when they felt a strong instinctive need to be present, to protect and comfort. These were also related to being not able to get to the baby in time due to the distance between their home and the regional unit, as illustrated in the following comments:

It was hard to go home...it is just too far...I really wanted to stay with her in case anything happened...and I can't get here fast enough. (Laura)

I found it very difficult to leave her (baby) at the (regional unit) because I didn't want to part with her...it's the fact that you're thinking well what if she turns for the worse...and I can't get here quick enough. (Elaine)

Going home while she (baby) is here (regional unit) is not an option...(baby) is so ill that anything can happen and home is just too far. (Joanna)

Some of the mothers felt they had to wait too long after the transfer before they were allowed to see their babies. Also a number mentioned their anxieties on finding that they had arrived before the baby:

Waiting for his (baby) arrival and not knowing how he was...was unbearable...we feared the worst. (Mary)

You know...from the time he left in the ambulance, I had no way of knowing how he was doing...and that is about three hours of his life...I worried...I might not see him...you know in time...at least in the (local unit) I am able to be around him...and I can get there (local unit) very quickly. (Elaine)

One of the mothers reported that she needed to hear confirmation that the baby was still alive and appreciated it when the staff took them to their baby as soon as they arrived (in the regional unit):

I was having all kinds of thoughts on the way here... that something would happen in the ambulance and I wouldn't be there....I was so relieved when they took me straightaway to him (baby)...at least I knew he was alright....It made me feel better. (Alice).

4.4.3 Guilt

Feelings of guilt were expressed by all mothers in relation to themselves and to family members. These women felt guilty for their perceived inability to continue caring for their families:

It is difficult being away from family because I have two other kids and I'm so involved in their lives...now I have to depend on my parents to take care of them while I am here with (baby)...I wished she (baby) was back at (local unit) ...at least there I don't have to stay as I could easily go to see her anytime....(Heidi)

I really have no choice...she (baby) needs me here....I feel guilty that (husband) has to look after the other two kids as it is just too far...if anything happens and I need to come here fast...it will just take too long. (Karen)

It is very difficult having to choose...but he (baby) is just too ill....I just want to be with him (Irene)

I do feel guilt that I have to leave the kids....every day they are with somebody different (Alice)

Some mothers experienced a strong sense of not being able to care for their children equally and having to apportion not only their time but also their affective commitment:

I have to make sure I don't spend all my time here as he (the other child) needs me too. (Alice)

You just have to prioritise everything...the travelling takes some time. (Irene)

Table 4.6 Emotional response

Relational incident theme	**Recurrent theme**
Emotional response	Uncertainty Anxiety Guilt

4.5 Information issues

Information is a concept that is often assumed, but seldom defined. Information is often thought of as any data that can be used to add to a knowledge base. Buckman (2002) postulates that information is a highly individual construct and, as such, are used to solve problems or fill gaps in knowledge and understanding. The importance of giving information to parents is a predominant theme in the literature (Miles 1989). Parents feel that there is not enough information given, that they are not given regular progress updates (Lau & Morse 2001).

The following section will present some examples of mothers' verbatim comments starting with the theme of 'lack of information related to the baby's condition' prior to transfer.

4.5.1 Information related to baby's condition

Many of the mothers identified the difficulties they faced trying to get accurate information about the abnormality or condition from the local unit. Mothers find such uncertainty particularly hard and wanted more information specifically related to the baby's condition as indicated by these comments:

It is awful...not knowing...not knowing what was...and quite scary because they (local hospital) obviously were not sure what was wrong...and that was quite frightening that they didn't know, what was wrong with her. (Barbara).

I know she (baby) is not well...she was breathing so fast...they told me she needs to go to (regional unit) for surgery...and that is all they told me...that she needs surgery...and she needs to go now...I was not told what the surgery is going to be. (Irene)

I just didn't know what was happening....I had no idea what was wrong. People kept saying that he was fine, but...you know, I hadn't seen him or, you know, or anything. (Nora)

Inadequate information can leave mothers distressed until they can get further sufficient information:

God knows what it would have been like if it was something really bad. Do you know what I mean.... it was really bad for us mainly because we didn't know anything about it. (Claire)

For some mothers there were added difficulties because other people were around at the time of diagnosis. This was particularly the case when the mother had been discharged home after the birth and, as often happens after the birth of a baby, returns with others, including the father, mother-in-law and other children. While this may be unavoidable especially when the baby is born prematurely and needs special baby care, it was particularly upsetting for the parents as illustrated:

Well...what I think was happening is that the....there were two doctors...I think, and um they had I think been waiting for me to return so that they could um...so that they could tell us all at the same time...um I think the mistake is that my husband's mother was there at the time we were told and that led to a bit of problem...she (mother-in-law) didn't really accept it and started to argue with them. (Nora)

4.5.2 Information about the transfer

Since tertiary level care was not provided at the local unit, the babies were transported to another unit (regional unit). Knowledge about transfer plans as they are being made is consistently rated as a primary information need by family members in intensive care units (Leske 1992).

Comments were made relating to a lack of information about the transfer as depicted in the following examples:

Not really told much about transfer. I expected him (baby) to be in (local unit) till he was big enough to go home. (Alice)

Well...we didn't know...there was no mention about it until we got the phone call the morning he (baby) was transferred. (Esther)

We were told that she (baby) needs to go to (regional unit)...the name of the (regional unit)...that is all....We did not know when the ambulance was coming...and how we were going ourselves...in the end we had to ask for directions. (Irene)

Mothers expressed a need to know when the transfer was going to take place. One mother said:

I was on my way to see my baby and they (local unit) called me to say that they were transferring her (baby) today rather than tomorrow. (Alice)

These comments demonstrate a lack of communication that seemed to leave mothers feeling unprepared and surprised by the timing of the baby's transfer. Nine mothers said that, because they were unprepared for the transfers, they did not have a chance to ask any health care professionals the questions about the regional unit that they would like to have asked.

4.5.3 Transfer of information between regional unit and local unit

Parents whose babies are transferred for treatment or surgery are naturally anxious, particularly when they have only recently discovered that their baby has problems. On arrival at the regional unit, mothers sometimes found that the staff had not had sufficient time to prepare for their arrival. The consequences of this were that there was nobody available to explain what would happen and nowhere to accommodate them on arrival.

Some of the mothers said:

The nurses in (regional unit) said they knew he (baby) was coming but did not know his arrival time and seemed surprised when he got there. (Alice)

I think that was almost no – no real co-ordination and communication between the hospitals other than there is a baby who has suspected (condition) will be coming in at a certain point in time. And I don't think anything else was communicated. (Gloria)

With the transfer…there's nobody here to take you aside…we were just left…you can't just treat one part of the family (the baby) and let everyone else float around. (Irene)

However when information was shared, as below, the mother and the unit was more prepared. This atypical experience was considered in the interpretation of the data as it is important to consider the range of experiences rather than the average experiences:

I went off to (regional unit) and followed the ambulance down. We got her there and transferred her into (regional unit) and the people at (regional unit) were absolutely brilliant, I have to say, they were just so professional...not only that...they were completely aware of how I was what an emotional experience it was for me and I was put at ease so quickly. (Heidi)

4.5.4 Baby-focused information from regional unit

Mothers were reassured when the nurses in the local unit used a personal approach when communicating with them. Some go on to describe how important it was for nurses to talk to them as individuals:

They (local unit) call you by your name...they comment, they tell you about their children and what they are up to...it makes me feel...well...as if I am really a mother. (Fiona)

Although many of the mothers identified how nurses in the regional unit provided them with up-to-date information and the day-to-day care of the baby, nearly half the participants identified that nurses in the regional unit were concerned with giving them information about the baby rather than communicating with them personally like the nurses did in the local unit.

They (regional unit) are very good...they tell you what (baby) has been doing...but that is as far as it goes...they don't asked you how you are doing...I felt as if I am just visiting you...know...a visitor. (Fiona)

People would come and talk to us...about (baby)...that was great...but at no point was there any sort of communication as to...you know how are you feeling...you must be feeling horrendous, you know...that sort of thing...makes feel as if I am not her (baby) mother. (Laura)

When nurses were sympathetic, mothers in this study felt that their feelings were justified and made them feel as if the nurses understood their situation and cared about them as people. It seemed important to the mothers that nurses communicated this recognition. They did not expect the nurse to be able to 'fix' everything but it alleviated their anxiety and uncertain feelings when they knew someone understood how they were feeling:

There was one particular nurse....She was lovely...every time she saw me she would ask how you were and how (sibling) and (dad) are doing. (Laura)

Hum...it is more like...the way she said it....You know...like really interested in knowing how I am...you know as a mother. (Karen)

The nurse asked me a lot of questions about stuff about what I had been doing for her (baby)...you know like nappy change, feeding that sort of things...kind of clarify what I used to do in (local unit)...that impressed me because obviously she valued my opinion and my capabilities in her (baby) care. (Nora)

4.5.5 Lack of empowering information

In order to understand what was happening with their babies, mothers needed to learn a compendium of information relative to prematurity, their babies' specific health problems and treatment needs and prognosis, and the NICU environment, just to name a few categories of information. Such information was vital for them in order to be able to evaluate their babies' care needs.

The mothers in this study needed empowering information. They often received much information from many members of the health care team, which they perceived was not sufficient to enable them to evaluate their babies' care needs. What the mothers identified as necessary for their learning and ability to care for their babies and themselves was information that empowered them to understand their babies' and their own situation.

Some of the mothers' statements are illustrative:

I need to know what this all means, what I should worry about and what to expect. (Karen)

I want to know how the nurses feel about my asking questions and what I can ask for or make suggestions about. (Alice)

I need to be able to ask questions and discuss what it means so that I can help decide what will work best for my baby. (Esther)

I need to know how things work around here, so that I know who to go to about what concerns or questions. (Nora)

Table 4.7: Information issues

Relational Incidental Theme	**Recurrent theme**
Information Issues	Information related to baby's diagnosis
	Information about the transfer
	Transfer of information between regional unit and local unit
	Baby-focused information from regional unit
	Lack of empowering information

4.6 Adjustment

The theme of adjustment is characterized by the mothers' descriptions of their experiences of having a newborn baby in a local neonatal unit and beginning the process of adjusting to unanticipated situations.

All the mothers explained how the transfer was not a gradual situation for which they had warning or could prepare. Instead they described that they felt as if they were uprooted from their everyday lives. All spoke at great length and in vivid detail about how the transfer affected them.

It was like throwing a baby into a cold swimming pool – all which is familiar and comforting is suddenly gone. Instead there you are in this place that is unknown…lots more machines and the noises. (Gloria)

Adjustment to the experience of having their newborn baby transferred meant that parents were required to look realistically at their situations. The mothers become experts on the environment of a neonatal unit and the emphasis in their comments shifted from the actual environment to the social atmosphere of the unit.

4.6.1 Environment

In Chambers dictionary (1993), environment is defined as 'the circumstances, objects, or conditions by which one are surrounded', as well as 'the aggregate of social and cultural conditions that influence the life of an individual.' Although these definitions are contextually broad, they do suggest the significance that humans place on personal environments. Relph (1986) emphasized the importance of environments, stating, *'they are important sources of individual identity...and are often profound centres of human existence to which people have kept emotional and psychological ties.' (p.141)*

All mothers noticed a change in the environment. The first major difference the mothers noted on entering the regional unit was the physical space. It was so big and yet seemed so cramped and crowded. The mothers spoke of the advantages and disadvantages of the unit environment:

Much bigger...but also rather crowded with lots more equipment. (Anna)

Well...babies and equipment everywhere...rather clinical. (Gloria)

Another mother, whose infant had had a prolonged hospitalisation (70 days) at the local unit, commented:

I got here (regional unit), and it was back into incubators, all hooked up to monitors...everything changes... it is just back into 'these are sick babies' again.... It is as if I am in another world...much bigger but full of equipment. (Fiona)

One of the limitations of being in a confined space is the realisation that the conversations and activities of all are under scrutiny. Thus in the regional unit parental contacts was limited to 'chats' in the family room.

Well...it just too cramped and noisy to talk...and the few times you did go to the family room you may meet some other parents but really everyone is in such a hurry to get back to their babies that you don't really talk much either. (Esther).

In contrast, in the local unit, with much more space and less noise, the mothers got to know their neighbours and developed friendships. They became supportive of each other and would accompany each other for lunch or talk in the family room.

It's like you got a close bond...you got this big, big thing in common. That you didn't have, you never had even with friends you had forever. (Anna)

4.6.2 Atmosphere

The other common comment concerned the atmosphere. Participants almost universally commented on the friendliness of the staff in their local unit and comparisons were made when they visited their babies in the new unit (regional unit):

It's nicer in (local neonatal unit)...sort of calmer and friendlier I think in (local neonatal unit). (Doreen)

I think it is...well the staff in (local unit) were much more friendly...they called you by name and asked you about your family...and there is not that...much rushing about and telephones ringing I suppose...much more relaxed. (Esther)

It's nice...more sort of homely in a way in (local unit) while in (regional unit)...there seems to be more equipment and...people everywhere....Guess they have more staff there (regional unit). (Irene)

One of the mothers, whose infant had had a prolonged hospitalisation (50 days) at the local neonatal unit, commented on the care at the regional unit:

They (staff in regional unit) seem nice and knowledgeable...but it just didn't feel like what we were used to...like the special care was gone...here it's like she is just another sick baby ...I feel like the girls at (local unit) take to their babies more...the whole atmosphere is so much more homely and relaxed in (local unit) while here (regional unit) it is like everybody is on the run...you can sort of sense it when you walk in...the hustle and bustle. (Laura)

4.6.3 Social relationships

Managing relationships with nursing staff in the regional unit was a central task. Learning how the unit 'worked' meant quickly realising that 'you can't say who you want to take care of your baby'. Obviously this is a feature of any hospital experience. However, a feature of neonatal transfer is that it is both an acute and emergency situation for the babies and the mothers who have been in their local unit for the past few days or weeks. This was problematic for mothers, as they knew the health care providers in the local unit.

It is a bit of an adjustment...we were comfortable in one spot...you become attached to the nurses...there were certain nurses who had become familiar to us....you feel a sense of loss, sort of...you become comfortable with your surroundings...and it is just a sense of loss of not going to the same place I guess. (Irene)

The mothers appeared to have developed a special relationship with the staff in the local neonatal unit and felt trusting of the care provided. They had established routines for visiting and for participating in care and they were comfortable. The mothers expressed difficulty with leaving the familiar and going to the unfamiliar.

Oh yes....You know it is for the baby's good to go there but still you are so used...we were ten weeks in the local unit...these people were our families you know and then you are going out to people who you don't know who they are....You know nothing about them. (Karen)

The reciprocity of the relationships was echoed by most mothers as they described the feelings that had occurred between themselves and the nurses in the local neonatal unit. A mutual feeling of respect had developed between the nurses and the mothers:

They treated us like part of the family…and they are looking after your baby. (Olga)

With the babies in the local neonatal unit for weeks and sometimes months, many important events in the lives of the mothers and their families were spent in the hospital. The efforts that the nurses made to recognise those special days and 'make a big deal' for them were meaningful for the mothers. Father's Day, Mother's Day and birthdays were celebrated with special mementos and cards, personalised with pictures of the babies. It also pleased the mothers to hear that the nurses liked to take care of their babies:

I think one built up relationship over time…especially when the nurses in (local unit) have been with you all this while…you know the ups and downs…you know she was born early but she did not need much help initially at all. (Mary)

He was born in (date) and the nurse (in the local unit) looking after him made me a beautiful Mother's Day card that weekend…and a very nice photo and hand prints….They took such good care not only of the baby but also the parents. (Joanna)

You know some of them (in the local unit)…used to say, oh got my girl tonight. (Grace)

The nurses in the local unit were in tune not only with the emotional needs of the mothers but also with their physical needs. Some of these mothers were balancing caring for a child at home with trying to take on the mothering of a baby in the NICU. It was tiring. The nurses' acknowledgement of the mothers' needs conveyed to the mothers feelings of support and caring:

They knew I had another kid and ...they get papers, coloured pencils…all ready when we came so that he (younger child aged 2 years) can play while I spend some time with her (baby). (Fiona).

Table 4.8: Adjustment

Relational Incidental Theme	Recurrent Theme
Adjustment	Environment Atmosphere Social relationship

4.7 Geographic distance from baby

Quite simply, the mothers in this study stated unequivocally that being with their babies in the NICU was their priority, their job now. The mothers' narratives and actions demonstrated that geographic distance imposed onerous burdens on the mothers and their families to achieve this goal. Whatever course the mothers took, they paid a price: be with your babies or with your family and friends and community. It would appear that many mothers perceived themselves as having no real access to their babies because of the geographical distance between their homes and the regional unit. Although mothers who lived in the same county as the study NICU could also experience lack of access to their babies due to lack of transportation, child care and financial resources, this was found to be magnified by distance and by lack of normal support in this study.

The extent to which mothers were geographically dislocated from their babies varied through- out the study. For those who commuted, the commute time for home to hospital ranged from 40 minutes to 5 hours. All the mothers who lived in outlying communities experienced the geographical distance between their homes and the regional units. Some of the mothers stayed in the facilities provided. In many instances, the mothers needed to return home for a few days just to pack and make arrangements for a prolonged absence from their families. Other mothers undertook a round trip commute of up to five or more hours on a daily basis or several times a week to be with their baby. Some mothers made a round trip commute once a week and used guest housing for one to two nights before returning home. The onerous psychological, physical

and economic burdens posed by geographic dislocation forced many mothers to make agonizing choices.

4.7.1 The burden of travel

Seven of the 15 mothers opted to commute on a daily basis. In contrast, eight mothers stayed in or travelled home at the weekend. Daily commuting allowed six mothers to maintain some degree of home life and familiarity. Three mothers noted that being at home ensured continued support of family and friends. For example:

I think that's another fact of why I am travelling back and forwards is...I (think I) would miss the children, I don't really want to be away from my children or my husband...you know to be down there, you're basically alone, and you have not got any friends there. (Nora)

Travelling on a daily basis to stay close to the family often required a great deal of organisation. One mother described the daily ritual of having to organise her children in order for her to travel to visit the baby:

Well, it's very disruptive for the children; they're all at school...and we got some very good friends who've offered to pick the children up in the afternoon and they look after them, it's usually four hours that we're away...it been very disruptive to the children but I suppose on the other hand, they know that I'm coming home at night , you know, they're still getting to see me, whereas if I was staying down there, it would be a week at a time that they wouldn't be able to see me. (Karen)

Most of the mothers generally disliked travelling to the city. One mother's comment is a typical example:

And the other thing is going into a big city, going into an unknown area, you know, that's another thing, you're round in an environment that is traffic everywhere and people everywhere, it's an ongoing thing. (Olga)

It is so tiring...you know the traffic...and everything really. (Alice)

4.7.2 Living in accommodation that is not one's own home

Mothers often discussed missing the comforts and familiarity of the home environment as well as being unable to continue with 'normal' life:

Oh, there's nothing like being in your own bed for one thing and the comfort of your own home and of course your friends are at that time, supporting you...here you really don't have anybody here and so you don't have the support from your friends either (Joanna).

It is okay here...but it is not home is it. (Mary)

4.7.3 The financial burden

Nine mothers reported that the transfer placed additional financial strain on the individual and their family. Financial burdens reported included increased fuel costs, wear and tear on the vehicle, maintaining two places of residence (home and temporary accommodation) and increased food costs. For example:

It's not, it's not cheap, and it is an expensive little event. I suppose we're lucky we've got an economical car, but it's money that you know, okay if you buy petrol weekly, usually but we have to fill up a couple times a week. So, and we're already financially disadvantaged because (partner) is not working as much...he has to take time off...so yeah, it's difficult. (Nora)

One mother who commuted daily but did not feel comfortable driving in the inner city traffic chose to park her car in the outer suburbs and to take the train into the city. As a result, she said:

It cost us a lot on the train all the time. (Esther)

Information about what is available in the locality and about 'park and ride' schemes was valued.

The nurse told me about the park and ride scheme and that has been helpful...at least I don't have to worry about the car parking. (Heidi)

On occasions, the mothers used expressions or displayed mannerisms that implied apology or justification whenever they admitted to focusing upon financial issues:

I probably shouldn't complain ...at least she (baby) gets the treatment she needs and we were allowed to stay in the accommodation provided but...it has still been hard as we still need to get our food and pay the mortgage...he (partner) has to take time off to ...obviously that affects his wages. (Karen)

The following diary entry captures one mother's sense of having unwittingly confessed to some great crime. She had been telling me about how long it took and how expensive it was to get childcare for her two children while she visited her baby. At one point she seemed to realise that she had hardly mentioned the baby:

I don't want you to think that I'm not glad that she is here (regional unit) as she needs to come here....It is for the best but it is so expensive (and then threw me an apologetic look). (Field note)

4.7.4 The lack of closeness to family and friends

Despite the fact that the majority of the mothers who stayed in accommodation travelled home on the weekend, seven reported separation from their family and friends as a negative aspect of being away from home. Because this separation came at a time when the mothers reported feeling vulnerable and in need of support, it added stress to the whole experience:

Whereas, you know, I had, used to get phone calls all the time, which was great, and I made phone calls, but you didn't really see anybody you knew, you know? (Karen)

I really feel I have to stay...what if anything happens to (baby) and I am not around...it is not as if I could just come....It takes time to get here...but it has been very hard being on my own here...there is nobody to talk to. (Doreen)

Mothers with family expressed sadness at having to leave their children at home, as well as the unsettling situation this created in their home environment:

I miss my other two kids....I called them everyday but I miss them...it is very hard. (Doreen)

The lack of closeness or support is clearly seen to affect the mothers in this study and an extract taken from my own diary following transcription of the fifth interview mirrors concerns about separation from family and friends which was expressed by the mothers.

The study journal entry reads:

'To date, completed verbatim transcription of five recordings...it is interesting that apart from other things, they are all raising the issues about being separated from their family and friends as being really important....I thought that, even if that were the case, the mothers may not feel as bad as they are with their baby...than being separated from their babies....Come to think of it, isn't this exactly what I've been feeling when I came over here alone while my two kids are in (another country)....I know that I can call them and they can call me...yet I remember feeling very stressed, not having any friends...and this based solely because I am new to the place.'(field note)

A note scribbled alongside this particular diary entry reminded me to 'do search on home and transfer'. This new focus upon the literature led me to undertake a complete review of the transcripts and original tape recordings to ensure that I was not putting my experiences over the mothers' experiences in this study.

4.7.5 The burden on family and friends

Fourteen mothers acknowledged the crucial role that family members and /or friends played in providing support during this period. One mother's elderly parents had to live in with the family in order to help out with household chores:

Well...my mother and mother-in-law actually had to come, and they are quite elderly, both of them, so they took it in turns coming and looking after the kids. (Cathy)

I have to depend on my friends to pick up my kids from school in the afternoon and look after them until my husband gets off work at six. (Doreen)

Two mothers who stayed with friends reflected on how it felt living in someone's household for a considerable amount of time. Issues raised were the additional food costs incurred for the host household and the inconvenience for everyone involved.

One mother explained:

You are aware of being in another person's home....you're conscious of being in somebody else's house and...it is difficult to relax....I didn't also want to impose on their family and all that sort of thing, you know...so in the end we opted just to drive down every day , but no, it was certainly different, you know, makes you aware of, you know, where you are and what you're doing. (Heidi)

One single mother who could not drive due to having had a caesarean section was faced with having to depend on her elderly mother to drive her despite the fact that it was also very strenuous for her (mother):

I don't know what I will do without mum...I can't drive at the moment and travelling must also be very tiring for her...but what can I do...I need to be at home for (elder sibling) and can only visit (baby) when he is at school. (Joanna).

Some of the mothers also worried about exhausting these sources of support:

And my two other sons are...just chucked about from pillar to post....I was at the hospital every evening so my kids were just with whoever would have them. (Nora)

4.7.6 Impact on siblings

Mothers who had other children were also concerned about the impact their absences from their other children's lives might have, and though the obligation to be with their sick babies partly ameliorated this aspect, many still experienced guilt, conflict and regret at being away from their other children:

It is so difficult....There is no choice...she (baby) is ill and she needs me here...yet you feel worried about (older sibling)....Obviously you don't want him to feel neglected....I try to tell him that he is still mummy's boy...I am not sure whether he understands it all or not. (Karen)

He (son) visited me the other day...and he is so clingy...just did not want to go at the end of the visit...I have to tell him again and again that he is still my number one boy...I am not sure whether he understands or not. (Olga)

Table 4.9 : Geographic distance from baby

Relational Incidental Theme	**Recurrent Theme**
Geographic distance from baby	The burden of travel
	Living in accommodation that is not one's own home
	The financial burden
	The lack of closeness to family and friends
	The burden on family and friends
	Impact on siblings

4.8 Chapter summary

The impact of having the newborn baby transferred from their local neonatal unit to a regional neonatal unit is similar for all mothers, regardless of the cause of the transfer. Issues arose for mothers around their feelings, which were influenced by the geographical distance of the unit. Emotions identified in this study indicated that most of the mothers experienced uncertainty about what they were going to find at the new unit in addition to feelings of anxiety about not being able to get to the baby in time if the baby's condition deteriorated in the regional unit due to the perceived geographical distance from their home to the unit. A feeling of guilt about their

perceived inability to care for their children equally and having to apportion their time between the sick infant in the regional unit and other children at home was also reported.

The majority of the parents stressed the heightened travelling demands related to the geographical distance. Problems with information-giving about the transfer and the baby's condition were highlighted, together with a need for empowering information and better co-ordination between the local and regional units, by most of the mothers in this study. The need for adjustment was perceived to be an important element in this study. This may be because the majority of the mothers had spent a period of time in the local unit prior to the transfer, and may be especially true for those whose babies have stayed in the local neonatal unit for a period of time.

This chapter has highlighted the findings that were elicited from the 15 mothers in this study. The meaning of the transfer experience for the mothers in this study was represented through the four themes. The following chapter will provide a conclusion to the study by discussing the findings in relation to the existing literature

Chapter 5: Discussion, implication and recommendations

5.1 Introduction

This concluding chapter provides a summary of the main issues emerging from this work and final comments. The chapter begins with a summary of the main study findings followed by discussion of the main findings in relation to the existing literature. Although some of the findings are in keeping with what is known from the literature relating to having a critically ill and / or premature infant transferred to a regional neonatal unit, there are, however, areas where findings differed from reported studies. These will be discussed in the context of this study. Implications and recommendations for nursing practice will be included.

5.2 Summary of the main study findings

The following list provides a summary of the main study findings:

- The transfer is an emotional event for the mothers, filled with uncertainty, anxiety and guilt. Not knowing what is going to happen or what to expect contributed to the mothers' feelings of uncertainty. Anxiety relating to their baby's condition, the distance and travelling time needed to get to their baby, and when baby was in transit was reported. Feelings of guilt are expressed by all mothers in relation to their responsibilities to other family members.

- Individual mothers had different **information** needs, and required varying levels and types of information in the situation, but service provision did not always account for these individualities. Information about the baby's condition and the transfer were reported as inadequate. The mothers found that co-ordination of information between units was poor. The importance of a more personal approach was emphasised by all mothers.

- **Adjustment** was an issue because of the mothers' perceptions of differences in the environment, atmosphere and relationships between the two units. The implications for the mothers of the perceived differences in the physical space between local and regional

units were reported by the mothers in relation to their being under closer scrutiny and having less perceived support in the regional unit.

- The impact of the **geographical distance** between home and the regional unit can affect not only the mothers but also family and friends. All the mothers reported the difficulties of getting childcare for siblings and financial difficulties due to the expense of travelling to the regional unit. The need to be with the baby in the regional unit necessitated living in hospital accommodation or commuting daily to the regional unit. The lack of closeness to family and friends was reported as a negative aspect of being away from home. For some mothers, their concerns also included the impact of their absences from their other children's lives and the perceived burden on family and friends who helped with childcare or household chores while the mothers stayed at the regional unit or travelled daily to visit the sick infant in the regional unit.

5.3 Discussion of main findings

This study sets out to gain through interviews with mothers some understanding of their experience of their babies' transfer to a regional neonatal unit. Four major themes emerged from the data: emotional response, information issues, adjustment and geographical distance. These themes characterised the mothers' experiences when their newborn babies were transferred from their local neonatal unit to a regional neonatal unit. The concept linking these four themes is 'distance mothering'.

5.3.1 Emotional response

Feminist theorizing on the family and motherhood has identified how for women in particular, motherhood is both a regulator of their lives (Boulton 1983) and a major component of their self identity (Richardson 1993). Though women increasingly adopt roles outside the domestic sphere, mothers' emotional identification with their children remains strong (Mayall 1996), and notions of maternal self sacrifice in 'putting the children first (Richardson 1993) and of children's 'best interests' (Sclater et at 1999) remain powerful in both public and private discourses about motherhood and childhood.

Motherhood is thus defined (at least in part) in relation to social constructs of children and childhood. The emerging sociological study of childhood has highlighted how the social construction of children has until recently been dominated by largely uncontested concepts, rooted at least in parent in psychology and how these concepts have structured in the cultural climate of mothering (Burman 1994) : children are seen as vulnerable and dependent upon adult attention to ensure well being.

Children's 'vulnerability' arises not just from their "immaturity': as people who are valued for what they will become as well as for what they are, much concern centring on protecting children's future selves. This view of childhood is embraced by most western societies and within its framework, parents and particularly mothers, is morally responsible, not just for their children's current well-being but also their future well-being. Unpleasant feelings such as anxiety, loss and sadness often arise when parents are unable to maintain proximity and provide protection for their children.

This would seem to be true for the mothers in this study when the mothers reported some of their anxieties as related to the perceived separation from their baby while their baby is in transit from the local neonatal unit to the regional neonatal unit.

Although the effect of distance was mentioned in the study by Wilman (1997), there was no mention of how that influenced the emotions of the mothers when the baby was in the ambulance. However, some of the mothers in Kuhnly and Freston's study (1992) study highlighted fears and anxieties as related to problems that could occur during transportation, and monitoring problems that might happen during travelling. This may be because Kuhnly and Freston's study was on back transfer, where the babies may have been in the NICU for some time and the mothers became dependent on the monitoring equipment in the NICU. This resulted in reported concerns about monitoring failure in the ambulance journey to their local neonatal unit. This was not highlighted by the mothers in this study. This may be because all the babies in this study were from the local neonatal unit which comparatively was not so highly technologically orientated, thus the mothers may not been aware of this aspect. However this study's finding of the mother's anxiety during their baby's transit emphasises the importance of being kept in touch during transit, which has not been fully acknowledged in any of the existing studies on neonatal transfer.

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Uncertainty in an illness situation has been associated with anxiety (Wong & Bramwell 1992). In this study, anxiety can be described as 'a feeling of apprehension caused by a threat to a person or his values' (Robb 1997). All the mothers in this study found uncertainty particularly hard, especially about what was going to happen to their baby and themselves as a consequence of their baby's transfer. Not knowing what to expect and what the future held for the baby contributed to their feelings of uncertainty. Kuhnly and Freston (1993) indicated that mothers' perceptions of anxiety can be related to the degree of the infant's medical problems while Wilman (1997) suggested that the transfer event is a anxiety-provoking event for parents as the very fact that the baby has been moved to another hospital is an indication to the parents of the severity of its medical state. Similarly, comments by the mothers in my study also indicated that some of their anxieties were related to the baby's condition.

Results supported previous studies that indicated that most parents experienced uncertainty about what was going to happen to the baby whether it involved initial or back transfer (Fischer & Gutterman 1992, Gibbins and Chapman 1996). Parents in Gibbins and Chapman's study (1996) reported this experience of uncertainty as being 'left in the dark' and not knowing what to expect, while some of the mothers in Frisher and Gutterman's study (1992) reported uncertainty and anxiety about the baby's condition as one of the mothers' emotional responses. Several studies investigating the experiences of parents with critically ill babies in NICUs also reported that the infant's uncertain survival is one of the most difficult parts of the parents' experience (Shields-

Poe & Pinelli 1997, Curran et al. 1997). Although this suggests that studies of parents' experiences with hospitalised infants in NICUs and with transferred babies reported a similar emotional response, it would appear that it is an area that has not yet received the attention it deserves.

Traditionally the role of women, as internalised by all mothers, has generated strong feelings of responsibility towards other family members and other children, with consequential feelings of guilt in having to prioritise. Graham (1984) and others have pointed to how keeping a child healthy is a key component of the work of women, one through which their adequacy is judged by themselves and by others. The process of 'prioritising', by making choices of how and where to place one's commitment of time, location and emotional energies, inevitably generates feelings of guilt (Robb 1997).

In this study, the mothers also described the emotional wrench of separation from their family members (e.g. other siblings), and / or inability to be with the sick infant, leading to feelings of guilt either way. Protecting and caring was seen as an integral part of mothering and yet many of these mothers were unable to enact this part of their role due to the geographical distance. The mothers reported the need to be with the sick infant but at times were not able to do so, due to family commitments or child care problems, leading them to feel guilty that they were unable to be with the sick infant. Comments also indicated that mothers felt guilty too when they were with the sick infant in the regional unit, as they would not be able to look after the other children at home.

Although guilt was also reported in three of the initial transfer studies (Fischer & Gutterman 1992, Newson 1991, Wilman 1997), the guilt was expressed focusing on the mother's perceived inability to have a normal healthy term baby (Newson 1991, Wilman 1997) and feeling neglected (Fischer & Gutterman 1992). In Fischer & Gutterman's (1992) study, the guilt was related to the feeling of neglect from the perceived lack of the husband's attention because he was taking care of the children at home and visiting the new baby in the regional hospital. However, this may partly be because most of the mothers in their study remained in the postpartum hospital while the baby was being transferred to another hospital with specialist neonatal care, while in my study, most of the mothers were no longer hospitalised and had other children at home. It would appear that in the current study, the mother felt guilty not because of the perceived inability to have a normal healthy baby, but because of her perceived inability either to be with the sick infant due to

other family commitments, and / or to assume responsibilities for the other siblings at home if she stayed with the sick infant in the regional unit.

Although studies on parents with hospitalised infants in NICUs have also reported feelings of guilt by the mothers, the guilt was related to the mother's perceived inability to deliver a full-term healthy infant (Padden & Glenn 1997, Shields-Poe & Pinelli 1997, Redshaw 1997). Thus in this study issues of prioritising and making choices between the sick infant and other children at home caused a different kind of guilt in the mothers in this study.

To summarise, this theme indicated the emotional nature of the transfer experience. Although this study's data corroborate earlier work in neonatal transfer, the nature of the reported emotions is qualitatively different. The results of prior studies supported the current findings that most parents in both initial and back transfer experienced uncertainties about the infant's outcome. However, the nature of the anxiety and guilt reported in my study differ from other neonatal transfer studies. Anxiety was reported as related to the perceived separation from the baby during transit and the perceived inability to get to the baby in time if the baby deteriorated, rather than related to the infant's medical problem as highlighted in the studies by Kuhnly and Freston (1993) and Wilman (1997). Similarly, although guilt was reported in some of the initial and back transfer studies and studies on hospitalised premature infants in NICUs, there are differences in the nature of the guilt experience reported in my study (Newsome 1991, Wilman 1997, Frischer & Gutterman 1992, Redshaw 1997, Reid & Bramwell 2003). Mothers in my study related their feelings of guilt to their perceived inability to assume responsibilities as a mother both to the infant in the distant regional unit and to other siblings at home. This issue of prioritising and making choices between the sick infant and other children at home inevitably generates feelings of guilt for the mothers in this study.

In recognising how having a transferred baby shapes emotions and obligations of mothers, the study suggest that these emotions are part of how the mothers used to represent their experiences and obligations as mothers , including their role as the mother of their other children and as a wife . This finding is very important as by understanding the emotions and the reasons will ensure that care can be tailored to meet these emotions needs more effectively.

5.3.2 Information issues

Rubin (1984) asserts that role and identity are acquired and modified during nurturing interactions between infant and mother where she assumes total responsibility. However the mothers in this study were not able to do so as most of the mothers identified difficulties they faced trying to get information that would help them to care for their babies themselves.

Many of the mothers in this study identified the difficulties they faced in trying to get accurate information about their baby's condition from the local unit. In this study the mothers found that local unit staff was not able to give them adequate information about the baby's condition. This may be because most of the local units in this study did not have specialist care, thus may not have been able to give adequate information about the condition or its management. The need to know what is wrong with the baby is consistently reported not only in studies on neonatal transfer (Frisher & Chapman 1996, Cross et al. 1995, Dodds-Azzopardi & Chapman 1995) but also in studies on parents' experiences with critically ill and or premature infants in the NICU (Bialoskurski et al. 2002, Redshaw et al. 1996). This suggests that despite the numerous studies that reported similar findings, it is a topic that has not yet received the attention it deserves.

On a cognitive level, most parents can understand the need for transfer of an infant who requires the services of a NICU. However, in addition to dealing with having a sick baby, the mother must suddenly release her potentially sick or dying infant to strangers who will take her baby to staff whom she will not immediately be able to meet. Most of the mothers in this study identified a need for more information about the transfer.

Knowledge about transfer plans as they are being made is consistently rated as a primary information need by family members in intensive care units (Leske 1992). Bloodworth (1995) considers communication and information giving as a key factor in the success of an efficient transport service, and postulates that it is as important as the reliability of the equipment being used. In order to alleviate negative responses, Bloodworth (1995), analysing the nurse's role in a transport team, reinforces the need for parents to be encouraged to ask questions whilst identifying that they should receive simplistic answer about their situation. The author also stipulates the importance of parents receiving appropriate information to adequately prepare them for the event they are to encounter. Cross et al. (1995) suggest that maternal attention may be limited due to the mother still being unwell or feeling drowsy following a recent general

anaesthetic, which may cloud the communication process and /or affect reception of the information being given. They also suggest the probable time constraint associated with an emergency transfer is linked to parents receiving inadequate information, acknowledging that time may not be available for parents to ask questions and voice their uncertainties, which increases the anxiety level. However, studies on back transfer, which are usually pre-planned and thus not emergency events, also indicate that parents do not feel enough information is given to prepare them for the transfer (Slattery et al. 1997, Flanagan 1997, Dodds-Azzopardi & Chapman 1995). The importance attached to information giving during transfer, regardless of whether the transfer is an emergency or elective, was acknowledged by Hayes (1997) and Middleton & Leslie (1995), who emphasise the need for effective communication.

In this study all the mothers repeatedly expressed their need for information about the transfer. It highlighted an overall picture that many mothers in this study felt the information about the transfer was inadequate. Similarly, existing studies on both initial and back transfer identified corresponding findings (Frisher & Gutterman 1992, Dodds-Azzopardi & Chapman 1995, Wilman 1997, Flanagan 1996, Kuhnly and Freston 1993). It would appear that, regardless of the type of transfer, the need for information about the transfer is a consistent theme in all the neonatal transfer studies. It may not always be feasible to thoroughly prepare the mothers for a transfer, but effective communication may reduce the impact of the crisis.

This study also showed that failures in information sharing between units were common, and the impact of this on the mothers was a cause for concern in this study. In particular, it sometimes meant that when the mother arrived at the regional unit, she found that staff did not seem to have been prepared for their arrival. The consequence of this was that there was nobody available to explain what would happen, and nowhere to accommodate her on arrival. However, when information was shared, the regional unit appeared to be more prepared. The mother felt more at ease as a consequence as it was felt that the staff were more aware of how the mother felt.

Dodds-Azzopardi and Chapman (1995) identified corresponding findings when they performed a retrospective descriptive study involving 44 parents by means of a questionnaire between four and seven days after the transfer had occurred. The authors concluded that a lack of communication between units regarding the baby's transfer was related to parental stress. Although this was also reported in most of the back transfer studies, it was only reported in two of the initial transfer studies (Frischer and Gutterman 1992, Wilman 1997).

It has been documented that the transfer itself is a risk for the critically ill baby (Wilman 1997) and that the staff might not consider the needs of the mother when the baby is transferred (Cross et al. 1995). In my study, mothers reported that most of the information given was baby focused. Mothers commented on how nurses were more concerned with giving them information about the baby rather than asking them how they felt. This finding was also reflected in Flanagan's study (1996), which indicated that parents felt ignored by the staff at the back transfer, at a time when they needed professional support.

Some of the mothers in this study felt that nurses in the regional unit did not treat them as individuals. When the nurses were sympathetic, as found in their local units, the mothers in this study felt they were cared for as people. They reported a tendency of only being given baby-focused information, although they acknowledged and accepted that that the nurses were more concerned with the baby due to the condition of the baby being more critical in the regional unit. However, the mothers in my study expressed a strong need to be treated as an individual / mother and to have their own needs acknowledged.

While it is appropriate that the baby is an important focus because of his or her special needs, this should not be at the expense of the mother. The mother will usually want only to do what is best for her baby, but she may suffer disadvantage to herself in the process if she finds herself relegated to the role of a 'visitor' rather than a mother in her own right, as mentioned by one of the mothers in this study. Communication issues with staff and the need for individualised information have also been identified as chief stressors among parents with critically ill infants in NICU environment (Affonso et al. 1992, Padden & Glenn 1997). Although most of the neonatal transfer studies report lack of information as an issue, it should be noted that there is a lack of detail on what aspect was lacking (Frischer and Gutterman 1992, Wilman 1997, Cross et al. 1995, Kolotylo 1991, Kuhnly & Freston 1993, Dodds-Azzopardi & Chapman 1995, Gibbins & Chapman 1996, Flanagan et al. 1996 and Slattery et al. 1998). The transfer, which created a new environment and a new relationship, may have resulted in a need for a more personal approach over and above what previous studies on parents with hospitalised critically ill infants indicated because of the nature of the unexpected event of the transfer.

According to Mercer (1985), maternal role attainment is a developmental process, in which the woman achieves competence and integrates the appropriate behaviours into her role set,

becoming comfortable with her identity as a mother. The process involves becoming attached to her infant, becoming skilled in care giving tasks and receiving gratification in the role (Mercer 1986). The transfer, which creates a new environment and a new relationship result in a need for information that would empower and help them to be involved in the care of their babies despite the perceived geographical distance.

'Empowering information' refers to information that is readily accessible, pertinent, and understandable in a way that mothers can use to guide their interactions and negotiations, their hopes and plans, and to inform them as to what is important and not so important for their concerns. It includes information about how care is organised in the NICU, about how resources are organised, and about NICU's philosophy and practice with regard to fostering mothers' independence while providing support. Enabling and empowering families is at the root of family support (Robb 1997). In my study the mothers reported that they needed information that would help them care for their babies themselves. Kuhnly and Freston (1993) suggested that the parents' experiences were influenced not only by the changes in care-giving practices and environmental changes, but also by feelings of powerlessness or empowerment. The mothers in my study found that information made it easier to accept and understand what was happening.

In summary, this theme suggested that mothers' information needs have not yet received the attention that they deserve, despite the numerous studies that report similar findings. Mothers clearly desire and need accurate, individualised and reliable information. The findings affirm the findings of the Audit Commission (1997), which found inadequate transmission of information in NICUs, and most of the studies on parents' experiences in neonatal transfer (Steeper 2002). Effective communication was the prime requirement during the perceived mother–infant separation when in transit / during the ambulance journey to the regional unit. Information relevant to the baby's diagnosis and transfer and empowering information were reported as important by the mothers in this study in order for them to accept and understand what was happening. Cohen (1993) reported that parents used information to manage the uncertainty associated with their child's hospitalisation. The necessity for more personalised information and better coordination between the two units was highlighted in order to reduce any negativity perceived by the mothers surrounding the transfer event. Knowing about their babies and understanding the baby's problems appeared to be an important way of maintaining their role as mothers of the transferred baby.

5.3.3 Adjustment

Many of the early sociology studies about motherhood used either a crisis or a transition to parenthood framework (Rossi 1968). Women have described the early months after birth as a stressful time of adjustment, a time characterized by considerable physical, emotional and social change (Gjenfingen 1994). Similarly Kitzinger (1993) argues that becoming a mother is not only a biological process but also a social transformation. For Oakley (1979), becoming a mother is a turning point, a transition, or a life crisis for women. She also contends that becoming a mother is like 'a journey into the unknown' (Oakley 1979 p59). The transition to motherhood may be facilitated or inhibited by the woman's personal conditions, cultural beliefs, socioeconomic status, knowledge and societal conditions (Meleis et al 2000). How a person is defined, and defines herself, occurs within the context of social interaction and social relationships. It would appear that for mothers to fulfil their role, they needed to develop an understanding of their baby's care and establish relationships with other key players within the social setting of the hospital - in this case, the nurses in the regional neonatal unit.

My study found little evidence that mothers had been prepared in relation to what to expect in terms of the environment, staff and policies of the regional unit. The finding suggested that mothers saw themselves as having to make adjustments to the new environment, atmosphere and social relationships in the regional unit.

Mothers in this study appeared to have become dependent on the staff, the routine and the surroundings in the local neonatal unit and were concerned by the differences in the regional unit. This finding may be partly explained by the fact that most of the babies had been hospitalised in the local neonatal unit for a long period of time prior to being transferred to the regional unit. As such, the mothers in this study would have become used to the environment and staff in the local unit. Dependence on familiar things and people was also reported in most of the back transfer studies (Kolotylo 1991, Kuhnly & Freston 1993, Dodds-Azzopardi & Chapman 1995, Gibbins & Chapman 1996). Some parents in Gibbins and Chapman's study (1996) reported feeling uncomfortable with the thought of leaving familiar faces and surroundings on which they had been dependent.

None of the initial transfer studies mentioned this and it may be because the length of time spent in the local neonatal unit had not been enough for the mothers to get used to the environment and

staff in the local unit. However, this is just speculation, as there is very little detail about the duration of the baby's stay in the local unit in most of the initial transfer studies (Wilman 1997, Frisher and Gutterman 1992, Macnab 1992, McLoughlin 1992).

The influence of environment on human health is well documented (Watson 1999). In this study all the mothers reflected and commented on the differences between the regional and local neonatal unit. Spatial comparison was made between the regional neonatal unit and the local neonatal unit and how interactions were constrained by the space available in the regional unit. In the regional unit, where mothers and nurses were forced to be closer together because of space limitations, mothers overheard more of nurses' and other parents' conversation in comparison with the more spacious environment in the local neonatal unit. This seemed to heighten anxiety and the need to adjust to the new environment on the part of some of the mothers in this study. The extent of the emotional responses has been reported to have been influenced by the nature of the NICU environment in studies on parents with infants hospitalised in NICUs (Redshaw 1997, Padden & Glenn 1007, Reid & Bramwell 2003). However, interestingly, the reported findings indicated that there were few significant differences found between NICUs of different sizes in Redshaw's study (2003).

The close bonds the mothers in this study formed with their local staff made it difficult for these mothers when their babies were transferred especially to an unknown unit in another hospital. They missed the staff who had supported them and with whom they had shared so much. This, together with the altered surroundings (a regional unit) creates a foreign environment to which the mother needs to adjust. Due to time lost in commuting to the regional unit to visit their ill baby, there may not have been sufficient time for mothers in this study to form any effective therapeutic relationships. Staff attitudes and behaviours can inhibit or encourage mothering skills (Barclay et al 1997) as demonstrated by the mothers' accounts in this study.

Comparison was also made between the overall atmospheres in the regional and local neonatal units by the mothers in my study. Mothers' accounts in my study reveal the central importance of nurses' caring approach, not only towards the baby but also towards them as mothers. Comments regarding the local unit staff were overwhelmingly positive and seem to indicate that the mothers in my study had developed strong relationships with the local neonatal unit staff and felt trusting of the care provided, as indicated in their interviews. A comparison between their previous relationships with the staff in the local unit and those in the regional unit proved problematic to

the mothers. Difficulties were reported by the mothers in leaving the familiar and going to the unfamiliar. It has been suggested that individuals are at risk of developing a form of separation anxiety when they are transferred because of the loss of close relationship developed with the staff (Odell 2000). This is, however, not mentioned in any of the initial transfer studies. This may be because mothers in this study had spent a period of time in their local neonatal unit, thus they got to know the staff in the local neonatal unit better. In addition, all the mothers were interviewed within ten days of their baby's transfer. As a result, there may not have been sufficient time for the mothers in this study to form the effective therapeutic relationships that are conducive to efficient psychological care, especially when time was lost in commuting to the regional unit.

This finding also affirms the findings in back transfer studies, where the parents often became comfortable with and dependent on the staff (Kolotylo 1991, Kuhnly & Freston 1993, Dodds-Azzopardi & Chapman 1995, Gibbins & Chapman 1996, Slattery 1997). Similarly, parents reported that they found it difficult to establish relationships and communicate with staff when their babies were looked after by a large number of carers in a regional unit (Padden & Glenn 1997).

To summarise, this theme has highlighted the issue of adjustment not only to having a critically ill infant but also to the new environment and social relations with staff. The altered surroundings, changed nursing expectations, and different health care team created a foreign environment to which the mothers in my study needed to adjust. The finding also suggested that considerations about the length of time the mother and baby have been in the local unit are an important factor to be considered when trying to understand the mother's experiences in neonatal transfer. Models of mothering need to take into account the variety of circumstances women came to motherhood. The way women mother and their perceptions of motherhood can be influence by the environment and social relationship formed in an new environment i.e. the regional neonatal unit.

5.3.4 Geographical distance

Attachment, the capacity to form enduring bonds, is a fundamental aspect of human experience (Bowlby 1969). Mothers look forward to becoming attached to their babies even before their birth, expect to spend time with their newborns, and limit situations that would interfere with this

relationship (Bowlby 1969). Mothers consider proximity to their newborn babies to be essential for them. Usually a mother and her newborn remain together. However, when a baby needs to be transferred to another neonatal unit, their contact is interrupted, her possibility of being close to the newborn is reduced, and the development of a relationship is delayed.

One persistent problem identified in this study that distinguishes families of transferred babies from those born at a hospital with a neonatal intensive care unit is the distance families must come to visit their babies (Frischer & Gutterman 1992). This study's findings reflect the importance of the perceived 'geographical distance' on the mothers. More than half the number of mothers in this study travelled more than 20 miles from their home to the regional unit every day to visit their babies. This often necessitated special travel arrangements or making home arrangements in order to stay with the baby in the regional unit.

In this study, most of the mothers reported the increased cost of travelling to a more distant hospital (i.e. the regional unit) in comparison with travelling to their local neonatal unit, which was within their home locality. Having a well baby adds to financial pressures in normal circumstances, and this load multiplies when the baby has been referred to a distant hospital. Moreover, when the distance between the regional unit and home is too far, the financial burden can be quite substantial, even for those staying in hospital accommodation or with friends. Some of the mothers who chose to do this reported that there was an additional food cost incurred for the host household and inconvenience for everyone involved. Childcare for the other siblings also has to be arranged while the mother is with the sick infant in the regional unit.

Similar findings were discovered in Macnab's (1992) study in Canada on parents of acutely hospitalised children who were transported to a regional unit. It reported 'financial problems' as first on a list of stressors mentioned by these parents. Both McLoughlin (1993) and Wilman (1997) suggest a strong case for offering appropriate financial help. Travelling was found to be time consuming and a handicap by the parents in Frischer and Gutterman's (1992) study. Mention of this is noticeably absent in the back transfer studies. This may be because infants are transferred back to their local units, which are usually closer to their families' home, thus travelling and childcare costs may not be as great as when travelling a longer distance to the regional unit.

Although some of the mothers chose to travel on a daily basis to stay close to the family, this often required a great deal of organisation. One mother described the daily ritual of having to organise her children in order for her to travel to visit the baby. They reported it as being disruptive to the children and also reported their dislike of having to travel to the regional unit, which was usually in the city. This burden of travelling was not mentioned in any of the neonatal transfer studies. This may be because half the number of the mothers in this study chose to travel on a daily basis.

The impact of childcare arrangement on the siblings was also highlighted by the mothers in this study. Nearly all the mothers had other children at home and they expressed their concerns regarding the well being of the siblings while they were with the sick infant in the regional unit, or when time was lost travelling to visit the sick infant. This may be because in my study the majority of the mothers have more than one child, hence the concerns expressed by the mothers regarding the well being of the other siblings. This was also mentioned by Holditch-Davies Hawkins(1985), who said that the siblings of the transferred infant may exhibit behaviour problems such as nightmares and difficulties at school because of the perceived separation from their mothers. Reaside (1997) in her study on mothers with hospitalised premature infants also highlighted arranging childcare as immediate stressors to mothers.

The mothers in this study who chose to stay in hospital accommodation missed the comfort and familiarity of the home environment. In this study, a 'home' near friends and relatives is exchanged for a room in a new place, among strangers. For the mothers in this study, the void created by the absence of family and friends made them appreciate what they had left behind. They provided evidence of a sense of closeness that was lost. Staying alone in accommodation inevitably removed the support system that family and friends provided for the mothers in my study.

This may be why some of the mothers in my study reported the benefits of commuting, such as being able to play their role and maintain a family life and to receive continued support from friends and families despite the long distance. Surprisingly, only one study (Macnab 1992) reported parental stressors associated with accommodation, although this was related to accommodation costs rather than the psychological effect of staying in accommodation that is not one's home. This may be because the methodology used in my study had enabled a more in-depth focus and thus allowed a wider range of different aspects of this issue to be explored. In view of

the current increase in inter-hospital neonatal transfer in the UK and as more and more premature and / or critically ill babies are being saved (CESDI 2002), there is a need to understand the importance of familiarity and home to future mothers. Mothers may have no choice but to stay in hospital accommodation due to the distance involved between their homes and the regional unit.

Several mothers in the current study reported their concerns about their dependence on friends and relatives looking after other siblings when they were either staying in the hospital accommodation or having to travel to visit the sick infant in the regional unit. They seemed to perceive it as a burden on their friends and family members, and reported their fear of exhausting these sources of support. Although the need for support was reported across most of the reviewed studies on parents with hospitalised infants in NICU and in transfer, how the mothers felt on having to depend on their friends and / or family has not been well reported (Redshaw 1996, Padden & Glenn 1995, Wilman 1997, Frischer & Gutterman 1992, Gibbins & Chapman 1992). This may be because almost all the mothers in my study had siblings at home who needed to be looked after while they were either travelling or staying with the sick infant. Thus their needs for childcare assistance were more pronounced and immediate.

To summarise, this theme emphasises the psychological, physical and economic impact associated with travelling as a consequence of the baby's transfer, not only on the mothers themselves but also on their family, relatives and friends. Financial burdens reported included the logistics of maintaining two places of residence (home and temporary / hospital accommodation), travelling costs and childcare arrangement costs. Family members and friends separated geographically from the mother and infant may not be able to provide emotional support for the mothers, as indicated by the lack of closeness reported by the mothers in my study. Consequently, some mothers reported the necessity of commuting daily to maintain some degree of familiarity and support. James (1998 p97) has suggested that childhood illness represents 'a condensed symbol of childhood itself through intensification of concepts of dependency and vulnerability'. Juxtaposed as they are for the mothers in this study, it seemed that perceived geographical distance that arises from the transfer and their maternal obligations combined to heighten the significance of being a mother with transferred baby.

There is a substantial sociological literature exploring the experiences of mothers for newborns, and the transition to motherhood of new mothers, both by women themselves and by experts and texts on parenting. Previous research into motherhood has shown how certain dominant

discourses pervade notions of what is considered to be a 'good mother' (Lupton 2000). 'Good' mothers are supposed to 'be there' for their children and to develop a strong' bond; with them. These perspectives on 'good motherhood' invariably tend to refer to the construction and practice of motherhood on the part of women whose infants are born in good health. Thus far, few sociologists have turned their attention to the experiences of mothers whose infants are transferred from their local neonatal unit to another neonatal unit in another region.

What has also been made clear in this study is that neither common-sense ideologies of motherhood nor the discourses that contribute to their production necessarily correspond in any direct way with the variety of circumstances a mother faced with a seriously ill infant that need to be transferred to another neonatal unit. In such a situation, women are forced to practice motherhood within a setting in which there are significant constraints upon how they can play their maternal role. Their infant's transfer has major implications for how women see themselves as mothers and how they construct and relate to notions of being a mother to the transferred infant and their other perceived obligations to functions in other roles, be it as a mother to the other siblings at home or as a wife.

5.4 Summary

This study has highlighted several issues that combine to shape mothers' experiences of their infant's transfer to a regional neonatal unit. Despite the most careful antenatal screening and referral, some infants will need to be transferred to receive the specialised care only available in a NICU. Location physically divides the family and brings the family under the care of two completely different health care organisations.

The meaning of the experience for the mother who had a transferred infant was multidimensional and was represented through four themes: emotional responses, information issues, geographical distance and adjustment. Together the four themes form a constitutive pattern of 'distance mothering', which was present in all of the interviews. All the mothers faced the problem of being a mother to a baby that is at a geographical distance from their home.

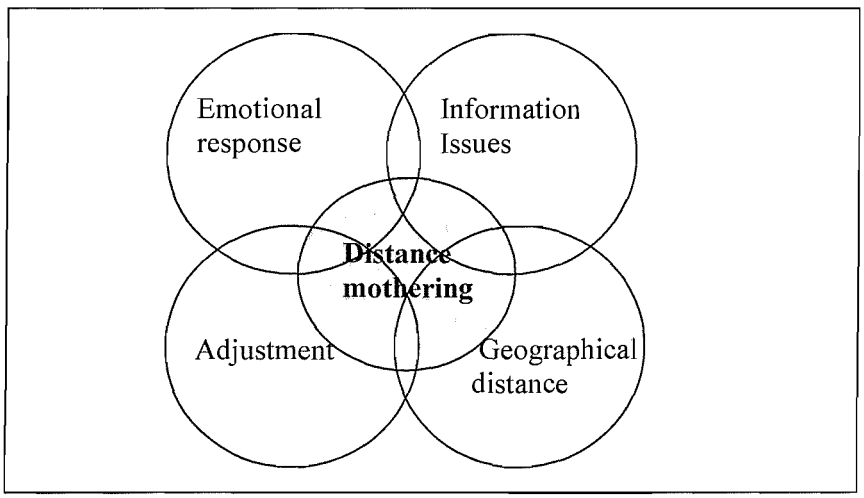
The first theme, emotional responses, was characterised by the feelings and experiences encountered by the mothers as they came to terms with having their newborn baby transferred to a regional unit. These feelings and experiences included acknowledgement of their uncertainty

about what was going to happen to the baby, anxiety about the infant while in the ambulance, and feelings of guilt due to the inability to be a mother to both the sick infant and other siblings at home.

The second theme, information issues, was characterised by the information needs identified by the mothers, while the third theme, adjustment, indicated that the mother needed to adjust to the new environment and social relationships. Comparison was frequently made between the local neonatal unit and the regional unit. Mothers who had already established a close relationship with the local unit staff reported the need to adjust to new relationships with staff in the regional unit.

The fourth theme, geographical distance, was characterised by the impact of the distance between the mother's home and the regional unit. Concerns were expressed as to its impact on siblings, and also on friends and families. For the mothers in my study, it would appear that the geographical distance, affected their efforts to play their role as a mother to the transferred infant and their other siblings. However, the role of the mother in such a situation has not been fully explored; although mothers mentioned this indirectly when they reported the conflict they felt towards staying with the sick infant in the hospital or staying at home with the other siblings. The relationship of the four themes was one that could be viewed as interrelated (see figure 5.1).

Figure 5.1: The meaning of the mother's experience of their infant's transfer



To summarise, because the regional unit was at a distance from the home, the **geographical distance** indirectly caused mothers to experience 'burdens' in terms of their finances, the logistics of travelling every day, on their friends and families, and loss of closeness to families and friends. Because of the long-distance separation, mothers' experiences are often more dramatic, intensifying their feelings of anxiety. In this study, this has led to **emotions** of anxiety and uncertainty about what they are going to find at the new unit and anxiety because of the long-distance ambulance drive the baby has to undergo without them. Feelings of guilt about either being with the sick baby in the regional unit and leaving the other siblings to the care of others, or about only being able to visit for short period of time because of the distance were also reported by the mothers in this study. Because they are in crisis, these mothers may not absorb the **information** they are given. Consequently they have critical needs for information that is tailored to their needs and circumstances. These reactions of anxiety and uncertainty are heightened as mothers attempt to adapt to an unfamiliar environment. Many mothers in this study perceive themselves as being unprepared for the new environment. There was a need to **adjust** to the new changes in their relationship with the staff, and in the new environment. The relationships that mothers in this study developed with the local unit were borne of a need and were time and context bound. The close bonds mothers formed with the local unit staff and other mothers in the unit made it difficult for mothers when their infants were transferred to another unit. They missed the staff in the local unit who had supported them and with whom they had shared so much.

Viewed as a whole, the findings show the significance of the emotional responses, information issues, adjustment and geographical distance as important factors to explain the concept of distance mothering.

5.5 Implications

My study both confirmed the impact of the baby's transfer and illuminated the issues that have implications for the development of care for mothers with transferred babies. The study points to the need to remain cognizant of what the baby's transfer means to the mothers. The understanding of what it is like to have a newborn infant transferred could potentially influence what kind of support could be made available to mothers over this critical period.

The delineation of these experiences, derived from first-hand accounts of the mothers in this study, has implications for the type of support that might help alleviate some of the strains of

caring of a baby who has been transferred to a new neonatal unit. The mothers' own accounts of their experiences could be used to pinpoint the kind of support that would be most helpful. The themes that emerged document the issues encountered by mothers, and these could be used by health care professionals as a guiding framework in understanding and tracking the health and emotional needs of these mother's care.

The detailed account of the mothers' experiences as derived from the data supports the view of mothering at a distance, specifically the emotional turbulence experienced as a response to the baby's transfer, and this information could be thoughtfully applied by those who are in a position to support mothers in caring for their babies, despite the geographical distance. The vivid description of how transfer impacts a mother's life might enhance the empathy of those involved in the care. The information embodied in the findings of this study might be usefully applied to the regional unit as a means of providing a supportive structure for those involved in the care of transferred infants and their mothers.

5.6 Recommendations

5.6.1 Introduction

This section addresses some of the recommendations for nursing practice and nursing research based on the findings from the current study.

Throughout this study, issues regarding the necessity for improvements to be made were highlighted in order to reduce the negativity perceived by the mothers in this study surrounding a transfer event. Some health professionals reading this study may find that the care given does not seem to meet the mother's needs. The distress associated with the sudden and unexpected discovery of having a critically ill baby who then needs to be transferred to another unit is such that it is probably unrealistic to think that even the most sensitive care can in any way cancel out the distress caused. However, the findings show that effective communication is the key for shared meaning between mothers and neonatal nurses. These mothers clearly desire and also need reliable and accurate information. Financial hardship related to travelling and accommodation needs to be acknowledged and addressed. There is also an urgent need for a more integrated approach to health care provision for mothers whose newborn baby is transferred, with the referring and accepting units working in partnership to ensure a 'seamless web of care'. It is not

my intention to provide a list of prescriptive recommendations for clinical practice but rather to enhance awareness and the possibilities for change in our practice.

5.6.2 Recommendations for nursing practice

There are a number of implications for care management both in cohesiveness and the environment of service delivery and a more emphatic consideration of the mother's experiences. The key areas will be highlighted here according to the study findings:

Emotional responses

- Services need to be geared not only to delivering treatment and care to the transferred infant but should also focus on the mothers. Nurses, physicians and other health care providers need to understand the emotional responses exhibited can be related to the perceived geographical distance between themselves and the new unit. Understanding the emotions and the reasons for these should ensure that care is tailored to meet these emotional needs more effectively

- The nursing process can be used to provide a framework for assessing and documenting maternal needs. A standardised assessment tool can aid in this process. Ideally this form would be begun by the nurses in the local unit and then sent to the regional unit with the transport team so that this assessment could be continued throughout the stay at the referral unit.

- On arrival mothers in this study were shown to the parents' sitting room and during this period of enforced separation the needs of the infant inevitably take priority over the needs of the parents. Mothers in my study appeared to be in need of psychological support during this time. The variations in the workload in NICUs may mean that there may be a delay in providing the psychological support needed during this time. This role could potentially be fulfilled by a nurse, social worker, or counsellor, but this may have additional implications such as funding. Another suggestion is to keep the length of separation as short as possible once the baby and the mothers arrive in the unit by taking the mother to see the baby in the unit as soon as possible.

- Intensive care nurses must be a good listener and allow the mother the opportunity to discuss her anxieties, and acknowledge how difficult it is to try to care for the transferred baby and her other commitments to the family

- The nurse should also recognise that this mother has to divide her time between her other siblings at home and one in the unit. She should assist the mother to develop strategies, such as bringing the other children to the hospital to visit the infant and providing guidance on how the mother can access other support to help her through this difficult time, to decrease her anxiety.

- Introducing the mothers to other mothers who had gone through the same sort of situation to talk to apart from BLISS.

Information issues

- Both verbal and written information regarding the baby's condition and treatment should be given to the mothers as soon as possible, with the mothers having the opportunity to ask questions through the hospital stay. The mother not only has responsibility of being a mother to the transferred baby but also to other family members. The mother needed understanding and information to deal with trying to perform her role to both the transferred baby and other siblings at home.

- Making information-giving part of the transfer process, supported by written material that the mother can refer to, may be of some help. The local unit should have brochures available to describe the regional NICU and a photo album perhaps developed by the regional NICU depicting the NICU environment and activities. This will provide some orientation to the new surroundings. However, this may not always be possible due to lack of available brochures about all the regional units in the UK. The staff in the local unit should then contact the transport team to ensure that they bring some written information about the regional unit the baby is being transferred to when they come to give information to the mothers.

- The reasons for the baby's transfer need to be simply and clearly presented, as well as basic information about the NICU. Staff should be willing to reiterate any material

because mothers in crisis may not have truly 'heard' what was said the first time. Repetition and provision of information in written form may assist mothers in processing the information given.

- Any explanations that need to be given should take into account the individual women's current physical, social and emotional state. The nurse should do an assessment of the mother emotional state when she first arrives in the NICU.

- The results also applicable and have implications for multi-disciplinary consideration, especially for medical colleagues. In particular, this study highlights the need for heightened awareness and consideration in relation to medical decision making regarding the baby's transfer. Where possible, the nurses should ascertain what was being told to the mothers by the local unit and base on mother's knowledge, the nurse should arrange for the medical personnel to provide the information about the changes the mother can expect.

- There should be a more co-ordinated and consistent approach to transfer preparation between the local and regional unit. The ideal would be for a family support key worker to be available to the mother from the day the baby is transferred. Written guidelines need to be developed to ensure accuracy and consistency of information given by the two units. Developments in communication channels between the two units should be explored, including a) the possibility of a copy of the transfer letter/plan being inserted into the infant transfer notes to the regional unit b) electronic mailing to the regional unit.

- A contact person should be designated to keep the mothers informed about the transfer and for the first 24 hours after arrival at the tertiary hospital. Specific information regarding the transfer process should be given, for example, how the infant is monitored, and who accompanies the infant on the transfer. The use of mobile phones may help to maintain contact with parents during the journey. This may address some of the parents' concerns and worries about the infant's condition during the journey.

Adjustment

- As reported in this study, reactions of anxiety and uncertainty are heightened as mothers attempt to adapt to the unfamiliar new environment. Communication needs are particularly great because the mother must learn to establish new relationship. Communication channels to these mothers can be opened through a friendly welcoming approach. Staff should welcome the parents and stay with them to explain the equipment and procedures, answer questions, review the baby's course, give emotional support, and orient them to the new environment. If possible, a reason or cause for the baby's problems should be communicated as soon as possible.

- Ensure that the infant is transferred with an up-to-date care plan that clearly identifies what is being told to the mothers and what level of care the mother is currently able to provide for her baby; this will ensure continuity of care and will ease the mother's adjustment to the new unit.

- Provision of both medical and nursing consultation services between local units and regional units can enhance teamwork, continuity of care and co-ordination of care. Mothers who are not able to visit their babies due to the geographical distance can then make an appointment in their local unit to talk to the staff looking after their babies in the regional units.

- Whenever geographically feasible, staff from local units and regional units should visit each others' facilities so that staff on the referral unit (local unit) can speak knowledgeably about the unit to which the baby will be transferred.

- Nurses from the regional unit should be responsible for ascertaining background information from the infant's accompanying documents from telephone contacts with the NICU nurse or from the parents themselves as to the former degree of parental involvement and any social or family issues (i.e. constraints on availability for feeding at a specific time).

- Nurses must be sensitive to the potential for mothers' initial heightened anxiety in the regional unit and must allow them an adjustment period to feel comfortable in the new environment.

- Some practices differ because of the level of care required and therefore may vary between the local unit and the regional unit. Educating mothers about the differences and the reasons for variation might improve and help them to adjust to the new environment faster.

Geographical distance

- One persistent problem that distinguishes families of transferred babies from those born at a hospital with regional neonatal unity is the distance families must come to visit their babies. This often necessitates special travel arrangements.

- Most of the mothers in this study highlighted the financial costs involved due to the geographical distance between their home and the regional unit. Since the indirect costs of travelling, including travel and accommodation for the parents are not covered by existing health care services, it is important for regional units to recognise the need to find other sources of funding. These include charitable and welfare funds, which are useful but limited, and the possibility of including the costs as part of the hospital budget that can be reclaimed from the government. This could involve establishing criteria for identifying emotional and financial needs through an interview with a social worker.

- Mothers identified their concerns about the well being of the other siblings at home while they were with the sick infant in the regional unit. Nurses need to assess situational conditions and family factors that may affect these mothers and develop intervention strategies for example negotiating for child care arrangement in the regional hospitals. Having a crèche at the hospital where mothers could leave their other siblings while the mother attended to the transferred infant may help in childcare costs.

- Sources of financial help or grants should be identified and mothers should be told and guidance should be given as to how to access these sources by the nurse or identified personnel in the hospital e.g. the social worker.

- Arranging for volunteers that would come and help with the childcare in the hospital while the mothers visit. Volunteers from secular or religious groups may offer free services such as transportation, meals or lodging with members.

- Mothers can be made aware of any resources available to ease the financial strain of travelling , or childcare by introducing mothers in the same situation so that they can plan 'car pool' or ' mutual child care exchange' which will enable them to minimise the burden of travel and costs

- Ensure that mothers are provided with information on what facilities are available (e.g. accommodation, travel subsidises, meals coupons) as soon as possible.

- Structures such as a phone support service may need to be employed to provide assistance to mothers who need to keep in contact with the other siblings at home while they are with the transferred infant.

- Assess mothers any financial hardship rather than just focusing on the health needs of the transferred baby.

In conclusion, the study findings permit implications for practice for the nurses in both the local and regional neonatal unit. The need for improved resources, such as having assessment tools, a designated contact person, support staff, and funding for the indirect costs of having a transferred baby, was also highlighted. A more integrated approach to communications between parents, the local unit, and the regional unit was proposed. However, further research is needed and this will be discussed in the following sections.

5.6.3 Recommendations for nursing research

The purpose of this study was to more fully delineate mothers' experiences when their babies were transferred to a regional unit. The results provide descriptive data concerning the mothers' experiences. This information provides a foundation from which to view mothers' experiences in neonatal transfer. However, further research is needed to explore mothers from different cultural or ethnic backgrounds. This would assist in ascertaining whether culture or ethnicity impacts on the meaning mothers attribute to this experience. Replicating this study with a larger, more

representative sample is necessary as this study was conducted in one site and most of the babies in this study was hospitalised in the local neonatal unit for some time prior to being transfer. A more diverse population derived from two or more sites would have provided greater credibility to the findings.

Comments of several of the mothers about the fathers' feelings would suggest a study eliciting both parents' responses to the transfer of their baby from local neonatal unit to a regional neonatal unit would be helpful. This will help to build a larger and more complete picture of the families' perceptions of a transfer situation.

Although this study highlighted the need to adjust to the new environment and relationships in the regional unit, it was not able to identify any differences between those who had stayed in the local unit longer and those whose infants spent a relatively short time in the local unit, due to the descriptive nature of the study, except for speculation on my part. It would be useful in judging whether their reactions to the transfers are similar by exploring these differences, as this could have implications for nursing practices. Other variables could also be studied to determine what relationships, if any, exist between the mothers' experiences and the following variables: length of NICU stay, distance from parental home to NICU, presence / absence of pre-transfer preparation / information, degree of differences between hospitals, and reason for the transfer. From this data it would be possible to build a more complete picture of the mothers' perception of a transfer situation.

Although financial difficulties were highlighted in initial transfer studies, they are not mentioned in studies of hospitalised infants. A comparative study on the financial difficulties faced by the two types of parents, those of inborn babies (those born in the local hospital and admitted to the local neonatal unit) and those from regional transfers, would address this gap in research.

Further studies testing interventions, such as appropriate communication styles, written information for parents, and strategies for improving co-ordination of care between units, would offer a stronger knowledge base to use in assisting parents through the experience of initial transfer.

5.7 Strengths and Limitations

As with all social inquiry, choices have been made through this study as to the best way to meet the aims of the study within the social context in which the research was taking place. I have

attempted to make these decisions transparent throughout the thesis and justified my choices to ensure they are understood by the reader. But I acknowledge that other researchers could have made different choices, which might have resulted in a different study. I have been transparent about the process of the research and given detail on the values I hold in order to make the research trustworthy.

In chapter three the limitations associated with taking a phenomenological approach were articulated. As explained, the intent of this study was to explore mothers' experiences and to extend knowledge and understanding of the meaning they attributed to this phenomenon. It was never the aim of this study to predict, generalise or generate theory; thus the approach taken was congruent with the purpose of this study.

One limitation of the study is that it is retrospective in nature and relied on participants' recollection of their lived experience after the event. The stories were told after a period of 10 days following the experience. It is difficult to determine whether the accuracy of recall may have been distorted as a result of the passing time. However, in honouring the chaotic narratives of these study participants, there was no requirement to obtain fully coherent and complete stories. It was also apparent that this experience was an emotional one that was vividly remembered by participants.

No two participants can be found who are the same in all essential respects. In this study, as long as the participants had all experienced the research phenomenon, they were purposively recruited to this study. The strength of this study lay in having inclusion and exclusion sampling criteria and a clear audit trail of the process of recruitment. However, the responses in this study may not be typical of mothers whose first language is not English or those with literacy problems, since by definition both these groups are excluded as a result of the sampling criteria in this study. Respondent validation was not carried out; however, the fact that most of the findings have been validated by other studies from the literature enhances their credibility. The integrity of the text was maintained by my reflective journal, as advocated by Koch (1994a). The process of analysis and how decisions were reached about the themes are clearly explicated.

Although the study was only conducted in one regional unit, details were given on how the unit were identified. Information about the regional unit was also given to ensure that the reader can understand the context in which the experience reported occurred (see section 3.8.1)

To summarise, despite the limitations mentioned, the main strength of this study is that the findings are based on the mothers' perspectives using a rigorous research method. The information obtained in this study is useful in that it suggests a number of ideas for potential interventions aimed at improving the transfer event. This study also emphasises the government's emphasis on both a) the importance of parental involvement in the care of sick children (Audit Commission 1993); and b) the need to attend to the experience of mothers in NICUs (DOH 2003). A mother's mental state is likely to have a direct impact on her ability to meet her sick infant's needs, both during the transfer and subsequently. It is, therefore, in the interest of the baby that we continue to explore and evaluate ways to facilitate parental coping in the difficult situation of emergency transfer. The findings in this study have provided valuable insight into mothers' experiences related to their babies transfer from the local neonatal unit to a regional neonatal unit, and thus, research-based implications for nursing practice was derived.

5.7.1 Closing reflections

This study was primarily an attempt to explore a phenomenon about what little is known, the experience of a mother having her newborn baby transferred from a local neonatal unit to a regional neonatal unit. To accomplish this, I used a research strategy, hermeneutic phenomenology. As a newcomer to the method myself and given the logic of the method, it is relevant to take the reader through my experience with the hermeneutic phenomenology method.

In the course of preparing for this study I reviewed most of the research, especially published literature that has used the hermeneutic phenomenology method, in addition to reading books and articles on the method. As well, I looked to my supervisors and colleagues for further understanding and clarification of the method. From my readings and discussions I gained a fairly broad understanding of the method and formed impressions of its strengths and weakness. At the time, I was concerned about issues of generalizability, validity and reliability as well as its significant deviation from positivistic, hypothesis- generating methods. Coming from an intensive care background where numbers and values dominated the care, my thinking is still very much indoctrinated into the positivistic ways of thinking. Although I liked the hermeneutic phenomenology method and the qualitative stance it derived from, I was reluctant to let go of my positivistic doctrines concerning generalizability, validity and reliability. I did not fully comprehend how one could conduct good, solid and valuable research without numbers and

values. I grappled with these issues and hungered for clarification. I read voluminous amounts of books and articles that addressed these issues, but most offered a superficial understanding of the method and related issues. Most authors suggested that notions of validity and reliability were not part of the hermeneutic phenomenology method nor did they matter.

Eventually I realized that the question I was asking pertained to the philosophical stance of the method. In effect, what I wanted to know what philosophical roots did it have and how was it contextualised. This journey of contextualisation was an arduous, time consuming, migraine-inducing venture. Most of the difficulty in contextualising the method resulted from the fact that the method's originator, Martin Heidegger, did not position his method within any particular framework. Fortunately, I was able to clarify and answer many of the questions I had when I found contacts with people who had used the method in their studies. This was an important step because it was difficult for me to follow procedures and carrying out a study using a method I did not fully comprehend.

Once I was able to contextualise the hermeneutic phenomenology method and understand its philosophical underpinnings and logic of justification, I felt equipped to begin my investigation of mothers' experiences in their babies' transfer. My first two interviews were with mothers who had their babies transfer to a regional unit. I found it difficult to analyse the transcripts from their interviews. Part of this difficult was attributable to the novelty of the task for me and the language used was not my first language, but part it had to do with the fact that I felt the participants were not discussing the aspects of their story I deemed important. Upon further reflection, I realised that the reason they did not fit well with my preconceived notions was because these notions were based on my experience as a mother, and a practicing neonatal nurse. I wrote down this reflection in my study journal and took great pains to ensure that my understandings did not unduly influence my analysis. I did what I could to let participants tell their story without being overly concerned about how it fit with my story or stories of friends and acquaintances.

The acknowledgement of my pre understandings and their recording in my study journal is an important feature of the hermeneutic phenomenology. If I had conducted a quantitative study of mothers' experiences, these same pre understandings would have been presented but I would not have acknowledged them or recorded theme in written form. In fact, I may not have even been aware of them without reflection.

The process of analysing transcripts produced another hurdle for me. I found it extremely challenging to let go of my positivistic influence. I had a tendency to be too rigid in my approach to analysis; sticking too closely to participants' own words. In effect, I was being too descriptive and not interpretative enough. This reluctance to be interpretative was due, in large part, to my fear of misrepresenting participants' accounts, and not being able to prove and validate my interpretations. The fear of being too far removed from the phenomenon resulted in a description of the phenomenon, in essence a descriptive account rather than an in-depth understanding of how the phenomenon was experienced. In order to get away from my rigidity, I tried to reanalyse interviews in chunks of three. Thus, my first analytical attempts resulted in categories that were closely tied to participants' own words and my subsequent analytical attempts resulted in more abstract, interpretative categories that derived from the initial sorting of categories. I found that in this way I could see how the descriptive account change to being an interpretation.

Upon surviving the arduous and time consuming process of analysis, I ventured into discussion stage. Presenting my findings in a coherent and interesting manner was more difficult than I had anticipated. I had no clue how to organise the material let alone how to make it sound coherent and interesting. I looked to my colleagues who had gone before me and my supervisor for guidance but soon realised that I had to carve my own discussion trail. In effect, this meant that I had to have ownership and develop my style of presenting the findings.

In writing my discussion chapter my task was to make the phenomenon come live for the reader. This was no easy feat. In fact, it required several rewrites and much time and energy. However, as I wrote and rewrote I gained a better sense of the phenomenon and was able to discuss it in what seemed to me to be a coherent and meaningful way. In fact, the written exposition of the essence of transfer on mothers could be rewritten still because my understanding is continually being shaped by my encounters, whether directly or indirectly, with it. As I have come to understand, this is typical of hermeneutic phenomenology research. For hermeneutic phenomenology researchers, there is no absolute truth but rather it is a dynamic ever changing entity.

Conducting hermeneutic phenomenology research is arduous, time consuming and extremely personal. It requires researchers to not only get in touch with the feelings and thoughts of others

n a personal way but also to be attuned to one's own feelings and thoughts. In this way, it is very emotional-draining. Despite its energy and time-consuming nature, I cannot imagine conducting a study into lived experiences of others in any other manner. I am left with the sense that understanding the complexities of human experiences is a worthwhile and valuable undertaking that requires arduousness, diligence, time, energy, a personal involvement in the lives of others and last but not least a capacity for self-exploration.

5.8 Conclusion

This study was conducted to explore the experiences of mothers when their newborn babies are transferred from their local neonatal unit to a regional neonatal unit. The previous chapters stand as testament that this has been achieved. The use of phenomenology was essential to capture the phenomenon of neonatal transfer.

This study has highlighted several issues that combined to shape mothers' experiences of having a transferred baby. The transfer required a redefining of mothers' role and intensifying some of their existing obligations. Discourses on the particular character of the mother-child relationship implicitly and explicitly shaped mothers' emotional responses and their reflexive constructions of their experiences of being a mother with transferred baby in this study. The four themes identified – emotional response, information issues, adjustment and geographical distance – should be viewed as interrelated. The detailed account of the mothers' experiences supported the view of distance mothering, - it demonstrates how the mothers' emotional responses, information issues and adjustment were interrelated to the perceived geographical distance and their maternal role to their transferred baby and their perceived obligations to function in other roles, including role as mothers of their other children.

It is evident throughout the study that the experience of having a baby transferred is a predominantly emotional experience, and / or one in which it is felt that information is inadequate. For a smooth transition, communication is essential and pivotal to diminishing parental anxieties caused by a transfer situation. Differences in the environment and personnel are reported as factors that cause the adjustment issues in this study. Geographical distance was identified as a representation of the mothers' experiences when their babies are transferred to a further away neonatal unit. Issues arising included financial and accommodation provision needed to respond to the baby's transfer.

With a basic understanding of how mothers themselves describe the transfer phenomenon, we will have a greater chance of understanding, for example, factors such as women's strategies for combining being a mother to a sick infant in a regional unit and a mother to her other children at home; how mothers see themselves as mothers being geographically separated from their infant; and how the geographical distance from the transfer affects their families. This could be used to understand how mothers with transferred babies perceive themselves.

The findings from this study and the examination of the available literature could support useful changes in the way transfer from a local neonatal unit to a regional neonatal unit is organised. Although generalisation to a larger population is not claimed from this study, the confirmation of the findings with studies reported in the literature suggests that the issues raised merit serious consideration by staff working in the both local and regional units.

Improving the experiences of these mothers requires action at a number of levels. At the societal level, adequate funding for hospital accommodation and travelling costs is essential if care is to be improved for mothers with transferred babies. At an organisational level, hospitals should ensure that the needs of parents of babies that were referred and admitted form a priority. Local unit staff should also ensure that there is a mechanism for maintaining contacts with the regional units to improve the co-ordination of care. At the level of the individual, staff must acknowledge and support the mother. Nurses must be sensitive to the potential for mothers' heightened anxiety in the NICU if they are to provide mothers with transferred babies with a positive experience of transfer.

Suggestions for further research include greater investigations of emotion and therapeutic issues, together with the environmental and cohesive management of care. Mothering and motherhood are the subjects of rapidly expanding bodies of literature. However attention to the different circumstances within which women mother is important so as to improve our care to mothers.

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Appendix 1

Clinical Research Advisory Group (CRAG) for Neonatal Transfer Study

Terms of Reference

Title of study

The experience of mothers when their newborn babies are transferred from their local neonatal unit to a level 3 neonatal unit

Aim and objectives of the study

The main aim of this study is to explore the experiences of the mothers when their newborn babies are transferred from their local neonatal unit to a Level 3 Neonatal unit.

The objectives of the study are:

- to gather data about the mothers' experiences when their newborn babies are transferred from their local neonatal unit to a level 3 neonatal unit

- to understand mothers' experiences and needs when their newborn babies are transferred from their local neonatal unit to a level 3 neonatal unit.

Methodology

- An exploratory descriptive study using hermeneutic phenomenology
- Face to face unstructured interviews
- Purposeful sampling up to 15 mothers who meet the sampling criteria

A mother will be included if

- Her baby has been transferred from their local neonatal unit to the unit in which the research is being conducted.
- Her baby's condition is stable at the time of her recruitment to the study.
- She is in a satisfactory physical and emotional state as judged by the consultant or nursing staff in the neonatal unit.
- Her baby must have been in the unit where the research is conducted for three days prior to the interview.

A mother will be excluded if

- Her baby was born in the unit the research is being conducted.
- Her baby was electively admitted to NICU for any elective procedure.
- Her baby is critically ill or dying at the time of potential recruitment to the study.
- Her baby has been transferred more than once into the neonatal unit in which the research is being conducted.
- She is not comfortable to conduct the study interview in English language.

Purpose of CRAG

- to advise the researcher on key issues about the research
- to discuss key decisions about the research
- to support the researcher in the planning and conduct of the study

Membership

- Consultant neonatologist x1
- Consultant peadiatric/neonatal surgeon x1
- Senior nurse x1
- Clinical nurse educator x1
- Neonatal nurse specialist x1
- Family support sister x2
- Social worker x1
- Consumer representatives x2
- Research supervisors x2
- Research student

Date and times of meetings

It is anticipated that the group will meet at three monthly intervals, or more frequently as necessary. Meetings will be arranged over lunchtime or teatime to enable as many staff to attend as possible.

Arrangements will be made by the research student. She will notify all members so of the group about the time and date of the meetings at least one month in advance and a record of the meetings will be kept by the research students and supervisor

Title/Author/Year/Country	Purpose	Study design/ sample/instrument	Conclusions	Limitations/comments
Maternal support needs : a study of unsatisfied support needs of mothers who delivered very premature babies who were admitted to a neonatal unit. Newsome, A 1991 UK (Masters thesis – unpublished study)	To identify unsatisfied maternal support needs	Descriptive research in the form of a case study Retrospective interviews- for some the birth of the baby had occurred 18 months prior to interview Development of the semi structured interview schedule described with rationale given. 21 (91%) of the 23 mothers who fit criteria approached agreed to be interviewed. 17(91%) of the 21 mothers had experienced more than one neonatal unit.	6 key themes were identified: comparisons of previous experiences, avoidance, separation and bonding issues, ceremonies, element of chance influencing the receipt of information and support.	Some of the study limitations were acknowledged although it was not mentioned that the researcher was a Family Support Sister working in the unit at the time of the study. Methodology not clearly justified. Minimal explanation about case study. Themes supported with quotations from participants. No funding.

Title/Author/Year/Country	Purpose	Study design/ sample/instrument	Conclusions	Limitations/comments
Paediatric inter-facility transport: the parents' perspectives Macnab, A.J. 1992 Canada	To evaluate the impact on families of inter facility paediatric transport to a tertiary care centre.	Telephone survey over a year. 54 parents whose children ranged in age from birth to 14 years of age with 52% (n=28) under the age of 12 months, 35% (n=19) between 1 and 5 years and 13% (n=8) between 6 and 14 years.	Primary problems identified were financial problems related to travel and accommodation for parents, child care arrangement for children that are left at home and separation from other family members.	- no supportive data to illustrate how findings were derived. Findings were summarised in 2 tables : the stressors encountered and accommodation arrangement Difficult to judge results due to the lack of details. -no funding nor mentioned about the relationship of the researcher and the participants
Parental costs of neonatal visiting McLoughlin A, Hillier VF , Robinson MJ 1992 UK	Parental perceptions of neonatal intensive care. (part of a larger study)	Not mentioned Interviews – the week before discharge or transfer (66%) or a week after the discharge (44%) 93 mothers of 109 babies admitted to a NICU who stayed on the unit for 10 days or more before discharge home or transfer to their local neonatal unit	There is additional financial and social stress imposed on parents by the costs of visiting A need to offer financial help to parents on low incomes to facilitate visiting and increase family contact for these parents.	- Pre determined topics related to parental visiting practice only explored. -No attempts to elicit any other issues from the parents. - No funding nor mentioned about the relationship of the researcher and the participants

Title/Author/Year/Country	Purpose	Study design/ sample/instrument	Conclusions	Limitations/comments
Emotional impact on parents of transported babies Frischer, L. Gutterman, D.L. 1992 USA	To provide a theoretical framework from which to understand parental experience during the transfer of a newborn baby.	Not clearly given Interviews No details about the transport team – who they are and how many were there in the team. Six parents involved in the transfer of their newborn	Emotional demands were identified by the transport team as being far greater than the physical demands and may be due to the parents not being given information that would ease the process. Parents' anecdotal accounts of their experiences showed that hey felt helpless, guilty, worry and overwhelmed. The need for ongoing information and support was highlighted	-No details about the methodological approach. Sample strategy was not explained. Very difficult to establish the questioning approach adopted as no details was given about the interview i.e. whether it is semi structured or structured or interview schedule was used which might affect the data collected. No indication of when exactly the data was collected – i.e. retrospectively or prospectively. No funding nor mentioned about the relationship of the researcher and the participants

Title/Author/Year/Country	Purpose	Study design/ sample/instrument	Conclusions	Limitations/comments
Communication from a distance- a study of maternal satisfaction with information giving during and after transfer of critically ill neonates Cross J 1995 UK	To evaluate the unit present approaches to communication with parents of critically ill transported neonates	Structured interview using a guided questionnaire All interviews completed within 72 hours of arrival to unit. 19 out of 20 mothers completed questionnaire.	94% found the information pack helpful. 25% felt more information was required although no specific details were given.	No further attempts to elicit maternal experiences. The researcher is working as part of the transport team. The mothers may feel it is in their baby's interest to respond positively as opposed to honestly
Neonatal Transport : The effect on parents Wilman, D. 1997 UK	Neonatal transport : the effect on parents	mentioned it being a survey in the abstract but no further explanations or details about the study design or sampling strategy	Highlighted the factors which can affect the transfer: emotional problems leading to information, and support needs.Increase in parental stress due to the emotional and financial factors as well as problems with communication and visiting at a distance	No details given as to the methodological approach. No supportive data to illustrate how the findings were derived. No indication of when exactly the data was collected No funding nor mentioned about the relationship of the researcher and the participants

Literature review on back transfer

Title/Author/Year/ Country	Purpose	Study design/ sample/instrument	Conclusions	Limitations/comments
Mothers' perception of their neonates' in-hospital transfer from a NICU Kolotylo,J.E.,Parker,N.I. & Chapman, J.S. 1991 USA	To describe mothers' experiences in in-hospital transfer from a NICU	Descriptive 15 mothers convenience sample interview within a week post transfer	The mothers expressed mixed feelings – feelings of relief accompanied by concern, fear of the unknown and feelings of alienation and helplessness. Expressed a dependence on familiar things and people.	No details about the interview process/schedule. Thought processes used to determine findings not explained.
Back transport : exploration of parents' feelings regarding the transition Kuhnly JE 1993 USA	To describe parents' experience of their experience of back transport of their preterm infant from a tertiary neonatal centre to a Level II or level I nursery	Exploratory qualitative methodology Convenience sampling of 14 parents Mentioned staff was recruited but no further details given semi structured interview parents interviewed 5-7 days after transfer staff nurse within 7 days of the back transfer and following parents' interviews	Response to back transfer influenced by initial transfer during period of crisis and this dictates how second crisis are perceived. Identified 3 phases parents went through Precrisis Transition Acceptance	Sample limited to married couple – what about single parents? No details about staff recruited Parents approached prior to transfer - ? more aware of the events during transition than they would otherwise would have been. No data on staff nurse interview and how it actually helps in the research objectives. Minimal data to illustrate how the phases were derived. No detail about the relationship between the site and the researcher.

Title/Author/Year/Country	Purpose	Study design/sample/instrument	Conclusions	Limitations/comments
Parents' perceptions of stress associated with premature infant transfer among hospital environments Dodds -Azzopardi E 1995 Canada	To determine whether parents perceived their premature infant's transfer among hospital as stressful	Retrospective descriptive survey Convenience sampling 44 of the 58 parents (76%) agreed to be in the study prepiloted questionnaire using Moos & Tsu model focusing on background and personal factors, illness of infant and socio-environment of facilities and 3 open ended questions Parents interviewed independently. Closed ended responses analyse with tabulated frequencies, percentages or t-test. Open ended responses were examined for commonalties and grouped into major themes	77% (34 of 44)reported stressful incidents stressful incidents divided into 3 categories -prior to transfer -surrounding transfer -after transfer no evidence that extent of illness directly linked to level of stress experienced greatest stress was found to be due to lack of communication	Sample – 38 married, 4 single parents and 1 couple divorced. None had previous experience with transfer. More than one third non whites – there were diversity with respect to cultural and socio economic factors Limitations acknowledged from small sample. Justification for tool was arrived through clinical positive appraisal of the tool and literature No data on how themes are grouped. Data analysis on closed ended responses was not clearly explained. No detail about the relationship between the site and the researcher or how the sample was accessed. No funding noted

Title/Author/Year/Country	Purpose	Study design/ sample/instrument	Conclusions	Limitations/comments
Holding on: parents' perceptions of premature infant's transfer Gibbons SA 1996 USA	Description of transfer process from parental perspectives	Grounded theory qualitative methodology Purposive sampling of 15 married , employed parents (8 families) only one father declined to participate unstructured interview parents interviewed 3 days before and up to 5 days after transfer	Identified the theory as 'holding on' with 4 phases: • Getting sicker • Going day by day • Getting prepared • Stepping toward home	Some explanation was given as to how the phases were derived but no details as to how the 4 phases concluded into a theory of 'holding on'.
Mothers' perceptions of the quality of their infant's back transfer: pilot study results Flanagan V et al 1996 USA	Pilot to test evaluation instrument of quality of care using quantitative and qualitative measures	Mailed questionnaire of 24 items based on pilot and literature survey (10 prior , 8 during and 6 after transfer) a week after the infant's transfer 55% returned (41 out of 74)	Transfer experience as fairly positive. Mild to moderate level of stress associated with the experience were reported by the mothers Better communication needed between the community hospital and the NICU	Questionnaire may not be the best for subject with high emotional content Mothers' perceptions of transfer experience affected by? time as mailed questionnaire was a week after transfer

Literature on back transfer

Title/Author/Year/Country	Purpose	Study design/ sample/instrument	Conclusions	Limitations/comments
Mothers' perceptions of the quality of their infant's back transfer Slattery,M.,Flanagan,V., Cronenwett, L., Meade,S. & Chase, N. 1998 USA	To determine the relationships that exist between 4 variables and the quality of mothers' experiences	Descriptive correlation 143 mothers completed the 24 item questionnaire. Questionnaire was mailed on average a week after the transfer. Response time varied	4 variables were important concerning perceived quality of the community hospital experience ; differences in nursing practice pre transfer preparation degree of medical problems communication	Tool developed from health care professional's perspectives Response time varied thus it is possible the mothers' perceptions of the transfer experience moderate to a memory of less stress than they actually experienced during the transfer.

Literature review on transfer

Title/Author/Year/Country	Purpose	Study design/ sample/instrument	Conclusions	Limitations/comments
Give and take in transport : communication hazards in hand over Leslie, A. 1995 UK	Identifying areas of potential conflict and tension in neonatal transportation	Based on experiences of a Transport team in a tertiary level	Raise awareness of the give and take in communication that is required for effective transfer of babies for neonatal intensive care unit	Not research based
Transferring sick babies Leslie, A. 1997 UK	To place best transport practice within a framework of safety	Literature review	Highlighted issues prior to, during and after transfer of a critically ill baby	Looks into issues relating to safe practice in the transportation only Parental needs nor preparation are mentioned

Some of the literature on mothers/parents of critically ill infant hospitalised in NICU

Title/Author/Year/Country	Purpose	Study design/ sample/instrument	Conclusions	Limitations/comments
Mothers, fathers and the crisis of NIC Affleck et al 1990 USA	To explore distress, and coping strategies To identify differences and similarities in mothers and fathers	50 parents Standardised questionnaires measuring distress, coping strategies	Mothers were found to mobilised more social support, and used more escapist coping strategies.	No details about what and how the questionnaires were formulated.
Correlates of anxiety, hostility, depression & psychosocial adjustment in parents of NICU parents Doering et al 2000 USA	To identify correlates of parental anxiety, hostility, depression and psychosocial adjustment	Explanatory correlational design 469 parents of infants hospitalised in 5 level 3 NICUs. Two instruments were used : Multiple Affect Adjective Checklist and Psychosocial Adjustment to Illness scale	Parents experienced high levels of anxiety, hostility and depression.	The magnitude of maternal anxiety , hostility and depression may be underestimated when measured by existing standardised checklist
Anxiety & depression in mothers of low birth weight and very low birth weight infants Gennaro et al 1990 USA	To compare two common pscyhologic stress responses : anxiety and depression	Interview from after delivery until 3-4 moths adjusted age. Multiple affect adjective checklist 27 mothers of VLBW and 35 mothers of LBW infants	Mothers of VLBW infants experienced higher anxiety and depression until 2 months	The magnitude of maternal anxiety and depression may be underestimated when measured by existing standardised checklist.

Some of the literature on mothers/parents of critically ill infant hospitalised in NICU

Title/Author/Year/Country	Purpose	Study design/ sample/instrument	Conclusions	Limitations/comments
Mothers stories about their experiences in NICU Holditch-Davies D Miles M 2000 USA	To let mothers tell the stories of their NICU experiences To determine how well these experiences fit the preterm parental distress model	Interviews with 31 mothers Data analysed using the conceptual model of Preterm Parental Distress model	Data verified six major sources of stress as indicated by parental role and NICU environment and staff communication	This study appears to be just a verification of the model. Mothers; experiences were not explored otherwise
The stress response of mothers and fathers of preterm infants Miles, M.S. et al 1992 USA	To explore the differences in NICU environmental stress, uncertainty and anxiety of mothers and fathers whose premature infants were hospitalised in an NICU	23 couples Parental Stressor Scale : NICU adapted from Parental Stressor Scale : Pediatric Intensive Care Units.	Findings suggest both mothers and fathers are distressed by the admission to an NICU.	Scale used pre determined topics No attempts to elicit any other issues related to stress from parents.
Sources of support reported by fathers and mothers of preterm infants. Miles et al 1996 USA	Perceptions of parents of critically ill baby regarding the support provided to them	Exploratory study Two interviews – a week after admission and the second one a week later Only 37 mothers and fathers were interviewed both times.	Findings showed that the highest source of support for mothers was the baby's father .	Did not indicate how the data were analysed.

Some of the literature on mothers/parents of critically ill infant hospitalised in NICU

Title/Author/Year/Country	Purpose	Study design/ sample/instrument	Conclusions	Limitations/comments
Maternal experiences of preterm birth and neonatal intensive care Padden , T. & Glenn, S. 1997 UK	Maternal experiences of preterm birth and NICU	Phenomenological study Semi structured Content analysis 36 mothers	Results most mothers were shocked and distressed at the appearance of the infant. Continuity of care was seen as important.	Themes identified were supported by extracts from the transcribed interviews. Not clear about the phenomenological approach as no details were given.
Maternal emotional response to preterm birth Pederson D et al 1987 USA	To describe the dimensions of stress perceived by mothers of preterm infants treated in NICU.	130 mothers interviewed near the end of their infant's hospitalisation using structured questions. Interviews coded for the presence of the presence or absence of 10 potential content areas of emotional stress.	The findings suggested that having an infant treated in a special care unit is very stressful and husbands , parents were seen as the major sources of support.	Although mention were made that the stress categories were based on previous research , there were no details as to which studies it was actually based on.
Mothers of babies requiring special care; attitudes and experiences. Redshaw, M.E. 1997 UK	To document the experiences and perceptions of mothers whose babies had been cared for in neonatal units	Questionnaire to 420 mothers from 23 NICUs in UK	External monitoring equipment caused anxiety to 50% mothers. There is very little differences between mothers' perceptions of large regional referral centres, and generally smaller district units	A more sensitive or a different method of data collection perhaps using interviews may review a broader range of effects of having a baby in neonatal units.

Some of the literature on mothers/parents of critically ill infant hospitalised in NICU

Title/Author/Year/Country	Purpose	Study design/ sample/instrument	Conclusions	Limitations/comments
Maternal perceptions of neonatal care. Redshaw M.E. & Harris, A. 1995 UK	To document and explore some of the practical and emotional issues for mothers whose babies had been admitted for neonatal care	420 mothers Questionnaire	The findings confirmed the crisis nature of the birth and admission to NICU. The equipment involved in neonatal care and how their baby looked concerned more than half of them. The busy atmosphere in the neonatal units also concerned some of them as did the rules and regulations they felt were imposed on them.	Complex parental reaction may be lost in the simplistic process of quantification.
Using the parental stressor scale in NICU Reid & Bramwell 2003 UK	An exploration of the validity of the Parental Stressor Scale with a sample of British mothers with moderate risk preterm infants	40 mothers completed the questionnaire within 48-96 hours of delivery	Good internal consistency on certain subscales measuring stress from environment, appearance of infant	The study serves its purpose of exploring the validity of a scale used in NICU only.
Variables associated with parental stress in NICU. Shields-Poe & Pinneli 1997 USA	To identify sources of parental stress in NICU	Descriptive study to identify sources of stress for parents (212) Data were collected by an interview and 4 questionnaires within 3 weeks of baby's admission.	Findings indicate that mothers and fathers differed in their response. How parents perceived the severity of their infant's illness was the most powerful variables associated with their stress scores	Complex parental reaction may be lost in the simplistic process of quantification

Some of the literature on mothers/parents of critically ill infant hospitalised in NICU

Title/Author/Year/Country	Purpose	Study design/ sample/instrument	Conclusions	Limitations/comments
Maternal psychological distress and parenting stress after the birth of a very low birth weight infant Singer L.T. et al 1999 USA	To determine the degree & type of stress experienced over time by mothers	Longitudinal prospective follow-up study Questionnaire using standardised normative self report measures of maternal psychological distress, stress, family and life stressors 206 mothers of VLBW infants	Mothers of VLBW had more psychological distress at 1 month . Severity of maternal depression was related to lower child development	Reliance on parental perceptions of family impact rather than direct measurement of family and maternal functioning.
Family reactions during infant hospitalisation in NICU. Spear M.L. et al 2002 USA	To identify family reaction in NICU	Questionnaire using tools measuring stress (SNAP)	No relationship between level of stress and illness of infant	One score cannot take the dynamic nature of an illness impact on family Complex parental reaction may be lost in the simplistic process of quantification
Perceived needs of parents of critically ill infants in a NICU. Ward K. 2001 USA	To identify perceived needs of parents of infants in a NICU	Convenience sampling of 52 parents (42 mothers and 10 fathers) NICU Family Needs Inventory used.	Findings suggested the need to inform parents of procedures, and treatment plan. Information related needs statement was given high rankings by the mothers	Complex parental reaction may be lost in the simplistic process of quantification

Appendix 3

Personal communication with David Wilman (dated 30/9/03)
(Author of study on Neonatal transport : the effects on parents. Journal of Neonatal Nursing 3(5)16.18-22.)

Hello Khaty,

Apologies for the delay in replying, what follows are some notes from your request.

You originally wrote:
< Thus my intention to explore parental needs, in particular their information and support needs, when their babies are transferred to another regional neonatal unit for my research project. >

Of course my study wasn't directed at this area, as I am sure you are well aware. I looked particularly at the effect on the parents of transfer to the regional unit. This effect might not be so noticeable in London with its compact geography and relatively good transport links. But in East Anglia, our area stretches from Boston in the north, to Southend in the south; and from Watford in the west to Great Yarmouth in the east. Transport links are not that good. I imagine, although I did not mention this, that areas like N Scotland must have greatly magnified versions of our parents' problems. This could be an interesting area of investigation, as could the relevance of family friendly accomodation at or near the regional hospital.

You noted: < From my literature search I found that that is very little being done on this type of transfer ie from place of birth to regional neonatal unit as most actually concentrated on back transfer >. Indeed they do! One of the major curiosities of my literature searches was the overwhelming prevalence of back transfer studies. I could only presume this was due to something in the way neonatal services are set up in the USA.

I am not sure of the main emphasis of your work: is it towards the back transfer from specialised units [eg GOS] to a regional unit, or on the transfer of a baby to the regional unit ? There is a marked difference between the two. I do not mean to interfere in your study, its just not clear to me at the moment.

I am not sure if you can Œborrow my study' as you requested: primarily it is because it was done mainly during the year 1995. I have the complete file in front of me of all the work, most of it is irrelevantly long searches, you know the sort of thing. Some of it was done on a college Windows 3.1 machine, most of the searches had to be printed out then, rather than stored on disc; and for years I have been running Apple Macs, which don't translate the little that was electronically stored very well. Pages of hand written notes are only relevant to the study for internal composition priorities and comprehensivity. It is worth searching still, as most of the articles will come up still, and search engines are better these days.

I note some things though, in addition to my article and its reference list:

Parental Stressor Scale:NICU. Miles, Funk. Nursing Research.42(3):148-52; 1993 May-Jun.
Transporting high risk newborns. Pinelli, Ferguson. Neonatal Network. 3(6): 23-6; 1985 Jun

The study by McLoughlin, Hillier on financing is worthy of further repetition/ reinforcement, and an important area which is largely ignored.

More babies are being transferred these days over longer distances, from out-of-region hospitals. This is almost always due to cot crises; London is badly affected by this.

It seems that emergency neonatal transports are nowadays less common and less intensive: this could be the result of several different factors. Certainly in our Regional Unit we do not have anything like the intensivity we had a few years ago, both in local and regional babies. Better obstetric care maybe? Or improved surfactants, more rotation of level 3 trained SPRs to DGHs?

I am unable to give you any contacts as I am only partially invoved in transport these days. The Region has started its own Neonatal Transport team, and for various reasons I have not joined it.

I would be interested in further information concerning your Peer review Group, sorry I cannot come up with more material,

Regards
David Wilman

forum for neonatal caregivers and other healthcare professionals

Neonatal Chat Monday, February 9 2004 Volume 01 : Number 345

Date: Mon, 09 Feb 2004 10:05:10 -0800
From: Neonatal Chat <neonatalchat@neonatalnetwork.com>
Subject: Re: Neonatal Chat V1 #344 Neonatal Transport

Just to add my 2 cents, we give the parents of the infants we transport, a booklet explaining the purpose of our unit, some terminology they may hear and what it all means, and phone numbers to reach our unit at any time. They are encouraged to visit as soon as they are able. The personal touch and time spent caring for them and the baby before the transport team leaves seems to alieviate some fears. Pat

---

Date: Mon, 09 Feb 2004 10:07:33 -0800
From: Neonatal Chat <neonatalchat@neonatalnetwork.com>
Subject: RE: Neonatal Chat V1 #344

Khaty,
HI, I guess I need to know what so you mean by
addressing parents' needs during their babies transfer?
Are you talking transportation for them, information
needs after the baby arrives to the unit? If I can
get a better idea of what you are looking for, I can
better assist you with what info I can!

Thanks, Ann

> Date: Wed, 04 Feb 2004 12:18:10 -0800
> From: Neonatal Chat
> Subject: RE: Neonatal Chat V1 #343
>
> Hi Ann
>
> I am also looking into neonatal transportation but from the user
> perspectives ie from the parents experiences - would you by any chance
> know of any work addressing parents' needs during their babies
> transfer.
>
> Cheers
> Khaty

> UK

End of Neonatal Chat V1 #345
****

In order to create a successful forum we encourage you to post your response directly to the list so that everyone can benefit. Please post your reply to neonatalchat@neonatalnetwork.com.

Neonatal Network Chat is a forum that is different from other discussion groups on the web. Our goal is to encourage discussion of issues related to all aspects of the neonatal care experience. These issues include working conditions, job opportunities, pay scales, and clinical issues as well as other professional issues that impact your life as a neonatal nurse or other heathcare provider in the NICU.We look forward to hearing your thoughts and feelings about neonatal care.

To unsubscribe send a single line email message with unsubscribe neonatalchat-digest YOUREMAIL (replace YOUREMAIL with your actual
email)
in the body to neonatalchat-request@neonatalnetwork.com.

Example

To: neonatalchat-request@neonatalnetwork.com
From: anyone@domain.com
Subject: unsubscribe

unsubscribe neonatalchat-digest YOUREMAIL

An example of CASP (2003)

Appendix 5

Screening questions (initial transfer)	**Maternal support needs : a study of unsatisfied support needs of mothers who delivered very premature babies who were admitted to a neonatal unit. Newsome, A 1991UK (Masters thesis – unpublished study)**	**Paediatric inter-facility transport: the parents' perspectives Macnab, A.J. 1992 Canada**	**Parental costs of neonatal visiting McLoughlin A, Hillier VF , Robinson MJ 1992 UK**
Screening question 1: Statement of aims/goal Importance /relevance of research	Purpose clearly given Explanation given of its relevance/importance	Purpose given Importance /relevance of project given in introduction	Objective given Importance/relevance given
Screening question 2 Is a qualitative methodology appropriate	No Descriptive Case study	Yes Retrospective telephone descriptive survey	Not mentioned study design
Research design : appropriate	Research design not clearly justified	Not justified	Not justified
Recruitment strategy	Convenience sampling Explained adequately about selection criteria Discussion around refusals	Convenience sampling All parents who fit criteria during the 12 months. No discussions of refusals	No mention of sampling strategy – Not explained about selection criteria No discussions of any refusals
Data collection Justified, clear., explicit, clear, explanation about any modification	Procedure section – semi structured interview with open ended questions Explanations about the interview guide and whether it has been tested and modified given	Explained adequately about how the telephone surveys was being carried out and the number of attempts – 5 unanswered phone calls classified as unavailable for interview. Calls made at different times and different days of the week.No details about questions being asked nor any pilot/modification.	Semi structured interview focussing on topics which may have bearing on parental visiting practice. No details of the interview questions nor rationale No details about any pilot or modification.

Screening questions (initial transfer)	**Maternal support needs : a study of unsatisfied support needs of mothers who delivered very premature babies who were admitted to a neonatal unit. Newsome, A 1991UK (Masters thesis – unpublished study)**	**Paediatric inter-facility transport: the parents' perspectives Macnab, A.J. 1992 Canada**	**Parental costs of neonatal visiting McLoughlin A, Hillier VF , Robinson MJ 1992 UK**
Reflexivity Potential bias/role Respond to events and any implications of changes	Not mention Researcher works as Family Support Sister in the unit – potential role bias	Not mention No details about any modifications due to events changes	Not mention No details about any modifications due to events changes
Ethical issues Sufficient details how research explain Issues discussed raised by study Approval sought	Approval obtained Ethical issues briefly discussed. No funding noted	Ethical approval obtained No discussion of any ethical issues No funding noted	No mention of ethical approval No discussion of any ethical issues No funding noted
Data analysis Any in-depth description Clear how themes/categories are derived Explains how data presented were selected to demonstrate analysis Critically examined any potential bias/own role/influence	Describe how data reduction occurs and clearly explained how themes were derived. Did not examined any potential bias or influence No mention of validation of findings	No supportive data to illustrate findings. No mention of validation of findings	No in-depth description. Insufficient data presented to demonstrate analysis

Screening questions (initial transfer)	**Maternal support needs : a study of unsatisfied support needs of mothers who delivered very premature babies who were admitted to a neonatal unit. Newsome, A 1991UK (Masters thesis – unpublished study)**	**Paediatric inter-facility transport: the parents' perspectives Macnab, A.J. 1992 Canada**	**Parental costs of neonatal visiting McLoughlin A, Hillier VF , Robinson MJ 1992 UK**
Findings Explicit Adequate discussion of the evidence Credibility Discussed in relation to the original research questions	Findings explicit in the form of diagram and quotes for parents to justified the phases Thematic analysis not validated	Findings are presented in table form with percentage. No discussion about credibility /validation Open questions analysis not obvious	Inadequate discussion of findings as frequency was given
Value of research Findings consider in relation to current practice/literature Identify any new areas of research Transferable or any other ways research may be used	Findings discussed together with results Identify further research focus Implications for nursing given Limitations acknowledged Relevant indirectly to problem	Identify further need for prospective research to clarify the nature of problems by families of transported children . Limitations acknowledged. Relevant to problem	Clear discussion section in relation to relevant literature Identify further need to do the research in more sites and diverse population. Limitations acknowledged. Relevant to problem

Screening questions (CASP 2002) (initial transfer)	**Emotional impact on parents of transported babies** **Frischer, L. Gutterman, D.L. 1992 USA**	**Communication from a distance- a study of maternal satisfaction with information giving during and after transfer of critically ill neonates** **Cross J 1995 UK**	**Neonatal Transport : The effect on parents** **Wilman, D. 1997 UK**
Screening question 1: Statement of aims/goal Importance /relevance of research	Purpose clearly given Explanation given of its relevance/importance	Purpose given Importance /relevance of project given in introduction	Purpose not given No explanation about importance of study
Screening question 2 Is a qualitative methodology appropriate	methodology not given	Methodology not given	Not mentioned study design
Research design : appropriate	Research design not clearly justified	Not justified	Not justified
Recruitment strategy	Not explained	Convenience sampling explained selection criteria discussions of refusals	No mention of sampling strategy – Not explained about selection criteria
Data collection Justified, clear., explicit, clear, explanation about any modification	Implied interviews being conducted – no further details about interview schedule/topics	Structured interview using guided questionnaire. No justification nor modification given	No details about how data was collected

Screening questions (initial transfer)	**Emotional impact on parents of transported babies** **Frischer, L. Gutterman, D.L.** **1992** **USA**	**Communication from a distance- a study of maternal satisfaction with information giving during and after transfer of critically ill neonates** **Cross J** **1995**	**Neonatal Transport : The effect on parents** **Wilman, D.** **1997** **UK**
Reflexivity Potential bias/role Respond to events and any implications of changes	Not mention	Not mention No details about any modifications due to events changes	Not mention No details about any modifications due to events changes
Ethical issues Sufficient details how research explain Issues discussed raised by study Approval sought	No mention of ethical approval No discussion of any ethical issues No funding noted	Ethical approval obtained No discussion of any ethical issues No funding noted	No mention of ethical approval No discussion of any ethical issues No funding noted
Data analysis Any in-depth description Clear how themes/categories are derived Explains how data presented were selected to demonstrate analysis Critically examined any potential bias/own role/influence	Some indication of how thematic analysis was done with some parents' quotation used to illustrate findings.	Findings were presented as percentage .	No supportive data to illustrate hoe the findings were derived.

Screening questions	**Emotional impact on parents of transported babies** **Frischer, L. Gutterman, D.L.** **1992** **USA**	**Communication from a distance- a study of maternal satisfaction with information giving during and after transfer of critically ill neonates** **Cross J** **1995** **UK**	**Neonatal Transport : The effect on parents** **Wilman, D.** **1997** **UK**
Findings Explicit Adequate discussion of the evidence Credibility Discussed in relation to the original research questions	Findings poorly discussed Credibility minimal	Findings are presented in table form with percentage. Inadequate discussion of findings as frequency was given No discussion about credibility /validation Open questions analysis not obvious	Findings poorly discussed Credibility minimal
Value of research Findings consider in relation to current practice/literature Identify any new areas of research Transferable or any other ways research may be used	Poor methodological details **Relevant to problem**	**Relevant to problem**	Poor methodological details **Relevant to problem**

Screening questions (CASP 2002) (back transfer)	**Back transport : exploration of parents' feelings regarding transition Kuhnly JE & Freston M.S. 1993 USA**	**Parents' perceptions of stress associated with premature infant transfer among hospital environments Dodds-Azzopardi,E & Chapman J.S. 1995 Canada**	**Holding on : parents' perceptions of premature infants' transfers Gibbins,S.M. & Chapman,J.S. 1996 USA**
Screening question 1: Statement of aims/goal Importance /relevance of research	Purpose clearly given Explanation given of its relevance/importance	Purpose given research questions given as in findings section Importance /relevance of project given in introduction	Objective given Importance/relevance given
Screening question 2 Is a qualitative methodology appropriate	Yes Exploratory inductive qualitative	Yes Retrospective descriptive survey	Yes?? Not too sure as objectives was just to describe parents' perceptions. Grounded theory
Research design : appropriate	Research appropriate justified	Justified usage of study framework	Not clearly justified
Recruitment strategy	Convenience sampling Explained selection by review of medical records to guide selection and who met criteria. Not explained why these criteria No discussion around refusals	Convenience sampling All parents who fit criteria during the 4 months. Not explained criteria No discussions of refusals	No mention of sampling strategy – All parents who fit criteria. Not explained criteria No discussions of any refusals
Data collection Justified, clear., explicit, clear, explanation about any modification	Procedure section – semi structured with open ended questions given as guide Parents interviewed individually 5-7 days post transfer-time selection justified No explanations about the interview guide and whether it has been tested and modified	Procedure section – approach clearly stated from recruitment by infant caregiver to interview. Explained the way parents are interviewed independently 4-7 days post transfer (justified time selection Tool used – interview using questionnaire which is adapted from Mao and Tsu model – explanation given why this tool was used – explained how it was developed and validated	Method section – most are interviewed together. selection of time justified –as soon as transfer and 5 days post. Open ended questions given. No mention of nay modification of the questions or any pilot – however do we need piloting if grounded theory??

Screening questions (back transfer)	**Back transport : exploration of parents' feelings regarding transition Kuhnly JE & Freston M.S. 1993 USA**	**Parents' perceptions of stress associated with premature infant transfer among hospital environments Dodds-Azzopardi,E & Chapman J.S. 1995 Canada**	**Holding on : parents' perceptions of premature infants' transfers Gibbins,S.M. & Chapman,J.S. 1996 USA**
Reflexivity Potential bias/role Respond to events and any implications of changes	Not mention Both researcher works as a neonatal clinical nurse specialist and a associate professor in Connecticut The research is done in 3 nurseries in Connecticut =?? role	Not mention Both researcher works as a ?private practice nurse and a professor in Ontario The research is done in one of the two community hospitals in Ontario =?? role	Not mention ? grounded theory and reflexivity
Ethical issues Sufficient details how research explain Issues discussed raised by study Approval sought	Approval obtained No details about how parents were approached /consent taken No discussion of any ethical issues Not funded	No mention of ethical approval Details given as to how parents were initially approached by their caregiver prior to the researcher who explain and obtain consent fro those willing to participate No discussion of any further ethical issues No funding noted	No mention of ethical approval Details given as how two nurses act as designates for recruiting prospective subjects No discussion of any further ethical issues No funding noted
Data analysis Any in-depth description Clear how themes/categories are derived Explains how data presented were selected to demonstrate analysis Critically examined any potential bias/own role/influence	Describe how data reduction occurs. Explain how data analysis was developed by writing in chart form quotes from parents that illustrated theme and categories. Validation by CNS with previous research experience in the same field. Interviews of nurses. Areas of agreement and disagreement were discussed and refined.	Insufficient data especially thematic analysis No mention of validation of findings	The two authors conducted independent and simultaneous data analysis according to Strauss paradigm of conditions, interactions, strategies and consequences.

Screening questions (back transfer)	**Back transport : exploration of parents' feelings regarding transition Kuhnly JE & Freston M.S. 1993 USA**	**Parents' perceptions of stress associated with premature infant transfer among hospital environments Dodds-Azzopardi,E & Chapman J.S. 1995 Canada**	**Holding on : parents' perceptions of premature infants' transfers Gibbins,S.M. & Chapman,J.S. 1996 USA**
Findings Explicit Adequate discussion of the evidence Credibility Discussed in relation to the original research questions	Findings explicit in the form of diagram and quotes for parents to justified the phases Content analysis validated by CNS with any disagreement discussed and refined	Findings are discussed under each research questions No discussion about credibility /validation Open questions analysis not obvious	Major categories given with quotes from parents to justify categories. Credibility by having the two authors doing analysis independently and simultaneously using Strauss paradigm. No mention of how agreement /disagreement are resolved.
Value of research Findings consider in relation to current practice/literature Identify any new areas of research Transferable or any other ways research may be used	Findings discussed together with results Identify further research focus Implications for nursing given Limitations acknowledged Some relevance	Small section in summary to discuss findings in relation to literature. Have provided valuable insight into parents' perceptions of infant care related to transfer between the 2 nurseries Did not identify further research. Limitations acknowledged Some relevance	Clear discussion section in relation to relevant literature Identify further need to do the research in more sites and diverse population. Limitations acknowledged Some relevance

Screening questions (CASP 2002) (back transfer)	**Mothers' perception of their neonates' in-hospital transfer from a NICU** **Kolotylo,J.E.,Parker,N.I. & Chapman, J.S.** **1991** **USA**	**Mothers' perceptions of the quality of their infant's back transfer: pilot study results** **Flanagan V** **1996** **USA**	**Mothers' perceptions of the quality of their infant's back transfer** **Slattery,M.,Flanagan,V.,Cronenwett, L., Meade,S. & Chase, N.** **1998** **USA**
Screening question 1: Statement of aims/goal Importance /relevance of research	Purpose clearly given Explanation given of its relevance/importance	Purpose given research questions given as in findings section Importance /relevance of project given in introduction	Objective given Importance/relevance given
Screening question 2 Is a qualitative methodology appropriate	descriptive	Mailed questionnaire survey	Descriptive correlational
Research design : appropriate	Not justified	Not justified	Not justified
Recruitment strategy	Convenience sampling Explained selection by review of medical records to guide selection and who met criteria. Not explained why these criteria No discussion around refusals	Convenience sampling Not explained criteria No discussions of refusals	No mention of sampling strategy – All parents who fit criteria. Not explained criteria No discussions of any refusals
Data collection Justified, clear., explicit, clear, explanation about any modification	No details about interview schedule/process	Attempted to explain the 24 items in the questionnaire – however insufficient details.	Mailed a week after transfer but response time varied although no details give in text.

Screening questions (back transfer)	Mothers' perception of their neonates' in-hospital transfer from a NICU Kolotylo,J.E.,Parker,N.I. & Chapman, J.S.1991USA	Mothers' perceptions of the quality of their infant's back transfer: pilot study results Flanagan V 1996 USA	Mothers' perceptions of the quality of their infant's back transfer Slattery,M.,Flanagan,V.,Cronenwett, L., & Chase, N.1998 USA
Reflexivity Potential bias/role Respond to events and any implications of changes	Not mention	Not mention	Not mention
Ethical issues Sufficient details how research explain Issues discussed raised by study Approval sought	Approval obtained No details about how parents were approached /consent taken No discussion of any ethical issues Not funded	No mention of ethical approval No funding noted	No mention of ethical approval No funding noted
Data analysis Any in-depth description Clear how themes/categories are derived Explains how data presented were selected to demonstrate analysis Critically examined any potential bias/own role/influence	Thought processes used to determine findings not explained	No mention of validation of findings	No mention of validation of findings
Findings Explicit. Adequate discussion of the evidence. Credibility Discussed in relation to the original research questions	Inadequate discussion of the evidence	Findings are discussed in percentage and frequency. Poor demonstration of how correlation was obtained. No discussion about credibility /validation	Findings inadequately discussed in relation to the evidence presented
Value of research Findings consider in relation to current practice/literatureIdentify any new areas of research.. Transferable or any other ways research may be used	Some relevance to problem	Some relevance	Some relevance

REC 036/04/W Appendix 6

INFORMATION SHEET FOR NEONATAL NURSES

(dated 2nd February version 9)

STUDY FULL TITLE :	Neonatal Transfer Study
STUDY RESEARCHER	Khatijah Abdullah

Dear Colleagues

My name is Khatijah Abdullah. I am a qualified nurse and midwife with neonatal care qualification and experience. Currently I am a fulltime postgraduate student in the School of Nursing and Midwifery at the Southampton University where I am studying for a Doctorate in Clinical Practice. I am preparing to carry out a research study, the Neonatal Transfer Study about mothers' experiences when their babies are transferred from their neonatal unit to a Level 3 Neonatal Unit. I am writing to ask for your help and support with the study.

The main point of the study is to ask mothers themselves about their experiences when their babies are transferred from their neonatal unit to a Level 3 Neonatal Unit. By doing this I aim to gain information to help improve the care we give at such a stressful time. Hermeneutic phenomenology and the work of van Manen (1990) will be use to guide the research process.

1. Background to the study

Technology continues to advance rapidly providing premature and critically ill babies with greater opportunities for survival. This rapid advancement has increased the number of babies being transfer from smaller unit to regional NICU. In 2003 the number of babies transferred to the neonatal unit in Princess Anne Hospital increased by almost 50%. It is expected to increase with the setting up of Managed Clinical Networks as recommended in the recent Neonatal Intensive Care Services Review (DOH 2003)

Much has been written about the stress and anxiety experienced by parents of babies requiring NICU but an understanding of the psychological and emotional impacts on the family of these transferred babies remains undeveloped. The literature provides very little information and few guidelines for nurses and support personnel regarding the emotional state of the parents during this critical and vulnerable period of time. Reliable evidence would make a significant contribution to improving care for these families and the aim of the study is to help provide this.

2. Who will be included in the study and what will parents be asked to do?

I aim to interview up to 15 mothers whose babies have been transferred from their local neonatal to a Level 3 Neonatal Unit

The mother will be included if :

- Her baby will have been transferred from their neonatal unit to the unit in which research being conducted
- Her baby's condition will be stable at the time of her recruitment to the study
- She will be in satisfactory physical and emotional state as judged by the consultant or nursing staff in the neonatal unit.
- Her baby's stay must be three days or more, from the day of transfer into the neonatal unit in which the research is being conducted.

The mother will be excluded if:

- Her baby was born in Princess Anne Hospital.
- Her baby was electively admitted NICU for further management.
- Her baby is critically ill or dying at the time of potential recruitment to the study.
- Her baby has been transferred more than once into the neonatal unit in which the research is being conducted.
- She is not comfortable to conduct the study interview in English Language.
- She does not consent to participate in the study.

For mothers who agree to take part I will aim to arrange to interview the mothers by the seventh to tenth post transfer day of their newborn babies into the NICU.

3. What will neonatal nursing staff be asked to do?

Neonatal nursing staff will be asked to give the mothers who meet the criteria listed above an introductory letter and information sheet about the study. The mothers are requested to reply at the tear off slip at the end of the introductory letter and post it in the reply box situated in the nurses' reception to indicate whether or not they are interested in taking part.

I will provide neonatal nursing staff with full information and support about the study before any mothers are recruited and during the entire time the research is ongoing.

4. What happens after the nurse gives the mothers the information sheet ?

I plan to come to the unit daily to answer any questions from the staff and to retrieve consent forms for me to contact the mothers directly to discuss the study and their participation. I will obtain written consent from the mothers for their participation in the study and once they have given this, I will then organise an interview with each mother in a mutually agreed place and time.

Many thanks for your interest in the study. I look forward to talking about the study more fully with you when I next visit the unit. If you would like to contact me before then, please call me at 023 80598250 or e-mail me at kagkl101@soton.ac.uk.

Yours sincerely

Khatijah Abdullah
RGN RM ENB 405 BSc (Hons) MSc.
Postgraduate research student (Doctoral student)
University of Southampton

Information Sheet for Mothers (dated 4th March 2004 version 10)

Study Title: Neonatal Transfer Study

My name is Khatijah Abdullah. I am a qualified nurse and midwife with neonatal care qualifications and experience. Currently I am a fulltime postgraduate student in the School of Nursing and Midwifery at the Southampton University where I am studying for a Doctorate in Clinical Practice. I am carrying out a research study called the Neonatal Transfer Study which is about mothers' experiences when their babies are transferred from their local neonatal unit to another neonatal unit. By doing this I hope to gain information to help improve care we give mothers at such a stressful time.

As a mother whose baby has been transferred from your local neonatal unit into this neonatal unit, you are invited to take part in this study. Before you decide 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 and discuss it with others if you wish. Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the study about?

You are invited to be in a study involving mothers whose newborn babies have been transferred from a neonatal unit to another neonatal unit. We want to find out what the experience is like for you and also if this can be improved in any way by offering different care and support from health workers.

Why have I been chosen?

You have been chosen because we wish to find out more about mothers' experiences. Health care professionals can guess what this experience is like, but only mothers can tell us what it is really like for them. I aim to interview around 15 mothers about their experiences.

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 I will ask you to sign a form saying you consent to join the study. Even if you decide to take part you are still free to withdraw at any time and without giving reason. A decision to withdraw at any time, or a decision not to take part, will not affect any care you or your baby receives.

What will happen to me if I take part?

If you consent to take part in the study I will arrange an interview with you in a place and at a date and time most convenient to you. During the interview I will ask you questions about your experience and thoughts about your baby's transfer. With your permission I will tape record our interview, which will last around an hour.

You will be asked for permission to inform your GP about your participation in the study. If you give the permission for the researcher to contact your GP, a letter will be sent to your GP about your participation in the study.

What are the benefits?

One of the main benefits will be that your experiences will be used along with those of the other mothers who take part to help inform future care for mothers whose newborn babies are transferred. You will be able to talk about your experience to me, someone who has not been involved in your baby's care. Some mothers find talking to someone who have not been directly involved in their baby's care a helpful experience.

What are the possible disadvantages of taking part in the study?

Sometimes talking about your experiences can be distressing. If this happens, I will stop our interview. I will not force you to continue with the interview if you do not wish to. If you would like information about how to get support and counselling, I will give you the necessary details. I will also give you my contact details in case you need to talk about anything related to the study.

What about confidentiality?

All information collected about you and your family during the course of the study will be kept strictly confidential. All written and taped information will be kept in a locked and secure filing cabinet at the University of Southampton. All information will be anonymous and you will not be personally identified. All information collected during the study, including audiotapes, will be archived as recommended by the Data Protection Officer for the hospital.

What if I want to make a complaint about my or my baby's treatment?

If you should have any complaints about your or your baby's treatment, I will give you advice about how to use the normal channels for complaints in the Trust. These include :

1. Encouraging you to discuss the issue with a staff member in the neonatal unit
2. Encouraging you to write to the Clinical Nurse Manager of the unit about your concerns.
3. Giving you written information about the Patient Advocacy Liaison Service (PALS).

What will happen to the results of the study?

You will be invited to review the transcript of your interview and a summary of the study report will be offered to you.

The study will be written as a doctoral thesis at the University of Southampton. I also aim to publish the results of the study in neonatal and nursing journals. In no way will any mother, baby or member of hospital staff involved in the study be identified in any report or publication.

Who has reviewed the study?

The study has been reviewed by the South and West Local Research Ethics Committee. Contact : Clair Wright, Southampton & South West Hampshire, Local Research Ethics Committees, 1st Floor, Regents Park Surgery, Park Street, Shirley, Southampton SO16 4RJ Tel no 023 80362466/023 80363462. REC Ref No : 036/04/w.

Contacts for further information

Khatijah Abdullah is the research nurse who can answer any questions you have about the study. Khatijah can be contacted on 023 80598250.

kagkl101@soton.ac.uk

Thank you for taking the time to read this sheet and considering taking part in this study.

REC 036/04/W

CONSENT FORM (4th March 2004 version 10)

Centre Number :	RHM O&G0112
Study Number:	REC 036/04/w
Patient Identification Number for this trial :	

CONSENT FORM

Title of Project : Neonatal Transfer Study.

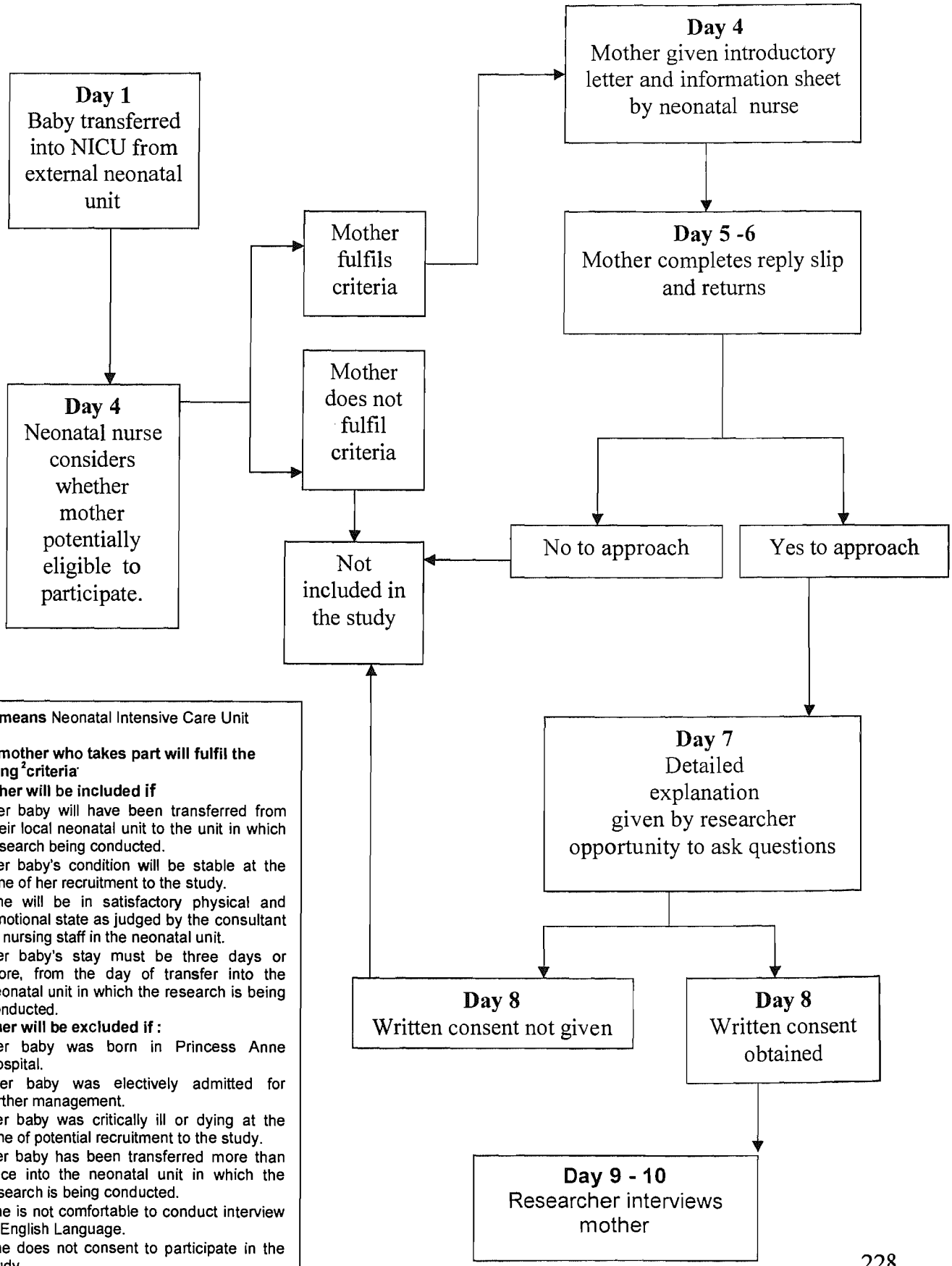
Name of Researcher : Khatijah Abdullah

Please initial box

1	I confirm that I have read and understand the information sheet dated **4th March 2004 (version 10)** for the above study and have had the opportunity to ask questions.	☐
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	☐
3.	I understand that sections of my baby's medical notes may be looked at by responsible individuals from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my baby's records.	☐
4	I agree to have the study's interview audio taped.	☐
5	I agree for my GP to be informed about my participation in the study.	☐
6.	I agree to take part in the above study.	☐

Name of Patient	Date	Signature
Name of Person taking consent. (if different from researcher)	Date	Signature
Researcher	Date	Signature

1 for patient; 1 for researcher; 1 to be kept with hospital notes



[1]**NICU means** Neonatal Intensive Care Unit

Every mother who takes part will fulfil the following [2]criteria

A mother will be included if

- Her baby will have been transferred from their local neonatal unit to the unit in which research being conducted.
- Her baby's condition will be stable at the time of her recruitment to the study.
- She will be in satisfactory physical and emotional state as judged by the consultant or nursing staff in the neonatal unit.
- Her baby's stay must be three days or more, from the day of transfer into the neonatal unit in which the research is being conducted.

A mother will be excluded if :

- Her baby was born in Princess Anne Hospital.
- Her baby was electively admitted for further management.
- Her baby was critically ill or dying at the time of potential recruitment to the study.
- Her baby has been transferred more than once into the neonatal unit in which the research is being conducted.
- She is not comfortable to conduct interview in English Language.
- She does not consent to participate in the study

Appendix 10

Written information for contact numbers for support

Information about contact numbers for support to be given at the end of the interview to all participants.

Family Support Sisters Neonatal unit	Sister Lisa Leppard Sister Sandra Edwards	02380798102 02380798899
Social worker for child health Southampton General Hospital	Ann Lyons	02380794298
BLISS		08707700337

Appendix 11

Field note : M1

I arrived at the unit one Sunday morning to wait for the mother (M1) to arrive. The baby was doing well and the nurse looking after her was very pleased with her. The nurse told me that mum called earlier to say that she might be a bit late.

While waiting for the mother to arrive, I checked the admission book, the reply box and make sure that the room is ready for the interview.

M1 arrived and was updated by the nurse the baby's progress. I then discussed with her what her plans were and whether she still would like to talk about her experiences - I noted that she appeared apprehensive when this was brought up – . She insisted that she is alright to talk and after letting the nurse knows where she is, we left the unit to go to a room just outside the unit.

Although the interview went well, – later when the tape recorder was switched off, she confessed that she was not sure what she can say to contribute to the study as she felt that everybody is doing the best for her baby and that was why she felt a bit worried about what to say – she did not realise that it will be like any conversation she has with the mums here!!!

There were difficult moments when the mother expressed her feelings when she was waiting for the ambulance to come to bring the baby to the unit. Although I offered to stop the interview, she insisted to continue – I can only at that time touched her hands briefly and used my eyes to offer expressions of understanding and compassion.

Personally I think the interview was a success in many ways – M1 was able to offer her story once she was reassured that she is the expert in this as she went through it, not anybody else. In the end I think she had re-energised me with her courage and for M1, she stated that the effects of the interview had been to 'put things in perspective'

On headed paper (School of Nursing) **Appendix 12**

Participant thank you letter and interview comment sheet

Date

Dear

I just wanted to thank you for giving your time on ..... (Date) to participate in the study regarding your newborn baby's transfer experience. It was very much appreciated.

As agreed I have informed /not informed your GP by letter of your involvement in the study and provided details of what this entailed.

As we discussed the study will be completed by November 2004 and I will ensure you receive a summary of the study findings.

I also wondered if you might also wish to comment on the interview itself, or perhaps any suggestions or thoughts that occurred after the interview. I enclose a reply slip and stamped addressed envelop for this, but please do not feel that you are in any way under any obligation to do so.

I hope the interview did not cause any difficulties or inconvenience. Thank you once again foe sharing your experience.

Yours sincerely
Khatijah Abdullah
Post graduate research student
University of Southampton

Interview comment slip

Please feel free to comment on any aspect of the interview, or any thoughts that you may feel are important

Thank you.

Appendix 13

Checklist prior to interview

Check

1. tape recorder
2. 2. microphone
3. batteries
4. tapes
5. notebook
6. pen
7. pencil
8. consent form
9. road maps/directions if needed
10. leave contact details in closed envelope for husband in case of any emergencies – to be opened only after 6 hours of non contact with husband

On headed paper (School of Nursing)

REC 036/04/W
Letter to GP (dated 2nd February 2004 version 9)

Khatijah Abdullah
Building 67 School of Nursing and Midwifery
Highfield
University of Southampton,
Southampton SO17 1BJ

Date

GP name and address

Dear Dr

Re: Ms/Mrs .....(name of participant)

I am a post graduate researcher working at the University of Southampton and I am carrying out a study at the Princess Anne Hospital (PAH) in Southampton. One of your patients ..... (name and address of participant) has been recruited into my research study called Neonatal Transfer Study (Research Ethics Committee registration number 036/04/W) and I am writing to let you know about the study.

The Neonatal Transfer Study explores the experiences of mothers whose newborn babies are transferred from their local neonatal unit to the neonatal intensive care unit (NICU) in PAH.In undertaking the study I will be conducting one-to-one interview with around 15 mothers who have experienced transfer of their newborn babies into a NICU.

Whilst the research should not be harmful in any way to participants, we are mindful of the possible distress that mothers may experience as a result of discussing their experiences. As a consequence the research has been carefully designed to minimise any distress to mothers with attention to issues of consent, how the interviews are conducted and the availability of support for the mother should she

become distressed as a result of the research. All participants will be made fully aware that they can withdraw from the research or stop the interview at any point without giving a reason and without any consequences for the care of themselves or the baby in the neonatal unit.

If you have any queries about the study or wish to discuss anything I have said please do not hesitate to contact me at 023 80598250 or kagkl101@soton.ac.uk.

Yours sincerely

Khatijah Abdullah
RN RM BSc MSc
Post graduate research student (Doctoral student)
Building 67
School of Nursing and Midwifery
University of Southampton
Southampton SO17 1BJ

On headed paper (School of Nursing)
Your ref : CPW/sta
LREC ref : 036/04/w

4th March 2004

Mrs Clair Wright
LREC Manager
Southampton & South West Hampshire
Ist Floor, Regents Park Surgery
Park Street
Shirley
Southampton
SO16 4RJ

Dear Mrs Wright

REC Ref : 036/04/w – The experience of mothers when their newborn babies are transferred from their local neonatal unit to a level 3 neonatal unit.

Thank you for your letter outlining the comments raised by members of the Research Ethics Committee relating to my application. I shall respond to each of the 4 points in the order you sent to me.

1) **The committee requested clarification as to where the interviews will take place.**

The study has been carefully designed to enable the participant to remain autonomous within the process of research. Thus for this reason, the participant and not the researcher will determine location for the interview. The researcher will interview the mother in a place and at a date and time most convenient to her. If the mother chooses to be interviewed in the neonatal unit, the researcher will negotiate with the Clinical Nurse Manager to use the parents' room or interview room in the unit.

2) **What strategy is in place should a mother have a complaint about her or her baby's treatment during the transfer to the Level 3 Neonatal Unit? This information should be included in the Information Sheet for Mothers.**

In the event of this happening, the researcher will follow the normal channels for complaints used by the unit as follows:

: the participant will be encouraged to discuss the issue with a staff member in the neonatal unit.
: the participant will be encouraged to write to the Clinical Nurse Manager of the unit about her concerns.
: the researcher will also offer written information about the Patient Advocacy Liaison Services (PALS).

This information has been added to the Information Sheet for Mothers. A copy of this document is enclosed and the added section highlighted (Appendix 1 - page 3)

3) **Consent Form for Mothers**
   - **should include a section to enable the mothers to sign giving consent for the GP to be approached**
   - **a separate section should be included for the videotaping**

The study involves audio taping of the interview only thus the consent for audio taping and informing the GP has been added to the consent form. A copy is enclosed and the added section highlighted (Appendix 2).

4) **Why it is necessary to access the medical records and whose records will you be assessing. If this is not necessary then it should be removed from the Consent Form for Mothers.**

The baby's medical notes will be accessed by the researcher after the mother has given consent to participate in order to collect data to validate that this mother is eligible for participation and to provide background information about transfer. The relevant section of the consent form has been modified. A copy is enclosed and the added section highlighted (Appendix 2).

I hope the above explanations and enclosed documents are satisfactory. If there are any outstanding queries please do not hesitate to contact me.

I would appreciate it if you would reconsider my application.

I look forward to hearing from you.

Yours sincerely

Khatijah Abdullah
School of Nursing
University of Southampton
Building 67, Nightingale Building
Highfield
Southampton
SO17 1BJ
e-mail address : kagkl101@soton.ac.uk
Tel no : 023 80598250.

Appendix 16

This appendix looks at an example of the list of composite themes (significant statements) from all interviews with the allocated relational recurrent themes allocated along each side of it.

Composite themes	**Relational recurrent theme**
No one told us..... I don't know what is wrong with her (the baby)	Information related to diagnosis
We were just in shock, terrified.. you just don't know what is going to happen next	Uncertainty
We didn't know what to expect	Uncertainty
I am not sure how the other unit will be like .. I was just getting used to this unit ..	Uncertainty Adaptation issues
It would be nice to at least tell us that they may be transferring the baby... suddenly they just tell us he (baby) needs to go to (name of regional unit)..	Information related to transfer
That was always that uncertainty.. will she be alright	Uncertainty
I don't know whether the baby will be alright after the surgery.... It is all this uncertainty .. I just don't know what the future holds for him (baby)	Uncertainty
For all I know she (baby) may collapse in the ambulance... and I was not even there	Anxiety
It was probably one of the hardest days in my life .. just standing there watching them (staff) rushing my baby to the ambulance ... she (baby) looks so small and pale.	Anxiety

Composite themes	**Relational recurrent theme**
It's nicer in (local unit).. sort of calmer and friendlier .. guess I will have to sort of get use to it ...	Atmosphere Environment Adjustment
It just didn't feel like what we were used to... like the special care was gone ..... here she (baby) is like another sick baby...somehow everyone is so busy here ... needs to get use to seeing so many people in and out ...	Adjustment Atmosphere Relationship
Very costly really ...	Financial
It's not cheap, it is an expensive event	Financial
It has been hard as we still need to get our food and pay the mortgage ....he (partner) has to take time off as I still can't drive (mother has caesarean section)...obviously that affects his wages..	Financial
I miss my other two kids.. felt torn between staying with him (baby) or going home to my other two kids at home	Guilt Lack of closeness
I had to depend on my friends to pick my kids from school and keep them till my husband get off work at six	Burden on friend
It is just not like home .. no choice really as just can't travel to and fro	Adjustment Living in accommodation Distance
He (eldest son) visited me and the baby the other day.. he is so clingy .. he kept on asking when I am going to go home	Impact on sibling
It is tiring .... Having to travel ...	Distance
It cost us a lot on the train all the time ..	Financial

Composite themes	**Relational recurrent theme**
It was very difficult .. I have to leave my other kids at home.	Guilt
I just don't know what was happening.. I had no idea what was wrong .. people kept saying he (baby) will be fine .. but I just don't know what was wrong with him (baby)..	Information about baby's condition Uncertainty
You know, from the time he left (baby) left in the ambulance.. I had no way of knowing how he was doing	Information about transfer
I was so relieved when they took me to straightaway to him (baby) .... I was anxious ..	Anxiety
It has been very hard being on my own here (this mother stays in the hospital accommodation provided since the baby was transferred)	Lack of closeness to family and friends Living in accommodation
We were comfortable in (local unit) .. you become attached to the nurses.. you feel .....different here ... a lot more people to get used to	Adjustment
I think there was almost no coordination and communication between the hospitals	Transfer of information between regional and local units
At no pint was there any sort of communication as to how are you feeling .... It was great telling us how the baby was doing but .. that that is not enough really	Baby focus information
I want to know what this all means.. what I should worry about and what to expect	Empowering information
You just have to prioritise everything ... travelling takes some time and I have to think of ways to spend time too with my other kids .. I just don't want them to feel I have just left them with their fathers	Distance Guilt

Composite themes	Relational recurrent theme
I need to be able to ask questions and discuss what it means	Empowering information
You never know what to expect ...	Uncertainty
Waiting for the ambulance to arrive and not knowing how he (baby) was....was unbearable .. we were so anxious ..	Anxiety Uncertainty
It was hard to go and leave him (baby) here but I have to go home with my two other kids .. I wish I could be with him (baby)	Guilt
it was really bad as we didn't know much ..we just knew he (baby) needs to go to another bigger unit...	Uncertainty Information about baby's condition
Not really told much about the transfer....	Information about transfer
I miss my two kids .. I called them everyday but I miss them	Lack of closeness to family
My mother has to come to stay in my house while I am here	Burden on family
It was like throwing a baby into a cold swimming pool.. All which is familiar and comforting is suddenly gone instead you are in this place that is unknown ..lots more machine and noises	Adjustment Environment
I need to know how things work around here so that I know who to go to about	Empowering information
Rather clinical.. lots more equipment and people going in and out .. so different really fro what we are used to	Environment Adjustment
The staff in (local unit) were mush more friendlier.. they called you by name and asked about your family and .. about you really .. here they are good at giving information about the baby but that sis it . it stops there . need to get used to really	Adjustment Atmosphere Information focused on baby

Participants' details

Name of mother	Age	Occupation	Marital status	Baby gestation/mode of delivery	diagnosis	Date of transfer	Date of interview	comments	Baby age
M1	35	Learning skills worker	S	Term/LSCS	D.hernia	6/4/04	12/4/04 (day 6)	G4P2 Son=7 years	Day 1
M2	37	Housewife	M	28+4/40	NEC	15/4/04	21/4/04 (day 6)	IVF Two miscarriage	Day 19
M3	30	H/W	M	25/SVD	NEC	16/4/04	26/4/04 (day 10)	G3P3 5 years 14 months	Day 30
M4	24	Nursery nurse	M	T/SVD	Hirshsprung	1/5/04	6/5/04 (day 5)	G1P1	Day 28
M5	35	H/W	M	26/SVD	NEC	5/5/04	14/5/04 (day 9)	G2P2 7 years son	Day 41
M6	30	Office cleaner	M	T/SVD	Spina bifida	2/6/04	9/6/04 (day 10)	G3P3 5years old son 3 years daughter	Day 2
M7	23	Carer	P	24/40 LSCS	PDA	9/6/04	18/6/04 (day 9)	GiP1	Day 33

Name of mother	Age	Occupation	Marital status	Baby gestation/mode of delivery	Diagnosis	Date of transfer	Date of interview	Comments	Baby age
M8	31	H/W	M	30+6/40 SVD	NEC	10/6/04	17/6/04 (day 7)	G7P3 1996 2003	Day 21
M9	27	Shop assistant	S	26+1/40 LSCS	NEC	14/6/04	21/6/04 (day 7)	G1P1	Day 9
M10	30	Shop assistant	P	24+5/40 SVD	Prematurity	28/6/04	4/7/04 (day 6)	G3P3 Girl 6 years Girl 3 years	Day 10
M11	32	House wife	M	29+5/40 SVD	Sepsis	30/6/04	6/7/04 (day 7)	G2P2 Boy 5 years	Day 22
M12	18	Not working	P	30/SVD	NEC	22/8/04	28/8/04 (day 6)	G1P1	Day 15
M13	31	Shop assistant	M	29/SVD	NEC	24/8/04	31/8/04 (day 7)	GIP1	Day 21
M14	28	Housewife	M	T/SVD	PPHN	6/9/04	10/9/04 (day 6)	G2P2 Boy 2 years	Day 1
M15	25	Clerk	M	33/40 LSCS	Prematurity	20/9/04	25/9/04 (day 5)	G1P1	Day 4

Further details

Baby age in weeks when he/she is transferred	Number
Day 1	2
Day 2 to Day 7	2
Day 8 to day 13	2
2nd weeks onwards	8

Nearly half the babies (eight) have been in their local unit prior to being transferred.

Mothers' further details	Numbers
SVD	11
LSCS	4
Siblings	8
Stay in	8

Date interview after transfer	Numbers
Day 5	2
Day 6	5
Day 7	4
Day 8	0
Day 9	2
Day 10	2

Majority were interviewed (11 mothers out of 15 mothers) within the first week of transfer.

Distance between places of transfer to regional neonatal unit in miles

Place	Distance (www.multimap.com)	Number	Name
Winchester	19.7 miles	2	Zara Caitlin
IOW	* 21.4 miles (£15 a day by ferry)	3	Lucy Meredith Lawrent
Portsmouth	30.7 miles	3	Jamie Emery Molly
Poole	42.7 miles	2	Daniel Tinsley
Dorset (Weymouth)	62 miles	2	Elaine Luke
Bath	65 miles	1	Nico
Devon (PL20 6BD)	156 miles	1	Luke
Guernsey	172 miles	1	Reis

Details of number of transfers, number recruited, number not recruited and number of refusals

Month/ recruited	T/I	T/B	4 days or less readmission via PICU died	Refused
April /3	6	1	2 (1 readmission , 1 less than 4 days)	-
May / 2	3	1	1 (less than 4 days)	1
June / 6	12	0	6 (3 less than 4 days, 1 via PICU)	
July/ 0	4	0	4 (3 died, 1 less than 4 days)	
August/2	4	0	2 (1 died, 1 Transfer out to GOS)	
Sept/2	10	2	6 (1 died, 3 social problems, 2 via PICU)	2
Oct/0	2	2	2 (2 via PICU)	
15 (RECRUITED)	42	6	23 (NOT RECRUITED)	3 (NOT RECRUITED)

REFUSED

Mother has an elder sibling who has cancer (remission). Present baby came for distended abdomen .Term baby (Winchester) – Mum decision

Mother has lots of social problems. Preterm baby (Salisbury).- Nurse & Researcher decision

Mother said has too much on her plate at the moment – three kids at home and this one will need long term tracheotomy. (Bath).- Mum decision.

Composite themes that were discarded

Significant statements were identified from each interview. Meanings were then formulated from these significant statements. The significant statements are allocated as composite theme using a process known as horizonalization (Moustakas (1994 p93-96). All the composite themes were examined by weighing the appropriateness of each theme by asking:

What does this then reveal about the experience (transfer) being described? (pg 93)

Is this what the experience (transfer) is really like? (pg 95)

This process was continuously informed by my personal reflection, also from reading the literature predominately about motherhood and from engaging in discussion with similarly experienced colleagues in neonatal care. Composite themes are then re-examined and eliminated if found to be not related to the experience studied (Moustakas 1994 p120).

Composite themes from	significant statements eliminated	
Being unwell	Sights and sounds	Disappointment
Changes	Infant's behavior	Communication needs
Emotional distress	Communication style	Own health
Coping strategies	Stress from having a premature baby	Not feeling like a parent (due to premature labour)
Fear of handicap	Premature labour	Unexpected labour
Low self esteem	Being unwell	Infant treatments
Feeling cheated	Not believing	Prenatal experiences
Baby's appearance	Lack of choice	Heath care providers
Sense of inadequacy	Beliefs	Relationship with infant
Illness	Family history	Making the best of it (of having a premature baby)
Information on reasons why babies are born premature	Risk factors	Duration of stay
Information on risks with subsequent pregnancies	Sharing	Lack of confidence
Developmental concerns	Undergoing tests	False protection
Feeding support	Attitude	Protocols
Disappointment	Dependence	Comparisons with previous experiences
Loss of ceremonies associated with full term pregnancy	Opportunities to talk to staff	Sense of surveillance by staff
Equipment issues	Adapting to having a sick infant	Reactions to birth
Baby's social responsiveness	Emotional preparation	Understanding difference
Grief preparation	Pregnancy issues	Stress issues
Adaptation to premature labour	Premature special needs	Perceived failure to deliver a term infant
Perinatal issues	Admissions issues to neonatal care	Experience of care in perinatal period