

Lived realities of NICU-to-home transition in Malta:

The experiences of parents of preterm infants,

and of neonatal staff

by

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of Doctor of Philosophy at the University of Central Lancashire

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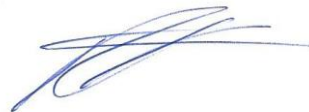
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ABSTRACT

Preterm birth and the premature infant have been predominately studied from clinical perspectives. The experiences of parenting a preterm child and the experiences of staff directly involved in the care of preterm infants have been studied much less. Additionally, less is known about the meaning of experiences around the preterm infant's discharge from the neonatal unit and life at home thereafter. This study addresses these gaps identified in research and aims to generate a deeper understanding of the meanings, and lived experiences of NICU-to-home transition from multiple perspectives: mothers and fathers, and neonatal staff.

This is a Heideggerian hermeneutic phenomenological study of the experiences of Maltese parents of preterm infants and, of neonatal staff of NICU-to-home transition. Using purposive sampling, open interviews were conducted with 9 mother-father dyads of preterm infants and 12 neonatal staff that included midwives, nurses and doctors working on the only neonatal unit in Malta. A modified vignette technique based on the parents' interviews was used to stimulate reflective talk with the staff. A longitudinal design was adopted for data collection from the parents: at 1 month, 3 months and 6 months after discharge of their baby from the unit. The research process including analysis of the data was guided by van Manen (1990).

The parents' experiences of NICU-to-home transition are represented through four main themes: 'Shadowed by fading clouds of uncertainty', 'Reaching out', 'Watching vigilantly' and 'Living the new family'. In addition, three main themes emerged from the staff data: 'Acknowledging good practice', 'Realising limits' and 'Awakening to needed improvements in care'. Findings indicate that, in the longer term in the home setting, parents translated their parenting approaches through the norms of neonatal unit routines and practices. Staff findings revealed that care focuses primarily on producing technically prepared parents in infant care which arises out of their sense of responsibility towards the babies' wellbeing that extends to after being discharged from the neonatal unit.

A further in-depth interpretation and synthesis of the findings was undertaken drawing on the philosophy of Heidegger (1962). This revealed 'oscillating realities' between parents' and staff experiences, particularly in the degree to which they endeavoured to solicitude which 'leaped in' or 'leaped ahead', and the extent to which technocratic ways of Being permeated their relationships to each other and to the babies. Implications of the findings and suggestions for further research are presented.

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To
My dear husband Luciano
and
our darling daughter Julia Marie

CHAPTER 1:

INTRODUCTION

1.1 Background to the study

The birth of a healthy newborn is usually a celebrated event, with parents expressing joy at their accomplishment and envisioning future plans with great expectations for their child (Ruchala, 1999). However, parents of preterm infants face a different, often stressful and traumatic reality. Preterm birth changes their anticipated idealisation of having a healthy term baby into feelings of grief and fear as they are faced with whether the infant will survive and if so, what the long term consequences might be (Bakewell-Sachs & Gennaro, 2004; Rabelo, Chaves, Cardoso, & Sherlock, 2007). Additionally, parents of preterm infants often experience separation from their baby from the time of birth as preterms are quickly whisked away to NICU (neonatal intensive care unit) for immediate intensive care. This forced separation severely jeopardises the parents' ability to commence their parenting role in the typical way experienced by parents of healthy term infants at birth, threatening parent-infant bonding processes (Berns, Boyle, Popper & Gooding, 2007; Broedsgaard & Wagner, 2005; Griffin & Abraham, 2006). Subsequently, these parents often experience long hospital stays of their infants on NICU where the high-tech environment and events occurring on the unit present parents with atypical parenting roles.

Preterm birth, i.e., birth occurring prior to 37 weeks gestation, is a serious health care challenge in many countries around the world. Preterm infants are at a greater risk of mortality and morbidity particularly for those born at the lowest gestations and/or with extremely low birth weight (less than 1,000grams) (Larsen, 1993). Advances in perinatal and neonatal care have led to improved survival rates of preterm infants (Bissell & Long, 2003). However, this means that more preterms and their families endure long periods of hospitalisation before they can be discharged home (Holditch-Davis, 2007; Sheikh, O'Brien, & McCluskey-Fawcett, 1993). Although the financial healthcare costs associated with prematurity are significant, parents, families and prematurely born children can also experience short and long-term psychosocial consequences.

Studies have shown that parents often have mixed emotions when the day comes for the discharge of their preterm infant from the NICU. They are often relieved and excited but also afraid and anxious as they take full responsibility for their infant's care at home (Jackson, Ternestedt, & Schollin, 2003; Mancini & White, 2001; Smith & Daughtrey, 2000; Sneath, 2009). Some studies indicated that feelings of fear and anxiety often prevail over the first few weeks at home and have been associated with the parents' perceived difficulties with taking on their parental role for their preterm infant (Jackson et al, 2003; Mancini & White, 2001; Smith & Daughtrey, 2000).

NICU discharge preparation is recognized as a long-term process and not as an isolated event in the care of preterm infants and their families (Mancini & White, 2001; Smith & Daughtrey, 2000; Sneath, 2009). Preparation for NICU discharge should aim to offer parents appropriate support, education and guidance to maximise parental competence and confidence and so ensure a smooth transition to life at home with their baby (Bissell & Long, 2003).

1.1.1 Family-centered care in neonatal units

Family-centered care (FCC) originated in paediatric care in North America during the 1960s (Shelton, 1987). Consequently, over the next decades, FCC became increasingly recognised as an optimal approach to care in various health settings, including neonatal care (Fegran, Helseth & Slettebo, 2006; Redhaw & Hamilton, 2010; Shields, Pratt & Hunter, 2006). FCC developed from attachment theories which emphasise and value the importance of early and continuous contact between parents and their infants for bonding and the development of positive attachment relationships (Thomson, Moran, Axelin, Dykes & Flacking, 2013). FCC is conceptualised as a philosophy. A set of guiding principles for FCC in the NICU was published in 1993 (Harrison, 1993). Preterm and sick newborns are usually admitted directly to the NICU before they have had time to be integrated into the structure of the family. This is a different scenario than that generally experienced in paediatric settings (Petersen, Cohen & Parsons, 2004). Harrison's (1993) principles are specific to the neonatal unit context and revolve around the formation of trustful and collaborative parent-staff relationships in a supportive, family-friendly environment. More recently, the POPPY model of FCC has been developed to deliver high quality care to parents of preterm infants, and to meet

parents' needs for information, communication and support, which emerged as key elements of FCC (Staniszewska et al, 2012).

FCC has been criticised for its lack of a consistent and concrete definition (Finlayson, Dixon, Smith, Dykes & Flacking, 2014; Malusky, 2005; Thomson et al, 2013). However, two commonly and relatively recent cited definitions of FCC include the one put forward by Shields et al (2006), who define FCC as “a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognised as care recipients” (p. 1318). Additionally, the Institute of Family-Centered Care (2010) describes FCC as “an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients and families”. Within a neonatal context, collectively these definitions recognise that hospitalisation of the infant affects the whole family unit (Thomson et al, 2013) and, in turn, parents also need to be cared for along with the infant. These definitions also recognise that FCC places parents at the heart of their infant's management of care, and it makes collaboration, and the development of a respectful partnership between professionals and the infant's parents, fundamental to FCC provision (Gooding et al, 2011; McGarth, Samra & Kenner, 2011; Saunders, Abraham, Crosby, Thomas & Edwards, 2003). Communication and information sharing are also key to the effective implementation of FCC (Fenwick, Barclay & Schmied, 2001).

The birth of a preterm or sick infant creates atypical life situations where parenting develops in unfamiliar settings dominated by medical and technological practices (Flacking, Edwald, Nyqvist & Starrin, 2006). FCC in neonatal care provides a unique opportunity to assist parents and families in initiating and developing ‘normal’ parent and family roles (Redshaw & Hamilton, 2010). Family support activities and programmes are intended to help parents to cope with the stress of having an infant in intensive care and support them to join in the care of their infant (Cooper et al, 2007; Gooding et al, 2011).

There is evidence of factors crucial to successful FCC, such as parent-infant contact, parent inclusion in hands-on-care, and a welcoming, supportive, family-friendly environment (Redshaw & Hamilton, 2010). Research findings have revealed positive outcomes of FCC including; enhanced parent-infant interaction and bonding

(Staniszewska et al, 2012; Melnyk et al, 2006), reduced hospital stays for preterm infants and decreased readmissions, (Brett, Staniszewska, Newburn, Jones & Taylor, 2011; Forsythe, 1998; Melnyk et al, 2006), enhanced breastfeeding outcomes, reduced parental stress (Staniszewska et al, 2012), increased staff satisfaction (Dunn, , Reilly, Johnston, Hoopes & Abraham, 2006; Malusky, 2005), improved wellbeing of preterm infants (Cleary, Spinner, Gibson & Greenspan, 1997; Van Riper, 2001), better allocation of resources and greater satisfaction with the care received (Eichner & Johnson, 2003; Moore, Adler & Robertson, 2000; Van Riper, 2001). Additionally, FCC has been shown to ease the transition from hospital to home as parents have reported increased feelings of competence and confidence after discharge being linked with their participation in their infant's care when on NICU (Cooper et al, 2007; Griffin, 2006).

The importance and value of FCC has been well recognised, accepted and reported in the literature (McGarth et al, 2011). However, published studies also highlight difficulties in implementing FCC principles into daily practices and considerable inconsistencies in the practice of FCC across different units have been identified (Corlett & Twycross, 2006; Gooding et al, 2011; Redshaw & Hamilton, 2010; Trajkovski, Schmied, Vickers & Jackson, 2012). FCC has been identified as a complex concept, which has only reached partial maturity in its development (Staniszewska et al, 2012). It is argued that FCC must be integrated into the culture and functioning of an NICU where strategies to improve the practice of FCC include facilities and practices that support parents all the way through their experience in the NICU and after discharge (Saunders et al, 2003; Staniszewska et al, 2012).

1.2 Impetus for the study

The impetus for this study evolved from two main perspectives. Primarily, this study originated from my professional interest in the phenomenon of preterm birth and the associated experiences relating to prematurity. My previous experience as a midwife practicing on the neonatal intensive care unit in Malta had often made me question what the parents of preterm infants experience once their preterm infant is discharged home following what is often a long hospital stay. Neonatal staff working on the unit, including myself, usually had no further contact with these parents following NICU discharge, and so was unaware of these parents' experiences when they go home with their baby. Additionally, I often found myself reflecting on NICU care practices towards

supporting parents while on unit and how these would reflect on their experiences in coping with and adjusting to the preterm birth, and subsequently when the baby goes home. I have always believed that neonatal staff had an important role in supporting parents' transition to home from the neonatal unit but yet the resultant impact on the parents' experiences remains unknown to the neonatal staff. Although through the years, I moved into midwifery academia, my interest in the phenomenon did not cease particularly since I have been responsible for teaching intensive neonatal care to midwifery students.

My second interest to studying this phenomenon emerged as I started searching and retrieving literature about experiences related to NICU-to-home transition with preterm infants. It became increasingly clear that this area of study required further research. Various gaps in the literature became evident and needed to be addressed. Research focusing on the intense emotions and the experiences of parents, mothers in particular, of preterm infants in the neonatal intensive care unit is well represented in the literature and has helped inform our understanding of the shock, grief, fear and anxiety they feel in the NICU environment. However, research which covers the transitional period extending from NICU discharge and continuing through the early months at home, has received little attention. Where research is available, this has often focused on mothers while fathers have only been sparingly studied. Additionally, previous studies have often addressed specific aspects pertaining to the preparation of parents for NICU discharge focusing primarily on teaching parents physical baby caregiving activities. There is a lack in our understanding of what the parents' experiential day-to-day realities are after they leave the unit with their preterm infant.

Moreover, the home transition of preterm infants has been rarely studied from the perspectives of neonatal staff and research exploring their experiences, is largely lacking. Collectively the identified research gaps have driven me to address the main deficiencies in our understanding of transition from the neonatal unit to the home, from the lived realities of both parents as a couple and of neonatal staff who work closely with preterm infants and their parents on the neonatal unit. This in-depth exploration is considered important to understand the meanings of home transition from NICU for both parents and neonatal staff and how these meanings are created and mediated in the interplay between parents and professionals.

1.3 Research question, aim and objectives of the study

In the light of the background literature and the impetus for the study discussed above, the guiding research question asked is, ‘What are the lived experiences of parents of preterm infants and of neonatal staff pertaining to NICU-to-home transition?’ Consequently in adopting an interpretive phenomenological approach, the following aim and objectives were devised.

Aim:

- To explore the experiences of parents of preterm infants and of neonatal staff pertaining to the transition from the neonatal unit to the home in Malta by looking at transition in the context of the wider parental journey.

Objectives:

- To explore Maltese parents’ (mother-father dyads) lived experiences of having their preterm infants in the neonatal unit and their transition to home during the first six months following discharge
- To explore the lived perspectives of neonatal staff about the transition of preterm infants from the NICU-to-home in Malta.

1.4 Originality of the study

Literature has indicated that transition experiences from the neonatal unit to the home from the perspectives of both parents of preterm infants and from neonatal staff, are under-researched and warrant in-depth exploration. This study addresses key research gaps by adopting original methodological considerations to study this phenomenon. Thus, participants in this study are not restricted to one particular group, instead both parents as a couple are included, together with different neonatal staff. The latter include midwives, nurses and doctors working on the neonatal unit so that their lived perspectives can be elicited together with how these perspectives influence their dealings with parents experiencing preterm birth.

Moreover, the longitudinal design adopted to collect data from parents in the early months following discharge home of the preterm from the neonatal unit adds to the

uniqueness of the study. Extending the collection of parents' experiences up to six months post discharge aids better understanding of the evolvement of their transition experiences over time. Such an approach is lacking in the literature and there is a need to uncover both the commonalities and individualities of parents' NICU discharge and transition to home experiences during the months following discharge, since currently there seems to be little information about this specific time period.

1.5 Significance of the study

The phenomenological approach adopted in the study seeks to uncover the meaning of the study phenomenon as experienced by the two participants' groups. Exploring the lived realities of both parents and neonatal staff could also illuminate the potential for misunderstandings and miscommunications that might give rise to gaps in the lived experiences and world view of these two groups. This could be vital in identifying potentially better practices towards enabling effective NICU-to-home transition for preterm infants and their parents. These findings can serve to inform healthcare providers of the needs of parents and infants once NICU discharge has occurred, and can serve as an evidence base from which to design discharge management.

Additionally, it is important to explore neonatal discharge practices from both health professionals' and parents' perspectives, to determine the similarities and differences between the lived perspectives of these two groups, in how effective they perceive the current practices to be. This insight can be vital in identifying potentially better practices for managing care of the preterm infant as findings can shed new light on this important area of neonatal health care and of parenting on the neonatal unit and beyond.

The findings from this study are directly relevant to the local Maltese context of neonatal care but could potentially also benefit the practice of intensive neonatal care in other countries particularly where a similar context and characteristics are shared with that described in this study. Health care professionals who work closely with preterm infants and their families could benefit from the information which emerges from this study in the necessary education, practice, and policy development in supporting the parents and families of preterm infants.

1.6 The Maltese context

This study has been undertaken on the Maltese Islands which are found in the middle of the Mediterranean Sea. The largest two inhabited islands are Malta and Gozo which spread over an area of 316 km² with a population of 421,364 inhabitants (National Statistics Office [NSO], 2015) making the country the most densely populated one in the European Union (EU) with 1,339 person/km² (Eurostat, 2015). The Maltese culture is significantly influenced by its long colonial history under British rule (Zammit, 2009). Malta is a bilingual country with Maltese and English as the official languages. The predominant religion is Roman Catholicism where most Maltese citizens consider themselves as Roman Catholics (Vallejo & Dooly, 2008). Religion is considered to be intertwined with the culture of the Maltese Islands (Abela, 1994). Characterised by their small size, the Maltese Islands have face-to-face community features where everyone tends to know each other (Abela, Frosh, & Dowling, 2005).

The traditional heterosexual parent-dyad families united through marriage predominate on the Maltese Islands. Compared to earlier decades, the Maltese family nowadays consists of the small nuclear family sizes typically having two children (Savona-Ventura, 2009). The family is highly valued and considered as an important building block of the Maltese society (Abela, 2009) making Malta one of the most family-oriented countries in Europe (McGregor, 2008). Within the Maltese family, children are cherished and prioritised (Abela et al, 2005) and this is supported by Maltese governments who regularly seek to enhance national family-friendly measures.

Maltese female public employees are entitled to 18 weeks of maternity leave which may be availed of from the last few weeks of pregnancy and extended beyond confinement. An employee on maternity leave is entitled to the first 14 weeks of maternity leave on full pay while the equivalent of the national minimum wage is received for the remaining four weeks. Male public employees are entitled to two working days paternity paid leave on the birth of each of their children. Maltese public employees are entitled to unpaid parental leave to look after their young children who are under eight years of age. Such parental leave allows employees to avail themselves of a maximum of one year unpaid leave of absence for each child. The chosen duration of parental leave may be shared by both parents. To facilitate a better work-life balance, public employees may opt to work on a reduced time-table which may vary between 20 to 35

hours per week. Reduced working hours are allowed until the child reaches the age of 12 years. These indicated family-friendly measures are the latest issued by the Public Administration HR Office, PAHRO (2015).

1.7 Neonatal intensive care in Malta

The total births reported in the Maltese Islands have been an average of 4,000 births per year since 2000. During 2012, 331 babies were born premature (at less than 37 weeks gestation) while in 2013, 282 babies were preterms. The premature birth rate amounted to 7.8% and 6.8% of total births in 2012 and 2013 respectively, while in the first six months of 2014, 155 babies were born preterm (National Obstetrics Information System [NOIS], 2014). According to the latest Euro-Peristat report (2010), the rate of preterm birth in Malta in 2010 (7.2% of all live births) was similar to the average preterm birth in other European countries for the same year. Additionally, when compared to other European countries, in 2010 Malta had the third highest neonatal mortality rate (5.5 per 1000 live births) after 22 weeks gestation (Euro-Peristat, 2010). However, in Malta termination of pregnancy is not legal and this may contribute to a higher mortality rate since deaths attributed to lethal congenital anomalies are accounted for (Euro-Peristat, 2010).

Across the Maltese Islands there is one neonatal intensive care unit which is situated in the main publically-funded hospital in Malta. This NICU (neonatal intensive care unit) makes part of a combined complex of intensive care for neonates and paediatric patients up till the age of three years. This intensive care unit is situated next door to delivery suite, which makes easy and quick transfer of babies who are born sick and preterm infants. Preterm infants requiring intensive care are admitted to the NICU part of the unit complex which comprises of a three-bedded critical care room and an open layout ward where another 11 neonates can be cared for. An average of 300 preterm infants are admitted annually to the local NICU. The average length of stay for preterm infants admitted to the local NICU and subsequently discharged home is 26 days (Hospital Activity Analysis [HAA], 2015). The health professional team on the unit comprises of consultant neonatologists/paediatricians, specialist paediatric registrars and trainees, midwives and nurses. The unit is managed by a midwifery officer, two deputy nursing officers and a consultant neonatologist. The care on the unit is consultant-led and is

predominantly a biomedical approach, although a more recent move towards embracing family-centered care philosophy is becoming evident. There are 37 nurses and 21 midwives working on this unit, 43 nurses/midwives work full-time, that is 40 hours per week, while 15 nurses/midwives work on reduced hours, varying between 30 to 35 hours per week. A compliment of 12 nurses/midwives work on day shifts (7am till 7.30pm) and night shifts (7pm till 7.30am). Nine nurses/midwives have received specialised training in intensive neonatal care while the rest of the nursing/midwifery staff are predominately qualified in general nursing or midwifery at a degree level. A few of the staff have a masters degree in nursing or midwifery.

Parents' visiting on the neonatal unit is said to be open, however there are restrictions and parents cannot be on the unit during shift handovers, during ward rounds, when new babies are admitted to the unit, in emergency situations or when particular procedures are being done on the unit. Visiting is usually restricted to the baby's parents only, other relatives, friends or siblings are not allowed on the unit. More liberal visiting is allowed in situations when a baby is approaching end of life.

Parents are provided with comfortable armchairs next to their baby's cot or incubator when on the unit. Each baby has a cabinet where parents can put the baby's belongings. Mothers who are expressing breastmilk, can do so when they are next to their baby or in another room allocated for milk expression on the unit but away from their baby. A kitchenette and a sitting room, for parents to utilise while on the unit, are not available. Parents make use of coffee and snacks vending machines available just outside the neonatal unit door. Some parents also make use of the hospital cafeteria which is some metres away from the unit. Transitional care occurs at the end of the baby's hospital stay where parents may room-in with their baby for one or two days and nights. Two rooms are available for such parent-infant rooming-in on the neonatal unit itself and include a double-bed, the baby's cot, cabinet for personal belongings and ensuite facilities. Other facilities, such as; television, telephone, internet access, kitchenette facilities where parents can prepare their own food and drinks, are not available. So when rooming-in, parents need to get such equipment from home, bring their own ready-made meals or purchase their own food and drinks from the hospital cafeteria.

Following the preterm infant's discharge from the unit, follow-up care is scheduled at out-patients' services within the same hospital according to the medical needs of the child. Referral to specialist medical services is also offered as necessary. These public

services are typically provided in the morning and early afternoon, either as out-patient hospital services or at the different health centres across the Maltese Islands. Parents of preterm infants may opt to self-finance follow-up care for their child by making use of private services which are usually available throughout the day.

1.8 Researcher's pre-understandings at the beginning of the study

At the start of my journey into this study, I had pre-understandings which were primarily informed by my previous experience of being a practising midwife on the same neonatal unit from where data for this study was eventually collected. One main pre-understanding I had was that practice on this unit was not guided by a family-centered care policy. However, I believed that staff, especially midwives and nurses, were generally aware of various principles associated with FCC and that many often out of their own initiative tried to adopt such care characteristics when caring for preterm infants and their parents on the unit. Additionally, I could observe that on this unit, through the last 15 years of neonatal practice, I held a pre-understanding that improvements have been made in more recent years where I believed that more staff and the management of care on the unit increasingly embraced and adopted changes in practice towards a more family-centered care approach. Two ways in which this has occurred include: the increased involvement of both parents in the care of the preterm infant and a more open visiting policy allowed parents to be with their babies for longer duration during both day and night, then had been experienced by parents in earlier years.

Another pre-understanding I held at the onset of the study, was that on the local unit the predominant focus of neonatal practice was on the clinical care of the infant. I believed that this reflected the consultant-led practice where the medical aspects of care set the ethos on the unit. Consequently, I felt that psychosocial and emotional care, known to be fundamental to FCC, received much less attention and despite improvements in more recent years, I believed that this was still not satisfactory. My pre-understanding regarding parents' discharge from the unit was that this was reflected by a similar focus on the physical aspects of the infants' care.

At NICU discharge, I believed that parents generally showed a sense of eagerness to take their baby home and that staff interpreted such parents' attitude as indicating their

readiness to care for their baby at home. I felt that such an interpretation masks parents' mixed emotions and unanswered questions, which are not readily voiced by parents and so not identified and addressed by the staff. Following discharge home, generally such infants do not require re-admission to unit and this leads to an understanding that parents were coping well with the care of their baby at home, which may not necessarily be true, particularly when staff generally have no further contact with such families and so the parents' day-to-day experiences in terms of how they cope and adjust to parenting their prematurely born baby at home were not really known.

1.9 Organisation of the thesis

This thesis is divided in ten chapters. This introductory chapter presents the background context to the study, the impetus to the study and its purpose. The second chapter examines the published studies which address the transition from the neonatal unit to home for preterm infants from parents and/or staff perspectives. Chapter three outlines the philosophical underpinnings of the study which is followed by a detailed description of my research journey in chapter four. Chapter five presents the demographic characteristics of the participants in the study. The findings of the study are thematically presented in the next two chapters, chapter six presents the parents' findings while chapter seven presents the findings from the staff. In Chapter eight, main findings from the two participant groups are discussed through a philosophical interpretive lens. Chapter nine discusses the findings in relation to the wider literature, together with methodological strengths and limitations. Chapter ten concludes this thesis by drawing primarily on implications for practice, which emerge from the findings. The study's contributions to knowledge are highlighted and suggestions for further research complete this work.

CHAPTER 2:

LITERATURE REVIEW

2.1 Introduction

This chapter reviews the literature through a meta-narrative systematic review. Smythe and Spence (2012) argue that exploring literature in hermeneutic research should aim to provide context and provoke thinking such that new insights emerge. Reviewing the literature through a hermeneutic lens creates new understanding by adopting the notion of dialogue where questions are asked of the literature such that the focus of the answers sought is on identifying meanings which may be concealed or hidden (Smythe & Spence, 2012). However, within Heideggerian phenomenology, historicity is an important notion, and the experiences and accounts of parents and staff are inevitably influenced by the prevailing normative dialogues in society, when they encounter/provide neonatal care. To get some sense of this background, against which the stories of staff and parents are likely to be set, the main purpose of this review was to identify the chronological storyline of research on transition from neonatal unit to home, based on the perspectives of parents and staff. Hence, reviewing the literature through a meta-narrative provided a way of uncovering the narrative emphasis in neonatal care and in transition to home and also in identifying the emergent storyline over time in the literature. These were of particular interest at the outset of the study and consequently as it progressed. Therefore, a meta-narrative approach was deemed most appropriate to answer the review question posed (see section 2.2).

A meta-narrative review looks historically at how particular research traditions have unfolded over time and how the kind of questions being asked have been shaped and the methods used to answer them (Wong, Greenhalgh, Westhorp, Buckingham & Pawson, 2013). This review applies this broad meta-narrative intent to a combination of qualitative and quantitative evidence about the topic of interest. It highlights the strengths and limitations of different research approaches to answering the review question. Summarizing, combining and comparing findings into over-arching narratives helps to illuminate what can be learnt from the different approaches used by different researchers (Wong et al, 2013). Where applicable, the review follows the publication

standard which has been developed as part of the RAMESES (Realist And Meta-narrative Evidence Syntheses: Evolving Standards) project by Wong et al (2013).

The six guiding principles: pragmatism, pluralism, historicity, contestation, reflexivity and peer review, on which meta-narrative reviews are based have been followed in this review. In terms of pragmatism, the inclusion decisions were guided by the need to develop a comprehensive storyline to answer the review question. Pluralism was addressed as literature from different research traditions which collectively explore the study area from multiple perspectives of mothers, fathers and /or different neonatal staff were included. Contestation and historicity were tackled by comparing and contrasting findings from different research traditions which helped to generate new insights depending on how different researchers framed the focus of their study and how different traditions unfolded over time. In terms of reflectivity, the emerging findings of this review were continually reflected upon and discussed with my supervisory team. The principle of peer review was addressed by presenting the emerging findings to an external audience with differing academic and clinical expertise and their feedback was used to guide further reflection on the analysis and presentation of the findings, and on the review process adopted overall.

2.2 Scoping the literature

An initial literature search was done by using keywords relevant to the topic area based on prior knowledge and by using ‘Google’ and ‘Google Scholar’ search engines to get a general feel of the literature around the topic area. This helped to acquire a broad idea of what kind of studies have been done around the issue in question, giving a good indication of the predominant perspectives studied and the research approaches adopted in studies exploring the phenomenon. Subsequently, the review question for the ultimate search strategy was developed iteratively through this scoping step, and in discussion with my supervisors. The final version was: *‘What are the perspectives of neonatal staff and parents about the transition of preterm infants from NICU to home, and how have these been characterised in the literature over time?’*

2.3 Searching process

Following an initial process of exploratory scoping of the literature, potentially relevant databases to conduct the subsequent searching process were identified. New databases were added iteratively as the review progressed (Appendix A). As different papers were retrieved, the literature searching became more focused on a more specific aspect of the phenomenon that included studies could inform. Subsequent searching thus became more refined, and inclusion and exclusion criteria were drawn up so that the included studies were those which focused on the study phenomenon, where discharge from the neonatal unit and/or transition in the first few months at home were studied. The next step was to extract the keywords making up the review question which were then utilised to search the literature (Table 1).

Table 1. Keywords in the review question

Perspectives – or other synonyms, as in ‘views’ or ‘perceptions’
Neonatal staff – doctors, nurses or midwives
Parents – mothers and/or fathers
Transition – a period of change relating to discharge from NICU to home
Preterms – babies born prior to the 37th completed week of pregnancy
NICU – neonatal intensive care unit

Synonyms and alternatives for these keywords were also identified. Inclusion and exclusion criteria were set after reflection on the relevance of papers identified in the scoping process to the overall area of inquiry of the review, in collaboration with my supervisors (Table 2). The search was limited to published full-text studies from 1990 till end of May 2015. This time-frame was selected because the earliest papers identified in the initial literature search were published in the 1990s. Only published empirical studies were included since these were considered to be the sources of research findings most accessible to practitioners and researchers in neonatal care and so were more likely to inform practice, and to reflect the philosophical beliefs of the profession over time.

Table 2. Inclusion and exclusion criteria set for review

Inclusion criteria	Exclusion criteria
Studies focusing around NICU discharge practices and / or transition to home of the preterm infant.	Studies with a restricted focus on particular aspects relating to preterm birth (e.g. psychological stress).
Studies where data was collected on approaching discharge towards the end of the NICU hospitalisation and / or in the first six months after discharge.	Studies published prior to January 1990.
Studies where the infants were discharged home without the requirement of any special care (e.g. tube feeding, oxygen therapy).	Studies which focused only on the NICU hospitalisation period.
Studies where the parents are the primary caregivers at home.	Studies focusing on specialised discharge procedures or intervention e.g. earlier NICU discharge.
Studies where NICU discharge was according to standard procedures.	
Studies done in any country, published in any language, using any research design and published from 1990 till end of May 2015.	
Published and accessible full-text studies.	

Two separate literature searches were done, one for the parents and another for neonatal staff. For each search, keywords were attributed to four main domains: population, topic, orientation and context. Boolean searches combined keywords being searched for each of the four main domains (Table 3). These terms were searched in the keywords, titles and abstracts in the literature. The included studies followed the inclusion and exclusion criteria set to answer the review question (Table 2). When searching the literature, no restrictions of language, research design or to the country where studies have been conducted were applied as it was thought that applying these restrictions would limit the review by potentially missing out on relevant studies and so a comprehensive account of the knowledge base available on the topic area would not be achieved.

Table 3. Literature search for neonatal staff

Population	<i>AND</i>	Topic	<i>AND</i>	Orientation	<i>AND</i>	Context
Staff		Discharge planning		Perceptions		Preterm
<i>OR</i>		<i>OR</i>		<i>OR</i>		<i>OR</i>
Nurses		Discharge practice		Views		Premature
<i>OR</i>		<i>OR</i>		<i>OR</i>		<i>OR</i>
Midwives		Transition		Perspectives		NICU
<i>OR</i>		<i>OR</i>		<i>OR</i>		<i>OR</i>
Doctors		Discharge management		Experiences		Neonatal unit

2.4 Selection of studies and appraisal of documents

The title and/or abstracts of studies retrieved using the search strategy were screened to determine which studies potentially met the inclusion criteria for the review. The full-text of these studies were subsequently obtained and assessed for eligibility by myself and one of my supervisors. Disagreement over the eligibility of any of the studies was resolved through discussion with another supervisor.

Appraising the quality of studies for inclusion in reviews is controversial (Popay, Rogers & Williams, 1998). Excluding studies on the basis of quality is debatable since valuable data may be lost if studies are excluded (Sandelowski & Barroso, 2003). Given that this review sought to capture changes over time, and to reflect the different perspectives held by mothers and /or fathers and neonatal staff about the transition of preterms from the NICU to home, and knowing that fathers and neonatal staff are particularly under-represented in such research, it was decided that excluding studies on the basis of quality could have potentially resulted in the perspectives of such participants to remain unheard in the review. Nonetheless, quality appraisal was still done for every study. This helped to increase familiarity with the papers and make limitations, identified in the reporting of the studies explicit, as these could have an impact on the results of the review.

The quality of qualitative studies was assessed using the tool developed by Walsh and Downe (2006) (Appendix B). Since all the included quantitative studies were survey research, a quality appraisal tool specific for this kind of research was sought, but not located. In the absence of such a tool, a new instrument was developed to appraise the quality of the survey studies (Appendix C). No specific tests for reliability and validity of the tool have been done and further development and refinement may be necessary. However, this tool was informed by the work of Bennett et al (2011) who analysed published reporting guidelines for survey research and found that there is limited guidance and no consensus regarding the optimal reporting of survey research. The authors (Bennett et al, 2011), ultimately developed a tool of reporting guidelines for surveys. However when I communicated with the first author (C. Bennett), she explained that the tool was not intended as a means of scoring the quality of surveys because some items carry more weight in terms of risk of bias and this was not incorporated in the tool. It was suggested that key items can be identified in the tool and used to determine the quality of the reported surveys. The tool developed specifically for surveys within this review incorporated this important information and, as the tool was utilised, discussion with my supervisors was maintained and further fine tuning of the tool was done as deemed necessary during the appraisal process. Each study, whether qualitative or quantitative, was appraised for quality individually and this was checked by one of my supervisors.

2.5 Data extraction

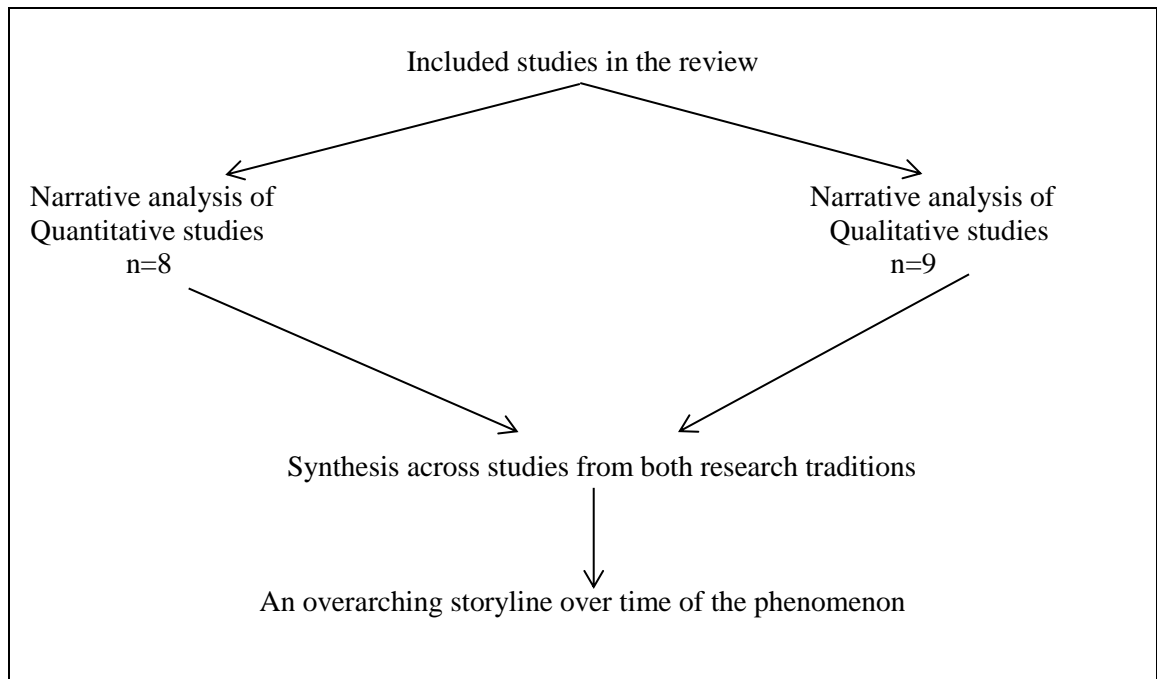
Data elements extracted in a meta-narrative review construct a storyline of how research on the topic of interest unfolded over time in a particular tradition (Wong et al, 2013). The data extracted included the characteristics of the studies namely; the publication year and country where each study has been done, the aim/s of the study or research question/s, the research methodology and design, sampling characteristics, data collection methods, data analysis utilised and the key findings which provided answers to the review question. Such data was considered to be paramount in building a narrative storyline about the phenomenon being studied, and to show how this evolved over time according to the chronological publication of each study in the two main different research traditions identified, the broadly interpretivist/sociological (using mainly qualitative approaches) and the broadly positivist/clinical (using mainly

quantitative research). Comparing and contrasting characteristics of studies helped to identify how the world views from the different research traditions contributed to posing the kinds of questions and therefore generating the kinds of findings that might answer the review question for the current study. Wong et al (2013) explain that reporting clearly what data was extracted and the rationale for choosing such data enhances the transparency of the review process. The type and amount of data extracted influence the subsequent analysis and synthesis processes.

2.6 Analysis and synthesis processes

Studies included in this review can be termed ‘descriptive or views studies’ where perspectives or views of participants were elicited. Depending on the research tradition in which the studies were based, they tended to either use closed quantitative questions based on researcher-generated topics, or more open techniques where the responses were more or less participant led. In view of this, formal synthesis between and across the data set was not appropriate. Narrative was therefore used in analysing and synthesising the findings. The analysis of each study focused on the data extracted as explained in the section above. Initially this was done separately for each study, grouped by qualitative and quantitative study designs. The descriptive themes and their essential features were examined in the light of the review question to infer the perspectives of neonatal staff and parents about the transitioning home of preterm infants. The findings across the whole set of studies were then logged by date, and a meta-narrative was constructed, to capture the storyline of the core topic over time, from the perspective of both research traditions (Figure 1).

Fig. 1. Analysis and synthesis processes



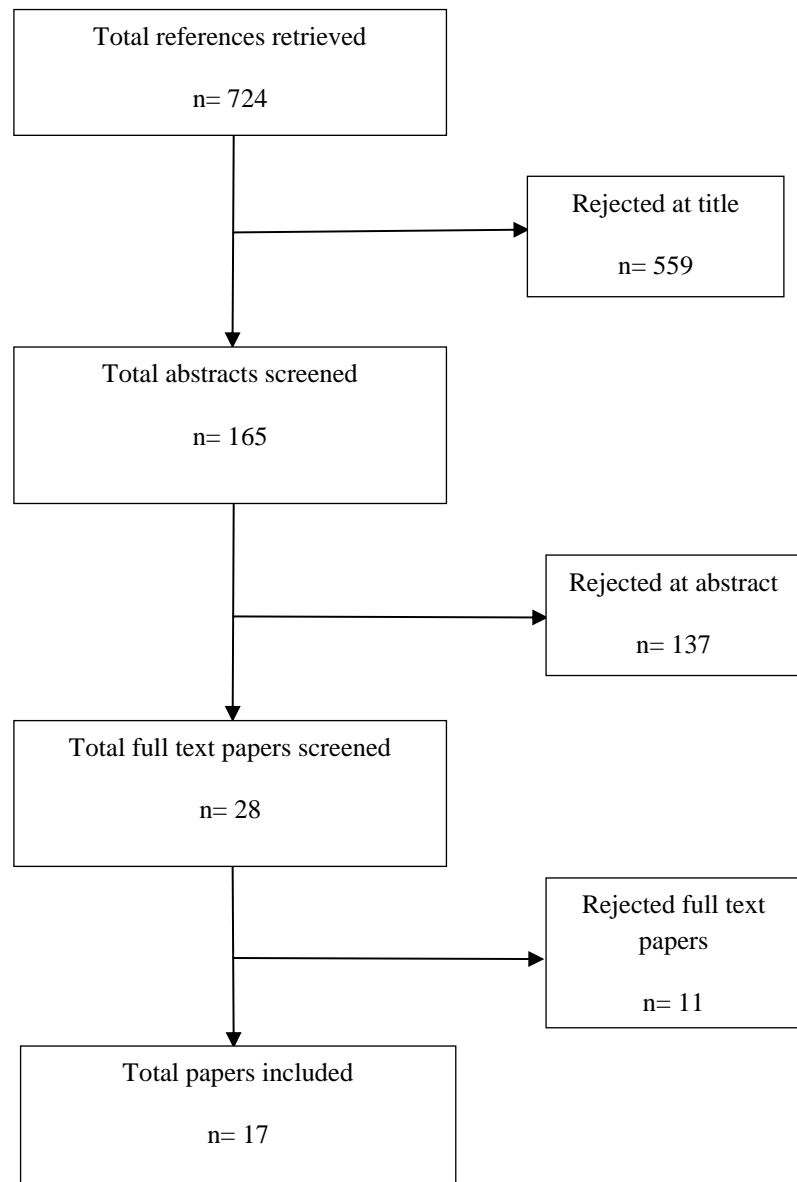
2.7 Results

A PRISMA flow diagram (Figure 2) was used to illustrate the total number of references retrieved, the total number of abstracts screened, the total full-text papers screened and the total papers included. Alongside each of these stages the numbers of rejected papers were also included. The characteristics of each study were collated in a data extraction forms. These included bibliographic information, study design characteristics, sampling characteristics and main study outcomes (Appendix D and E).

From a total of 724 references, 165 potentially relevant search results were retrieved. The abstracts of all these were read and most of these papers were read in full to determine their relevance to the review question. From these, 28 papers were empirical studies which clearly or loosely met the inclusion criteria. These studies were obtained in full-text, read and re-read a number of times. These included eight quantitative studies and nine qualitative studies which clearly met the inclusion criteria, together with 11 studies which were deemed to be ambiguous whether they ought to be included or not. These ambiguous studies were eventually excluded after discussions with my supervisors. Studies which have been excluded mainly focused on stress relating to preterm birth or on the hospitalisation period only when the baby was in neonatal care. Others were excluded because the timing when data was collected was not clear, of the inclusion criteria was not met or the aim of the study was not reflected in the findings.

Consensus was reached for all studies included in the review following discussions with my supervisors.

Fig. 2. Flow diagram of selection of eligible papers



2.8 Characteristics and quality of the included studies

The characteristics of each study are tabulated in Appendix D and Appendix E, for quantitative and qualitative studies respectively. All eight included quantitative studies used survey methods. They were published between 1993 and 2012. The timing of data collection ranged from a few days prior the preterm infant's discharge home to the end of the sixth months after discharge. Six studies collected the data only once. The other two studies (Mancini & While, 2001; Meck et al, 1995) collected their data at two different time points. Five surveys were done in America, two in the United Kingdom and one in Canada. Thus, it must be noted that collectively these studies may give a limited view of cultural differences which could be relevant to the phenomenon. The most common participants were mothers, while fathers and neonatal staff were under-researched within this set of studies.

The included qualitative literature was published between 2003 and 2013. As for the surveys, the participants were predominantly mothers. Almost half of the studies sought to explore the participants' experiences of their transition from before NICU discharge to some months after discharge home of the infant. The timing of data collection ran from early hospitalisation, to some months after the infant's discharge home (Bissell & Long, 2003; Burnham et al, 2013; Jackson et al, 2003; Hutchinson et al, 2012; Lee et al, 2004). In three studies (Rabelo et al, 2007; de Souza et al, 2010; Griffin & Pickler, 2011) data were collected only once from the participants; at discharge of the infant in the study of Rabelo et al (2007), and at a time between one and four months post-discharge in de Souza et al (2010) and Griffin & Pickler (2011). Only one qualitative study collected data from neonatal staff (Valizadeh et al, 2013).

The predominant research design adopted in six of the qualitative studies was descriptive, with content analysis of the data. Two other studies adopted a descriptive phenomenological approach utilising Giorgi's (1985, 2000) and Colaizzi's (1978) method of analysis respectively. Grounded theory was used only in one of the studies (Hutchinson, Spillett & Cronin, 2012) with a constant comparative method to analyse the data, as described by Strauss and Corbin (1998). The data collection method adopted across all but one of these qualitative studies was through interviews. The remaining study used focus groups (de Souza et al, 2010). The studies were conducted in a range of countries: one each in Sweden, UK, Korea, Canada and Iran, two in Brazil, and

another two in the USA. These widely dispersed settings contrast to those in quantitative studies reviewed above, which were done in very few countries.

For the quantitative studies the overall quality was average (C). The majority were small scale surveys with non-random convenience sampling. Power calculations for determining sample size were usually not reported, and in some cases, the design was not justified, recruitment of participants and sampling was not clear, and discussions on issues of validity and reliability were limited.

Overall, the quality of the reported qualitative studies ranged from good to average (B to C). Generally, flaws in these studies were evident in a lack of theoretical perspectives and reflexivity. Some studies also lacked a justification of the research design used, did not include details for the recruitment of the participants, and did not report important details, such as inclusion criteria and sampling, details of the characteristics of the sample, and the context of the studies.

2.9 Perspectives of neonatal staff and parents about the transition of preterm infants from NICU to home

As the main purpose of the literature review in this study was to identify the changing storyline of research on transition from neonatal unit to home, based on the perspectives of parents and staff, the detailed narrative analysis of the included studies is given in Appendix F. The thematic results are summarised in this section, as a basis for understanding the emerging chronological storyline, which is examined in the next section 2.10.

2.9.1 Theme and sub-themes from quantitative studies

The main theme across all the eight survey studies was *NICU discharge teaching*. The instructive teaching and acquisition of skills reflect a competence-based approach to NICU discharge practices. Three sub-themes emerged: *content and perceived importance of discharge information*, *discharge preparedness perspectives* and *parental post NICU discharge outcomes* (Table 4).

Table 4. Main theme and sub-themes identified in quantitative studies

Theme	Sub-theme	Reference/s in which each sub-theme was identified
NICU discharge teaching	Content and perceived importance of discharge information	Sheikh et al (1993) Meck et al (1995) Drake (1995) Mancini & While (2001) Bain et al (2003)
	Discharge preparedness perspectives	Sheikh et al (1993) Meck et al (1995) Smith et al (2009)
	Parental post NICU discharge outcomes	McKim (1993) Smith et al (2012)

- **Content and perceived importance of discharge information**

A common aim in many of the survey studies, was to determine what the content of standard NICU discharge teaching included for parents being discharged home with their preterm infants. Mothers in different studies identified that the predominant focus of topics related to caring for the physical needs of the baby while many reported not receiving information about developmental issues, information related to prematurity, interacting with the baby and family roles (Bain et al, 2003; Mancini & While, 2001; Meck et al, 1995; Sheikh et al, 1993). There were notable discrepancies between nurses and mothers about what was actually discussed as part of standard discharge teaching. Mothers recalled receiving less information in various topics than nurses said was included (Sheikh et al, 1993). When investigating the importance nurses and mothers placed on particular discharge topics, Sheikh et al (1993) found that nurses and mothers generally agreed on the importance of different discharge topics where infant feeding, taking care of the baby's health and monitoring wellbeing were rated by both staff and mothers as the most important topics. On the contrary, in Drake (1995) nurses and parents often ranked differently the importance they attributed to various discharge topics.

- **Discharge preparedness perspectives**

Research findings indicate that there are variations amongst mothers across studies on how prepared they felt at the time of discharge to take their baby home from the neonatal unit. The findings by Sheikh et al (1993) indicated that at discharge many mothers felt that they were not adequately prepared for their baby's discharge home. Meck et al (1995) found that most mothers reported that they felt prepared to care of their baby at home while some mothers said that it was difficult to leave the neonatal unit. Smith et al (2009) indicated that most parents were prepared for discharge as assessed by both parents' and nurses' assessment. Parents identified that being confident with their child's health and maturity, and having their home environment ready for their infant to go home contributed mostly to their discharge preparedness. Generally parents rated their discharge preparedness higher than the nurses' ratings.

- **Parental post NICU discharge outcomes**

When recalling the first week at home with the baby following NICU discharge, almost half of the mothers in McKim's (1993) study recalled having had a difficult first week post-discharge. These mothers indicated that they had specific information needs which had not been met and consequently experienced uncertainty and lack of confidence when caring for their baby at home. Smith et al (2012) found that mothers who positively perceived their NICU discharge had received extensive instructions in infant care and recognising ill-health, had spent time at the infant's bedside on the unit and became familiar with his/her needs and also received written instructions on how to care for the baby.

2.9.2 Theme and sub-themes from qualitative studies

The main theme from the qualitative studies was: *From premature birthing to parenting*. This captures the phenomenon of mothers and/or fathers progressively attaining their parental role, through a process that was influenced primarily by the experience of events and emotions throughout NICU hospitalisation and after homecoming. This main theme was subdivided according to the particular timings where phases of parenting have been identified in the studies included here. The sub-themes included: *premature parental beginnings*, *adapted early parenting* and *unreal-reality parenting*. These are illustrated in Table 5 below and discussed briefly thereafter. For full details see Appendix F.

Table 5. Main theme and sub-themes identified in qualitative studies

Theme	Sub-themes	Reference/s in which each sub-theme was identified
From premature birthing to parenting	Premature parental beginnings	Jackson et al (2003) Lee et al (2004) Griffin & Pickler (2011) Hutchinson et al (2012)
	Adapted early parenting	Jackson et al (2003) Bissell & Long (2003) Lee et al (2004) Rabelo et al (2007) de Souza et al (2010) Griffin & Pickler (2011) Hutchinson et al (2012) Burnham et al (2013)
	Unreal-reality parenting	Jackson et al (2003) Bissell & Long (2003) Lee et al (2004) de Souza et al (2010) Griffin & Pickler (2011) Hutchinson et al (2012) Burnham et al (2013)

- **Premature parental beginnings**

At the time of preterm birth and during early NICU hospitalisation, mothers and fathers in different studies expressed various emotions. Mothers described mixed emotions of happiness and grief (Jackson et al, 2003), self-blame (Lee et al, 2004), guilt (Griffin & Pickler, 2011; Hutchinson et al, 2012; Lee et al, 2004), relief and uncertainty (Griffin & Pickler, 2011). Fathers felt unprepared and perceived the experience as unreal (Jackson et al, 2003). Both mothers and fathers in different studies expressed that their main concern was their fear of losing the baby (Griffin & Pickler, 2011; Hutchinson et al, 2012; Jackson et al, 2003; Lee et al, 2004). Hutchinson et al (2012) also found that

parents' inability to hold the baby related to feelings of emptiness, being upset, disappointed and sad.

- **Adapted early parenting**

In their early experiences with their preterm infant on the NICU, parents constantly sought to adapt to parenting their baby in an unfamiliar environment and in ways which they had not expected. Mothers expressed that the NICU environment restricted their possibility to parent their child and felt that the baby belonged to the health care system (Jackson et al, 2003). Mothers felt limited in their participation in infant care (de Souza et al, 2010; Jackson et al, 2003). Fathers were more confident in entrusting the staff to care for the baby and did not really seek to participate in care (Jackson et al, 2003). Increased participation in infant care was experienced by parents when the infant's health became more stable (Burnham et al, 2013; Hutchinson et al, 2012). Learning and practicing providing care to their preterm infant while on the neonatal unit was perceived by parents to help them feel ready for discharge home (Burnham et al, Griffin & Pickler, 2011; Rabelo et al, 2007). When feeling well prepared to go home with their baby, parents expressed positive feelings of excitement and looking forward to go home (Bissell & Long, 2003). Mothers in other studies expressed mixed emotions at discharge. Crying, happiness, relief, fear (Lee et al, 2004; Rabelo et al, 2007), insecurity and anxiety (de Souza et al, 2010) were common feelings among mothers. Parents also expressed concerns particularly about the baby's health and development when at home and identified the need for more information tailored to the specific needs of premature infants and their parents (Burnham et al, 2013; Rabelo et al, 2007).

- **Unreal-reality parenting**

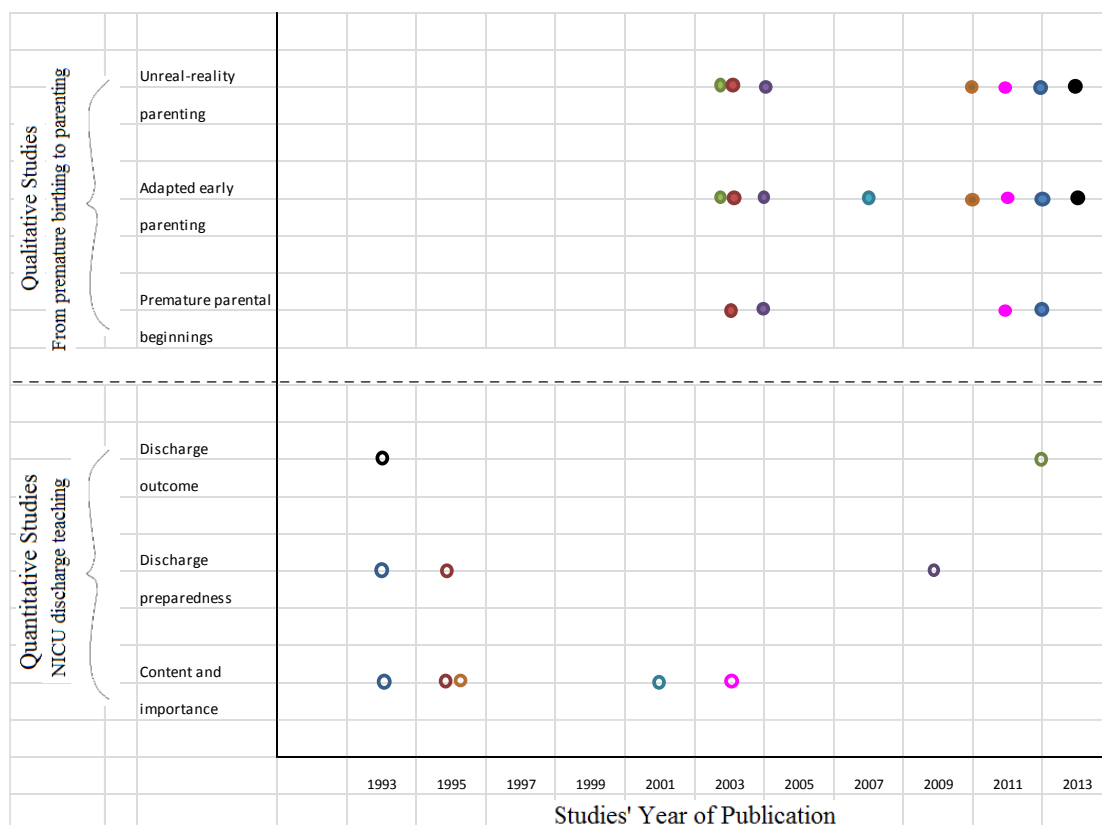
After leaving the neonatal unit, studies indicated that parents experience a shift from a sense of not being a 'real' parent, to the shock of the reality of parenting in their home environment. Mothers felt mixed feelings of fear, responsibility, happiness and relief to be home. Mothers and fathers felt insecure in providing care to their baby in the first few weeks at home (Jackson et al, 2003). However, as parents cared for their baby they felt that their parental role became more real (Bissell & Long, 2003; Griffin & Pickler, 2011; Jackson et al, 2003). As they gained confidence in parenting, parents worried less about prematurity and the infant's condition, felt more in control and that they could make decisions for their baby (Bissell & Long, 2003; Jackson et al, 2003). Parents described being at home in the first few weeks and months after discharge as a period of adaptation where they gradually adapted to life at home using their own practices and

parenting skills while learning to meet the unique needs of their baby (Bissell & Long, 2003; Jackson et al, 2003). Mothers who lacked support expressed more negative feelings when the baby was home including fatigue, isolation, continued concerns about the baby, distress and anxiety and also being overwhelmed (de Souza et al, 2010; Lee et al, 2004).

2.10 Identifying the emerging storyline

In addition to the different kinds of data that resulted from the use of different methods, there was evidence of a change over time in the underlying concerns of researchers in this area, and of responding participants. This is illustrated in Figure 3 below, which maps the emerging themes to the studies in which these themes are most evident, over time, and by study design.

Fig. 3. Findings of quantitative and qualitative studies across time



Colour coding of each study:

Qualitative Studies

- Jackson et al (2003)
- Bissell and Long (2003)
- Lee et al (2004)
- Rabelo et al (2007)
- de Souza et al (2010)
- Griffin and Pickler (2011)
- Hutchinson et al (2012)
- Burnham et al (2013)

Quantitative Studies

- McKim (1993)
- Sheikh et al (1993)
- Meck et al (1995)
- Drake (1995)
- Mancini and While (2001)
- Bain et al (2003)
- Smith et al (2009)
- Smith et al (2012)

In the quantitative studies included, a positivist ontology and an objective epistemology are adopted and these are reflected in the research questions asked, which infer that the answers to such questions are all that is needed to be found and known, and that these

answers reveal the whole of the truth about NICU discharge. Thus, the quantitative data which emerged come from a tradition which values pragmatism. In terms of its historicity, the kind of truth that emerges, being based on positivism, does not see the need to justify itself. In keeping with this tradition, the quantitative studies in the review do not leave space for contestation around their findings, or the way they are generated. There is therefore very little shift over time in what is discovered in, and claimed for in this set of data. There is little evidence of reflexivity, and the focus is clearly on what is important for the researcher/clinician /organisation; getting ready for looking after the practical needs of this preterm baby, and therefore, leaving the hospital setting.

The quantitative data in this review, therefore, seem to stress that neonatal care relating to the phenomenon studied is about turning people into prepared parents. So if one had to look only into the quantitative data, one would believe that neonatal care relating to NICU discharge and home transition is about being able to change the baby's nappy, bathing the baby, keeping the baby warm and so on. The way reality is perceived, particularly by how the clinical staff respond to the parents, is framed by what they think is important, and the studies and the research questions asked particularly in quantitative studies reflect this too.

Qualitative studies, in contrast, are generally underpinned by an interpretive ontology and constructionist epistemology. From this perspective, it is assumed that meaning is embedded in the participants' experiences, and that this meaning is mediated through the researcher's own perceptions (Merriman, 1998). Thus, essentially, the basic assumption guiding the qualitative paradigm is that reality is socially constructed by people active in the research process (Ping, 2000). This paradigm emphasises that reality is a product of the values of researchers and researchers cannot be independent of it. Qualitative research takes everyday experience and ordinary life as its subject matter and asks how meaning is constructed and interaction is negotiated in natural practices. The task of research is to work with, and make sense of the world consensually in a holistic fashion. It is the perceptions of the individuals being studied that are important (Wiersma, 2000). Qualitative researchers believe that the world exists but different people construct it in very different ways (Cohen, Manion & Morrison, 2000). Reality is therefore subjective, multiple and socially constructed by its participants (Lincoln & Guba, 2000; Guba & Lincoln, 1994).

The findings based on qualitative data reflect a wider perspective of what NICU discharge and home transition are about. From this perspective, the key issue goes beyond just being able to care for the preterm infant in practical ways, and includes reflections on engaging with becoming a mother or a father to a preterm infant, psychological and emotional implications of parenting, and the meaning of adjustment to new roles. Transition is viewed as a period of developing parental identity.

The shift in focus over time from mainly quantitative to mainly qualitative studies, suggests a move away from specific clinical phenomenon as the fundamental markers of success in neonatal care research, and towards a more socially mediated interpretation of the reality of neonatal care transition. Given that research in health care tends to be driven by the concerns of researchers, who are usually clinicians, and that, in turn, research shapes and forms norms among clinical staff, it is likely that the storyline revealed in this review expresses an ontological change among staff over time in the meaning of successful transition. Research also informs the background normative stories of neonatal care in the media, and therefore the expectations of individuals in society, including those who will go on to be parents of babies in neonatal units. This review has therefore framed the historical and contemporary space in which the interview data from this study are set.

2.11 Strengths, limitations and insights from the meta-narrative

This review has iteratively adopted rigorous steps in the review process and attempted to study the phenomenon of NICU discharge and home transition of preterm infants from multiple perspectives including mothers, fathers and health professionals, over time. No restrictions to research designs were made and this resulted in having the review question answered from studies from both qualitative and quantitative research paradigms. The review is, however, potentially limited by the eligibility criteria set for the inclusion of studies, which could have excluded other potentially relevant research findings to the phenomenon being studied. The limited data from fathers and neonatal staff also limit the findings to the accounts mostly from mothers of preterm infants.

This review used the principles of meta-narrative to examine a micro situation, as opposed to the usual use of the method to examine macro-level political and policy change (Wong et al, 2013). Additionally, the storylines in a meta-narrative are usually

constructed around different disciplines, however, although studies from various disciplines were sought in this review, only published studies from the clinical perspective were retrieved by the search strategy.

Despite such limitations, this review has established the body of knowledge published between 1993 and 2013 from both qualitative and quantitative research, and has made explicit the variations evident across the data, and in the narratives in this area over time. It has, for the first time, addressed ontological and epistemological assumptions adopted and reflected in the methodology and methods used across the literature.

In terms of historicity, this review has shown that the kind of questions that are asked in research and the answers which follow, frame the understanding of what is normal and real. Accordingly, understanding the way that the research agenda has been shifting over time in this area helps in understanding the ontological framing, what is the nature of reality in neonatal care, as it is understood by society. Neonatal care is not an absolute, not always and forever the same, it is inevitably shaped by social discourse, which is shaped by clinical priorities, which are certainly shaped by research. Therefore, the kind of research that is done changes the kind of conversations we have about what neonatal care is and what it does.

Having done this review which is about the chronology of the nature of knowledge in this field, I am able to understand a bit more the shaping and framing of what comes out of my data. This review has identified that over time there was a shift in emphasis in the ontology, what it means to be the parent of a preterm infant. The new kind of narratives, evident in the more recent research indicate that, the nature of Being is understood differently over time. Hence, the storyline in this review enabled me to see a shift in the nature of the ontology of being a parent in the neonatal unit and beyond, which has been expressed through the changing emphasis in the research methods that were used.

2.12 Conclusion

The purpose of this review was to explore the perspectives of neonatal staff and parents about the transition of preterm infants from NICU to home, and how these changed over time. This helped to establish the current state of knowledge about the study phenomenon, identified gaps in knowledge and contextualised the current study.

Specifically, it permitted a description of the space of historicity into which the stories of contemporary neonatal nurses, and parents of babies in neonatal care, are set.

NICU-to-home transition in quantitative data is based on parental competence acquisition in meeting the practical needs of their preterm infants, while qualitative data reflect relational developments between parents and their infants. This review shows how the different research approaches, whether quantitative or qualitative, have created different kinds of reality over time. The data which emerge from the quantitative perspective tend to replicate the same rather instrumental findings over time, while a more reflective and holistic understanding of what it means to parent a preterm infant emerges in the more recent qualitative studies. The evolution in these storylines suggests a growing awareness, in the literature and in practice, that NICU discharge is not the end of transition and if parents are to be better supported at making a smooth transition from NICU to home, then their experiences need more in-depth exploration. As the evidence from research both reflects and creates the reality that parents encounter, the particular gap that is addressed by the current study builds on the emerging storyline of a more interpretive notion of what it is for parents to move from NICU to home, and on the gap in the evidence about the meaning of this transition for the staff who walk alongside parents in that transition.

The next chapter presents the philosophical framework which guided the study. The philosophical notions and their relevance to the study are discussed.

CHAPTER 3:
PHILOSOPHICAL UNDERPINNINGS OF THE STUDY

3.1 Introduction

This chapter outlines the philosophical notions that guided this study, which dwells in the philosophy and methodology of hermeneutic phenomenology. It is principally informed by the philosopher Martin Heidegger [1889 – 1977] and his seminal work, *‘Being and Time’* (Heidegger, 1962). The chapter starts by outlining the evolvement of Heidegger’s hermeneutic phenomenology from Husserl’s phenomenology. This is followed by the rationale for my choice of hermeneutic phenomenology as being considered an apt fit to this study. Subsequently, the discussion focuses on the Heideggerian notions considered pertinent to my study. Further details and discussion of such philosophical notions used in the interpretation of the study’s findings are integrated within the relevant chapters which follow.

3.2 Phenomenology from Husserl to Heidegger

Phenomenology has its roots in the Greek words ‘phenomenon’ and ‘logos’, phenomenon meaning ‘to show itself’ (Ray, 1994) and logos meaning speech and so, ‘letting something be seen through what is talked about’, which Heidegger translates as ‘discourse’ (Moran, 2000). Edmund Husserl [1859 – 1938] is acknowledged as the founder of phenomenological philosophy (Moran & Mooney, 2002). He came from a positivist perspective and used a mathematical reductive process (phenomenological reduction) or bracketing where the researcher is required to set aside any pre-assumptions held in relation to the phenomenon studied in order to generate valid data and to move towards understanding the essences of consciousness (Koch, 1996; Owen, 1994). Epistemology (the nature of knowledge) formed the basis of Husserl’s phenomenology which is often termed descriptive phenomenology where his fundamental emphasis is on description rather than understanding (Dowling, 2004; Moran, 2000). Husserl viewed phenomenology as the return to ‘the things themselves, to lived experience’ by emphasising the ‘facticity of life’ or ‘factic life-experience’, a means of sourcing the essence of pure consciousness and so he was concerned with

what is inbuilt in consciousness. Facticity constitutes the individual's pre-philosophical understanding of Being (Schalow, 2013). In other words, Husserl claimed that one must suspend all that one already knows and believes about the focus being studied.

Martin Heidegger [1889 – 1977] was a 20th century philosopher initially guided by Husserl's work, his mentor. Heidegger's thoughts centred on exploring the nature of human life. He turned to the philosophy of the ancient Greeks which he saw as the ground of thinking about human Being. Heidegger's thinking was radical in the way it departed from previous notions of human Being and he rejected many of Husserl's thoughts, as he believed these objectified experience. Instead, Heidegger sought to uncover the nature of Being human (what is being?) in everyday living (Grondin, 1995). Heidegger transformed phenomenology by rejecting Husserl's Cartesian dualism of object-subject split and mind-body divide (Moran, 2000). He accepted Husserl's views on phenomenology as returning "to the things themselves" but where Husserl emphasised "a consciousness-of-the-world", Heidegger held a "being-in-the-world" perspective (Kearney, 1994 p. 30). Heidegger argued that an analysis of the self (and others) could not start from an isolated "I" of pure consciousness, or from negating (bracketing) own beliefs and experiences (Walsh, 1996). For Heidegger, one could not stand back and isolate himself from a phenomenon because 'the self' is involved in the world and such involvement forms part of conscious experience and knowing (Walsh, 1996).

Heidegger developed an interpretive approach to phenomenology and redirected the orientation from consciousness (epistemology) to existence (ontology) of 'Being' (Grondin, 1995). He believed that there were many influences of perception on both conscious and unconscious levels which define human lived experience and that it is only by uncovering them through interpretation that we can approach a fundamental understanding of what it is to be human; what it is to 'Be' (Harman, 2007). This interpretive perspective seeks to illuminate the nature of experience through understanding how the person subjectively experiences something, rather than referring a person's experience to a pre-established theoretical framework (Owen, 1994). Heidegger's thoughts unite the subject-object divide, bringing greater insight into what it means to be in the world rather than what is achieved through objective scientific knowledge (Harman, 2007; Heidegger, 1962).

Heidegger's hermeneutic phenomenology seeks to gain a deeper ontological understanding of the nature or meaning of our everyday experiences, of what it means to be human (Heidegger, 1962). The word, hermeneutics is derived from the Greek word 'hermenein' meaning to interpret and makes hermeneutics both a philosophy and method of interpretation and Heidegger believed that man's existence in the realm of Being was unavoidably hermeneutical (van Manen, 1990). Hermeneutics considers that "lived experience itself is essentially an interpretive process" (Cohen & Omery, 1994, p. 48). To interpret descriptions such as the stories of 'NICU-to-home transition', is to come to understand the possibilities of 'Being' in the participants. The stories in this study reveal what it is to experience everyday modes of Being for both neonatal staff and parents of preterm infants. Parents and neonatal staff are seen as active participants in the world, creating understanding and meaning to their existence. In this way, this study seeks to uncover some of the taken-for-granted and possibly overlooked aspects of neonatal care practices and related experiences.

3.3 The choice for hermeneutic phenomenology

The meta-narrative review discussed in the preceding chapter, indicated that issues of transition from the neonatal unit to the home have been studied by predominantly focusing on specific aspects relating to discharge from neonatal units, primarily using quantitative surveys and descriptive qualitative methodologies. The experiences of neonatal staff have largely been neglected in previous studies and the experiences of both mothers and fathers, over time and extending beyond the hospitalisation phase of their preterm infant, have only been sparingly studied. In this study I sought to move beyond the understandings, which were "already there" (Smythe, 2011, p.37) and indicated in the literature as discussed in the previous chapter.

The use of hermeneutic phenomenology is a response to identified gaps in the current understandings and to the focus of the study, which seeks to unpack the meaning of Maltese parents' and neonatal staff experiences of caring for preterm infants on the NICU, through the transition of leaving the unit and going home. This approach fits the research question which asks: 'What are the lived experiences of parents of preterm infants and of neonatal staff about NICU-to-home transition?' In asking this question, the study sought to understand the participants' experiences of their day-to-day activities in the context of neonatal unit to home transition with preterm infants. This

was also in harmony with my own interest in seeking a deeper understanding of the phenomenon and uncovering the meanings about 'what it is to Be' for those experiencing the phenomenon, rather than with describing experiences (Walsh, 1996).

Hermeneutic phenomenology has the potential of showing a greater depth of understanding and uncovering meaning within lived experiences of the study phenomenon which to-date seems to be understudied. Such qualitative inquiry is inductive and conducive to new understandings and meanings. A natural scientific enquiry decontextualizes the lived world of the Being that is there and is therefore not appropriate for this study. On the other hand, phenomenology, seeks to stay as close as possible to the experience itself (Heidegger, 1962). In this study, what it means and how it feels to experience transition of the preterm infant from the neonatal unit to the home is sought from the perspectives of parents and neonatal staff who have experience of the phenomenon. Positivistic studies give helpful information and surely have their place in generating knowledge, however they do not explicate the experiences of people as they live various phenomena. By shedding light on the lived experience, hermeneutic phenomenology can open up thinking and highlight the need for change and possible improvements in neonatal practice.

My research pre-understanding assumption was that such lived experiences have not been adequately voiced in previous literature and so remain concealed within those central to these experiences. I therefore sought for a methodology that would encourage participants to reveal what was important for them to disclose about their experiences. Pascal (2000) adds that accessing lived experience helps to gain understanding of the meanings and perceptions of another person's world and this forms the basis of interpretive phenomenology.

Heidegger diverged from Husserl's notion of 'bracketing' and claimed that it is impossible to be a detached observer of the world, for one is always a part of that same world and this resonates with my own experience throughout this study (Ray, 1994). Considering my background experiences, I felt it would be impossible to completely 'bracket out' my pre-understandings and beliefs and so chose to fuse my horizon of beliefs and experiences to that of the participants to interpret the phenomenon being studied which is in accord with a Heideggerian stance.

Mirroring Heidegger's concept of temporality, I was interested in exploring the temporal experiences of parents along the infants' hospital stay and in the first six

months after discharge and also staff experiences of this unfolding process of neonatal care practice. As a study of lived experience, I decided not to operationalise the concept of transition, but rather to understand and elicit meaning through the participants' self-definitions and perceptions.

3.4 'Being' and 'Being-in-the-world'

Heidegger's analysis of Being is the focus of his seminal work, *Being and Time* (Heidegger, 1962). His philosophy centres on the exploration of the 'meaning of Being' and the foundation of his thinking rests on the question, 'what is the meaning of 'Being'?' According to Heidegger, 'Being' is a phenomenon of the contradiction of knowing something is there because we feel it, experience it, live with it, yet at the same time we struggle to show 'what is' (Schalow, 2013). This philosophical concept is captured in Heidegger's term 'Dasein' which although not directly translatable into English is 'to be' or 'being' (King, 2001), and the literal meaning is 'Being-there', as 'Being' [sein] and 'there' [da]. Hence, for Heidegger, we exist as 'Being-there' in the world and because we cannot exist 'Being-there' without a world in which to exist, he referred to Dasein's existence as Being-in-the-world (Thomson, 2011) because the fundamental nature of Dasein is always to be in a world. Similar to Heidegger's concern with the question of Being, I was concerned with Being-parents of preterm infants and Being-neonatal staff in their experiences of intensive neonatal care on the neonatal unit and beyond.

Heidegger suggests that 'Being' is about our humanity and seeks to open up what it means to be human and to describe the situatedness of Being human. Fundamentally, Heidegger's philosophy aims to discover or uncover "the universal structures of Being as they manifest themselves in phenomena" (Heidegger, 1962). He essentially considers what it means to Be-in-the-world, hyphenating the words as a way of showing that there is no separation between our Being and our world; they are as one (Wrathall, 2005). Moran (2000) explains that 'world' refers to a context, an environment, a set of references and assignments within which any meaning is located. Heidegger claims that Dasein relates to the world and what lies within it such that our understanding of the world reflects our experiences and dealings in our world (Healy, 2011). He emphasises that 'Being-in-the-world' provides the context for all our daily activities. As such, Being-in-the-world pertains to the various human activities, interactions and

involvements. Thus, Heidegger emphasises the ‘practical’ domain of doing, acting and interacting or connecting (Schalow, 2013). Heidegger considered Being-in-the-world to be *a priori*, “not pieced together, but is primordially and constantly a whole” (Heidegger, 1962, p. 65).

Heidegger claims that Being is in a dynamic relationship with the world where we act upon the world and, in turn, are acted upon by the world (Crotty, 1996). Thus, as Moran (2000) claims, Dasein is always world-involved. For Heidegger there is an intimate relationship between Dasein and world, there is reciprocity. According to Heidegger (2010), we can understand ‘world’ as an encompassing structure of significance, by virtue of which everything Dasein encounters becomes meaningful and is revealed. In this regard, the world has the character of a ‘horizon’ which is the ‘wherein’ Dasein encounters all Beings, including itself. As such the ‘wherein’ also includes the field of possibilities in which Dasein engages in activities and thereby ‘resides’. In everyday sense, Dasein occupies the world, resides in the world or ‘dwells’ in the world. This gives a more lived and existential hermeneutic sense of world (Schalow, 2013).

Since Dasein is an occupant or inhabitant of the world, crucial to the phenomenon of Being-in-the-world is the distinctive manner in which Dasein is ‘in’ the world, that is, the manner in which Dasein finds itself (Schalow, 2013). For Heidegger (2010), Dasein is ‘in’ the world, not in a geographical sense but rather as both belonging to it and as occupying a unique ‘place’ within it. The ‘there’ of Dasein, the ‘there’ of Being-in-the-world, as being active in opening up that place (Schalow, 2013). According to Johnson (2000), Heidegger claims that ‘Being-in-the-world’ is a basic state of Dasein and adds that he views Dasein as “always involved in the practical world of experience” (Heidegger, 1962, p. 136).

Being-in-the-world emphasises the relational, existential and temporary basis of our daily lives and understanding(s) of the world as opposed to the traditional notion of experience and knowledge (truth) being separate, static and non-relational. We do not exist parallel to our worlds but we are always submerged and embedded in a meaningful world (Leonard, 1989). This places us in context with all there is around us, with people, with things, with sights and smells, with everything that is within our awareness indicating that experiences are intertwined with so many influences. Heidegger (1962) believed that this lived context of the world in which things are encountered is the fundamental source of their meaning. We cannot distance ourselves from our lived

experience of the world for we are an integral part of that world. He argued that the circumstances of the human involvement are what make things meaningful and that meaningfulness and function are altered by the context of the world in which things are encountered. Consequently, Sheehan (2005) argues that Heidegger's hermeneutical shift which identifies the world as the source of all meaning, is what ultimately separated Heidegger's phenomenology from Husserl's.

Being-in-the-world of health care, specifically in neonatal care on the neonatal unit is of particular interest to the phenomenon in this study for both parents and staff participants. Additionally, Being-in-the-world at home following discharge of the preterm infant from the neonatal unit presents another world particularly for the parents in the study. Capturing the participants' life as it is lived, helps to reveal the meanings and understanding derived from the situations parents and staff experience as Being-in-the-world both on the neonatal unit and at home. Thus, the concept of Being-in-the-world resonates with both parents' and staff involvements with each other, other people and things around them and reflects the multiple ways of their Being-in-the-world.

3.5 Being-in-the-world-with-others

According to Heidegger (1962), human beings are always already relating to other people and things in the world and meaning is determined in the context of these relationships that we share. Hence, we live in a world shared with others, 'the-they' such that our self-understanding occurs in relation to how others affect our notion of self (Symthe, 2002). We are aware of others, even when we are alone due to the physical absence of others, in which case others are experienced as missing (Moran, 2000). However, Heidegger (1962) also suggests that even if there are others around us, "Dasein can still be alone" (p.157). Consequently, Being-alone is still Being-with in the world as we cannot feel Being-alone outside Being-with-others. To this effect, everything Dasein does is involved with others, as in the context of this study of providing and receiving neonatal care.

Being-with-others is mediated through 'care' and 'concern' in our involvement with daily doings in the world around us. The concern that we have towards others is referred to as 'solicitude' (*fursorge*) or 'caring-for' (Healy, 2011). According to Heidegger (1962) it is 'care' or 'concern' that structures our actions in the world, together with the

meaning we attach to those actions. For Heidegger 'to be' with another is 'to care' and so caring is not only symbolic of Being-in-the-world but a foundation of human interaction, of being connected to others (Schalow, 2013). 'Caring-for', being a fundamental concept and function in healthcare practices, is particularly relevant to this study which aims to reveal the 'solicitude' in the explored neonatal practices both on the neonatal unit and at home.

Healy (2011) explains that for Heidegger (1962) solicitude ranges from deficient or indifferent to positive modes of caring. According to Heidegger (1962), there are two possible ways of caring for others: one which takes care away from the other by 'leaping in', and where the other is taken over, 'disburdened' or becomes dominated and dependent, while the other possibility of caring for others is 'leaping ahead' where the others' potentiality for Being is made clear to them and frees them for their own possibilities and to become 'authentic' (Healy, 2011).

Heidegger (1962) continues to argue that our Being-with-one-another can dissolve one's own Dasein completely into the others. In going along with everyone else we become disburdened from having to think or decide for ourselves. He suggests that it is our close proximity to others that, paradoxically, our own self (Dasein) recedes into the distance in a way that the everyday 'self' or everyday Dasein disperses into 'they' (Heidegger, 1962). Becoming lost in the 'they-ness' of others is a problem which Heidegger recognises as a result of Being-with when we come to exist only in reference to others (Thomson, 2011). This absorption into what 'they' say and do has been termed as 'fallenness' and in falling Dasein is lost in the publicness of 'they' and lost its authentic potential for deciding for itself. We tend to follow and agree to what 'they' do and think with a desire to be both accepted and acceptable and doing things in the right way. Heidegger (1962) refers to this everyday mode of 'Being-in-the-world' as the 'haziness' of life. For Heidegger 'fallenness' is an inauthentic state of Being which is perceived to be the basis of our 'thrownness' of Being-in-the-world (Heidegger, 1962).

The notions of 'Being-in-the-world-with-others' and 'solicitude' resonate with this study in the interplay of relationships between neonatal staff and parents as care is provided to the infant on the NICU along the hospitalisation period until ultimately the baby is discharged home. The shift in the responsibility of care from the staff to the parents along this transition is a reflection of their different involvement in the everyday undertakings with the preterm infant. Hence, the meaning of transition from NICU to

home is situated in the activities, the everyday involvements, the concerns and needs which parents and neonatal staff experience and encounter whilst caring for preterm infants.

3.6 ‘Thrownness’ to Being-in-the-world

Heidegger (1962) talks of how coming into ‘Being’ between the physiological events of birth and death is largely unknown. Nonetheless, we are born into existing structures of concern due to our historical and cultural immersion in a world of others. Our ‘thrownness’ into a particular period of history within a particular family and society provides us with our foundation for Being-in-the-world. Healy (2011), claims that for Heidegger ‘thrownness’ is a basic characteristic of Dasein and refers to the certainty with which we find ourselves ‘thrown’ into a context without having a choice; a context which is culturally and historically significant.

Steiner (1991) describes ‘thrownness’ as being delivered over to “an actuality, to a ‘there’, to a complete, enveloping presentness. Dasein must take up this presentness; it must assume its own existence. It cannot do otherwise and “continue to be” (p.88). This is what Heidegger (1962) refers to when saying that we are ‘thrown into the world of facticity’ (Svenaeus, 2001). In other words, Dasein is not a free floating self-projection but determined by ‘thrownness’ as a fact (Heidegger, 1962). Heidegger (1962) says that “as something thrown, Dasein is thrown into existence. It exists as an entity which has to be as it is and as it can be” (p. 231). Through our ‘facticity’, certain possible ways of Being are opened up and others are closed off. We are ‘thrown’ into a world that both supports and limits our possibilities. We are ‘thrown’ in a social world which is saturated with rules, expectations, standards, tasks and roles (Schalow, 2013).

However, despite the unavoidable ‘facticity’ of our Being-in-the-world, Heidegger’s work shows that we can also influence and shape our own Being-in-the-world. We are what we do, we are always projecting or acting on possibilities of ‘Being’. Getting beyond what limits our possibilities allows us to move more towards our own true possibilities of Being. Experiential understanding of the participants’ ‘thrownness’ is relevant to the study phenomena and resonates particularly with the ‘thrownness’ parents experience resulting from the premature birth of their child.

3.7 Being's mood

Heidegger (1962) perceived that regardless of the phenomenon, the starting point is always the 'mood' (feeling) or 'disposition' in which the experience is lived (McConnell-Henry, Chapman & Francis, 2009). Moreover, Heidegger (1962) affirmed that 'mood' or 'disposition' arises out of Being-in-the-world. Wrathall (2006) adds that 'moods' arise out of the ways we act and relate to other things and people around us and so 'moods' influence our relation to experiences of Being-in-the-world (Todres & Wheeler, 2001).

According to Heidegger, due to its 'facticity', Dasein encounters the world as being always 'attuned' to it and making sense of what matters. Such 'attunement' in our Being reflects our mood which we are 'disposed' (Heidegger, 1962) by in a manner that our interpretations of meanings of our everyday existence are always influenced by our particular 'mood' (Healy, 2011). According to Heidegger (1962) "a mood assails us. It comes neither from 'outside' nor from 'inside' but arises out of Being-in-the-world" (p. 176). For Heidegger, 'moods' are a basic characteristic of our familiarity with the world which indicate how we are doing or feeling. We also experience moods in a passive manner since they often affect and reflect the situations we experience (Healy, 2011).

For Heidegger (1962), all moods and how they relate to our Being-in-the-world share what he terms as 'disposedness' to which there are three features: 'thrownness' (discussed above) which reflects our inability to control particular situations in our world; 'discloses being-in-the-world' where our mood reveals certain characteristics in our situation more strongly than others, and 'submission to the world' when in vulnerable situations, particular possibilities bear more significance to us than others (Healy, 2011). Consequently, moods disclose or reveal the significance that other people, situations and things have for us.

This study seeks to reveal the moods experienced by the participants and the influences reflected on their experiences. In revealing the participants' moods careful attention is needed not only to the narrations of their experiences but also to non-verbal expressions as they tell their story. Additionally, moods may not become clearly evident at the first instance and a glimpse of moods or feelings is more likely to be revealed on interpretation of the data.

3.8 Modes of engagement when Being-in-the-world

Heidegger (1962) explicates his conception of Being-in-the-world through our contact with the people and things in the environment through three different modes of engagement: 'present-at-hand', 'ready-to-hand' and 'unready-to-hand'. Heidegger (1962) asserts that we may see things as standing on their own as they are, bracketed from their connections and engagements with our interests. Seeing things in this theoretical mode are 'present-at-hand', they are simply there (Moran, 2000). 'Present-at-hand' refers to anything which is independent of our lives (Blattner, 2006). Heidegger (1962) claims that viewing the world in this way, can detach things from their referential meanings and relations of Dasein.

When we relate to other entities with familiarity as part of being 'in' the world, we experience the 'ready-to-hand' mode. In the 'ready-to-hand' mode, life events, equipment and the human mind and body run smoothly and transparently. This reflects our everyday living which we do not think theoretically about. In being 'ready-to-hand', things often withdraw from view or become taken-for-granted. Meaning remains in the background and hidden as we dwell in the world of 'everydayness' (Parsons, 2010). According to Heidegger (1962), Dasein also identifies objects as ready-to-hand when seeing a practical use in them, such as equipment, which become an unconscious present part of reality. Hence, we also come in contact with others and objects depending on their use or availability for particular activities which are of interest to us, depending on our goals. When things present themselves as available to us, they are called 'ready-to-hand' (Moran, 2000).

Nonetheless, when life events, equipment and the human mind and body no longer run smoothly, then they become noticed by the person. This is when the world shows itself in the 'unready-to-hand' mode of involvement, where the significance of what the person was involved in shows itself or becomes visible (Parsons, 2010). Hence, in the 'unready-to-hand' mode, we react in a less familiar way when provoked by something or some person in an unusual way. In other words, we continue to interact with people and things in our everyday existence without thinking about what we are doing until we are stimulated by the unusual. At the point when we become aware, at some level, of what we are doing, we change our level of awareness and way of interacting to fit the context and make it work (Conroy, 2003). When things are 'unready-to-hand', they are not available to use (Blattner, 2006) as when some equipment breaks or malfunctions,

then we are forced to concentrate on it. According to Heidegger (1962), whatever is experienced as ‘unready-to-hand’ is disturbing to us, makes us concerned and requires our attention.

The entities of our worlds make subtle shifts according to our level of engagement with them. The world that is experienced is constantly changing from one person to another, and alters yet again within the context of the lived experience of each person. How these different modes of engagement change, between the participants and along their experience of transition from NICU to home resonates with this study.

3.9 Temporality and Spatiality

Within Heidegger’s hermeneutic phenomenology lay the relevant concepts of time and space. Heidegger (1962) conceptualises time and space from the perspective of Being. Therefore, time is experienced as temporal and space as situated. He did not define time and space as chronological, linear or measurable entities (McConnell-Henry et al, 2009).

In *Being and Time*, Heidegger’s aim is to understand the meaning of Being in relation to time (Moran, 2000). Heidegger suggests that Being is in some ways understood through its link to, and connection with time or temporality. Heidegger aimed to rediscover the hidden connection and synergy between ‘Being’ and ‘time’ which is reflected by the ‘and’ used in the title of his *opus magnum* implicating the relation of ‘Being’ to ‘time’ (Schalow, 2013).

Heidegger views time as “the horizon for all understanding of Being and for any way of interpreting it” (1962, p. 39) and so considers that all human experience is grounded in time, which makes the experience of time fundamental to understand Being. Heidegger (1962) considered Being to be temporally situated in-the-world and so temporality refers to awareness of time through the experience of being-in-time. Consequently, Gelven (1989) adds that time is experienced as giving meaning within the life of the Being-in-the-world.

Heidegger (1962) claims that ‘Being’ is influenced by the past, the present and the future and asserts that these three time frames are connected and are experienced as a unity. In other words, what is experienced in the present is coherent with what was

experienced in the past and is expected to be experienced in the future, such that awareness of them is as one, in the present (Heidegger, 1962). According to Parsons (2010) this means that humans live simultaneously in the present, influenced by the past and always looking to the future and that what we encounter in our past sticks with us as memories or as nearly forgotten experiences that leave their traces on us and allow for the possibility that things will be meaningful to us.

Heidegger (1962) declared that time is the foundation of Dasein, who is always 'in time' and for whom time is infinite. Time lies behind us, around us and even as it is present, it flows by us to become the past while the future can only be speculative. Time can therefore only ever be temporal. According to Heidegger (1962), to understand a phenomenon one must interpret the three different time perspectives and adds that when reflecting on a phenomenon chronological time does not matter but what matters is *what*, or *why*, it stands out from the general flow of time (Mackay, 2005).

Time is considered to have an important influence in the interpretation of the lived experiences of parents and staff of the transition from NICU to home, especially since transition in itself indicates experience over a span of time. Being alert to the participants' descriptions reflect their Being-in-the-world-in-time which as Heidegger (1962) claims, situations may be limited by a 'temporal horizon', meaning the range of possible ways for the experience of time to be disclosed (1962, p. 416). Heidegger (1962) refers to the 'ectastical character' (p. 377) of temporality where the experience of time is reflected through the situations which stand out from the flow of time (Mackay, 2005). Being attentive to situations which stand out in the parents' and staff descriptions situating their experience 'in time' is considered particularly relevant in this study, in order to enhance understanding of the experience of time and the nature of Being. Mackay (2005) adds that the date and time of day of particular events may be rendered irrelevant compared to the significance of identified events which stand out from the general flow of time.

Being-in-the-world means existence is not only temporal, but also spatial (Mackay, 2005). Interpretive phenomenology considers the concept of space, not in terms of a place *per se*, but rather how it feels to be in that space and how that feeling influences experiences. Spatiality grounds the person in a location. Space pertains to the relative distance and proximity of things, that we encounter within the environment. For Heidegger (1962), space is a dynamic where we interact with things and others in our

environment. The basic characteristic of Dasein's spatiality lies in 'bringing close' and spatiality belongs to the 'openness' by which Dasein uncovers and accesses things within the world (Schalow, 2013). This spatial dynamic echoes with what parents and staff access within their worlds and how experiences are influenced by the spaces they encounter, namely the neonatal unit and their home.

Being-in-the-world has this spatial characteristic because everything in the world "belongs somewhere" (Heidegger, 1962, p.136). Heidegger refers to this spatial situatedness, "the there" (1962, p.171), where from such position, a person either brings something close to him ('here') or experiences it as remote ('yonder'). What is brought into the foreground of the horizon of space and what lies in the background, depends on the unique situatedness of the person-in-the-world (Heidegger, 1962; Pollio, Thompson & Henley, 1997). Space in this study can be reflected in the space of caring for the preterm and the parents from the health professionals' perspectives and for the parents, the space of parenting the preterm baby in the NICU and at home. Listening to participants' descriptions of their experiences can bring to light which situations are brought close, to the foreground and what resides in the background of their horizon of awareness since those things which are of concern are not always situated on the spatial horizon in such a way that they are present to awareness (Mackay, 2005).

Heidegger (1962) claims that we are located within our own temporo-spatial circumstances, and that it is the context which influences the meaning of an event. In other words, if the time and setting are to be different then so would the experience, since every experience is specific to its context (McConnell-Henry et al, 2009). This is considered particularly relevant and important to keep in mind in my study because parents and staff tell their stories in the perspective of their own temporality and context of events surrounding their experiences.

3.10 Modes of Being-in-the-world

Every human being's possibilities are limited in some way and 'concern' is a means how humans can decide upon their options in order to move from one situation to another. Heidegger (1962) believed that Dasein can make choices amongst a set of possibilities and is oriented towards its own potential to the possibilities of existing

within one of two modes: authentic or inauthentic existence (Moran, 2000; Thomson, 2011).

From a Heideggerian (1962) perspective, the possibility of becoming authentic or experiencing the ‘authenticity of self’ is when Dasein realises who it is and recognises itself as a distinctive entity. Once Dasein realises it has its own destiny to fulfil, then its concern with the world will no longer be that of others but becomes an ‘authentic’ concern to fulfil its own unique potential in the world (Duffy, 2011). An authentic existence is when we do not just accept what is handed down to us but seek our ‘own-most potential to Being’ (Heidegger, 1962). Authentic existence occurs when we realise who we are, we take ‘responsibility’ for our actions and can grasp that each human being is a distinctive Being. When Heidegger (1962) speaks of being authentic he suggests that it is a choice: we can choose our possibilities but we can also limit them. For Heidegger (1962) there is always a possibility to become, we are constantly becoming through a reflective process of our situation (Duffy, 2011).

On the other hand, according to Heidegger (1962) an inauthentic existence is whereby we operate in the everyday mode of existence as ‘the-they’. For Heidegger an inauthentic Being creates a passive self who is disburdened of moral autonomy and responsibility (Thomson, 2011). If Dasein embraces the standards and beliefs of others, than it does not differentiate itself from the rest and Heidegger (1962) regards this as ‘inauthentic’ existence. Inauthentic Dasein does not live as itself but as ‘they’ live. For Heidegger, ‘Being-with’ presents the possibility of comprehending our own Dasein as an everyday Being-with-one-another where we may come to exist not on our own terms, but only in reference to others. In so doing, Dasein comes not to be himself and surrenders his existence to a formless ‘theyness’. ‘Belonging to others’ deprives Dasein of its own accountability to take decisions. For Heidegger, this passivity creates the alienated ‘they-self’, the opposite of the solid singularity of a Dasein which has grasped itself (Moran, 2000).

Being-lost in the publicness of the ‘they’ declines our potential to be authentic and would have “fallen into the world” (Heidegger, 1962, p. 220). Heidegger argues that when ‘fallen into the world’ we act in a programmed way with each other by conforming and not trying to obtain a unique perspective. According to Heidegger (1962), ‘falling’ relates to our everyday ‘absorption in’ our activities of life where we do not become fully engaged with our particular responsibilities (Healy, 2011).

Similarly, Moran (2000) explains that ‘falling’ means getting caught up in the ‘public self’, so that we no longer have proper access to our authentic sense of our lives. Heidegger (1962) believes that when one is ‘absorbed in’ the ‘they’ and in the ‘world’ one escapes from facing up to his or her possibilities to be authentic. Falling is a situation which most beings drift into when we take-for-granted our background or our familiarity with the world, as we become absorbed in our everyday life. Living in an everyday mode of being and not stopping to reflect on it makes us unable to define our own state of Being (Healy, 2011).

Heidegger (1962) explicates his concept of authenticity in terms of ‘ownness’ and ‘ownership’. My existence is something which is mine; or more generally, Dasein has the structure of ‘mineness’, that is not something which merely occurs in the world, or is ‘present-at-hand’, but is revealed in a first-person way (Moran 2000). ‘Mineness’ is a structure which itself is capable of being grasped either authentically or inauthentically. “As modes of being, ‘authenticity’ and ‘inauthenticity’ are both grounded in the fact that any Dasein whatsoever is characterised by mineness” (Heidegger, 1962, p. 68). Moran (2000) explains that for Heidegger, authenticity and inauthenticity can only arise as modes of Dasein’s being, because Dasein is always mine or yours, always individualised into the life of an individual. One relates to one’s existence rather authentically or inauthentically, or else in some kind of undifferentiated state between these two. In this study it is particularly important to understand the authentic and inauthentic modes of Being-in-the-world of parents and staff and how these modes impact their lived experience of the study phenomenon.

3.11 Fore-structures of understanding and the hermeneutic circle

According to Heidegger, we understand in terms of what we already know otherwise there would be no understanding (Geanellos, 1998). Situating understanding on what we already know is based on what Heidegger refers to as, the three fore-structures of understanding. These are fore-having, fore-sight and fore-conception. Fore-having, refers to the understanding we already have in advance. Fore-sight is the view from which we approach the phenomenon, and fore-conception is how our understanding leads us to question and our expectations of what might be found. In hermeneutic phenomenology, the researcher is obliged to address the fore-structures influencing the interpretation of the phenomenon studied (Geanellos, 1998).

For Heidegger fore-having, fore-sight and fore-conception are the ‘upon which’ interpretation is founded (Heidegger, 1962, p.193). Heidegger uses the term ‘fore-structures’ to acknowledge that interpretation already exists fully formed, but in need of expression. Interpretation uncovers what is ‘already there’ in its totality and facilitates that which is already understood, to be revealed. Meaning is when interpretation has led to understanding. When this is achieved, the reality of what is already there is made explicit, and so the phenomenon is uncovered (Heidegger, 1962).

Heidegger (1962) asserted that it is not possible to completely separate ourselves from our preconceptions and pre-understandings. According to Johnson (2000), Heidegger’s message is clear and claims that, understanding is never without presuppositions. We do not, and cannot, understand anything from a purely objective position. We always “understand from within the context of our disposition and involvement in the world” (Johnson, 2000, p.23). According to Taylor (1994), the only true way for the researcher to conduct a hermeneutic inquiry is to have prior knowledge, some fore-structure to ensure that the questions asked are pertinent (Taylor, 1994).

These notions suggest the need to become aware of my own fore-structures of understanding which influence my interpretations of the study phenomenon. In view of this, my own Being-in-the-world particularly as a midwife with experience in intensive neonatal care leads me to agree with Heidegger, that I cannot ‘bracket’ out my understandings of what it means to be in a world of neonatal practice, which cannot be eliminated because it ‘already is’. Every step from research question to interpretation of the data, is embedded in my pre-understandings of Being-in-*this*-world. Hence, my fore-structures have not been set aside, but were made explicit and used throughout the research process including when collecting and interpreting the data. This makes the interpretive process reflexive where the researcher also reflects her impact on the research (Finlay, 2003).

Heidegger (1962) adds that these fore-structures of understanding form the basis of the hermeneutic circle and refers to the flow of understanding that takes place through Being-in-the-world. This indicates that there is a circular back and forth movement between partial understandings and the more complete whole. In other words, interpretation is a circular process whereby the fore-structures of understanding are made explicit, then considered in terms of the whole of understanding of a phenomenon and then re-considered in a new way (Geanellos, 1998).

Within the hermeneutic circle meaning lies in both the parts and the whole, each informing the other, each finding new meaning from the other. The hermeneutic circle forms a 'circle of understanding' (Crotty, 1998) which is dynamic and has no beginning and no end. Each understanding is taken back to all previous understandings and moves forward to all new understandings. No one understanding stays static or fixed; instead all are open to change and growth (Moran, 2000). In a hermeneutic study such as this, the interplay between my fore-structures and the hermeneutic circle becomes particularly evident when analysing and interpreting the texts of the study participants and in asking the text what the experience of the phenomenon in question means. To gain understanding within the hermeneutic circle requires moving from overall interpretation of the texts and the shared meaning between the parts of the text and back to the whole of the texts again. This circular and dynamic process leads to deep understanding but also knowing that there is always more to be revealed and understood (Smythe, 2011). Healy (2011) adds that the interpretive process is never ending and always tentative, based on the assumption that no single correct interpretation exists.

3.12 Conclusion

This study sought to uncover what it means to 'be' a parent who had the lived experience of having a preterm baby in NICU and later discharged home, and for neonatal staff who experience caring for preterm infants on the unit and their role in the transition for such babies to their home with their parents. Through this study, some of the taken-for-granted and overlooked aspects of providing and receiving care in NICU setting and beyond are revealed. I believe that hermeneutic phenomenology brings to light the voices of the participants who have experienced the phenomenon being studied and for these to be heard most clearly. Utilising an interpretive approach acknowledges that the world can be understood in terms of the different perspectives people bring to their existence. In view of this, in this study it is understood that meaning is made by the participants in telling their stories, the researcher in dwelling with the data and ultimately by the reader who interprets what is said through his or her own historical and social horizons. Interpretive phenomenology aims to advance understanding, rather than creating new knowledge (Koch, 1999). In keeping with this paradigm, the research methodology is informed by the philosophy of Martin Heidegger, whose philosophical notions and their relevance to the study have been discussed in this chapter. The next

chapter extends this discussion by laying out the ways in which these methodological considerations have been applied to the research design and procedures.

CHAPTER 4:

THE WAYS AND MEANS

4.1 Introduction

This chapter presents my research journey by describing the steps, procedures and strategies used in gathering and analysing the research data commonly referred to as the research method. This chapter includes details on how participants were recruited, the data collection methods, together with transcribing and translating procedures. These discussions are followed by an explanation of the analytic processes adopted in this study. The chapter ends with the ethical considerations and the strategies adopted to establish trustworthiness in the study. van Manen's (1990) six methodical steps provided a workable means to undertake this research, while notions from Gadamer (1975) have also been borrowed and applied to the process of analysis. The contributions of these authors' work and how they have informed my research method are discussed in the relevant sections in this chapter. In view that two participant groups formed part of this study, some sections in this chapter are discussed separately to enable the reader to clearly distinguish what was done with each group of participants.

4.2 Research approach

The research approach adopted in a study should reflect the question/s being asked (Robson, 2002). According to Streubert and Carpenter (1999), qualitative research emphasises discovery, description and meaning and so is particularly useful when researching phenomena that involve human experiences and interactions. Morse and Field (1996) add that qualitative research methodologies offer a humanistic approach and are often used when the phenomenon being researched has not been adequately examined in the past or seems to be sparsely represented in the research literature. The lack of research about NICU-to-home transition experiences is clear in the literature, hence a qualitative approach to this study was considered fitting. Polit and Beck (2004) claim that qualitative methodologies have a number of common features including, broadly stated questions about human experiences and realities, and sustained contact with the research participants where the rich, descriptive data generated helps in

understanding their experiences and feelings from their own perspective. Nonetheless, different qualitative methodologies including ethnography, grounded theory and phenomenology, differ in the type of questions considered appropriate to elicit the data in each specific qualitative paradigm.

Phenomenology is one such qualitative paradigm which encourages participants to describe their 'lived experience' of a given phenomenon (Polit & Beck, 2004). Phenomenology, as discussed in the previous chapter, is both a philosophy and an approach to the enquiry of lived experiences. An interpretive phenomenological study of lived experience relies on participants who have been through the experience in question, together with their memory and reflections on the experience. Phenomenology is a human science which goes beyond mere explanation and observation to interpret and understand, while hermeneutics is concerned with the description and interpretation of experience (Morse & Field, 1996). Application of these two approaches together provides a unique means to search for meaning in research where depth of information is sought revealing respondents underlying attitudes, feelings and opinions. Hence, interpretive phenomenology was considered apt to answering the research question and to achieve the aim and objectives of the study, which will be discussed shortly. As a research approach this study adopts both philosophical underpinnings and methods congruent with interpretive hermeneutic phenomenology, to study the lived experiences of home transition from the neonatal unit of parents of preterm infants and of neonatal staff.

4.3 Overview of van Manen's guide to the research method

van Manen's (1990) six steps which offer a guide to the research method, are very broad and allow for flexibility through the research process which supports the non-fixed nature of the philosophy of phenomenological hermeneutics (van Manen, 1990). van Manen's (1990) procedures are therefore neither fixed nor absolute and I found them a useful guide in exploring the participants' lived experiences of NICU-to-home transition. These six steps include:

1. Turning to a phenomenon of interest
2. Investigating experience as we live it
3. Reflecting on the essential themes which characterise the phenomenon

4. Describing the phenomenon through the art of writing and rewriting
5. Maintaining a strong and orientated relation to the phenomenon
6. Balancing the research context by considering parts and whole.

(van Manen, 1990, p. 30 - 31)

Although these steps appear in a sequential manner, they are not linear in practice. The researcher moves back and forth along the steps several times during the research process. However, for coherence, the rest of this chapter discusses each of van Manen's (1990) steps in turn, according to the different processes adopted during the research process.

4.4 Research question and aim of the study

According to van Manen (1990), the first step in doing hermeneutic research, is turning to a phenomenon of interest and so identifying some aspect of human experience to explore. In essence, the first step involved formulating the research question which was instigated primarily out of my interest in the care of preterm infants and influenced by my experiences of working in neonatal care. Consequently, the literature review presented in chapter two helped me to refine, and to ultimately determine, the research question being addressed in this study, informed by gaps identified in previous literature. The resulting question was, *'What are the lived experiences of parents of preterm infants and of neonatal staff about NICU-to-home transition?'* This research question led me to the aim and objectives of the study. Throughout the research process the research question, aim and objectives were continually referred back to so as to ensure that the methods adopted adequately answered and achieved what they were aimed for.

Aim:

- To explore the experiences of parents of preterm infants and of neonatal staff pertaining to the transition from the neonatal unit to the home in Malta by looking at transition in the context of the wider parental journey.

Objectives:

- To explore Maltese parents' (mother-father dyads) lived experiences of having their preterm infants in the neonatal unit and their transition to home during the first six months following discharge
- To explore the lived perspectives of neonatal staff about the transition of preterm infants from the NICU-to-home in Malta.

4.5 Operational definitions

The research question gave rise to the need to clarify the meaning of what keywords within the research question are taken to mean for the purpose of the study (Cormack, 1996). Hence, operational definitions needed to be clearly established. The definition of 'parents' was taken to refer to the biological mother and father of the preterm infant hospitalised on the neonatal unit. 'Lived experience' refers to episodes, occurrences, events or happenings and is a conscious reflection on one's own actions and thoughts through a particular, present or past, lived time-period. Additionally, according to Crotty (1996) in understanding the participants' experiences as a whole in a phenomenological approach, experience refers to the feelings, emotions, perceptions, attitudes, events, meanings of events, reactions to events, and functions or roles that are being explored. Thus, in this study the parents' experiences of their baby's hospitalisation on the neonatal unit and up to six months after the baby was discharged home were explored. For the neonatal staff, their experiences of their role in caring for preterm infants and parents on the neonatal unit were sought. In this study, 'neonatal staff' included midwives, nurses and doctors who were directly involved in the care of preterm infants on the neonatal unit. 'Preterm infants' referred to those infants born prior to 37 completed weeks of gestation (Llewellyn-Jones, 1982) and who required care on the intensive neonatal care unit in Malta. 'Transition' in this study referred to the progressive shift from caring for the preterm infant on the neonatal unit to being discharged home up to a period of six months post discharge. 'NICU' refers to the neonatal intensive care unit within the main public hospital in Malta which specialises in the care of preterm and ill newborn infants. 'Home' was taken to refer to the place where the parents in the study reside and where the baby was ultimately discharged to from the neonatal unit.

4.6 The research setting

The setting of this study was the sole neonatal intensive care unit available on the Maltese Islands where preterm infants were cared for, from the time of birth until they were discharged home. The neonatal staff recruited in this study provided care for preterm infants on this local neonatal unit and the parents have had preterm infants cared for on the same unit.

4.7 Recruitment of the study participants

4.7.1 Parents

The midwife in charge of the local NICU and her appointed designate acted as contacts in recruiting potential parent participants using purposive sampling (Smythe & Giddings, 2007). I discussed with the midwife in charge and her appointee, information pertaining to my study. Then, they provided a brief verbal outline of the study together with further written information available on the participant information letter, (Appendix G) to those parents who were identified as meeting the inclusion criteria set for the study. Such communication was conveyed to the parents towards the end of their infants' hospitalisation at the NICU and asked to consider their participation in the study, and indicate whether they were interested in the study prior discharge.

Potential parent participants included those who were Maltese and had their first experience of preterm birth, had a singleton preterm baby who had been hospitalised in the local NICU for more than seven days and was being discharged home without requiring any special care needs at home, like oxygen therapy or nasogastric tube feeding. Each mother-father dyad needed to agree to be interviewed together and both parents needed to be living together in the same household. Parents were also required to be both over 20 years of age with no mental, drug or alcohol problems. Those parents having multiple births, a baby with severe or life-limiting illness, or with congenital abnormalities were excluded from the study.

Inclusion and exclusion criteria helped to create some homogeneity in the sample of parents' participants yet enabling unique and individual differences to emerge in their lived experiences. The decision to include 'healthy' preterm infants that did not require additional medical support at home was based on the lack of transition research with

this particular group of preterms. The decision to interview the parents in couples was informed from my pre-understandings from my previous experience, that in Malta parents tended to live their experience of having a preterm baby together. Parents are often seen together with the baby on the neonatal unit. Interviewing parents as a couple was also perceived as a way for them to have each other's support, particularly when recalling some event from their experiences which could have been distressing.

Potential parent participants who communicated their interest to participate in the study to the midwife in charge or her designate, agreed that their contact details could be forwarded to me (the researcher). They were informed that they would be contacted by the researcher who would discuss further their involvement in the study and if they agree to proceed, negotiate arrangements to meet up and be part of the study. All potential parents identified and invited to participate in the study agreed to share their stories.

4.7.2 Neonatal staff

In view of my previous work experience as a midwife working on the local neonatal unit, I was familiar with the neonatal staff working on this unit and so a purposive sample of those staff meeting the inclusion criteria for the study were identified, and invited to participate in the study via an email which included an information letter explaining the nature and purpose of the study (Appendix G).

Potential neonatal staff participants included midwives, nurses and doctors who were directly involved in the clinical care of preterm infants and who worked in the local NICU for at least 20 hours a week and had been working on this unit for one year or more. Any other staff working on the unit other than those specifically indicated in the inclusion criteria were excluded from participating in this study. These eligibility criteria were informed by the lack of research involving neonatal staff in this particular aspect of NICU-to-home transition.

The neonatal staff who were invited to participate in the study, indicated their interest in the study by replying back to my email of invitation. Subsequently, further communication ensued to negotiate a time and location to meet up for data collection. All neonatal staff invited to participate in this study agreed to be interviewed and share their experiences.

4.8 Data collection

The second step in van Manen's (1990) guide to the research method is investigating experience as we live it, since establishing renewed contact with original experience is aimed for in phenomenological research (van Manen, 1990). In this study I sought the parents' and staff's own voices, who experienced the phenomenon of interest, mainly using in-depth, open face-to-face interviews. Open interviews with prompts based on an interview guide are typically used in phenomenological research (Langdridge, 2007) as they offer some structure to the interview, yet spontaneity and flexibility are possible. Face-to-face interviews offer an opportunity to establish a rapport with the participants (Smith & Osborn, 2003) and allow for clarifications as data is collected and thus ensuring the researcher's understanding of the participants' stories, and avoids misinterpretation (Leonard, 2003). Face-to-face interviews with both participant groups were also chosen for their advantage in observing non-verbal communication which reinforce what is said by the participants (Flick, 2007).

As I was conducting this research, in every step of the process, I attempted to re-live and understand the nature of the participants' experiences as narrated to me, enabling me to enter the lives of those who had lived the experience. van Manen (1990) talks of 'conversational interviewing' being a characteristic of hermeneutic phenomenology and this was kept in mind while interviewing both participant groups where although an interview guide designed specifically for each group was utilised, yet participants were encouraged to narrate freely their experiences and probes were used according to the participants' narrations. Being open to the participants' life story is important in phenomenological research. I have learnt to listen to the participants and stay silent for most of the time, using mostly nonverbal cues showing interest, understanding and encouraging participants to continue with their flow of conversation (Smythe & Giddings, 2007; Sorrell & Redmond, 1995). Interviews encouraged the participants to narrate in their own words and so re-live their experiences with the researcher which help to add depth and breadth to the current understanding of the transition experiences with preterm infants from the neonatal unit to their home.

Recruitment and data collection from the two participant groups was done simultaneously over a period of one and a half years, between January 2012 and June 2013. An initial round of interviews was done with four neonatal staff and two sets of parents at one month post NICU discharge of their preterm infant. These interviews

were predominantly done as a means of piloting the two different interview guides designed for each participant group and to see whether these would achieve the aim of the study, in terms of revealing the lived experiences of neonatal staff and parents of the transition of preterm infants from the NICU to home.

At the beginning of each interview, the required demographic information was obtained from the participants: parents and staff. This information related to characteristics which helped put their experiences in context and so were perceived to be important for me to know prior to commencing their stories to aid my understanding from the outset. The demographic information sought from the parents included: the gestation at which their baby was born, the birthweight of the baby, the gender of the baby, the duration of NICU hospitalisation, any medical needs of the baby following discharge home, the age of the baby at each interview, the age of each of the parents and the occupation of each of the parents. Neonatal staff were asked to indicate their occupation on the neonatal unit: a midwife, nurse or doctor. The gender of each of the staff was also noted, together with the length of experience on NICU of each of the staff participants.

4.8.1 Interviewing the parents

Parents were asked to tell their own stories of preterm birth through the subsequent NICU hospitalisation of their baby, till after being discharged home. Each set of parents (mother-father dyad) was interviewed three times after their baby's discharge from NICU; at one month, three months and six months after discharge. These time-frames were chosen based on allowing periods of time of being at home with the baby from one interview to the next which is congruent with transition being a time-dependent process. The timing of the first interview, at one month post discharge was perceived to allow time for settling in and time for the parents to live with their baby at home following what was often a prolonged period of hospitalisation. The last time point, at six months post discharge was informed by previous literature which indicated that at this stage, parents were more settled with being at home with the baby. This was also informed by expert advice from a neonatologist on the local neonatal unit and also the supervisory team. They agreed that following parents until six months post discharge would achieve the aim of the study without committing the parents to the study for too extensive a period of time and would allow for the parents' experiences of living through an intensive period of growth and development with their baby. Holding the final interview

at the six month point was also influenced by feasibility in terms of the study's time-scale. The third month interview was chosen as an in-between timing of the two other interviews, enabling ongoing exploration of lived experiences of transition at home and also maintaining connection with the parents, and avoiding a wide time-gap between the other two interviews. This was also intended to maintain the parents' engagement and interest in the study.

The longitudinal research design was advantageous as it allowed for an extended period of data collection utilising repeated interviews with the same sample of parents (Creswell, 2008). This related well to the exploration of the study phenomenon of transition and was advantageous in exploring the lived experiences of NICU-to-home transition as they evolved over time in the same parents. It was a means of gathering more comprehensive experiential stories from the parents and what it meant for them to have their preterm baby being cared for in NICU and subsequently at home where they were then the primary carers of their baby. The danger associated with a longitudinal design was that of having participants withdrawing as the study progressed (Flick, 2007). However, this did not happen and all parents recruited in the study committed to all three interviews at the different time-frames.

At each interview both parents, were interviewed together. All parents agreed to hold their interviews in their own home. This was suggested to the parents as the ideal location, as it was likely to be the most comfortable place for them to narrate their stories freely. One alternative would have been to conduct the interviews in the NICU environment. However, taking them back to that environment could have been a barrier to the free expression of their experiences. Home was also less disruptive for them particularly since they had a young baby, and travelling issues would not be incurred. In addition, the home environment was not only the parents' familiar space but also reflected the stage in the process of transition in which they were presently in at the three different time frames at which the interviews took place. I was aware that the decision to interview parents as couples was challenging. Hence, prior to commencing each interview with the parents, I reminded them that I was interested in both their stories, and I asked them to avoid talking concurrently as much as possible. I was also careful to give space to both parents to talk.

The interview guide prepared for collecting data from parents was divided into three sections, each section reflecting the timing of each interview (Appendix H). However,

each section consisted of broad questions to encourage participants to express themselves freely. The design of the interview guide was informed by the literature review discussed earlier (chapter two) and an informal overview of the literature in this area, my experiential knowledge, and consultations with the supervisory team. Piloting the interview guide with two sets of parents, indicated it's adequacy to reveal the parents' experiences of NICU-to-home transition with their preterm infant and so it was not changed for the remaining interviews.

Before commencing the first interview, I let the parents decide which language they preferred to use during our conversations; Maltese, or English, also an official language in Malta. The interview guides for the parents' interviews were prepared in both languages (Appendix H). All the parents indicated that they were more comfortable narrating their experiences in the Maltese language. Yet, since Malta is a bilingual country where both Maltese and English are commonly used by the people, it became clear that as the conversations unfolded, parents tended to naturally use both languages interchangeably to express themselves. This code-switching between the Maltese and English language is very extensive in Malta and it is described as the "alternate use of two or more languages in the same utterance or conversation" (Grosjean, 1982, p. 145).

At the end of the first interview and after parents indicated their willingness to meet up again for the second interview, a tentative date and time for our second meeting was agreed. This was scheduled for around three months after the baby's discharge from the NICU. Three days before the upcoming interview date, I phoned the parents, as had been previously agreed, to confirm whether it was still convenient for them to meet on the date and time we had previously scheduled. There were only a few instances when the interview had to be rescheduled to another date and/or time, usually due to work commitments of either one of the parents. However, this did not pose any problems and the necessary rescheduling was agreed to during the telephone conversation itself and ensured that the changed timing for our next interview was maintained within the same time-frame. Similarly, this process of negotiating interview timings with the parents was followed for scheduling the third interview, at six months post NICU discharge.

4.8.2 Interviewing the neonatal staff

Utilising a specifically designed interview guide different from that used with the parents, staff were asked about their experiences of their role on the neonatal unit with

preterm infants and their parents related to preparation for home transition. A broad question and a few probing questions made up the interview guide which was informed by my experience of working on NICU, literature in this field of study and advice from my supervisory team.

The interviews with neonatal staff were done in the English language because in Malta, health professionals are considered to be proficient in this language particularly since they have received their pre-registration training in English and all documentation in practice is done in the English language. This was communicated to all the neonatal staff participating in the study prior to commencing the interviews and no objections to using the English language was expressed by any of the staff.

Each of the 12 neonatal staff participated in a one-time, face-to-face interview which was a means of uncovering their experiences with preterm infants and their parents on the NICU. This provided a richer understanding of the transition of preterm infants from the NICU to their home from the perspectives of professional carers than has been included in previous studies. Three neonatal staff chose to be interviewed in their own home, while the rest preferred a quiet room on the NICU.

In the first round of interviews, when piloting the interview guide with four of the neonatal staff, I noted that they talked very much in general terms of their experiences and roles on the NICU. The focus of their conversations was predominately on the physical and medical aspects of care. This outcome was extensively discussed with the supervisory team who also accessed the transcribed interview data. It was decided that, for the main study, the predominant nature of the interview guide would not be changed, but that, in order to try and engage staff into deeper reflection and narrate their experiences in more depth and beyond the medical and physical care they provide, vignettes based on the parents' interviews (Appendix I) would also be used to collect data from the subsequent staff participants.

- **Using vignettes**

Vignettes have been used in both quantitative and qualitative studies especially in social research (Barter, Renold, Berridge & Cawson, 2004; Hughes, 1998; Wilks, 2004), particularly as a complementary method alongside other data collection techniques (Hazel, 1995; Hughes, 1998). However, there seems to be few detailed methodological accounts on the use of vignettes within qualitative research (Barter & Renold, 2000). Vignettes have only been used sporadically in health science research (Barter & Renold,

2000; Gould, 1996) and their use in phenomenological studies, seems particularly lacking.

Various authors have offered numerous definitions to explain what constitutes a vignette (Finch, 1987; Hazel, 1995; Hill, 1997; Hughes, 1998) but seem to agree that vignettes are short stories about a situation which study participants are invited to respond to. The use of vignettes has most commonly sought participants' behaviour and actions in response to the vignette characters and this presents the main methodological challenge associated with their use. How participants say they would behave in response to a character in the vignette does not necessarily reflect how they would act if faced with a similar real life situation. However, Barter and Renold (1999) claimed that this weakness with the use of vignettes can be avoided if the aim of study does not intend to make any associations between perceptions and actions but aims to elicit views, thoughts and feelings. They suggested that when using vignettes as 'elicitation tools' along with other data collection methods such as interviews, they can help to generate talk and enhance existing data (Barter & Renold, 2000). This alternative purpose of using vignettes seems to be more recently supported with the increasing use of vignettes in qualitative research (Wilks, 2004). Wilks (2004) argued that this reorients research towards the meanings respondents ascribe to situations and practices, and suggests that a more phenomenological approach overcomes the acknowledged limitation of vignettes as predictors of behaviour.

Following these arguments, the aim of introducing vignettes in this study was to encourage more discussion in the participants, and to elicit their views, thoughts and feelings about what was presented in the vignettes. As Hazel (1995) suggested, I followed the participants' response to the vignettes and facilitated a discussion around the opinions expressed, or particular thoughts and feelings revealed in their comments. Using vignettes in this manner and as an adjunct to interviews echoed the aim of the study together with the methodological and philosophical framework adopted. For the same reasons, I chose to present the vignettes to the participants by reading them out myself so that the nature of the phenomenological interviewing was not altered and the conversational approach adopted during the interviews was maintained.

Another issue with the use of vignettes as a complementary technique to other means of data collection is the stage at which they are introduced (Barter & Renold, 1999, 2000). In this study, I used the vignettes in the second half of the interview with the staff.

Guided by the interview guide, participants were first given the opportunity to express their experiences to the full, and when it became clear that they had nothing else to add spontaneously, four vignettes were introduced, one at a time, enabling the participants to reflect and voice their thoughts, perceptions and feelings about each one before moving on to the next.

In order to increase the trustworthiness of how vignettes were utilised in my study, I adopted certain principles previously identified to guide research utilising vignettes (Barter & Renold, 1999; Braun & Clarke, 2013; Wilson & While, 1998). Since they must appear meaningful, plausible and real to the participants (Braun & Clarke, 2013), I decided to include exemplar quotes directly from real parents' experiences of the study phenomenon shared *in vivo* during the study itself. Before introducing the vignettes during the interviews I made staff aware that what they were about to hear was taken from real parents' experiences. This helped to capture their interest in listening and responding to the vignettes which followed. Great care was taken to ensure that none of the parents' identifying information would be revealed in any of the vignettes. The fact that the vignettes were not reconstructed stories but directly taken from real parents' experiences, appeared to add to their credibility, as the staff participants indicated that they perceived the vignettes to be real (Wilson & While, 1998).

For vignettes to be vivid and engaging, they must be readily understood (Braun & Clarke, 2013) and this was kept in mind when choosing exemplar vignettes from the parents' transcripts, where the language was simple and clear and the chosen vignettes were short, lacking extensive detail, provided enough contextual information but yet giving participants space for them to interpret the situation in their own terms based on their perceptions and experiences. According to Wilks (2004) a non-directional approach to vignettes has greater potential to empower and engage participants in research.

The use of vignettes in a study allow a degree of flexibility (Wilson & While, 1998) as vignettes can be altered and new vignettes developed in response to emergent issues as the research develops (Fook, 2001). In this study four different areas of practice relating to the care received on the NICU which were repeatedly emerging in the parents' narratives were identified. The four topics which emerged from the parents' data included; learning on NICU, contact with the baby, rooming-in and information giving. Each of these topics depicted a different aspect of neonatal practice on the NICU

pertaining to the study phenomenon and was revealed as the research unfolded with the four identified topics becoming increasingly clear from the data being collected during the parents' interviews.

The specific vignettes used across the different participants were varied so that not all of the staff were presented with exactly the same four vignettes, yet they were all given two vignettes where the parents indicated positive experiences and another two vignettes which related to practices perceived rather negatively by the parents. I also avoided using standard vignettes amongst all the participants in view of the close contact between staff participants in the study who worked together on the same unit. It was thought that details of the content within the vignette could have easily been communicated among the staff, possibly influencing the subsequent staff responses in subsequent interviews and was best avoided. Nonetheless, all the chosen vignettes were used to direct the staff participants to focus on salient issues in neonatal practice revealed by parents' experiences. The 'what' question which followed was intended for the staff to reflect on such practices and voice their thoughts, feelings and perceptions. Through the nature of conversational interviewing, I presented to the staff not only quotes from the parents' data but also the context in which these were told without revealing any identifying information. This resulted in what I named 'a modified vignette technique', which appears to be new to phenomenological research.

All vignettes were shown to the supervisory team, two of whom had previous experience as staff on a neonatal unit. The team agreed to the appropriate choice of the vignettes identified for this study and they confirmed that they were clear and of an adequate length, and in enough depth to engage participants in further discussion (Wilks, 2004). Since the supervisory team confirmed the suitability of each vignette, and all were perceived to be short and straightforward (Gould, 1996) and because each vignette was followed by a similar open question inviting participants to reflect and voice their perceptions and thoughts about what was presented, it was agreed that formal pilot-testing was not required. Examples of the vignettes used are presented in Appendix I. In the next chapter, further details are presented on how staff responded when vignettes were introduced in the study.

4.9 Interviewing issues in both parents and staff participants

During interviewing, participants were encouraged to describe specific situations or experiences in more detail. Prompts like, “can you tell me more about that?” or “how did you feel when that happened?” usually worked to draw out more detailed descriptions. Whenever pauses of silence became evident during the interviews, I encouraged the participants to continue spontaneously without saying anything. However, sometimes prompts to encourage the participants to continue with their story were used like, “what else can you tell me?” or “then what happened?” Such prompting, was informed by established phenomenological techniques (van Manen, 1990). On some occasions, long pauses reflected that the participants had said what they had to say about a particular part of their story, and that the interview needed to move on. When participants became repetitive in their narrations it was indicative that they had offered all they had to say about their experiences and the interview was concluded.

After interviewing twelve neonatal staff and nine sets of parents, a depth and breadth of experiences had emerged from the narratives (Smythe & Giddings, 2007). Initial key concepts were becoming clear and the later interviews did not reveal any new information which had not emerged in the preceding ones (Morse & Field, 1996). At this stage, I discussed the outcome of the interviews with my supervisors and it was decided that sufficient data had been acquired to reveal the phenomenon being studied and to answer the research question. In phenomenology, it is usual to have small numbers of participants, since the goal is to achieve a rich understanding of a specific lived experience, rather than to produce findings that can be generalised. All neonatal staff and parents who had agreed to participate, ultimately did take part in the study and none of the parents dropped out along the longitudinal process of data collection.

4.10 Transcribing and translating

Following each interview, I listened to the recording in full and any reflections which needed to be noted were added to the fieldnotes taken during data collection. This was done as soon as possible after each interview as non-verbal responses were still fresh in my memory and could easily be attributed to different parts within the interview. All interviews with both neonatal staff and parents were audio-recorded with their consent and the resulting data were transcribed verbatim. The transcription process was intensive and on average required six to seven hours to transcribe one hour of interview

time. I decided to do the transcriptions myself since I felt that I needed to take every opportunity to engage with the data throughout the different phases of the study. An external transcriber could have introduced errors due to unfamiliarity with the phenomenon and the context surrounding the participants' experiences and transcription could have been influenced by the external transcriber's perspective, affecting the study outcome. I also felt that in view of Malta's small population, confidentiality and anonymity of the participants and their stories needed to be safeguarded as much as possible and this was another reason why I opted to transcribe the interviews myself.

Listening to and transcribing all the audio-recordings was a lengthy task but it helped me to recall not only what had been said but also the non-verbal responses which accompanied the spoken words. When emotions, facial expressions and body language were deemed important to a better understanding of the participants' experiences but could not, for obvious reasons, be recorded on the audio, were added to the transcriptions. In this way the transcripts captured not only *what* was said, but also *how* things were said, providing a detailed version of the complex nature of conversations. The Jefferson (2004) transcription system was used to transcribe the participants' recorded interviews. Jefferson (2004) utilises many transcription symbols and I utilised some of the most common, as indicated in the Table 6 below, in congruence with their identified relevance to the transcripts in my study. Any personal thoughts and responses I had with each of the interviews were also noted. I felt that these measures were important to allow a more complete story for each of the participants, where not only the exact spoken words were expressed but also the context in which these were said and also the feelings expressed but not spoken by the participants.

Table 6. Selected transcription symbols

Symbol	Description
(2.0)	A number inside bracket denotes a timed pause. (2.0) means a pause of 2 seconds
<u>Wait</u> a minute	Underlined word or part of word indicates an emphasis.
STOP	Capital letters denote that something was said loudly.
No:::	Colons represent elongated speech, the preceding sound or letter has been stretched. The more colons, the more the sound is stretched.
((laughter))	A description enclosed in a double bracket indicates a non-verbal activity.
()	A description enclosed in a single bracket denotes words not spoken but perceived by the transcriber as having been implied by the speaker.
...	Dots indicate that a few words were omitted from the data segment.
!	An exclamation mark indicates an intonation of surprise.
.	A full-stop is a 'sentence-final', indicating falling intonation at the end of phrase.
?	A question mark means a questioning intonation.

(Selected from: Jefferson, 2004)

All participants, both parents and staff, were emailed a copy of the resulting transcript after each interview so they could verify their story. I asked the participants to reply to my email to indicate whether they verify the transcription or not and if they wished to edit or delete any of the data. All participants replied back to me and indicated that they verified all that was written and that I could use the data for the study. Some of parents made a few additional comments to their stories. Using electronic mail in this process reflected the preferred suggestion received from all the participants.

Since three interviews were done with each set of parents, I made sure that they received each transcribed interview prior to our next interview to give them time to go over the transcription before moving on to narrating their next phase of transition. Following the first interview at one month post discharge, parents were asked to narrate their experiences of transition since the previous interview, at each of the remaining time-frames, that is at three months and six months post discharge. Before commencing

the second interview (at 3 months after discharge) and third interview (at 6 months after discharge), I verbally went through a summary of their story which served as a link to the narration of their next part of their story within the next time-frame of home transition.

Since the data from the parents' interviews was predominately in the Maltese language, translation work had to be done so that their data could be presented and reported in the English language. My main concern was to ensure that none of the meaning of what had been said would be lost in translation. As language is the basis of phenomenological research and words are the main source of the data for interpretation (van Manen, 1990), I paid meticulous attention to translation issues for the data collected from the parents to ensure that no meaning would be lost in translation. This was extensively discussed with my supervisory team and in view of my language background, we agreed that I would do the translation of the data myself. This was decided since I am a bilingual, proficient and fluent in both the Maltese and English languages. Also my primary language and culture was the same as that of the participants, I had knowledge of the study area and the context in which the data were collected.

Translation work primarily included repeated reading of the verified transcripts followed by phrase by phrase translation of the data. While translating the data, I kept in mind the context in which the words were being used so that the meaning being conveyed could be captured. Consulting a well renowned Maltese to English dictionary (Aquilina, 1990) was useful at this stage. Difficulties in choosing the most appropriate words in the target language (English) were based upon the contextual meaning. Socio-cultural issues became evident when translating Maltese idioms or metaphors. Consulting a Maltese teacher and a linguist expert helped to ensure that translations focused on 'contextual' rather than 'verbal' consistency. Some issues may have been taken for granted by the participants and not directly verbalised but rather implied as in non-verbal means of communication. On translation such issues were conveyed by including relevant description in parentheses. Once this process was complete, I reviewed thoroughly the entire translations and the necessary corrections were done. Back-translations were also done in full by an independent health professional familiar with the study area and also proficient and fluent in both languages. Any disagreements were discussed between the back-translator, a Maltese teacher and myself. Consensus was reached in identifying equivalence of terminology based on the contextual meaning. A Maltese teacher checked the full versions of the scripts in both languages. A linguist

expert re-checked the Maltese to English translations of the exemplar quotes included in this thesis and confirmed that the translations in the target text were equivalent to the source text (Appendix J). Translations were also proof read by the supervisory team independently to ensure the readability, flow of the translations and that they made sense. Using a combination of techniques helped to eliminate translation-related problems and ensure a true conceptual equivalence in the target language (English) as expressed in the original language (Maltese).

The full-text translational work described above was carried out for the three interviews for each of two different sets of parents. Discussions with the supervisory team led to an agreement that no further full-text translations of the parents' transcripts were necessary as they were convinced that the data in the translated transcripts were readable and answerable to the research question and that the steps taken achieved translations of high quality. Thus, for the subsequent parents' interviews, I transcribed the audio recordings verbatim, in the Maltese language and worked through analysis in this original language. Maltese to English translations then followed similar patterns discussed above, but only for naming the emerging themes and presenting exemplar quotes when writing up in the English language. Translating from the original Maltese language to English following analysis has helped me to keep as much as possible the meaning and richness expressed in the original Maltese language.

Since the vignettes used alongside interviews with staff participants were taken directly as verbatim quotes from the parents' transcripts, translations were done at the outset from the Maltese language to English, following the same detailed translation processes described above. This was done because the English language was used when interviewing the staff and to avoid having an extensive mix of the two languages in each of the staff interviews. The vignettes were translated and presented to the staff in the English language so that in their entirety each of the staff transcripts were in the English language.

4.11 Data analysis

Phenomenological analysis seeks to uncover the structure, meaning and essence of a lived experience of a phenomenon (Patton, 2002). Data may be analysed using various methods, however the chosen approach needs to be congruent with the philosophical

underpinnings of the study, in this case interpretive phenomenology. van Manen's (1990) third and fourth steps, particularly relate to the analysis of the data in a hermeneutic study, which I utilised to reach understanding and meaning of the participants' data. This was done separately for the data offered by the parents and that shared by the staff.

The data offered by the staff in response to the vignettes introduced, was analysed together with the rest of the data in each of the interviews shared by staff participants. This decision was informed by the fact that the issues identified in each of the vignettes and on which the staff elaborated upon, in reality, had already surfaced in the staff narratives prior to the vignettes being introduced.

In step three, van Manen (1990) advised on the need to reflect on the essential themes which characterise the phenomenon. This is the step concerned with bringing forth the understanding of the meaning of a phenomenon in terms of structures, units or themes of meanings (Polkinghorne, 1983). While listening to the audio-recorded interviews and repeatedly reading through the transcribed interviews, I selected statements, keywords or phrases which formed the initial phase to giving meaning to the phenomena and which were later refined into sub-themes and themes. This process is discussed in more detail further along this chapter, under the heading 'Isolating thematic statements' and tabulated in Appendix K.

van Manen (1990) considers writing as an important part of the phenomenological research process and refers to this in step four of his analytic guidance, termed, '*describing the phenomenon in the art of writing and rewriting*'. Through my (re)writing of the participants' findings, I attempted to reveal to the reader in a comprehensive manner, not only the descriptions narrated by the participants but also the thoughts, feelings and attitudes attributed to the lived phenomenon. Within the findings chapters (chapter six and chapter seven), the interpretation chapter (chapter eight) and discussion chapter (chapter nine), I sought to explicate the stories of the participants and to show how I arrived at a deeper understanding and interpretation of the study phenomenon. Writing and rewriting were cyclical within this research process as thoughts were constantly revised and refined. Initial ideas formed during data collection and transcription became clearer during writing, reading, rewriting and re-reading processes. Deeper understanding of the lived experiences resulted from the constant questioning and reflections on the emerging themes.

4.12 Gadamer's (1975) contributions to my analysis

My approach to the data was also informed by Gadamer (1975), whose work supplemented and extended van Manen's (1990) steps. Gadamer, influenced by the work of Heidegger developed a hermeneutic philosophy. In this approach, Heidegger's fore-structures of understanding and the hermeneutic circle remained central to understanding and interpretation but were also extended to incorporate Gadamer's (1975) concepts of 'prejudice', and the 'fusion of horizons'.

According to Gadamer (1975) eliminating the researcher's own concept in interpretation is not possible and so the awareness of my own prejudice needed not to be put aside but form part of data analysis and interpretation (Polkinghorne, 1983; van Manen, 1990). Gadamer (1975) claims that prejudices are the very conditions by which we understand, and that the challenge is not to set them aside but rather to work with them in the quest towards understanding. Hence, my unique perspective was used to reflect on and interpret the emerging data (Koch, 1996). According to Gadamer (1975) the researcher's prejudices constitute the understanding through which interpretation becomes possible.

Gadamer (1975) also coined the term 'fusion of horizons' which links the researcher's prejudice and the participants' experiences in the text. According to Geanellos (1998), prejudices influence the fusion of horizons between the text and the researcher. Thus, every researcher, with his unique prejudices, can come up with different interpretations of the same text. In the process of analysis and interpretation, my horizon of understanding evolved my earlier prejudices to include the parents' and staff experiences, requiring me to re-examine my prejudices in the light of what I found. Thus, the horizon is not static and moves and changes as the researcher constantly dialogues with the text (Gadamer, 1975). This movement occurs through 'play' where the researcher moves between her thoughts about the phenomenon being explored and the participants' experiences of the phenomenon.

In this study, the hermeneutic circle is reflected in the dynamic and circular nature of the process of analysis and interpretation that emerged from first readings of the text, through identifying keywords and concepts, which then led to sub-themes and themes. The whole process was circular with both forward and backward movements through constant awareness of the parts and whole (van Manen, 1990). I found myself moving from the parts of each interview, to the whole of that interview, and then all interviews

were analysed together to bring out the sub-themes and themes. As indicated this was not a linear process but circular and looped, because when the analysis was completed, I went back to reflect on the research question to ensure that I answered it in my work. Hence, from beginning to end, I moved backwards and forwards through the processes reaching a deeper level of understanding within the hermeneutic circle arriving at interpretation of the data.

van Manen (1997) claimed that the researcher needs to acknowledge and make explicit any previous experience, knowledge and beliefs about the study phenomenon so that the reader can follow the influence of the researcher's background on the different phases within the study. As the researcher of this study, the phenomenological interpretation of the participants' experiences are a reflection of my own lens which includes all of my background. It is therefore one interpretation only, with the possibility of other interpretations, which may be deeper, richer or complimentary (van Manen, 1990).

In order to reveal my prejudices, I kept a reflective diary from the very beginning. Early in this process, I exposed my awareness about the study phenomenon, including pre-conceptions, opinions and expectations. Reflections and thoughts were regularly revisited throughout the study period and helped in illuminating and refining earlier thoughts along the process. Therefore, this study is influenced by my background particularly as a midwife who previously worked on the neonatal unit from where data was collected, being a midwifery lecturer whose special teaching area related to the care of healthy and sick neonates, my personal experience as a mother and also having experience of a close family member who had a preterm birth during the course of this study. All these experiences (and others that I may not be consciously aware of) have in some way impacted me in the processes of data collection, analysis and interpretation of the participants' data.

From the very beginning, I was conscious of my own prejudices, my own ideas about what it was like to work with parents on the neonatal unit and what it might be like to parent a preterm infant and transition from the neonatal unit to the home. Having written these down in my diary helped to keep me aware of my own prejudices and interview the participants in a non-directive manner. In analysis, I was aware of my own pre-knowledge about prematurity. I used this as I dialogued with the text within the hermeneutic circle. There were times when my own horizons and those of the participants reflected in the text fused really well and at other times I discarded earlier

ideas based on the new information revealed in the text. My reflective diary served as an important reminder of earlier thought processes, and of my initial impressions about the participants and the concepts emerging in their data. They also illustrated how my thoughts evolved in this research process leading to writing up. The researcher's ongoing reflection on own pre-understandings and prejudices, taking account of old and new pre-understandings and their influence on the interpretation is in congruence with Gadamer's (1975) thoughts.

In terms of the concept of fusion of horizons (Gadamer, 1975), 'play' occurred through dialoguing with the text which brings about understanding of the phenomenon in question. 'Play' was also adopted when copying and pasting participants' quotes from different interviews and organising them under different keywords, concepts, sub-themes and themes in word documents on my computer, as discussed below.

4.13 Isolating thematic statements

Once the transcripts had been sent to the participants for verification of accuracy and their confirmation was received back, I noted the little additional comments which some of the participants indicated. Then, I began the process of analysing and interpreting the narratives using van Manen's (1990) principles of thematic analysis. According to van Manen (1990) the theme is the means to get at the phenomenon; it gives shape to the shapeless, describes the content of the experience and is always a reduction of the full meaning of the experience. van Manen (1990) proposed three ways in which themes can be isolated from the data. In this study I used all three approaches in combination during the data analysis which helped to reveal both explicit and implicit themes. Explicit themes were easily revealed early in the analysis, as they stood out from the text more readily. Implicit themes related to the hidden meaning behind the words which were not readily evident on first readings of the text but required dwelling with the data (van Manen, 1990). The experiences, words and phrases of the participants converged with my own thoughts and ideas forming an ongoing fusion of horizons of lived experience. I have included theme tables (Appendix K) to illustrate analytic steps and how themes were developed from keywords to concepts to sub-themes and then themes. These should allow audit of the decisions I made throughout the analytic process and enhance the reader's understanding of how the final themes have been arrived at from the participants' narratives (Koch, 1994).

Exemplar quotes used in this thesis refer to narratives from parents' data or the data from the staff. Following each of the parents' quotes, in parenthesis reference is made to whether the mother or father of a particular baby said the quote, along with the interview number according to that allocated to each couple followed by a letter: a, b or c indicating the timing of the interview post discharge, 'a' refers to the interview at 1 month post-discharge, 'b' refers to the interview done at three months post-discharge and 'c' refers to the sixth month interview. Following the interview number and letter in each of the parents' quotes, the page number of the transcript from where the quote was taken is indicated, (e.g. Elsa's mum, 6b p. 5 which means the quote was said by Elsa's mum (couple no. 6), during the second interview, that is at three months after NICU discharge and is found in page five of the transcript). For the staff, the profession and fictitious names of the staff, together with the page number from where the quote was taken, are indicated in parenthesis following each quote (e.g. Midwife Diane, p. 8).

Table 7. Quote descriptors for parents

Couple's no	1	2	3	4	5	6	7	8	9
Baby's fictitious name	Sofia	Sven	Aurora	Kristoff	Hans	Eric	Elsa	Eugene	Anna

4.13.1 The detailed reading approach

This was the process adopted in the initial analysis. The detailed reading approach asks what each sentence or group of sentences reveals about the phenomenon or experience being described (van Manen, 1990). This included reading and re-reading the transcripts, identifying and grouping together keywords and concepts appearing in particular sentences or groups of sentences. With each repeated reading of each transcript, I got a deeper 'feel' of the data and was then able to draw out salient experiences which often announced themselves from within the text due to detailed descriptions and emotions expressed by the participants. However, as I dwelt deeper into the stories, I recognised that some less descriptive and emotive accounts often had implicit meaning towards home transition experiences. An example of the detailed reading approach from the staff data is from Dr Green, who said:

Quote 1:

“We have certain discharge criteria on the unit, so for preterm babies to go home they have to be above 35 weeks, they have to be out of oxygen usually.....They have to be above 2 kilos in weight and most of them are feeding orally and there are no complications.” (Dr Green, p.1)

This quote shows how the clinical staff determined the baby’s fitness for discharge home.

Quote 2:

“..... even from the parents’ point of view, they can, by the time they’ve been here (NICU) for so long, they know that those are the aims that their baby is trying to get before eventually going home.” (Dr Green, p.1)

This quote shows that the expectations of the baby’s fitness for discharge are transmitted to parents too.

The detailed reading of these quotes lead to the keywords: *discharge criteria* and the concept: *fitness for discharge*. Through further analysis, these keywords and concept formed the sub-theme: *ensuring clinical stability* and ultimately the theme: *acknowledging good practice*.

4.13.2 The selective or highlighting approach

This method was adopted in the second stage of analysis by repeated reading of the text and inquiring which statements or phrases appeared most revealing about the experiences being described. These appeared particularly relevant in discerning the meaning within the text (van Manen, 1990). These statements were then highlighted, carefully labelled, copied and tabulated. The following example from the staff data illustrates this approach.

“I think with some talk and if you listen to them (parents) and give them time so you (staff) would know what they need to learn....they will be much more comfortable and reassured once they go home.” (Midwife Diane, p.6)

This quote was highlighted and linked to key words; *talk, listen, time, increased comfort and reassurance*, leading to the concept; *the need to be with*, the sub-theme; *listening and less talking*, and the theme; *awakening to needed improvements in care*.

4.13.3 The 'wholistic' reading approach

This is the third approach to isolating thematic statements according to van Manen (1990) and was used following the previous approaches. The 'wholistic' approach looks at the text as a whole, seeks the phrases that capture the meaning of the text as a whole and represented in the constructed themes (van Manen, 1990). These themes were then used as a framework around which the text was created, aiming to capture the essential meanings of the phenomenon that have become evident within the data. For example, as I searched for themes within the parents' data, I found the phrase "shadowed by fading clouds of uncertainty", to be representative of the data in the first theme. This is because all parents shared their experience of preterm birth filled with uncertainties which seemed to reduce over time and started to fade away but their life never became void of uncertainties. The quote below from the parents' data made up the sub-theme; *disturbing uncertainty* and the theme; *shadowed by fading clouds of uncertainty*.

"In the first week I felt there was a 50% chance of losing her (baby) because first they (staff) say that the first 3 days have to pass, then when those 3 days passed and she was still receiving phototherapy, and all the other things...the first week needs to pass, then once the first week was over, heqq they were still checking for this and that, it was like the first two, three weeks we felt like being with our heads in the clouds." (Anna's mum, 9a p.7)

The next quote made up the other sub-theme; *embracing reality*, which still lead to the above mentioned theme; *shadowed by fading clouds of uncertainty*.

"The glass is still half full...we're trying to get out the positives from what we have gone through, otherwise we despair. We shouldn't say that things could have turned out worse either, things have turned out as they did, this has been our story, we accept reality and walk on forward." (Kristoff's dad, 4a p. 23)

4.14 The first level of analysis - development of keywords and concepts

The detailed reading and highlighting approaches were primarily used to analyse each interview separately. Keywords, phrases and ideas were grouped together leading to the development of concepts through a repeated process of reading and re-reading the data, and spending considerable time dwelling in the data, as meanings started to emerge from the text. From each transcript, accounts from the participants where similar keywords and concepts emerged, were copied and pasted into a series of tables in a Microsoft Word document. This identification of keywords and concepts involved a coding process which was done utilising MAXQDA11 data management. After all transcribed interviews were uploaded in the MAXQDA11 software programme, they

were labelled according to the fictitious names given to the different participants. It was advantageous to have all transcripts coded, which could easily be visualised on the computer screen. However, having had minimal training in how to utilise the software I found it challenging to continue pursuing its use to the further data analysis which was needed and found myself resorting to manual analysis, a procedure I was comfortable with and used to due to my previous research experience. So, following this coding process I continued analysing the data manually. Coding enabled me to retrieve segments of textual data according to similar keywords and concepts (Coffey & Atkinson, 1996). Similar ideas were grouped when going from the parts referring to aspects of each interview, to the whole picture of the data, that is, each interview as a whole. This process was repeated with each and every interview transcript and so moving again, from ‘parts’, that is coding each interview separately, to the ‘whole’ when all interviews were coded in a similar manner. I ensured that all textual extracts were correctly labelled. Below is an example from Dr Brown who said;

“...it’s lack of communication...maybe ourselves (doctors) too might be at fault when we are too busy, when we have the NICU with 20, 25 patients, so we don’t really have the time to spend with each and every individual parent. Ehm, so yes I think communication or lack of it, is the main cause of any problems that might arise.” (Dr Brown, p.4).

The keywords identified were; *busyness* and *lacking time* which were related to the concept *communication issues*. This process of identifying similar concepts was repeated with each of the interview transcripts, both for parents’ and staff data. Common keywords and concepts across different interview transcripts for each participant group were then grouped together. A tabulated example of this primary level of analysis is included in Appendix K, which illustrates further how the differing keywords and concepts emerged from different participants. This can aid the reader to gain insight into the decisions I made during analysis (Koch, 1994).

4.15 The second level of analysis – from keywords and concepts to sub-themes and themes

After gathering all transcripts from all interviews, separately for the parents’ and staff data, similar keywords and concepts were grouped together into sub-themes and ultimately themes. At this stage themes and sub-themes were not finite, but refined many times until those presented below were clarified. The credibility of the themes

was checked by my supervisory team. Similar to the previous stage of analysis, excerpts from the participants were copied and pasted into different word documents, as I grouped them into respective sub-themes and themes. This ‘segmentation’ temporarily frees parts of the text from its wider context and allows a concurrent view of the parts and whole (Smith, 1998). So although the extracts were separated from the original transcripts, they were then brought back together as a whole, through the reconstructed thematic format. Ultimately the themes represented meaningful connections between all the participants’ stories for each participant group, as a whole. Below are two exemplar quotes from different parent participants which from the sub-theme; *longing for proximity*, lead to the theme; *reaching out*.

Sven’s dad said,

“...going there (to NICU) once a day was a heartache, because I wanted my baby, my newborn, I wanted to see him all the time...I wanted to cuddle the baby with me all the time” (Sven’s dad, 2a p. 3)

Aurora’s mum said,

“At first I was afraid to touch her (baby) because she was so small (when in incubator), then when she was taken out of the incubator and put in a cot, that was different cause then I could hold her, bathe her and so on; in the cot she became more my baby.” (Aurora’s mum, 3a p. 3)

Using tables (see Appendix K) to illustrate the analytic processes has helped me to organise the data in a simple and straightforward manner. It helped me to continually visualise what I was finding within the data and to refine the analysis while ensuring that I was sorting the data extracted adequately with the right sub-theme and theme. Many times this was not a straightforward process and required iterative reviewing of the congruence between the data and the emergent sub-themes and themes. Along this process, the sub-themes and themes underwent further review and development. I constantly ensured that the words, phrases and themes represented the data as closely as possible involving a lot of thought, reflection and discussions with my supervisors. This helped me to reach the truest representation which I could make out of the data. The emergent themes and sub-themes were also discussed in both oral and poster presentations at university postgraduate seminars and an international conference where many delegates have indicated that they could relate to the findings. van Manen (1990, p. 27) termed this recognition as the “phenomenological nod” which he claims, adds credibility to the findings.

4.16 The third level of analysis

van Manen (1990) also suggests consulting phenomenological literature as an aid to uncovering new meaning in phenomenological interpretation. New understandings were gained from Heidegger's philosophy, and particularly the notions of 'solicitude' and 'machination', which were incorporated in my analysis and interpretation, added further depth. This analytic phase brought together the salient findings from the two participant groups, parents and staff. Consultations and feedback from my supervisory team added to the credibility of this interpretive analysis and re-writing completed my further understanding attained from this deeper level of interpretive analysis. This philosophical interpretation is presented in detail in chapter eight.

Writing up of the final synthesised interpretations achieved through the different analytic levels completed the analysis as presented in the following chapters. Findings chapters (chapters six and seven) were written thematically whilst providing varied excerpts of lived experiences from the participants' own voices. Throughout the writings of the findings, not all participants were equally represented and some may appear to have stronger presence than others. However, this is only a reflection of the different participants' abilities in their articulation of experiences. I felt that the choice of exemplars used to illustrate the findings needed to ensure clarity in depicting the relevant themes being discussed. Nonetheless, such a decision does not negate the value of any of the participants' stories as all data from the different participants in the study contributed to the understanding of the experiences, used throughout the different analytic phases and determining the final themes.

4.17 van Manen's final methodical steps

Phenomenology demands that the researcher remains devoted to the fundamental question or notion and avoids being side-tracked. van Manen (1990) acknowledges this researcher's obligation in his fifth step, *maintaining a strong and oriented relation to the phenomenon*. The researcher's integrity is therefore called in throughout the research process as van Manen (1990) advises that the researcher must be aware of one's preconceived conceptions and opinions, beliefs and experiences. Keeping a reflective diary was helpful in becoming aware of my own preconceptions and how my thoughts evolved throughout the research process. Although my preconceptions, thoughts and feelings were not data per se, yet they became integrated through the

‘fusion of horizons’ outlined by Gadamer (1975) as they helped me when interpreting the data. Note taking in my reflective diary permitted me to refocus my attention on the research question whenever I felt diverted in some way as I became immersed in the participants’ stories. Discussions with the supervisory team and other colleagues were important to maintain focus on the study as we reflected on the research process.

van Manen’s (1990) sixth methodical step is, *balancing the research context by considering the parts and whole*. Movement between the parts of the phenomenon and the whole picture matches the back and forth movement of the researcher and the text to the hermeneutic circle, to which Gadamer extended his philosophical perspective where the researcher enters the circle through dialogue with the text, in what he referred to as the ‘fusion of horizons’ (Gadamer, 1975), which has been discussed earlier. In this study, analysis included the data from 27 interviews with mother-father dyads and another 12 interviews with neonatal staff. Each one of these interview data formed the ‘parts’ of the study which through reflection, these stories were gathered together and became a ‘whole’. Reading the interview transcripts, in part or in whole, writing and rewriting were processes which required me to move to and fro with the data. Once keywords and concepts emerged from the individual parts, the different participants’ stories, they were then analysed further in the light of the whole perspective where themes and sub-themes were elicited. This was a constant flowing process as I carried out this research where all of van Manen’s (1990) six steps flowed into each other, back and forth, with the sixth step burrowing into the first step, as the research question was kept in focus. Hence, as noted at the beginning of this chapter, despite the processes being presented and written here linearly, in reality, it was non-linear and emergent.

4.18 Ethical considerations

Study participants must be protected throughout the research journey and the researcher has the responsibility to safeguard the participants throughout the study (Tilley & Woodthorpe, 2011). Ethical issues relating to this study were considered from the early planning phase. Permissions to collect data from neonatal staff working at the local NICU and parents whose preterm infants had received care on the same unit were granted by the respective personnel after personally discussing with them the details around the nature and purpose of the study and then signing a permission letter (Appendix L). Ethical approval for the study was gained from the Faculty of Health

Sciences Research Ethics Committee and the University Research Ethics Committee, both from the University of Malta and the University of Central Lancashire Research Ethics Committee (Appendix M). Participants' recruitment and data collection was not initiated until all the necessary ethical approvals were obtained.

From the outset eligible participants, both neonatal staff and parents were made aware that participation in the study was voluntary and that they had every right to accept, refuse or withdraw from the study at any time (Morse, 2007). These issues were clearly explained in the participants' information letter (Appendix G) to ensure that participation was an informed decision. More detailed information about the interview process was given verbally prior to commencing data collection. Participants were reminded that their identity would not be revealed and that the information they provide would be used only for the purpose of the study. Anonymity of the participants and confidentiality of the information they provided was assured and any identifying information was removed from the data (Walford, 2005). Fictitious names were used throughout the study for both parents and staff participants. I felt these measures were very important since Malta is a small country with a face-to-face community, where people tend to know each other. This became particularly relevant in the study since both participant groups; neonatal staff and parents, provided or have received care on the only NICU available in Malta.

Once it was clear that potential participants understood what the study entailed and accepted to participate in the study, they were asked to sign a consent form regarding their participation, including the recording of interviews before commencing data collection (Appendix N). Following each interview with the parents, a debriefing session was offered however, none of the parents indicated the need for this. Prior to using the data, participants were given the opportunity to check and verify the transcription of their narratives and had the right to ask for editing or removal of any of the research data. All audio recordings and transcriptions of the participants' interviews were stored on my personal computer with password protection which only I, as the researcher could access (Morse, 2007). Transcripts from the participants were only shared with the supervisory team after having removed any identifying details of the participants and given fictitious names to each of them. Further detailed strategies used to safeguard the participants are discussed in the relevant chapters of this thesis.

4.19 Trustworthiness

The notion of ‘goodness’ in qualitative research has been extensively discussed, however as yet it seems that no consensus has been reached regarding the establishment of trustworthiness in qualitative studies (Rolfe, 2006). What seems to be agreed, is a general move away from the replication of the quantitative criteria of reliability and validity. Several writers have outlined possible methods for determining trustworthiness in qualitative methodologies although no definitive guidelines seem to exist (Emden & Sandelowski, 1998; Koch, 2006; Rolfe, 2006). The two most common terms used in qualitative research seem to be ‘rigour’ and ‘trustworthiness’. However, I feel that ‘rigour’ reflects a more rigid approach which does not reflect the dynamic nature of hermeneutic phenomenology and that ‘trustworthiness’ is the more appropriate term to use in this respect. According to Koch (1994), trustworthiness of the study is enhanced when the researcher establishes a ‘decision trail’, describing and justifying all the steps undertaken in the research process. The reader can follow my audit trail by following the methods, thoughts and decisions adopted throughout the research process, as documented within the different sections in this chapter. Trustworthiness of this study is further discussed using the notions of reflexivity, credibility, transferability and dependability which were first put forward by Lincoln and Guba (1985) and more recently described and applied by Koch (2006).

4.19.1 Reflexivity

Researcher’s reflexivity is often argued as being an essential part of qualitative research and this is particularly so in hermeneutic phenomenology where the meaning within the participants’ experiences is interpreted through the researcher’s lens. Making my reflections explicit allows readers to recognise how the meaning I gave to the participants’ experiences was shaped. In view of this, it was essential for me to explore and make explicit the context in which I came to the study as well as my pre-understandings of the phenomena to be explored. Ongoing observations of myself as a researcher relating to pre-existing and new understandings of the study phenomena were necessary throughout the study. Reflexivity is essential to the trustworthiness of the study (Thomas & Magilvy, 2011).

I have previously discussed how I came to this study, predominately my experiences as a midwife who has worked on the same NICU from where data has been collected, my

relations with staff who up to a few years back were my colleagues at work and my own experience of a having a close family member having a preterm baby who received care on the same unit during data collection. Other influential experiences included the extensive reading of Heidegger and other relevant literature, my involvement with the participants themselves and discussions with other researchers and with my supervisory team. So, although the interpretation of meaning within the participants' experiences is my interpretation, yet this meaning is simultaneously shaped by my being-in-a-world of others and thus contains many other voices (Koch & Harrington, 1998). Keeping a reflective diary was a useful way to keep a record of my thoughts, feelings and evolving understandings throughout the research process. I was aware that having had a prior working relationship with the staff who participated in this study, could have an effect on the study. To reduce this possibility, I felt that I needed to reflect on my preconceptions about each individual staff by writing in my reflective diary so that these would not influence my attitude during interviewing and also later on when analysing the data. By noting my reflections it was helpful for me to maintain my researcher role throughout the study. My reflections through my research journey have also been discussed with my supervisors during regular supervisory meetings from prior to commencing the study till completion of the write-up of this thesis, and also to wider audiences at presentations both in national and international seminars and conferences.

4.19.2 Credibility

A credible or believable study is one which presents descriptions that are faithful to the participants' experiences facilitating readers to recognise the experiences contained within the collected stories (Koch, 2006). This requires a clear description of how the interpretations were derived from the participants' narratives (Koch & Harrington, 1998). The consistency in the study methods adopted in this study reflect the strategies I adopted to establish credibility in this study. I spent varied and prolonged time with participants when interviewing them, during transcriptions and through writing and rewriting. Using audio-recording and a consistent approach to interviewing the participants, giving all participants a similar opportunity to express their stories ensured the collection of a similar range of experiences. A consistent process was also adopted when transcribing and analysing the data and so all stories were handled with equal care and transparency (Thomas & Magilvy, 2011). The iterative processes described earlier

when undertaking Maltese-to-English translations provides assurance to the importance put on the meanings of what the participants said and helps to account for the credibility of translations. All participants verified their interview transcriptions and could request alterations if they wanted, however none of the participants indicated such a need. Keeping my own diary to record my own reflections, thoughts, beliefs and assumptions also helped to strengthen the credibility of the study as all influences could be monitored throughout the interpretation of the data (Tuckett, 2005). My supervisory team also helped by reviewing and discussing my interpretations of the stories during the analysis of the data. Using the participants' own words through exemplar quotes to illustrate specific interpretations derived from the data, was also adopted when writing up.

4.19.3 Transferability

This reflects the degree to which the results of the study can be transferred to other contexts or settings. Transferability can be enhanced by doing a thorough job of describing the research context and the assumptions that are central to the research (Trochim, 2006). The findings of this study represent an interpretation of the unique experiences of 12 neonatal staff working with preterm infants and nine sets of parents whose preterm baby was cared for on the NICU and subsequently was discharged home. Thomas and Magilvy (2011) suggest that an important strategy to establish transferability is to provide a comprehensive description of the participants studied by providing descriptions of demographics and geographic boundaries of the study as will be discussed in the next chapter. They argue that this understanding informs the fit or applicability of the research to practice (Thomas & Magilvy, 2011). Throughout my writing in this thesis, I sought to provide clear descriptions of the participants, the settings, their experiences and the context in which these have occurred. Using purposive sampling of participants according to clearly indicated inclusion and exclusion criteria, also increases the potential for transferability of findings from this study (Tuckett, 2005). It is anticipated that providing these 'thick' descriptions, readers will have a clear sense of the study phenomenon and the circumstances in which it occurred.

4.19.4 Dependability

Dependability relies on the researcher to account for the ever-changing context within which the study occurs and so emphasis on the thorough and open reporting of the research process should be made. Dependability occurs when another researcher can follow the decision or audit trail used by the researcher (Koch, 1994; Trochim, 2006). In this study the audit trail which I adopted included describing the specific purpose of the study and discussing how and why the participants were selected. I have also described how the data were collected and how long the data collection lasted together with explaining how the data were analysed. Finally, I also discussed the interpretation and presentation of the research findings and communicated the specific techniques used to determine the credibility of the data.

Other strategies used to establish dependability in the study included the use of a reflective diary to record ideas, insights, questions and feelings throughout the research process together with field notes which were written during and after every interview noting primarily my impressions of the interview, anything that struck me and important non-verbal communication of the participants (Tuckett, 2005). Having others participate in the analysis process also helps to establish dependability (Thomas & Magilvy, 2011). The discussions and feedback received from the supervisory team, together with discussing preliminary findings with other university students and academic staff helped me broaden my reflections on the emerging notions and themes. Following feedback and reflection, interpretive decisions were made more explicit and refined through writing and rewriting.

Maintaining a reflective attitude, a sense of awareness and openness to the study and unfolding results are important characteristics which the qualitative researcher should exhibit (Trochim, 2006). As has been discussed, throughout this study, strategies have been adopted which helped me to establish the study's credibility, transferability and dependability, which together with reflexivity enhance the confirmability of the findings (Trochim, 2006).

4.20 Conclusion

This chapter has outlined the research method used in this study. van Manen's (1990) methodical framework and Gadamerian notions were identified as useful guides adopted

through the research process. Recruitment of participants, data collection, transcription and translation issues were discussed. Analysis and interpretation of the data were then extensively reviewed showing how sub-themes and themes developed, and how the end understanding and interpretations emerged from the data. The chapter concluded by explaining the ethical considerations and issues of trustworthiness adopted in this research.

The next chapter includes characteristics of the different participants and my reflections on how they responded during data collection as they shared their experiences of transition from the neonatal unit to the home. The findings and interpretations that emerged are then discussed in the subsequent chapters.

CHAPTER 5:

THE PARTICIPANTS

5.1 Introduction

This chapter presents the demographic characteristics of the nine sets of parents and their preterm infants and the, 12 neonatal staff, who took part in this study. For each participant group my reflections during data collection are also discussed. Since all participants received or provided care on the only neonatal unit in Malta, a country which is characterised by its small population, an overview of the participants' demographics is discussed, rather than individual details, to protect the participants' identity.

5.2 Characteristics of the parent participants

Following the approved data collection procedure and the inclusion criteria for the parent participants as outlined in chapter four, nine mother-father dyads participated in face-to-face interviews at three time-frames following their preterm infant's discharge from the neonatal unit; at one month, three months and six months post-discharge. As stipulated in the inclusion criteria, each separate mother-father dyad lived together in the same household. Eight of the couples were married and one couple was cohabiting. The nine mother-father dyads in the study lived in different localities across the Maltese Islands.

The ages of the parents ranged from 23 to 42 years for the mothers and between 30 and 42 years for the fathers. The average maternal age was 32.4 years, while the average age for fathers was 34.8 years. To further protect the identity of the parent participants, their occupations were classified according to that identified by the International Labour Office (ILO, 2012) where seven parents (five mothers and two fathers) out of the total 18 parents (nine mothers and nine fathers) held professional occupations, five fathers had technical jobs, two mothers had clerical jobs, one father was a skilled worker while another father had a managerial occupation. Two mothers in the sample were homemakers and so not in economic employment. The other seven mothers were on maternity leave at the time of the first interview. At the third and last interview, four

mothers (out of seven mothers) had returned to paid employment while three mothers extended their maternity leave to longer term parental leave. In five of the couples, the preterm infant was their first born, while three couples had another older child and one couple had another three older children, and this made their preterm child their fourth born. None of the parents had a previous premature birth experiences. The ages of siblings in the families ranged between 3 years and 13 years.

5.3 Characteristics of the preterm infants

The preterm infants of the parents who participated in the study included four girls and five boys, with a gestation at birth ranging from 28⁺⁴ weeks and 34⁺³ weeks, with an average gestation of 31⁺⁴ weeks. The babies' birth-weight ranged between 970 g to 2.76 kg with an average birthweight of 1.68 kg. These preterm babies spent between one and half weeks and nine weeks hospitalised on the neonatal unit. The average hospital stay across all babies was 4.6 weeks. All nine prematurely born infants were considered 'healthy preterms' requiring no special medical needs at discharge from NICU. All nine infants were discharged home having daily multivitamin supplements, which is routine practice in Malta where this supplementation is given to all preterm infants, usually up to one year of life. One of the infants was also discharged having a low dose of thyroxine which was discontinued by the third interview, at six months following discharge from NICU. To safeguard anonymity of the parent participants each preterm infant has been given a fictitious name. Parents are referred to by the baby's name; e.g. Anna's mum or Anna's dad (see section 4.13).

5.4 Researcher's reflections during data collection from parent participants

The reflections and thoughts I am sharing in this section emerge from the field notes taken during and following data collection and also the comments I entered in my reflective diary. As I met each couple for our first interview, I felt that knowing I was a midwife who previously worked on the neonatal unit, helped to put the parents at ease. It seemed that this information helped them to trust me with their stories before commencing their narrations. None of the parents requested any other information which was not previously written on the information letter or verbally explained prior commencing the first interview.

Since all parents agreed to meet for data collection in their own home, I always felt a bit uncomfortable initially, as I was entering into their own space which was unfamiliar to me. In the parents' homes, interviews took place sitting on the sofa in the living room or around the dining table, which were the locations indicated by the parents to utilise during the interviews. These locations worked very well as both parents and myself seemed comfortable. Prior to commencing each interview, parents offered me a hot or cold beverage, which also helped in creating a comfortable setting. I appreciated these gestures as they helped me to feel increasingly more at ease in their home. On each of the occasions that I met the parents for data collection, it seemed that parents felt that their baby needed to be in the same room. The baby was either held by one of the parents as we talked or lay sleeping in his/her crib beside them. I felt that the parents also wanted to show me their baby at each of our encounters. Occasionally, one of the parents attended the baby during our conversation; however, the narrative flow of the conversational nature of the interviews was not really disrupted as parents continued narrating their experiences while meeting their baby's needs in the same room.

Prior to commencing each interview, I reminded the parents that I was interested in both their stories. I asked them to avoid talking simultaneously as much as possible. I was careful to give space for both parents to talk. This seemed to have worked well and although there were some instances when parents talked a little at the same time, this did not pose any problems when transcribing interviews because, through voice recognition of each of the parents, I could easily focus on listening to one parent at a time and transcribing their part of the conversation, then re-listening to the recording and focusing on the other parent's voice and transcribing accordingly.

In the first round of interviews with the parents done at one month after the baby was discharged from the NICU, I started each interview by asking them to tell me about their experience of having their preterm baby in NICU. I wanted to encourage them to express themselves as freely as possible and keeping true to the nature of phenomenological interviewing, I did not probe or ask further questions particularly at this initial phase of the interviews. The reactions received from the parents at this initial question were diverse, some looked quite stunned, and taking a deep breath said that there was a lot that they experienced while others were somewhat confused and with a laugh asked whether they should start from any specific part of their experience. Some of the parents were so eager to talk about their experience that the question had hardly been posed that they started narrating their story. I felt that the parents should not be

restricted to start from any particular event and I left it up to them to start from which ever part of the experience they decided to. In each of the first interviews, it was the mother who started with her narration. All mothers started talking about the events that led to the preterm birth of their child. This seemed to reflect what was considered most crucial to them and helped to put their story in context of their unique experience.

Seven of the mothers told how they experienced antenatal complications and were referred to the maternity unit by their private obstetrician. Pregnancy complications included pregnancy induced hypertension in three of the mothers, antenatal bleeding experienced by two mothers, oligohydramnios and urinary tract infection. The latter two complications were each experienced by one mother respectively. Each of the seven mothers with antenatal complications eventually gave premature birth by an emergency caesarean section due to worsening of their condition. The remaining two mothers experienced preterm premature rupture of the membranes and went into preterm labour resulting in vaginal birth of their preterm babies. Fathers were often quite silent at this initial part of the interview especially if the events leading to the preterm birth happened quickly and they were not present with the mother at that point in time. However, once fathers recalled receiving the phone call informing them of the impending birth, they quickly got into the picture and from here on they too contributed to narrating their story. It was surprising to me how vividly and at length both parents recalled the birth experience. This seemed to indicate their need to come to terms with such happenings before moving on, like a key unlocking subsequent transitions.

After the parents recalled the events surrounding the preterm birth and moved on to narrating their experiences of their baby's hospitalisation on the neonatal unit, they generally started by talking of the good care they received on the unit and how thankful they were to the staff who provided the care. However, as the conversations unfolded and parents probably felt more at ease, they also talked about aspects of care which they did not experience very positively. Being open to the participants' life story is important in phenomenological research. I have learnt to listen to the participants and stay silent for most of the time, using mostly nonverbal cues showing understanding and encouraging them to continue with their flow of conversation. I felt it was very important to note the parents' non-verbal responses and how these complemented their narrations. A multitude of emotions and feelings could be picked up not only from how parents expressed particular events in their experiences but also through their non-verbal communication. Heartache, shock, disbelief, anger, being upset or confused, joy,

hope, love are a few of the mixed emotions evident in the parents and expressed not only through what they said but also through the tears in their eyes, a fist banging on the table, a raised voice, a shake of the head and other gestures which together with their narratives provided a more complete picture of their experiences.

During the parents' conversations, I noticed how the parents narrated their experiences in a complementary way which seemed to extend my previous pre-understanding of how Maltese parents tend to live through this experience together in an interconnected way, from the time around the preterm birth, when on the unit and also beyond. Parents often used the term 'we' as they narrated their stories to indicate that they had been through the experience together as a couple. In fact, fathers indicated how they often made work arrangements to be with their baby and partner when still on the unit and also in the first days at home.

However, as anticipated, when the parents were narrating their stories away from the neonatal unit, mothers and fathers talked more on their daily experiences of being home with the baby and although parents shared many common situations, yet unique experiences between mothers and fathers emerged particularly depending on the time they were spending with their baby at home. Once the baby went home, most mothers continued with their maternity leave, while fathers usually returned to their usual work routine after the first few days of the baby being at home, such that they were away from home for most of the time during the day. Mothers then talked more of their experiences of being with the baby at home during the day while fathers were at work. Conversely fathers expressed their daily experiences with the baby during the time they were at home, before going to work, when they returned home and on days off work. Those mothers who returned to work by the third interview, experienced another transition in their life and their stories reflected these changes too.

The first interviews with the parents, were the longest, as anticipated, since the parents were narrating their stories starting from before the preterm birth, through the baby's hospitalisation up to one month post-discharge. Generally these first interviews were between one and two hours in length. The other two interviews, at three and six months post discharge, were shorter in duration and ranged between 45 minutes to 1 hour. In each of the second and third interviews parents were narrating their experiences of being home with the baby since the time of the previous interviews. I was quite surprised that although as more time passed by and the NICU experiences became more

distant, yet there were events and situations that had happened on the unit which parents mentioned repeatedly, not only in the first interview but also in the second and third interview. This seems to highlight the impact which certain experiences have had on the parents' subsequent transition from the neonatal unit to the home.

I felt that most of the parents in the study indicated their willingness to share their experience from the very beginning. This became increasingly more evident as the first interview progressed and reached the end where many parents, especially mothers, were eager to negotiate the timing of the next interview. This seemed to repeat itself at the end of the second interview. At the end of the third interview then, many of the parents, mothers in particular, expressed a kind of sadness that we were not meeting up again for more interviews and indicated that they were willing to be interviewed further should this be necessary. I felt that the hospitality and interest shown by the parents in this study helped to create a comfortable atmosphere for both parents and myself, where the conversational interview really became evident and aided in rapport building between the parents and myself. I felt that the parents' response as they narrated their stories indicated their need to talk about their experiences implying the lack of opportunity they had previously had to do so. At the end of the third and last interview, many mothers and some fathers expressed this feeling and some even thanked me for having listened to them, which further shows how for them this was an opportunity which provided them with solace.

Reflecting on the stories I heard during the parents' interviews and as I analysed the data, I became increasingly aware that the parents in the study, both mothers and fathers, experienced both similarities and differences characterised by their unique life circumstances. These reflected on how they experienced home transition over the first six months post NICU discharge and the meanings which emerged from these lived experiences. When writing up the findings (chapter six), parent participants are referred to as 'parents' unless there are elements of the findings which are distinctive between the mothers' and the fathers' experiences, in which case findings are distinguished between mothers and fathers respectively.

5.5 Characteristics of neonatal staff participants

The neonatal staff who work closely with preterm infants and their parents on the NICU in Malta include; midwives, nurses and doctors. In Malta, on the neonatal unit there is no distinction between the work of midwives and that of nurses. In this study four midwives, four nurses and four doctors participated in one-time face-to-face interviews according to the inclusion criteria discussed previously (chapter four). All midwives were females (to-date there are no male midwives in Malta). Three of the nurses were females and one was a male. Three doctors were females and one was a male. The length of experience on the NICU of the different neonatal staff ranged between three to twelve years for the midwives, between seven to thirty years for the nurses and between six to fourteen years for the doctors. The average length of experiences on NICU was; 6 years for midwives, 19.6 years for nurses and 8.6 years for doctors. The interviews with the neonatal staff were between 30 to 45 minutes long. All staff were given fictitious names along with their particular profession, for example Midwife Carla, so that the reader can clearly identify the profession of each of the staff (see section 4.13).

The demographic characteristics across the different staff, which seem to have reflected on the staff experiences relate to the length of experience of working on the neonatal unit. Those staff who had been on the unit longer than others were more likely to compare experiences of the current practices on the neonatal unit to those at earlier times, and could often highlight differences. Other differences across experiences could be noted in the specific roles of doctors compared to those of midwives and nurses. The gender of the staff participants in this study was dominated by female participants. This reflected the almost total female staff population on the unit. Any staff characteristics which influenced the findings in some way are discussed accordingly within the relevant themes in the staff findings chapter (chapter seven).

5.6 Researcher's reflections during data collection from staff participants

My reflections in this section are consistent with the happenings around data collection from the staff and my perceptions on how they responded during the interviews. Similar to my reflections on the parents' data collection discussed above, the field notes which I took during interviewing and immediately after, together with the comments

kept on my reflective diary became valuable in writing up this section, and help to put the staff participants' stories more in context.

Three of the female staff participants happened to be on a few days off from working on the unit and they preferred to be interviewed in their own home. Each of these three female staff members had a young child at home and this was probably why they felt it was more convenient to hold the interview in their own home. I felt that this informal setting worked well for the staff to narrate their experiences and although occasionally they had to attend to their child, this did not disrupt the interview because they remained in the same room and could continue with their conversation. I had never been to these staff participants' homes before, and, initially I felt rather awkward to be invited into their homes. However, staff seemed very comfortable with this which probably reflected our previous working relationship on the neonatal unit. In fact, they made me feel welcome in their homes and the interviews took place at the dining table over a cup of tea or coffee.

The rest of the staff were interviewed when on duty, at a time during the day when they indicated that work on the unit was not very busy. Although all these staff members were interviewed on the neonatal unit, the specific locations where interviews were held varied according to their preferences. The doctor's office, board room and interview room were the different locations on the neonatal unit where interviews were held according to the participants' preferences. These locations were identified by the staff for privacy and to limit distractions during the interviews as much as possible but at the same time the staff participants were still within reach, should their help be required on the unit during the interview. In fact, all staff interviewed on the unit informed another member of staff of their whereabouts before commencing the interview so that they could easily be reached should they be needed. These interview locations worked well for staff to narrate their experiences and there were only minimal distractions on a few occasions, like a phone call or a knock on the door which were quickly attended to and the interview continued immediately afterwards without having an effect on the flow of conversation with which the staff were telling their story.

Prior to commencing each interview, I assured staff participants that there were no right or wrong answers and that I was interested in their particular experiences. However, when interviewing neonatal staff, I could sense that they tried to appear in favourable light and focused their conversations on the good aspects of care provided on the

neonatal unit. This was particularly evident at the initial part of their interviews, however as the conversations unfolded I felt that generally neonatal staff became more relaxed and talked about their experiences of providing care more fully, including both positive and negative aspects of practice. Additionally, in the first few interviews with staff, it became clear that they also talked very much in general terms focusing on the physical aspects of care to the baby. This is when it was decided to introduce *in vivo* vignettes from parents' experiences, as detailed in the previous chapter.

As noted in chapter four, the vignettes were introduced to tap deeper into the staff participants' perceptions, thoughts and feelings as they responded to experiences voiced by parents who had preterm infants on the same neonatal unit where they provided care as neonatal staff. I felt that staff opened up more following the introduction of the vignettes. Their reactions and responses to the vignettes also generated further discussion beyond their responses to the specific vignettes. Vignettes seemed to have acted as reminders of other experiences, which then staff reflected upon and told their story.

I felt vignettes brought the interviews more to life especially when staff became aware that they were obtained from real parents on the neonatal unit, and were not fictitious stories. This seemed to add interest in the study amongst the staff, since they noted that they do not generally get feedback from parents. They acknowledged that hearing parents' experiences provides feedback on how the service provided could be improved to better support parents in their transition from the neonatal unit to their home with their preterm baby.

I felt that, in their responses to the vignettes, staff could locate themselves according to their role on the unit within the parents' stories. They elaborated on experiences of their role related to the vignette, enabling them to draw deeper on their experiences of neonatal practice. Indeed, in many cases, they seemed to become more interested with each vignette that was introduced. I felt that in this study, vignettes stimulated thought and further discussion, facilitated rapport and eased staff participants into interview situations.

5.7 Conclusion

This chapter discussed the demographic characteristics of both participant groups in this study; parents and neonatal staff. Great care was taken to avoid giving individual details of participants to safeguard their identity. My reflections on the data collection process were also discussed, which helps to put the findings discussed in the next chapters, more in context of the thoughts and processes during data collection.

The parents' and staff findings are thematically presented in the next two chapters, chapter six and chapter seven respectively.

CHAPTER 6:

FROM NICU-TO-HOME: PARENTS OF PRETERM INFANTS TELL THEIR STORIES

6.1 Introduction

This chapter presents the findings from the parents' stories of transitioning home from the neonatal unit with their prematurely born baby. Nine Maltese mother-father dyads narrated their stories at one month, three months and six months following their preterm infant's discharge from the neonatal unit. As has been detailed in chapter four, the hermeneutic analysis followed van Manen's (1990) processes which helped to illuminate the main themes and sub-themes central to these experiences. Each main theme and its corresponding sub-themes are described and illustrated with excerpts from the parents' narratives using transcription symbols and quote descriptors as discussed previously (see sections 4.10 and 4.13). For each main theme, the writing is organised so that both descriptive and interpretive reflections are discussed as they emerged directly from the parents' descriptive experience, with the intention of revealing a deeper understanding of the meaning within parents' experiences.

6.2 Emergence of Main themes and Sub-themes

Each of the nine parents' stories share common features, but they are framed differently through the narratives, being largely influenced by unique personal events experienced by the different parents. Moving from parts to the whole repeatedly across the parents' stories helped to establish relationships between each mother-father dyad's descriptions of their experiences across the nine sets of parents, identifying through reflection the final main themes and sub-themes which characterize their experience. Utilising this cyclical interpretive process, moving back and forth between stories through writing and rewriting (van Manen, 1990), four main themes and their corresponding sub-themes emerged, as illustrated in Fig. 4 below.

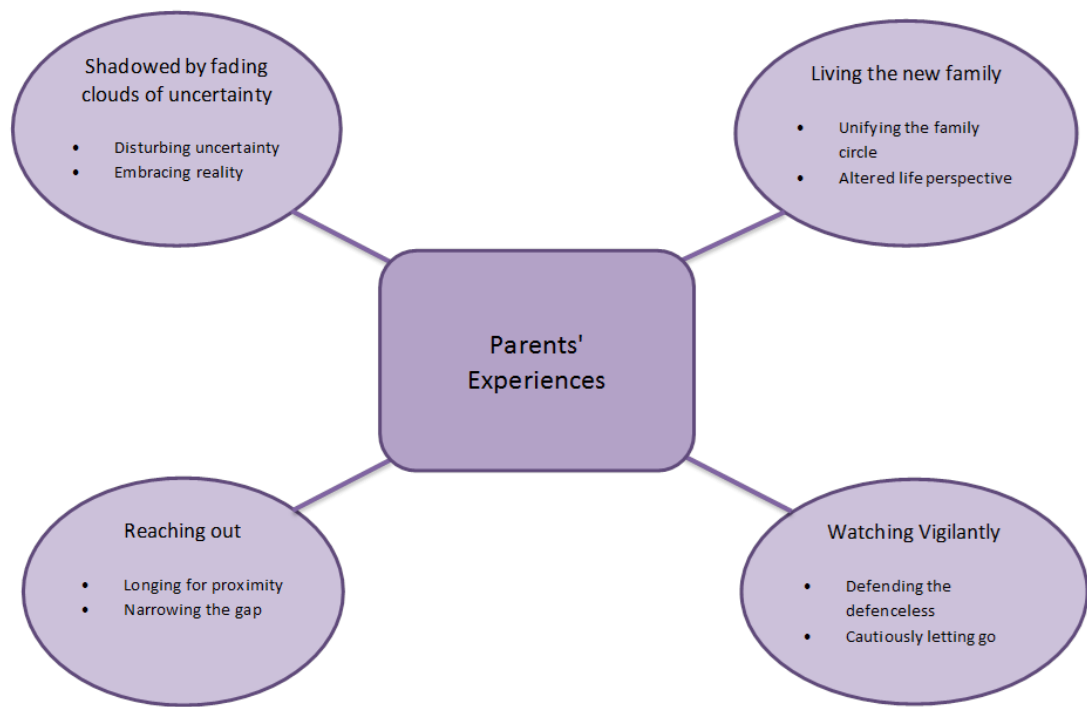


Fig. 4. Parents' experiences of NICU-to-home transition

The first main theme, *Shadowed by fading clouds of uncertainty*, reveals the life of uncertainty that the parents in this study seemed to enter into as a result of the premature birth of their child. This took various turns along their child's hospitalisation and as they transitioned with their baby to their home. The second main theme, *Reaching out*, discloses the parents' expressed need to be close to their baby. The separation parents experienced from their baby became particularly significant through the child's hospitalisation on the neonatal unit. The third theme, *Watching vigilantly*, reflects the vulnerable perspective through which the preterm infant was viewed, necessitating careful watching over. The vigilance over the baby experienced by the parents on the neonatal unit marked their subsequent experiences, even following the child's discharge home. The fourth theme, *Living the new family*, reveals the parents' experiences of embracing the new baby into their family as they sought to move on together into the future. The themes and sub-themes are reciprocal and interrelated. The following sections in this chapter describe these themes and their respective sub-themes in more detail.

6.3 The first main theme: Shadowed by fading clouds of uncertainty

Theme 1 – Thematic structure

Main theme:

Shadowed by fading clouds of uncertainty

Sub-themes:

Disturbing uncertainty

Embracing reality

The first main theme, *Shadowed by fading clouds of uncertainty*, is characterized by the numerous uncertainties and unknowns that parents experienced from the onset of preterm labour through the time of the last interview, at six months following discharge from the neonatal unit. The uncertainties encountered by the parents seemed to be constantly there throughout their experience. It became apparent that the specific nature of this uncertainty changed over time, along the NICU hospitalisation and through the move from the neonatal unit into the home setting. As more time elapsed the uncertainties shadowing parents' lives seemed to reduce. Ultimately their life-world became more certain, as they settled into a pattern of living with their baby at the end of the data collection period. Hence, the clouds drifted away causing less shadowing on their lives and as time went by, their future lives became clearer and more in focus. Encompassed in this main theme are the sub-themes: *Disturbing uncertainty* and *Embracing reality*.

6.3.1 Disturbing uncertainty

The participants were unprepared for their preterm birth experience, which shattered their anticipations of having a healthy baby born at term. Intense feelings of shock, disbelief, helplessness and fear were common among the parents in this study. Some of the mothers experienced pregnancy complications like pregnancy induced hypertension or antenatal bleeding, for which they were being monitored with the aim to continue

with the pregnancy for as near term as possible. Other mothers had spontaneous onset of preterm labour which they were not aware of, and which ultimately resulted in the premature birth of their baby. Although those mothers whose pregnancy became complicated had an indication that their baby could be born preterm, they were faced by an unexpected emergency caesarean birth when their condition worsened. Mothers were not prepared for the early arrival of their baby. The unexpected preterm birth and the related uncertainties were faced by fathers too, who were often at work when they received the phone call telling them that their baby was about to be born.

Eric's mum described the onset of her antenatal complication and how this led to preterm birth. The emotions both parents felt at the sudden decision of birthing their baby prematurely emerged very clearly as they narrated.

Eric's mum: *"we went for my antenatal visit on Wednesday and she (obstetrician) found it (blood pressure) high, and the next day I went to work as usual and she (obstetrician) had told me to re-check the blood pressure at my own doctor in the evening or on the next day so that we would see how the blood pressure remains, because I had been quite active on that day (of the visit) and that could have effected it (the blood pressure). I was at work and I went to the doctor there and as soon as he found it (blood pressure) high again and I phoned her (obstetrician) she immediately told me to go directly to hospital. At that moment, I was shocked to tell you the truth and at work they (colleagues) just stared at me, I just started to cry. We had just finished preparing the hospital bag the day before because I used to tell him (her husband), that there is no rush, there were ten more weeks to go and he (husband) had told me to prepare it cause you never know what might happen. Then, when I went into hospital, I thought I would stay maybe for three days and go back home. I used to ask the doctor, when she thought I would be going home and she used to say that if I do go back (home) she wouldn't suggest that I go back to work, however she used to say that she couldn't tell me (if I would go home) and it would depend on the blood pressure. But it (blood pressure) remained high, although I was having the pills, it was still high, so they couldn't give me a date (for discharge) because they were taking blood tests every day to check how things were. Then, when they saw that things were becoming worse...in the morning she (doctor) came and she said she would speak to the consultant for his decision. And she came back and told me that at two o'clock we would do it (an emergency Caesarean Section). It was so sudden that there was no time for me to prepare myself for the event that was going to happen on that same day. I phoned him (husband) immediately and told him to come quickly because it (the birth) was happening on that day."* (Eric's mum, 6a p. 21–22)

Eric's dad: *"when she (wife) called me, I just couldn't believe it, I froze (2.0), I didn't know what to do, so many thoughts passed through my mind (2.0), then I just left work and went to hospital."* (Eric's dad, 6a p. 22)

Many mothers tried to establish what could have caused their premature birth and searched for an answer to their uncertainty. Some took the blame upon themselves and

attributed the prematurity to some activity they had done, whether at work, leisure or some accident like a recent fall down the stairs. Fathers, on the other hand, were not so much preoccupied with finding a reason resulting in preterm birth. However, when their partner had been faced with a pregnancy complication and the decision regarding the timing of delivering the baby was being constantly reconsidered to prolong the pregnancy as much as possible, fathers became very uncomfortable and helpless with the uncertainty around this decision particularly due to the adverse effects this could have had on their partner and their baby. Fathers feared adverse outcomes for their partner due to complications if pregnancy was prolonged and also feared complications and the survival of their baby due the premature gestation at which it would be born.

Eugene's mum tried to identify the cause for her premature birth.

"My waters broke...but what I know is that the week before (the birth) I had fallen down the stairs and I landed with a blum sitting down...I really hurt and my bones were aching but I told him (husband) 'I didn't hurt my tummy' and it was like at that moment instinctively I told him (husband) 'no, don't worry cause I didn't hurt my tummy' ...but I sprained my ankle and I was really in pain for two days...so I don't know if this (the fall) could have triggered it (the preterm labour)...I don't know if it was because of this (fall) because he (baby) was born the week after." (Eugene's mum, 8a p. 4)

Kristoff's father expressed his fears and concerns at the time of preterm birth for both his baby and his wife.

"I was worried because the baby was 31 weeks, then I said 'thank God that he made it to 31 weeks' because I began to realise the difference when a baby is born at 31 weeks and one born less than 31 weeks and the consequences there could be. Between 30 weeks and 31 weeks I had learnt from my reading that there is a big difference. I didn't know anything in this field before, but having arrived to 31 weeks, I said 'thank God he (baby) made it to 31 weeks'. At least there could be problems related to 31 weeks and not 28 or 27 weeks and the fact that they told me that the baby cried and started breathing, he had responded well, they bagged him and he responded well, that was a relief because from what I read I said 'than he mustn't be bad considering the complications he could have had'. Then they passed by me with the baby, I saw him and they took him to NICU straightaway. I wasn't interested to go near the baby then, I knew he was in good hands, I was more concerned about my wife, until she comes out of there (theatre) (1.0). Then the consultant came to talk to me about the complications my wife has having, he was telling me about the hysterectomy (2.0); but when I knew that she (wife) was ok, out of theatre, then I went to see the baby." (Kristoff's dad, 4a p. 7-8)

Once the baby was born the parents' uncertainty did not disappear. Indeed, they experienced intensifying uncertainty. Seeing the baby for the first time, both mothers and fathers were struck by the physical appearance, the small body and the associated

fragility. None of the parents had previously experienced a preterm birth or seen a preterm baby and seeing their own preterm baby for the first time was unexpected and triggered their uncertainty relating to their baby's survival. The uncertainty around the possibility of losing their child became exacerbated when the parents experienced another first sight, this time in NICU where they could hardly see their baby with all the machines and monitoring attached to and surrounding the baby.

Anna's mum shared her view on being prepared from before the birth that she would only get a very quick glimpse of her baby at birth.

"They prepared me, they told me 'you know that we can't give her (baby) to you (to hold), and she has to go in an incubator because she is 29 weeks' and I said 'I know but at least I wish to see her face before you take her, and they said 'but it is going to be a quick one' and they just held her up and told me 'see the baby so that we take her'. I just saw her face, which I don't really remember it, and they took her straight away.'" (Anna's mum, 9a p. 4)

Sofia's dad conveyed his feelings when he first saw his daughter on NICU.

"When I went there (NICU) for the first time I got a shock out of this world, when I saw my daughter like that (2.0)((eyes welling up)), obviously I wasn't expecting her to be like that...I spent one minute, two minutes maximum and I left in a state of shock." (Sofia's dad, 1a, p. 1)

Most parents in this study sought to cope with their initial uncertainties through hope which seemed to encourage them and reduce their psychological distress. In the initial acute phase, parents sought hope for their child's survival from the neonatal staff. However, staff were unable to give parents the hopefulness they desired. Specifically, they could not guarantee the survival of their baby. Nonetheless, most parents perceived that the information they had been given, particularly on admission of their baby felt like a ray of hope which they seemed to cling to until their baby's condition improved.

Anna's mum explained how although she was not completely reassured that her daughter would be alright, yet she felt filled with courage as a result of the explanations she had been given by the neonatal staff.

"When we (mum and dad) went to see our daughter (in NICU), at that time they (neonatal staff) didn't fill us with many hopes but didn't make us lose hope either. They just said that there was a chance that anything could happen, they told me that our daughter was in like an ITU for children....it was a bit of a shock because you start thinking that there was still quite some time before she is born and then all of a sudden you see her there in such a state, it was a bit of a shock...but the fact that they filled me with courage but at the same time

informing us what could happen, that was of great help.” (Anna’s mum, 9a p.1–2)

Other parents, particularly fathers who were often the first to see the baby in NICU, were less disturbed by the uncertain survival of their baby especially when their preterm baby was born beyond 30 weeks of gestation and had not experienced major difficulties with respiratory function at birth. Most fathers trusted the care being given to their babies and felt that all efforts were in place to promote the survival of their baby. Many of the mothers did not see their baby on NICU until the next day following the birth due to an operative delivery, and the feelings of pending loss of their baby were more pronounced in these mothers.

Eric’s father explained how he felt reassured when he received explanations from the neonatal staff as his son was admitted to NICU.

“(on arriving at NICU) I found the baby in an incubator, everything prepared and the doctor who was taking care of him (baby) came immediately. He explained exactly how the baby was, he told me that everything seemed ok, that he needed to spend some time in the incubator, anyway he explained the whole procedure, why he is in the incubator and it was quite safe for me then, I put my mind at rest. When you see your son like that, I didn’t expect it...with all those wires, so small, because he was born two months earlier, so for me he was very small. But then that had been really good on the staff’s part that they came straight away. The fact of not having to wait in front of the incubator, seeing your son full of wires and spending around one hour or half an hour waiting, that was really good because you would be eager for someone to tell you what’s going on but as I am saying, not even two minutes had passed, as soon as I went through the door, it seemed as if they were waiting for me, he (doctor) came and said so, so and so...that he was on a respirator which was set very low because he (baby) had his own lungs which were working...anyway he explained everything.” (Eric’s dad, 6a p. 1–2)

Anna’s mum expressed her feelings over the first few weeks on NICU, about her daughter’s uncertain survival.

“Initially I felt there was a 50% chance of losing her (baby) because first they (staff) say that the first 3 days have to pass, then when those 3 days passed and she was still receiving phototherapy, and all the other things...the first week needs to pass, then once the first week was over, heqq they were still checking for this and that, it was like the first two, three weeks we felt like being with our heads in the clouds.” (Anna’s mum, 9a p. 7)

During the course of NICU hospitalization, most of the babies included in this study did not experience major setbacks except for one baby who experienced respiratory

complications in the first days following birth. In this case, the parents did express significant concerns over the uncertain survival of their baby.

Aurora's mum explained the rather smooth course of NICU hospitalization for her daughter.

"Basically at NICU we were just waiting for her (baby) to grow because she never needed intubation or anything, it was simply because she was born small. I mean, I wasn't happy, of course, that she was born prematurely, but at the same time we were just focused on her weight every day until she reaches 2kg and we could take her home, that was all. We didn't have any worries, say about breathing and so on because it was always only a matter of waiting for her to grow." (Aurora's mum, 3a, p. 1–2)

Hans' father expressed his feelings when he faced his son's worsening condition and his increased fear of pending loss.

"((with tears in his eyes)) Listen, I really thought of the worst (2.0) I said to myself 'we have lost our son' (2.0). She (wife) was talking to me (on the phone) and she started crying and she stopped talking and a doctor talked to me, I don't know who she was, and I thought my son died and they don't want to tell me...then the doctor said 'It is better that you come (to NICU)' and I asked 'but what happened?' and she repeated 'it is better if you come'. As if she didn't want to tell me. I wanted to ask whether he (baby) was still alive and she (doctor) didn't say that he was still alive, just that I should go immediately and I asked her again, 'but did something happen?' and she said 'no, but come!' Probably she was saying so because she was afraid that I could have an accident on the road cause I needed to drive to the hospital." (Hans' dad, 5a p. 6–7)

Following the initial critical days, the babies started to progressively become more physiologically stable with the result that the parents' uncertain pending loss of their baby was greatly reduced, although it never completely vanished. Fathers particularly expressed how they felt constantly on edge to the ongoing possibility of receiving a phone call with bad news from the NICU. Eugene's father said:

"I didn't sleep at night, always waiting, fearing they (neonatal staff) would call....that something happened, the mobile phone always left switched on because you never know what could happen." (Eugene's dad, 8a p. 24)

Along with the babies' progressive improvement as their condition stabilized, parents' reassurance over the baby's survival increased. However, at this point, their sense of uncertainty took another turn, as there was now space for many unknowns and doubts during the baby's hospitalization. Parents expressed how they had continually sought to

thrive through their uncertainty by seeking information, particularly from neonatal staff, from the internet, and from other parents. Many of the parents, and particularly the fathers, felt that the information they received from the neonatal staff was adequate. Despite their ongoing uncertainty, they were reassured by staff explanations as these reduced the predominant parental reaction of fear of the unknown.

Hans' parents talked of the day-to-day information they received from the staff:

Hans' mum: *"When you ask them (staff) something they always help you and if they don't know, they go and ask."*

Hans' dad: *"they used to say 'I wasn't with him today (the baby), let me go and ask nurse/midwife X because she/he was with him today' and nurse/midwife X used to come and tell us the diary of the whole day, that he (baby) opened his bowels, they (doctors) have increased his milk, they would give us the details of the day."* (Hans' mum & dad, 5a p. 33)

However, despite the information they obtained, the uncertainty felt by some parents was never completely resolved, and this was disturbing for them. Such parents felt that neonatal staff often did not give them definitive answers, and information on the internet was often too generic and medically untrustworthy to allow them to identify what information would apply to their baby and situation. Talking to other parents of preterm infants was often reassuring in terms of identifying that the feelings they were experiencing were similar to those of other parents.

Sofia's parents talked extensively of their need for clear information. Although they believed that neonatal staff had given them a lot of information, there were times when they still felt that their questions had not been fully answered, which exacerbated their uncertainty:

Sofia's mum: *"As a parent I think that something that used to make me feel uncomfortable was that whenever I used to ask a question, they (staff) used to say 'That is normal, it happens in a lot of babies', but 'WHY does it happen?' It is like there is a big question mark on a lot of things, either because they had not been tested or because they (staff) don't know exactly the cause or maybe because they feel it is something too technical for us and so they don't tell us."*

Sofia's dad: *"Unfortunately when they (staff) give you an answer they never, not even the doctor or the consultant mind you, they are never definite about it."*

Sofia's mum: *"they (staff) often said, 'you never know because in babies...' that is always echoing in my head."* (Sofia's mum & dad, 1a p. 5)

Uncertainty featured not only directly related to the baby's physiological functioning but also to other aspects of care, as in conflicting advice regarding infant feeding particularly for those mothers who wanted to breastfeed their preterm baby. Such uncertainty left mothers confused especially about how to manage with breastfeeding their baby at home following discharge from the NICU. These situations of added parental stress, highlight the need for parents to receive adequate on-going information tailored to their needs and situation.

Kristoff's mum shared this view:

"What I feel had confused me was how I was going to feed the baby when I go home. There (on NICU) he was fed every three hours for eight times a day and with the other child I always breastfed him on demand. So when we came for discharge I asked them (staff), 'how am I going to feed him?' ... I got confused and everyone started giving me their opinion, and if I spoke to six, the six of them told me differently. Some were telling me that he is still small and to try and force him to drink every three hours, wake him up, so I got confused what I should do ((confused expression)). Then there was a midwife and I asked her, because I was asking everyone to get everyone's opinion, and this one asked me 'What did you do with your other son?' I told her that I breastfed him on demand, and she said 'then do that and just keep an eye on his weight' and she also said 'try to give him a bottle of expressed breastmilk before he sleeps so that you are sure that he has had his amount' and that is what I did when I came home and I started going to breastfeeding clinic to check that his weight was good and that was working (for me)." (Kristoff's mum, 4a p.17–18)

Some parents, and especially mothers, were uncertain if their baby would ever leave the hospital. This was worse for parents when they were given no indications of their baby's discharge date. Some could not believe it when the day had come for them to take their baby home. For some fathers, timing of discharge was experienced as being unexpected, unannounced and occurring suddenly especially when parents were asked to room-in with their baby on NICU for the last day prior the baby being discharged. Parents were confused by what seemed to them as having been hasty decisions about discharging the baby, with the result that they could not understand the scope and purpose of rooming-in with their baby. In these cases, rooming-in turned out to be a negative experience for them. It was felt that discharge was abrupt and the NICU door closed too quickly on them, literally and philosophically.

Kristoff's mum shared this view about rooming-in and the unexpected discharge day,

"I don't know why we did rooming-in, I mean because ok they (staff) tell you to do it so that they see how you (parents) get along on your own, but I don't know really what difference it would have made if I came home not having done it (rooming-in)...we were pressured to do it. Pressured to do it on that same day...they (staff) didn't allow us to do it say, on the next day." (Kristoff's mum, 4a, p. 14)

Elsa's dad added,

"I think the NICU door closes a bit too fast (on the parents), this is something I felt...when we left it felt very scary. It was like 'eh she is being discharged today, good, ok thanks, bye' It was literally, 'thanks, bye'...it was abrupt, you know, there had been all that caring then, when it came to leave...it was very impersonal when we left...it was too abrupt....there was too much coldness when we left, you know?, 'eh ok, ok, bye bye' ((father imitates the sound of a door slamming shut))." (Elsa's dad, 7c p. 37)

6.3.2 Embracing reality

Many parents seemed to accept that there would always be uncertainties in their life with their child and many feared the unknown of what the future holds. Some uncertainties which parents faced from early on in their experience, when their preterm child was born, still lingered on later in the process, especially for mothers. This became clearly evident when uncertainties cropped up in their narratives in each of the three interviews held with the same couple, even at six months after the baby's hospital discharge. Some mothers were still concerned about what had caused the preterm birth, and both parents often expressed continuing concerns with the possible future long-term consequences in their child's health and development, believing that their baby must have missed something in utero and subsequently feared future repercussions.

Sofia's mum expressed her concern about her daughter's development:

"Obviously what is mostly on my mind, is that she (baby) reaches the milestones according to her age and in fact every time we go to the doctor I make sure that I ask the question, 'what should she be doing in the next weeks?' so that I am on the alert to know what she is supposed to be doing." (Sofia's mum, 1b, p. 3)

Kristoff's parents shared their concern regarding the possible repercussions their son could have due to the prematurity:

Kristoff's mum: *"I always have these thoughts, until I see certain developments in him (baby), the thoughts are always there....there were two months missing*

from the pregnancy so until I see certain developments...this is my major concern."

Kristoff's dad: *"for me it's the same thing, I worry because the natural process was not complete (the pregnancy), so something must have been missed."* (Kristoff's mum & dad, 4b p. 3)

Over time most participants came to cope through acceptance of uncertainty as part of their daily living. This gave most parents a changed perception of reality, accepting the reality of what happened in their lives, having had a preterm child and the resultant NICU experience and with that accepting any future repercussions related to prematurity. Accepting this new reality as part of their daily life seemed to have given the parents strength and aided them to cope with life adjustments and enabled them to move on.

Eugene's mum said:

"In my heart I say that if there had to be something (wrong) with him (baby) I must be able to take care of him, I don't think much about this but this is how I reason, after all whatever happens." (Eugene's mum, 8c p. 4–5)

Ultimately, most parents took a positive outlook to their lives and chose to live positively, being hopeful and focusing on the positive aspects of their child's wellbeing. Having had healthy preterm babies, the parents in the study were also continually being relieved from the burden of uncertainty when an unknown was positively answered as when the child progressed to a new milestone. Parents appreciated every little progress that the baby made and this caused them to rejoice and overcome the fears related to uncertainty.

Hans' father talked of appreciating the changes in his son's development:

"I appreciate it when I see changes in his developments, two days ago he started to sit down and holds on and when I call him he tries to come to me although he doesn't walk yet...and also he waits for me with that smile, as I go in (into a room) on tiptoe and when he sees me he smiles and giggles...now there is something new each day." (Hans' dad, 5c p. 3–4)

Most parents looked back at their NICU experience as having been an opportunity for learning and felt privileged that they had learnt how to care for the baby prior being on their own at home. The many uncertainties parents had regarding caring for their baby and meeting its basic daily needs, such as handling, bathing and feeding were answered while on the NICU as parents felt that the neonatal staff prepared them on how to care

for their baby, so that once at home most parents, especially mothers felt confident and competent in care taking tasks. Anna's mum said:

"Someone who had a baby at forty weeks and spent only three days in hospital and went home, had only three days chance to learn and I had six weeks chance to learn...this is something positive, cause I spent six weeks learning at NICU." (Anna's mum, 9c p. 17)

However, once at home other uncertainties emerged relating to caring for the baby in the home environment, like achieving an adequate ambient temperature or establishing the baby's sleeping pattern. From time to time through the first six months at home with the baby, parents, and especially mothers, experienced changes in the baby's daily routines and found themselves readjusting the care they gave. Their capacity to adjust to the uncertainties faced as the child grew became a positive source of confidence for future accommodation to new uncertainties.

Aurora's mum talked of changes in the baby's routine and the adjustment around her:

"Since we came home it is much better now, before she wouldn't sleep the whole night, she used to wake up every two hours. During the day she used to cry for most of the time, you have to lift her up all the time. Now she wakes up in the morning, drinks, sleeps for another two hours, so she gives me time to do more things, and it is easier to go out with her too...it's a matter of getting used to her and her routines." (Aurora's mum, 3b p. 2)

As more time elapsed, parents realised that for them the reality was that the outcome of their premature birth was good, and their child was healthy. They felt constantly reassured by the baby's progress and their fears and uncertainties gradually subsided. Everything seemed to have turned out well in the end. The participants were grateful to the neonatal staff who had cared for their preterm infant on NICU. Many parents felt lucky that their baby had a positive outcome particularly since they had seen other preterm babies on the neonatal unit whose condition had remained critical.

Sven's mother talked about the neonatal staff on NICU and the care they gave to her son while on the unit:

"They (neonatal staff) are so dedicated there (NICU) that I used to come home with my mind at rest knowing that I left him (baby) in good hands. It's true, I never used to worry that I left him there because I knew whom I left him with. I used to say that there (NICU), there are his second parents and the baby needed to get well so he needed to be there. And he really improved quickly thanks to their care, they are truly dedicated, a lot, a lot. My mind was at rest." (Sven's mum, 2a p. 26)

As time went by, parents particularly fathers, seemed to cope by focusing on the present and looking positively ahead to the future. They chose to put the NICU experience of prematurity behind them. It was now over their shoulders like a closed chapter and moving on to the next episode, hopeful of a brighter future with their healthy growing child. They chose to live day by day, appreciating the moment and not lingering on the past. When narrating their experiences, parents focused on the day-to-day happenings at home, indicating the significance of the present to them. For them, thinking far ahead would be missing the present, life in the here and now and they became aware of the need to capture the present moment because once gone, it would not be back.

Kristoff's dad had this to say about living life 'in real time':

"I think that when one thinks far ahead one would be missing the present. Thinking too much on what might happen, makes you miss the present."
(Kristoff's dad, 4a p. 29)

Many parents expressed how they looked positively ahead, while the NICU experience seemed like a bad dream in the past, which was over and gone. They talked about accepting the future with whatever it holds, and believing that destiny cannot be changed. Despite this apparent fatalism, they believed that the future would in fact be brighter, as the child grew, started school, and became an adult, and they wondered what their character would be like.

Kristoff's dad said:

"The glass is still half full...we're trying to get out the positives from what we have gone through, otherwise we despair. We shouldn't say that things could have turned out worse either, things have turned out as they did, this has been our story, we accept reality and walk on forward." (Kristoff's dad, 4a p. 23)

Mothers who intended to return to work after a period of maternity leave were faced with another uncertainty of the changes this would bring in their daily life. Those who had returned to work prior to the third interview were relieved that the uncertainty they feared had been resolved since in reality they felt that they managed to adjust their life's balance to include their new work routine too. Some other mothers who had extended their maternity leave into child care leave, were still faced with the uncertainty of what adjustments would be needed in their life once they return to work. Although these mothers still had some more months before they would resume employment, they were

often thinking ahead and were already planning how to manage childcare when they and their husbands would be at work.

Sofia's mum talked about her experience of returning back to work:

"What I can say is that I thought it (going back to work) was going to be much worse, in the sense that I feel that the transition was smooth for me, because everyone told me that I would really miss her and so on; I am not saying I didn't miss her, I don't want to sound badly, but going back to work in a way it's like my life was coming back to normal because before I was with her (baby) for 24 hours, and I am a person who enjoys working really, I am quite ambitious and the fact that I was at home all the time I was noticing that my mind was slowing down ((laughing))...and even with her (baby) I realized that after not seeing her for eight hours, I play with her more then. I am working reduced hours so I still feel I am spending a lot of time with her, because every other day I'm home fulltime with her. When I am working, I phone during the day to see how she (baby) is doing. Obviously we go out early in the morning, I leave at about seven or quarter past seven, and I take her (baby) to my mum then I phone about two times during the day. I pick her up around quarter to five and we come home." (Sofia's mum, 1c p. 5–6)

Eric's parents were thinking ahead for when Eric's mum returns to work and how they would manage child care:

Eric's mum: *"I am going back to work in January, so we are thinking about who will be taking care of him (baby)."*

Eric's dad: *"We have already told my mother that once she (wife) returns to work, she (grandmother) would be keeping him (baby) quite a bit and it is possible that even her (wife's) mother would be keeping him a bit too, we have no problem with that. So we are thinking far ahead." (Eric's mum & dad, 6b p. 7)*

6.4 The second main theme: Reaching out

Theme 2 – Thematic structure

Main theme:

Reaching out

Sub-themes:

Longing for proximity

Narrowing the gap

Reaching out reflects how parents constantly sought closeness with their baby following the initial detachment experienced at birth. While in hospital, parents often experienced their child as being out of reach as multiple barriers kept them distant from their baby particularly in the early days on NICU. The parents' longing for proximity towards their child was reflected through their struggles to be as close to their baby as possible. Their strong desire for proximity ultimately led to a narrowing gap. Parents gradually experienced growing connectedness with their baby when the distance started to narrow, particularly towards the end of hospitalisation and even more effectively once at home. The sub-themes encompassed in this second main theme are: *Longing for proximity* and *Narrowing the gap*.

6.4.1 Longing for proximity

Following the preterm birth, fathers usually accompanied their babies on admission to the neonatal unit, so they had a chance to look at their child. At birth, some mothers got a glimpse of their baby, while many mothers did not get this until the next day, having had their newborn quickly wheeled away and taken to intensive care. Kristoff's mum said:

"I didn't see my baby after being born, the first time I saw him was the next morning (following birth)." (Kristoff's mum, 4a p. 6)

Parents experienced the birth of their preterm baby as a process of becoming disconnected and distant from their child. Mothers felt a real, visceral sense of disembodiment, as their babies had been taken away from within their bodies to somewhere else, somewhere that they did not know and could not even effectively imagine, to people who may or may not care for their child with the kind of loving kindness they themselves wished to express. Having experienced a disconnected start, parents were left with longing to be in close proximity to their baby, to be able to see, touch, hold and care for their baby.

With eyes welling up, Sven's mum expressed her heartache as her baby was taken away soon after operative birth:

"Initially I took it really badly the way it happened, sort of at one point he (baby) is inside me and all of a sudden they (staff) took him away, not even

giving me a chance to cuddle him. It's like I didn't realise I just had a baby of my own ((surprised)). I felt as if they had taken something from within me. They (staff) are not to blame, because it was for the best of the baby, but for me it was traumatic." (Sven's mum, 2a p. 1)

Bodily disconnection has been so deeply felt that some mothers explained that they felt as if they did not have a baby at all. Having the baby taken away made the birth unreal for many mothers, it felt like a dream. This was particularly so for those mothers where this preterm birth had not been their first childbirth experience and they could compare the feelings they experienced with the preterm birth to their previous birth/s where the baby had been born at term and they could see, touch and hold their baby from shortly after being born without having their baby taken away from them.

Eugene's mother said that having the baby felt like a dream and both parents expressed how they could not be happy at the birth of their preterm child.

Eugene's mum:

"when I came home, sometimes I would be hanging the baby's clothes and say, 'did I have a baby? did I have my baby?' It was like I was in a dream." (Eugene's mum, 8a p. 10)

"I felt like I couldn't say that the baby was born (1.0) because to me the fact that I had not taken him home, it was like he hadn't been born yet...I couldn't celebrate, I couldn't be happy. I used to say, let me wait until he is home, I put it on hold (2.0) that is how I felt." (Eugene's mum, 8a p. 33)

Eugene's dad:

"It all happened so suddenly, we weren't expecting it...I couldn't be happy." (Eugene's dad, 8a p. 11)

At the time of data collection, the local neonatal unit had an 'open' visiting policy with some restrictions where parents could be with their baby on the unit at any time of the day and night except during ward rounds, shift handover, emergencies and admissions of new babies. In the early days of NICU hospitalisation, when mothers were still hospitalised on the maternity wards, mothers spent long hours next to their baby and most of the time they were accompanied by their partners, who often made work arrangements to be with their partner and baby in the first few days following birth. Aurora's mum said:

"I used to spend my days there (at NICU), it was like I was at work." (Aurora's mum, 3a p. 20)

Parents sought to be with the baby as much as possible on NICU even if their contact was only through their presence and looking on at the baby. The emotional pain which accompanied early disconnections left the participants longing to be close to their baby resulting in parents' need to be on the unit for as long as possible every day. Indeed, their presence, Being-there, on NICU next to their baby was felt to be the only way they could parent their child.

Aurora's mum felt restricted from Being-with her baby as much as she wanted:

"I used to see the morning go by slowly until it was time to go to NICU, because in the morning I couldn't go before 11 o'clock. Sometimes they (staff) even let me in later (than 11 o'clock), because of the doctors' round. I used to feel very bad in the morning." (Aurora's mum, 3a p. 24)

In the early days of hospitalisation of the baby, which were often restricted to just looking at the baby, parents sought to move closer to their baby by obtaining information about the baby and the daily happenings pertaining to their child. It seemed that parents needed to fill gaps in their baby's story and the information they received from neonatal staff about their baby's condition and progress provided missing pieces in their puzzle. For parents this felt as a way of getting to know their child more.

Hans' father talked of having been kept well informed:

'They (staff) used to tell us about the whole day, 'today he (baby) opened his bowels, his feeds were increased' and so on, so they used to give us all the details of the day, I feel I cannot thank them (staff) enough'. (Hans' dad, 5a p. 33)

Sofia's mother expressed how she wished to read through her baby's history on the hospital file, so that she could put more puzzle pieces together and know more about what her child had gone through.

"I knew that a file (baby's records) was being written about her (the baby) but I had no access to that information, that thing really upset me...how I wish I could read that book (medical records), so I would know exactly what my daughter has been through, cause I was not there (on NICU) for 24 hours'. (Sofia's mum, 1a p. 15)

On the contrary, when parents felt that they had not received sufficient information, especially over the phone when they were not physically present on the unit and phoned to ask how their baby was doing, the situation made them feel more, and not less distant from their baby.

Sven's dad: *"They (staff) used to tell us that we could phone NICU to see how the baby was, so we used to phone to ask about our baby, ok, but then their reply would be 'we can't give you information' (over the phone)."*

Sven's mum: *"That used to annoy me because you might as well not phone in the first place. We used to phone, cause you know, when you wake up the first thought that you have, having him (baby) there (on NICU), is about him, so when I wake up the first thing I used to do was phone NICU. But, I might as well not have phoned at all because they would just say, 'Ok good' and hang up, so it's like you didn't phone at all."* (Sven's mum & dad, 2a p. 7)

Generally parents described only occasional contact with the doctors on the unit who gave them information regarding their baby's condition and treatment. Consequently, most parents would have liked to have more contact with the doctors and felt that communication with them had been lacking. Some parents believed that the relationship that they had with the midwives and nurses was generally sufficient since they provided the daily updates about the baby's condition and care and they had not really sought to have contact with the doctors. Yet, some other parents were often distressed by this and expected regular contact and updates from the doctors too, primarily because they viewed the doctor as the person who ultimately was prescribing the treatment and care to their child. On the first interview, at one month after NICU discharge, Anna's mum said:

"The doctors never talked to us, in the six weeks that we spent there, we always talked to the nurses and midwives...the consultant or the doctors in whose care she (baby) was never spoke to us...but we didn't feel the need to talk to them as such either because we felt that the nurses and midwives used to tell us everything, how she's doing, her progress, the equipment, test results, we got to know everything from them." (Anna's mum, 9a p. 12)

However, although this mum was happy with her interaction with the nurses and midwives, later she expressed that there should be more contact between the doctors and parents, and identified that this had been missing in her experience on the unit. She said:

"...I think the doctors, the consultant, they should have more contact with the parents....although the nurses and midwives there are all very good...but you (as parent) would wish to hear certain things from the consultant." (Anna's mum, 9c p. 11)

Taking pictures of their baby was another way how most parents sought to fill the gaps in their baby's story. They sought to create memories by taking photographs as the child progressed on the unit. Taking pictures acted as proof of reality, that having had the baby was real in the midst of the unreal and unexpected circumstances of commencing parenting. However the parents' needs for physical photographic evidence (both to keep them in touch with what was happening with their baby currently, and as a means of future memory-making) seemed not to be understood by neonatal staff, who often barred parents from taking pictures of their baby, claiming to be bound by hospital policy. Sven's father said:

"We had no idea when he (baby) would be discharged, so we felt we were going to miss all those changes in his growth and we would have no memory, no memory of how he was in hospital, so I just took the photos." (Sven's dad, 2a p. 13)

NICU hospitalisation often denied the parents' need to hold and cuddle their baby. For many parents minimal touch had been experienced through most part of hospitalisation. The incubator was experienced as a major barrier between the parents and their baby. Parents felt distant from their baby when their contact was limited. Gradually, most participants felt that they were moving closer to their baby when on the unit and were overjoyed when the baby was transferred from the incubator to a cot. Eric's dad talked about the incubator and the barrier it created and how it prevented him from moving closer to his son:

"When he (baby) was in the incubator we used to open the ports next to him and we used to stroke him a bit. We used to enjoy it when he opened his eyes, because he was with his eyes closed for most of the time, when he used to grab my finger and feel him pulling...then it was much better (in the cot), we could hold him, we could see him better, because as long as he was enclosed in the incubator, there was a certain distance between us and the baby...it was a moment we were waiting for. When he was in the incubator, we used to see other babies in the cot, and we used to say, 'when is our baby going to be in the cot?' we were looking forward to that (to have the baby in the cot)." (Eric's dad, 6a p. 6–8)

NICU routines were also experienced as being restrictive to parenting on the unit. Elsa's father angrily expressed how these made him feel that his daughter was not really his and how he spent the first week on NICU with the monitors and not with his child.

"I spent my first week with the monitor not with my child, as if it were the monitors that were born, because I couldn't keep my eyes of them." (Elsa's dad, 7a p. 24)

Parents expressed how they felt further distanced and disconnected from their baby when the mother was discharged from the maternity ward and they went home *without* the baby. This was a major blow for the parents particularly the mothers. Going home without the baby felt like leaving a part of them behind. Elsa's mum sadly recalled:

"It is so awful to go out of there empty handed ((looking sad))." (Elsa's mum, 7a p. 34)

Sven's dad expressed similar heartache by saying:

"People brought us cards, balloons or soft toys, and we left the hospital (2.0) with only these things, without him (the baby)((eyes welling up)) (3.0); we were already separated (from baby) as he was in the unit, but it felt worse when we arrived home without him. Being away from him (baby), coming home and the baby is still there (NICU). That was a heartache." (Sven's dad, 2a p. 8)

Being-with the baby on NICU after the mother had been discharged home was often an emotional and physical struggle for many parents, who felt restricted by the unit's visiting policy, work, home and travel arrangements. Consequently, they felt robbed of precious time to be with their child. They tried to make up for it by spending as much time as possible in the neonatal unit despite the logistical difficulties, the physical pain and the fatigue they felt. This was particularly true for the mothers as they made every effort to be with their child as much as possible, but both parents usually visited the unit together every day. Sven's dad expressed his heartache at having limited time to be with his baby on NICU:

"...going there once a day was a heartache because I wanted my baby, my newborn, I wanted to see him all the time. I wanted to cuddle the baby with me all the time." (Sven's dad, 2a p. 3)

Parents' expressed their craving for closeness to be with their baby through their constant fight against time, to make maximum use of the time they had to be with their baby. This often meant going directly to the hospital after work for many fathers, spending more time in travelling than time actually spent next to the baby, leaving other siblings at home. For many of the mothers, it meant enduring the fatigue from travelling following an operative birth. Eugene's mum explained her discomforts when visiting her baby after her husband's return from work:

"The trips to hospital were very tiring, I mean first of all, I had just had a baby, so instead of resting, we were walking all that distance, that long corridor, it

seemed never ending....then we used to stay there till 10 o'clock every night, sitting down with the sutures I had, I used to become numb and not able to stand up, but I didn't bother physically, I always looked forward to going next to him (baby)." (Eugene's mum, 8a p. 6–7)

Many parents talked of the long walk they had to make every time they visited the baby. The NICU location within the hospital is very far away from the visitors' car park and parents' accounts revealed the suffering this caused them. They felt that the wasted time until they got to the unit, particularly from walking the long distance, meant that they were being denied valuable time which they could have spent with their baby, especially when they were already restricted with having limited time to visit. Sofia's mum said:

"The thing that used to annoy me most was the walk to NICU (1.0); it is really not positioned well, it is a long walk and I would be eager to see the baby...I would really want to see her (2.0) it is useless phoning NICU in the morning and they tell you everything is alright, still I would want to see the baby. Until I got to her, I saw it as a very long way." (Sofia's mum, 1a p. 12-13)

On the neonatal unit, some parents dared not touch their baby, fearing they could harm the baby and so looked on from a distance. The baby's small size and the associated fragility caused some parents, particularly fathers to keep a step back from touching or holding their baby, restricting their connection with the child. Aurora's mum talked of how she was afraid to touch her daughter when seeing her so small and fragile:

"At first I was afraid to touch her (baby) because she was so small (when in incubator), then when she was taken out of the incubator and put in a cot, that was different cause then I could hold her, bathe her and so on...in the cot she became more my baby." (Aurora's mum, 3a p. 3)

While on NICU parents often felt they needed to seek permission from the staff to touch or hold their baby. This often denied the parents' contact with their baby particularly when some parents did not dare ask any of the staff, especially when staff appeared to be busy doing other tasks on the unit. Parents depended on the staff's attitudes and behaviour and generally waited to be invited to connect hands-on with their baby. Variations between staff could be identified by the parents. When not encouraged by the staff, parents often experienced missed opportunities to connect with their baby in this way. These situations reinforced the unreality of parenting on the unit and that the baby belonged more to the staff than the parents. This may explain why some parents, especially fathers, experienced their connection with their baby as being slow to evolve. On the other hand, parents appreciated when they were approached by staff themselves, and helped and encouraged to establish their needed contact.

“We wouldn't open the incubator ourselves, we used to ask the staff, I mean they used to come immediately, so don't get me wrong, once you ask them, they would just come instantly eh, but the fact that we had to ask them. That stopped (once the baby is put in the cot) so we could just go and pick the baby up and say that this baby is ours. So we were very eager for the baby to be in the cot.” (Eric's dad, 6a p. 8)

Seeing staff giving compassionate care to the baby as if the child was their own, was appreciated by many parents. However, there was a delicate balance to strike for staff, there were instances when parents felt that they became overpowering and took over the parenting role, restricting them from parenting their own baby. Elsa's parents expressed their frustration as they felt that on NICU their daughter belonged to the staff, who often took over, particularly with feeding the baby when she was slow to feed. Hence, there were parents who felt restricted to moving closer to their baby as much as they wanted due to limitations from the baby's condition and staff behaviour:

Elsa's dad: *“I used to tell her (wife) that this baby is my daughter, but here (on NICU) she's not...I walk in there, to see my daughter...but in there she is not my daughter.”*

Elsa's mum: *“Some staff are too much of a mother themselves. They are mothers, I know most of them are and they start mothering your baby themselves. I wanted to try (to feed her) myself, to try myself as much as possible but it's like some didn't give me that chance because they became overprotective on her, they get attached maybe, I mean I don't blame them but it's like I didn't have the opportunity, then I started realising that I needed to start taking over...by all means they do a very good job but at times they are too much a mother themselves. Some tell you to try, they give you a chance, but not all of them.”* (Elsa's mum & dad, 7a p. 5–6)

There were also times when parents felt ignored by staff especially when they were not adequately informed about some aspects of the baby's care. Such instances were experienced by the participants with feelings of helplessness and disconnection from their baby as they felt that their parenting role was being overlooked. Consequently, parents felt dominated by and dependent on the staff. Sofia's parents expressed their anger when their daughter was being given medication which they were not aware of.

Sofia's dad: *“I remember once, a nurse came and I got really angry that day; she came and with a small syringe, she just xu:::pp! (father makes sign as if pushing the syringe very quickly), she gave her (baby) some treatment. I was really angry, I felt like 'what are you giving her?' because I was following everything what she (baby) was going through and the treatment given”*

Sofia's mum: *".....she (baby) was in my arms, (to husband) 'do you remember?' She was in my arms, and she had the tube in her mouth; she (nurse) took away the tube and without saying anything to me, she just got the syringe and injected something. I asked her 'what's that?' I hadn't yet finished my question, she had already given it. She (nurse) said that it was routine medication. No one had told me that she (baby) was taking something; then I realised it was thyroxine, until then I didn't know that my daughter had been taking it for about two weeks. I mean, I wasn't informed. The nurse was startled then because I told her (angrily) 'how dare you give her something without telling me, I am her mother, she (baby) is on me, you just take the tube away, and I am telling you I don't know what it is and you just give it?' Couldn't she by mistake have given it to my daughter instead of to someone else! Because as far as I knew my daughter was not on medication."* (Sofia's mum & dad, 1a p. 15–16)

Despite the many positive interactions the parents had as Being-in-the-world with others, namely with the staff on the neonatal unit, each of the parents' stories was influenced by negative staff encounters, as described above, which increased the parents' feelings of disconnection from their own baby when on the unit. On reflection the impact of negative experiences on the parents has been quite extensive considering the detail and anger with which parents recounted the events. Additionally, the effect of such interactions seemed to be long lasting since parents often referred to the same negative situations on more than one occasion when the data was being collected for the study and extending even to the last interview done, at six months post discharge of their baby from the unit.

Sven's parents expressed their distress resulting from a negative incident they experienced on NICU which including their son and a staff member, who they believed did not feed their baby gently enough through the naso-gastric tube. As a result the baby started vomiting and experienced a setback in his care and consequently prolonged his hospital stay. For the parents this incident added to being distant from their baby since they believed that if this had not happened the baby would have been discharged and united with them at home earlier:

Sven's mum: *"Once we believe that our son didn't retain the feed because it had been given in an uncivil way. We saw her (staff) with our own eyes, it was because of her that then he (baby) had to spend another three days on the drip only, and not drinking anything, because then they had to see whether he vomited because it was something wrong with his stomach. I don't know, but that's what we think) (2.0) because we both saw her with our own eyes ((upset)) (turning to husband) you can confirm this."*

Sven's dad: *"yes, and I told her (nurse)"*

Sven's mum: *"He told her to her face, he told her, 'don't you think it's because of the way you gave him the feed (that is why he vomited)?' Because it was only when she gave the feed that this happened, he had retained all other feeds, I mean we had seen her, it was not like someone told us about it, we saw her how she gave him the feed. It was like she forced it down - then he threw it up..."* (Sven's mum & dad, 2a p. 14-15)

6.4.2 Narrowing the gap

Although many mothers talked of feeling an instant and early bond on seeing their baby, they expressed the difficulty they experienced in strengthening such a bond. Some mothers found it difficult to bond with their baby from an early stage after birth. They felt bonding with their baby really started later on. The lack of direct physical contact with their child has been expressed as being the cause for these disconnections. Fathers talked less explicitly about bonding with their baby in the early days after birth. They expressed their bonding through their interaction as the baby grew beyond the intensive phase of hospitalisation. Elsa's mum shared her view about her instant bond with her daughter:

"I don't know how some say that they didn't bond with their baby, now I really had things against me, I didn't hold her (baby), didn't touch her, but that thing of feeling an instant bond, it was like static, it is something which I cannot really describe." (Elsa's mum, 7a p. 37)

Sven's mum expressed her difficulty in bonding with her baby:

"The NICU staff did their best and after a few days they removed him (baby) from the incubator and gave him to me to hold so I start feeling a bit of a bond. He was still in the incubator and it was really nice for me, a surprise. When we went there (on NICU) she (staff) told me 'of course you can hold him'. I told her that up till then I wasn't feeling anything towards him, it was like I didn't have a baby, I didn't feel a bond towards him, he was still without a babygrow, naked with just a blanket. That was the nicest day for me because when I held him for the first time I felt an instant bond and joy. From then on the bond started to get progressively stronger." (Sven's mum, 2a p. 16 – 17)

Parents reported that they became more connected to their baby as the distance between them started to narrow and they were in closer physical proximity to their baby. Holding the baby for the first time and having the baby being transferred from an incubator to a cot were major turning points for the parents as they felt moving closer to their baby. Progressively the parents in this study felt that the baby became more accessible to them although still under the restrictions of the NICU environment. Kristoff's mum talked of her increased contact with her son after being transferred to a cot:

“As soon as they (staff) put him in the cot and I could handle him, I took the initiative and began changing him when it was the time to do it, every three hours. So there was contact, but only when he was taken out of the incubator.” (Kristoff’s mum, 4a p. 12)

Parents felt that through their relationship with supportive and encouraging staff, who instructed them on how to physically care for the baby, they were helped to move closer to their baby. Many fathers also felt they were encouraged and included in caring for their baby on the unit. Parents felt happy to become bodily engaged with their own baby while meeting his basic care needs on NICU. When they participated hands-on in the baby’s care, parents felt a growing, closer relationship with their child. Anna’s dad described how he was involved and learnt to care for his daughter:

“...at NICU they (staff) taught us practically everything what we needed to do, how to change the nappy, wash her and everything, and they supervised over us doing these things, we have learnt....they taught us everything.” (Anna’s dad, 9a p. 5)

Towards the end of hospitalisation, many parents felt that they had gained good contact with their baby as they could do most of the caring activities themselves. Consequently they felt an increased sense of well-being, as progressively increasing participation in care-giving aided them in getting to know their baby and increased their sense of bonding. Anna’s mum explained her increased contact with the baby towards the end of hospitalisation:

“In the last week they wrote on their report ‘nursed by mother’ because I used to go every day at one o’clock (afternoon) to bath the baby, I used to tell them not to wash her at 8 o’clock (morning) and as soon as I arrived, I used to give her a bath myself, feed her, take her temperature ((laughing)), I mean what was left was for me to write her report because I used to stay there till 11 o’clock in the evening. He (husband) used to come at 6 o’clock (evening) and we used to stay there till 11 o’clock (evening).” (Anna’s mum, 9a p. 8)

Although most parents felt that they had gradually moved closer to their baby while on NICU, many still felt some degree of disconnection from their baby in this environment, and they eagerly waited for the day to take their baby home. Elsa’s dad shared his eagerness to take his daughter home after refusing to spend the last day prior discharge rooming-in with the baby:

“I told them (staff) ‘I’ve had enough of this place (NICU)’, I told them ‘you guys are fantastic, you’re great and I’d like to be your friend’...but ‘I want to take my child home.’” (Elsa’s dad, 7a p. 31)

When the baby was discharged home, parents felt that they became parents, they were overjoyed to have their baby all to themselves. Being at home facilitated free, unrestrictive access to their baby, without having to acquire any permission to touch or hold their baby. Anna's dad said:

"now (at home) we are very confident and we got used to the baby, we can do everything for her and don't depend on the staff (1.0) we can pick her up when we want and not in front of all those people (at NICU)." (Anna's dad, 9a p. 13)

Eugene's mother expressed her reactions on being told that her son was discharged from NICU and how going home had felt as if the baby had been born then and that it was then that she really felt the baby belonged to her:

"When we took him (baby) home it was the ultimate joy...at that instant it felt as if he (baby) became ours, there (on NICU) it was like I didn't feel that the baby was mine, I don't know why...it was probably my way of dealing with it (the situation). At that time when I picked him up (to take him home) I felt that he was mine.....when they gave him to me, it was then that I felt that the baby is mine, it felt like it was at that moment that the baby had really been born." (Eugene's mother, 8a p. 20)

Many parents talked of their need to enjoy being with their baby for as much time as possible and this seemed to reflect their need to make up for the time the baby had been away from them. Many mothers expressed how they spent a long time holding and cuddling their baby once at home. Elsa's mum said,

"I spend a lot of time with her (baby) in my arms, I know that to a certain extent I got her used to staying in my arms ...I am ready not to sleep at night and stay like this all day (baby in her arms), the important thing is to give her all I can because I've read that they (preterms) need more security...to be honest with you, if I see her awake in the cot and she is not crying I still grab her, it's the truth...I want to enjoy her as much as possible." (Elsa's mum, 7b p. 10)

In the early weeks at home, some parents insisted that they were not ready to share their baby with others and so they hardly ever left the baby with anyone else and took the baby with them wherever they went. This seemed to reflect the continued craving for closeness the parents had, and now that they had the baby to themselves at home, they still needed to make up for the denied contact they experienced on NICU. Eric's mum explained:

"...he (baby) goes out with us, I don't leave him with anyone as much as possible....generally we take him with us everywhere we go.'" (Eric's mum, 6b p. 3)

Parents expressed that having participated hands-on in caring for the baby when on the unit helped to ease settling down when they were home with their baby. At home they felt able to meet the baby's daily needs and progressively got to know more their baby and were able to identify particular needs, like how to comfort their baby. Aurora's dad talked of how being supported by the neonatal staff on how to care for the baby on NICU helped to make settling at home easier:

"What is good there (at NICU) is that first they showed us everything (caring activities), then they gave us the baby so it is not like she (baby) came home and we didn't know anything... and start worrying how to do things at home to settle down, so for me our transition was more settled." (Aurora's dad, 3a p. 6)

Parents also expressed how they experienced difficult times especially in the first few weeks following discharge from the unit. Changing patterns in the infants' behaviours were perceived as challenging by many parents, especially mothers, resulting in them being fatigued and tired from lack of adequate rest and sleep. Sometimes babies became irritable particularly in the evenings and were difficult to comfort. At times mothers felt restrained to being only with the baby, and not able to do anything else. However, the participants also accepted these challenges as being part of parenthood, and as events that continued to strengthen their connections with their baby. Parents progressively coped with such difficult times and learnt to identify the baby's behavioural cues and meet his needs. All this became part of the parents' new Being-in-the-world at home with their baby. Aurora's mum explained how busy and tiring it was getting as her daughter got older:

"before she (baby) used to sleep more, now she doesn't sleep at all, I am with her all the time...I mean I spend more time with her now more than when she was younger...I don't think I am living these days ((laughs)), I am just with her...I mean because she doesn't sleep much during the day, maybe an hour in the morning, so I get tired because I am just with her, can't do anything else and even in the evening she is sleeping later, she doesn't always sleep at 8 (pm), yesterday she slept at 11 pm." (Aurora's mum, 3c p. 1–2)

In the first month at home, when the baby was still quite small, some fathers continued to experience physical detachment from their baby and did not seek to hold and cuddle their baby so much. The baby's fragility and lack of response at this stage seemed to have held some fathers back from moving closer. Kristoff's dad expressed such difficulty and talked of how he spent more time with an older child, allowing more time for his wife to be with the new baby. However, as the baby become more active, their bond improved, and so he felt more able to communicate with his child. He said:

"I can't wait for the baby to grow so I can communicate with him. I don't feel I can communicate with someone like this (young baby), to be honest, I'm not really that tender. I see him like this, inactive ((baby sleeping))...I prefer it when he's older." (Kristoff's dad, 4a p. 29)

"When I am at home, I try to help her (wife), generally I prepare breakfast for the older child, I try and see that she (wife) takes a break from him (older child) and she stays more with the baby. I try and involve the older child in what I do, we go to the garage, he really enjoys it..." (Kristoff's dad, 4b p. 14)

"Now that he (baby) started smiling at me, that makes a difference for me because when I see him smiling at me and see that he recognises me as I go next to him...I realise we are starting to communicate." (Kristoff's dad, 4b p. 15)

Sofia's dad also expressed how the physical changes in the baby caused him to draw more attention to her:

"When we brought her home, she (baby) was 2.085kg on the first day, so she was still very small. I think at almost 2kg, I saw her as being very small for a new parent like me. I used to be afraid to handle her (2.0) but I still used to hold her although I was really tense. Now that she is growing, it is much better for me to handle her." (Sofia's dad, 1a p. 19)

All parents experienced growing interaction with their baby as the child grew more. Parents were happy to engage in activities that not only included care taking activities but also interaction with the baby especially through play. Fathers often sought to have their own 'daddy time' to be alone with the baby, usually after work, to play and interact with their baby. Fathers often expressed the wish to have more time to be with the baby especially when their contact was much less compared to their partners', who spent much more time at home. In fact, even when at work fathers tried to maintain contact by phoning home and asking about their baby. They appreciated receiving on-line pictures of their baby from their partners.

Eric's dad talked of his limited time to be with his son:

"I wish I have more time to be with him (baby) because the time that I have is limited, it is not like her (wife), she has all day with him, I come from work and my time with him is much less." (Eric's dad, 6c p. 2)

Eric's dad continued by saying:

"when I come home from work, I always spend at least an hour with him (baby), because I am not here as much as her (wife), he sees me much less, but that hour with him, I feel I have to do it because I want to and I won't do anything else before I spend that hour with him." (Eric's dad, 6c p. 2)

The more the babies grew and developed, it seemed that they were also doing their own part to move closer to their parents, as they learned to identify their familiar faces and respond to their love and care. This gave the parents great joy as they experienced a new sense of parenthood, that now their child acknowledged them as his parents which was the affirmation that they ultimately needed to feel that they had become new parents to their newborn. Aurora's parents talked about their daughter's increased interaction:

Aurora's dad:

"Now I notice (baby) that she enjoys looking around and observing, observing us (parents). Even if I walk away, I can see that she is following me with her eyes, she smiles back. We didn't expect her to do such things so early, we thought it would take much longer, but she is doing them accordingly with her age...." (Aurora's dad, 3b p. 11)

"Before it was just feeding her (baby) and she sleeps, now I hold her, talk to her, she smiles back, I play with her, now it is different, there is more interaction." (Aurora's dad, 3b p. 13)

Aurora's mum:

"Now she (baby) tries to play, she smiles back when I play with her, she wants to interact. Sometimes I feel like doing nothing and just play with her, I enjoy it ((laughs))." (Aurora's mum, 3b p. 11)

Eric's dad expressed his delight when he was welcomed home by his son's smile when returning from work:

"When he (baby) sees me coming through the door, he recognises me immediately and smiles. I play with him a lot...I come in (from work), wash my hands and I spend an hour playing with him." (Eric's dad, 6c p. 3)

6.5 The third main theme: Watching vigilantly

Theme 3 – Thematic structure

Main theme:

Watching vigilantly

Sub-themes:

Defending the defenceless

Cautiously letting go

The third main theme, *Watching vigilantly* reflects the parents' experiences in surveilling and protecting their preterm baby as much as they could, both when on the neonatal unit and even more so when at home, when the responsibility of the child's care became completely their own. The sub-themes identified in this theme, *Defending the defenceless* and *Cautiously letting go*, reflect how parents transitioned from times when they were very protective over their preterm infant, particularly when the baby was still very small, to becoming less obsessed with such protection as the child grew more and they started letting go of the more extreme practices they had adopted earlier, when they had still viewed their baby as being very fragile and vulnerable.

6.5.1 Defending the defenceless

As parents entered the NICU space they were overwhelmed by the highly technical environment associated with the intensive care given to the babies admitted in this place. The frequent beeping of alarms on numerous monitoring equipment, was something which more often than not alarmed and distressed parents from their earliest days on the unit. Parents would fear that something was wrong with their baby whenever the alarms beeped. Sofia's dad said:

"Alarms alarming all the time" (Sofia's dad, 1a p. 4)

Over the first few days of NICU hospitalisation, parents learned what the monitoring equipment was used for and understood the role of such devices in surveilling the wellbeing of their preterm infant. The technical environment resided at the parents' 'foreground' for most part of their experience on the neonatal unit, so parents developed a feeling of security over time in this lived space on NICU especially when they believed that their child's health was adequately monitored by both staff and the technology used. Anna's mum said:

"When she (baby) was in the small room, the more intensive (area), in front of the (staff) desk, they (staff) would immediately know that she (baby) moved a little...thank God they (staff) were very vigilant on her (baby)." (Anna's mum, 9a p. 6).

When still on NICU but following the critical phase of their baby, the focus of monitoring shifted to the amounts of oral feeds and the daily weight measurements of the baby. Parents closely observed the daily changes in such aspects of care and recalled being very eager to know daily how much their baby's feeds had been increased and

whether their baby had increased in weight. Observing the documentation charts on the baby's incubator or cot was one of the first things most parents did daily as soon as they went next to their baby. Parents were anxious for their child to reach the 2 kilogram weight because they knew that this was the discharge weight according to the local NICU discharge protocol. Every decimal value in weight that the child put on, was perceived by the parents as being a closer step to going home. Sofia's mum said:

"When she (baby) started to gain weight, because initially she lost weight, she was 970 grams and lost more...when she started increasing in weight, for us every gram (she put on) was something really big!" (Sofia's mum, 1a p. 11)

Parents became dependent on staff and monitoring devices which instantaneously detected any changes in the child's wellbeing. Leaving the unit was a joyous moment for most parents but it also meant losing the security which the neonatal unit offered and on taking the baby home, many parents felt anxious about the change in space, despite this had been a much awaited event. Although parents were moving to a familiar space, home was a 'new' space for them to live 'together with' their baby. Until discharge, the NICU had become their 'known' lived space, where they had lived with their baby. Anna's mum said:

"At first it was a bit scary, because here (at home) if something happens, it's just us two (parents), there (at NICU) there were all those staff and the machines, so it is different (being at home)." (Anna's mum, 9a p. 11)

Hans' parents explained how they had mixed emotions on leaving the NICU and taking their son home.

Hans' mum: *"We felt happy and afraid at the same time"*

Hans' dad: *"Happy because we were going home and afraid because of what might happen to him"*

Hans' mum: *"I was afraid, because from all that care there (NICU)"*

Hans' dad: *"there (on NICU) we felt secure with them (staff) because if something happened we just called out 'nurse, nurse'. Sometimes whilst she (wife) was feeding him he coughed and we called out and they (staff) came right away or we just pressed the buzzer and they come instantaneously. Here (at home) what can we do? So it's like everything depends on us, it's not the same like when we were there. There (on NICU) you call out for help and they (staff) come, but here what do you do?"* (Hans' mum & dad, 5a p. 23)

Elsa's dad said:

"I know that over there she (baby) had constant surveillance, I know that she had that special plate (apnoea mattress), I know that the things that she had

were constantly monitoring her and I realised that after we left there (NICU), that I have to constantly monitor (the baby at home too)." (Elsa's dad, 7c p. 39–40)

Once at home with their baby, parents created a sense of safety for themselves by trying to mimic the NICU environment into their own home. These practices reveal how they had been greatly influenced by the NICU space and that letting go of the practices which stood at the foreground for so long was not easy for them. Many sought to pursue similar vigilance as they had witnessed it in the NICU space, despite being told that their baby did not require close monitoring anymore.

Past experiences of apnoeic attacks, in particular, triggered the parents' need to watch over their child as much as possible. Many parents felt safer having a monitoring device at home to detect apnoea. Eric's parents explained:

Eric's dad: *"the first thing that we bought was the baby monitor."*

Eric's mum: *"ehe, the baby monitor for the cot, because there (on NICU) he used to have it, so our minds were at rest for sure."*

Eric's dad: *"of course, look at him, he's got the monitor there."* (pointing to the monitor) (Eric's mum & dad, 6a p. 9–10)

Sven's mum expressed her fear that her son would choke and stop breathing when at home:

"My fear is that he chokes and stops breathing. This really frightens me. At night I'm not putting him to sleep in his cot or pram. I mostly stay awake, because I am afraid to put him to sleep after feeding him because God forbid, he chokes (and stops breathing) and I don't notice. I am really terrified of this thing, but maybe two more months will pass and I will feel better about it." (Sven's mum, 2a p. 26–27)

Many parents said that, during the first month at home in particular, they were watching closely and checking on their baby frequently even during the night. Eric's dad said:

"Before (in the first month at home) at night even when he (baby) was sleeping, we didn't sleep well (mum and dad), because we were afraid that he stops breathing." (Eric's dad, 6b p. 8)

"When he (baby) was smaller (in the first month at home), I was afraid (in the night), I used to see him quiet and I used to doubt whether he was breathing or not and I used to get out of bed to check on him." (Eric's dad, 6c p. 7)

Sometimes some parents maintained high vigilance over their baby even at six months after discharge home. Elsa's dad shared how he felt that he had become so obsessed

with checking on his daughter during the night because of the constant surveillance the baby had during her NICU stay:

“At night I still suffer from my constantly waking up looking at the cot to make sure she’s ok. Getting up, holding her, checking her breathing...I still can’t get through a night’s sleep because I wake up every few minutes, every few hours, to see her (baby), I turn her, I check her breathing, I move her, I mean I have this fixation.” (Elsa’s dad 7c p. 2)

“I know the fear that I feel, fear which makes me go check on her in the cot, because I remember the machines there (on NICU)....so I took more like the professional’s role” (Elsa’s dad, 7c p. 31)

Another routine NICU practice which many parents, especially mothers, felt that they needed to adopt at home, was the strict three hourly feeding. This became particularly evident in those mothers who initially experienced feeding their preterm as being a challenging task, whether because the baby was a slow feeder, having difficulty to latch onto the breast for breastfeeding, or because the baby’s sucking reflex took a while to be established.

Aurora’s mum, whose baby was slow to feed, said:

“When we were sent home I was afraid that she wouldn’t drink enough and she loses weight, we became obsessed with her weight, obsessed. We would weigh her everyday even here (at home) because we were always afraid that she might not be feeding enough and she loses weight.” (Aurora’s mum, 3a p. 10)

“I think, because she (baby) was born prematurely and I was always conscious that she needed to put on weight, because for us that was our problem (for the baby to increase in weight), the problem was always that, that she needed to put on weight so I think this got so much into our heads, that for example, I always needed to make sure that she drank, although they (staff) advised us to feed her on demand, but because we knew that she needed to drink a certain amount, automatically I always checked on the milk tin to see how much she should drink. Sometimes I would calculate how much she drinks in a day...it’s been like a rule that I feed her every three hours.” (Aurora’s mum, 3b, 9 p. 13)

Anna’s mum expressed that:

“I kept the same feeding routine she (baby) had there (on NICU), I feed her every three hours, and if she doesn’t wake up (after 3 hours), I wake her up and feed her” (Anna’s mum, 9a p. 10)

Elsa’s parents talked about feeding their daughter in the first month at home following NICU discharge, when their baby’s sucking reflex was still developing.

Elsa's mum: *"the paediatrician said that if she sleeps at night, I should not wake her up, but I am not able to do that, I panic if she doesn't drink, I want to wake her up ...even if she doesn't drink till the last mille, I get panicky, I play with her (with the bottle) until she takes it all, because I am obsessed with having to increase her weight, increase her weight"* (Elsa's mum, 7a p. 26)

After three months with the baby at home, Elsa's dad continued by saying:

"sticking to NICU rules has not stopped...we still feed her every three hours, if she is sleeping we still wake her up...it's not good for her not to drink, or she doesn't drink everything, we worry cause she didn't drink enough." (Elsa's dad, 7b p. 1)

At NICU discharge, parents still saw their baby as being quite small and so fragile and vulnerable. To the parents, smallness was related to weakness and they often saw the weakness behind the small size. With this image in their heads, parents tried to anticipate possible risks to the child's wellbeing and sought to modify their way of living particularly within their household, to fit their need to protect the baby as much as they could. Parents sought to protect their child from any threats within their environment which could come in contact with the child and which could cause harm to the child's wellbeing. Eugene's parents talked of how in the first month at home, they viewed their baby as being small and vulnerable, fearing ill-health:

Eugene's mum: *"being afraid that he chokes, these kinds of fears...that he stops breathing"*

Eugene's dad: *"it's because he was very small (when discharged from NICU), that's why"*

Eugene's mum: *"yes that's it, because you see them as being so fragile when they are so small, for me at least that's how it was... being afraid that he gets sick...such babies are fragile, maybe not as much as we think, but for us parents that's what we think, that they are fragile, we see them just like a feather, literally."* (Eugene's mum & dad, 8b p. 2)

Parents sought to protect their baby by keeping him away from being in direct contact with other people and so many parents avoided having other people visiting their home particularly in the early weeks after the baby's discharge home. This meant that the prematurely born baby did not receive the welcome that a term baby usually gets, where relatives and friends usually meet together and rejoice at the addition of a new family member. Parents felt that protecting their child's health was a priority at the time of discharge and such a cultural tradition was postponed until they were reassured that the baby was in good health following a period of growth.

Staying with the baby at home was another measure which many parents took to protect their baby, particularly in the first month after discharge. Parents often felt that their home was a safe space which offered protection to their baby. Kristoff's mum said:

"I am scared for this one (baby), more than the other (older son) who was born at term. As the elder son was full term, we had told relatives to come to our home, for example, but with this one (baby), no one has seen him yet except our own parents because I am afraid, especially now (Winter time) that there's a lot of illnesses around so I am more frightened...even going in crowded places. I haven't gone anywhere with him (baby) yet, I locked myself at home." (Kristoff's mum, 4a p. 22–23)

Elsa's mum expressed that:

"No one was allowed to touch the baby, neither kids nor adults. When relatives came (to see baby), I left her (baby) in the cot, I stood next to them and I didn't allow them to touch her." (Elsa's mum, 7b p. 13)

Mothers, in particular, often demonstrated their awareness of the need for a high degree of cleanliness in their home and whatever could come in contact with their baby to avoid transferring any germs to their baby. Some of the measures adopted at home were once again a reflection of the practices adopted on the NICU setting and which mothers transferred to their home. Elsa's mum said:

"Up to a few weeks ago, I was still using an apron and gloves (at home) to hold her (baby)." (Elsa's mum, 7b p. 13)

Hans' mum, who had three other children, expressed how she sought to avoid having her other kids transmitting any illness to the baby:

"I see that they (other children) take a bath when they come (home from school) cause I am terrified of anything they could get from school...that is what frightens me, that they get something, that they are carriers (of disease)...so when they come (from school) I tell them to change (their clothes) and get washed." (Hans's mum, 5a, 17 p. 26)

Parents felt that they needed regular reassurance that their baby was growing adequately and so they did regular check-ups at a private paediatrician of their choice and breastfeeding mothers also visited regularly the breastfeeding walk-in clinic at the hospital, along with the follow-up appointment they had at hospital. Regular check-ups provided peace of mind to the parents but also indicated that their informational needs did not cease following discharge. Guidance provided in this way helped parents to assist and promote their child's development. Mothers, especially, felt that the baby's

adequate growth provided a confirmation that they were doing a good job in taking care of the baby and meeting his needs. This reassurance enabled the participants to become more relaxed and confident with their baby and helped them to move on, away from the issues of prematurity. The recognition that the baby was healthy and growing well stood out from the flow of time in the parents' experiences through transition, while moving ahead through lived time.

Aurora's mum talked of her weekly visits to weigh the baby at the breastfeeding walk-in clinic:

"I always take her (to the clinic) to weigh her, every week. It's like your mind remains obsessed whether she is growing enough...so I need to check, whether she is growing from week to week...because I still see her small even though she is growing...so I start saying I hope she grows to have normal weight." (Aurora's mum, 3b p. 7)

Eric's parents talked about the regular check-ups that they had for their baby at their private paediatrician.

Eric's dad: *"we like going for a routine check so that our minds are more at rest and we don't have to wait for about six months (for hospital appointment) without knowing what's happening."*

Eric's mum: *"we go every month."*

Eric's dad: *"exactly, every month so we know what's going on, he is checked and weighed."* (Eric's mum & dad, 6b p. 5)

Eugene's mum shared:

"The fact that we see him grow and taking him to the paediatrician and everything is alright, we become more relaxed, we say that what we are doing is good, I mean we are on the right track so I think we are moving positively forward" (Eugene's mum, 8a p. 17)

These findings suggest that the participants felt that they needed further follow-up care post-discharge particularly to continue monitoring the baby's growth and development and to seek advice. However, in Malta since the public neonatal services did not provide such follow-up care beyond hospital discharge, except for what has been mentioned above, parents in this study self-funded their own follow-up care by attending private neonatal services at a paediatrician's clinic where they could schedule appointments with a paediatrician of their own choosing and where continuity of care could be provided following discharge by the same paediatrician.

Many mothers in this study also expressed how they sought reassurance about the baby's growth and development by comparing the baby to his/her other sibling/s, if this was not the first child or to other babies that mothers came across. Kristoff's mum compared her two children when looking at pictures of her older son:

"...it's not that I want to compare (between her two sons) because it is the least thing I want to do, but I still say, for example, that at a certain age, he (older son) did this, so this one (baby) will probably do the same thing, say a week later, but there isn't a big gap." (Kristoff's mum, 4b p. 4)

At six months after discharge home from NICU, Kristoff's mum added:

"If I see a baby who is of a similar size, I still would want to know how old he is ((laughs)) so I would see if my son is progressing well. Well even with the older one (son), I did this, so let alone with this one, you would want your kids to progress and that everything is ok...but on the whole I can't complain." (Kristoff's mum, 4c p. 8)

As more time went by, parents often reflected on the increase in physical size and weight of their baby and compared it to the earlier days on NICU when their baby was small and perceived as very fragile. The increased strength developed in the baby confirmed to the parents that he was growing not only in size but also overcoming the earlier fragility. The joy and relief parents experienced when they could see not only by looking at the baby but literally black on white, that the baby was gaining weight, was clearly expressed when continuing to monitor the baby at home. This gave them the reassurance that they needed. Along with monitoring growth, parents sought guidance and information about the infant's development, primarily from their paediatrician so they could watch for the child's developmental milestones. Thus, through their experience of Being-in-time, parents' ongoing experiences directed them to what they were expected to experience with their baby in the future. Knowing what to look for, helped them to determine whether their child's development was progressing as expected at different ages reached by their child. Anna's parents' said:

Anna's mum: *"We go to Dr X privately, we are following his guidance, even when to start weaning her, he is going to guide us....and for vaccines, he is explaining everything to us and we are following his advice."*

Anna's dad: *"we need to have some guidance....because otherwise how would we know certain things, like all those vaccines?"* (Anna's mum & dad, 9b p. 10)

Anna's mum: *"when we go to our private paediatrician, it is true that we are paying but the doctor is really friendly and helpful, so much that he even sends us emails with information, he answers every question that we ask... he helps us*

a lot, he tells us not to worry and explains things...he puts our minds at rest that we are doing a good job.” (Anna’s mum, 9c, p. 7)

6.5.2 Cautiously letting go

As the baby grew and more time went by, beyond the first month following discharge of the baby from NICU, parents, and particularly mothers, developed a new sense of awareness of their own child. They let go from relying on monitoring devices and started trusting themselves and the awareness they gained of their own child, noting any changes in their child’s development and wellbeing. As parents became more confident in parenting their baby, their focus shifted from observing closely the child’s physical growth and wellbeing, to watching out for the child’s developmental milestones. Parents’ fears that their child could easily get sick, not feed or grow well, subsided as more time went by. However, parents continued to seek professional reassurance about their child’s growth and development.

For many of the parents, their baby had reached normality when he became full-term and from then onwards, they often felt they could look ahead and move further away from the days of prematurity. At the end of the first month following NICU discharge, Sofia’s parents said:

Sofia’s mum: *“for me she is normal now, she is full-term.”*

Sofia’s dad: *“exactly she is a term baby now”* (Sofia’s mum & dad, 1a p. 26)

After six months post discharge, they continued by saying:

Sofia’s dad: *“Now that she is like normal babies, I don’t think it makes a difference that she was born preterm (2.0), we are lucky that she is smiling all the time ((looking happily at baby)), she is full of energy, she is in a happy mood all the time.”*

Sofia’s mum: *“this is normality for us.”* (Sofia’s mum & dad, 1c p. 1)

Seeing the progress the baby had made, was testimony of the baby’s normality for many parents. Anna’s dad, while admiring his lively daughter bouncing on his lap said:

“we have seen a lot of progress, now she grabs things, she is interested (in what is going on around her), she communicates more, she laughs...now that everything is alright thank God, I look back at the first months like being a bad dream and now I have a normal baby.” (Anna’s dad, 9c p. 1)

Aurora's dad said:

"we can see that she is growing, she is growing normally and we put our minds at rest." (Aurora's dad, 3b p. 9)

Hans' mum said;

"Now it's like everything is normal, it's like nothing ever happened...all that fear has gone, now it is not like before when I used to worry all the time and check on him, whether he's breathing and so on, that is all gone now." (Hans' mum, 5c p. 1)

Parents identified various factors which contributed to 'letting go' of their initial vigilant surveillance of the baby. Protection from cold subsided as the weather became warmer and the child became more active. Also parents shifted their focus more on protecting the child from physical harm as he became more agile.

Eric's mum explained:

"now (after 6 months from NICU discharge) obviously it's much better than before, first of all, now it's Summer so I think less about the cold, illnesses and such things and apart from this, initially my son was still small so I had to be more careful, now it's not that I am not (careful), but now I have to be more careful that he doesn't hurt himself. What I mean is that now that he has grown, my mind is more at rest." (Eric's mum, 6c, p. 6-7)

Eric's parents also talked about the need to protect their baby from harm and Eric's dad saw this as being a greater part of their responsibility as their son grows.

Eric's mum: *"now he plays but we need to be careful that he doesn't get hurt because he can easily hurt himself."* (Eric's mum, 6c p. 1)

Eric's dad: *"The more time passes I see that our responsibility increases, that's how I see it, because before, for example, if you put him there ((pointing to the play mat)), he used to stay, now you can't leave him, because he starts bending forward, so the more time goes by, our responsibility increases but I think we are handling him well, let's say that, but we have to be very careful, he is a baby after all."* (Eric's dad, 6c p. 4)

Over time parents settled into baby-led routines at home, and this made them feel more confident and relaxed as they felt able to identify and adjust to their child's needs, confirming their parenting abilities. The participants indicated that they learnt through their own experience of caring for their own baby and associated this with experiencing the reality of parenting. They became confident in trusting themselves, that they could identify and meet their baby's needs. They felt more in control and could take decisions

for their baby, especially when they let go of NICU practices and routines which they had initially adopted at home. Sofia's mum said:

"It's like, the more she (baby) grows, the more we (parents) become relaxed because we know her routine, we are now more relaxed with her." (Sofia's mum, 1c p. 6)

Anna's parents expressed how they became used to their baby being at home and how they learned to identify their baby's needs:

Anna's dad: *"Now we are used to her and more confident"*

Anna's mum: *"Exactly, we are more confident, before we used to look at the clock, (and say that) the baby is due for a feed in fifteen minutes, hmm, I guess what was left was for me to start writing the feeds down in my diary ((laughing)). Now we say 'I think she is hungry because she is putting her fingers in her mouth so let me prepare her feed.'"*

Anna's dad: *"we have learnt to identify her needs"*

Anna's mum: *"now our minds are more at rest because she is feeding on demand, hmm she is sleeping (at night) so she is giving us time to rest....so it is like we have entered into a routine...'"* (Anna's mum & dad, 9c p. 3–4)

Letting go of NICU three hourly feeding routines was initially challenging for many parents until they became confident in feeding their baby on demand. It took some parents more than others to adjust and feel confident with demand feeding. Elsa's dad talked of how things at home settled more when letting go of the strict three hourly feeding:

"Now she drinks when she wakes up and that's it and when she sleeps, we let her sleep and now since we've started that rhythm it is no longer stressful in the night...she was waking up at 1am and then again at 3am because it was like we were ruining her sleep, and now since we're feeding her when she wants, things have calmed down... now we have settled down, after three months, now we can say we've settled down with Elsa and we're treating Elsa like people treat a baby when it comes home and we're not treating her like an NICU baby.'" (Elsa's dad, 7b p. 1)

Parents had also been seeking normality when shifting their monitoring on physical growth to watching out for the child's developmental milestones according to what is expected at various age groups in children, though many were aware that due to the premature birth their baby could be delayed in reaching particular milestones. Even the focus of follow-up visits shifted to developmental milestones where parents not only

sought reassurance about the baby's development but also to acquire information about the next stages of development. Kristoff's dad explained:

"We are constantly observing him, we start seeing that he reacts to sounds and so on. We put our minds at rest that things are working well with him. Cause, even when he hears me talk, he turns his head and looks, so seeing him like this we put our minds at rest." (Kristoff's dad, 4a, p. 23)

Elsa's mum said:

"I am keeping track on her milestones, I mean I am attentive to see what she is supposed to do at her age...so I watch out for these things, but I know she may be a bit slower." (Elsa's mum, 7c p. 18)

By the sixth month post discharge, the parents' concern over the child's weight and size gradually subsided, because most parents were convinced that their baby was growing satisfactorily. Aurora's mum said:

"...now we don't go every week to weigh her. Now we wait for when we have an appointment because they weigh her anyway, so we can wait." (Aurora's mum, 3b p. 9)

"...now I can trust (myself) more, I don't worry so much about her weight and so on, now we got used to her." (Aurora's mum, 3c p. 3)

Many parents, particularly mums let go of the over-protection they had been giving their baby. Letting go was achieved when mothers let go of constantly being with their baby. Allowing others into their lives to help them care for their baby, whether while mums were at work or when the mothers needed to go somewhere without the baby. Hans' mum said:

"Now I am not as I was before, because I was even afraid to leave him with my mum. Now if I have an errand, I tell her to come over so she can stay with him until I come back...even she (grandmother) is not the same as she was before, in the beginning she was afraid to feed him, now she feeds him, but before she was afraid" (Hans' mum, 5b p. 4–5)

On returning to work, Eugene's mum said:

"now I am more relaxed, I mean the more he grows, the more I relax, and now that I went back to work, working half days, it's like I haven't remained so overprotective over him because now I leave him with my mum, so it's like work has removed that anxiety, not being so over him all the time...it's not just

him...now I have restarted my own rhythm, there is work and then there is him, after work I spend time with him but it's not being with him all day, only him. I am more relaxed, the more he grows, the more I learn to trust myself (1.0) so it's all these things together." (Eugene's mum, 8b p. 2–3)

Hans' parents said,

Hans' mum: *"now it is much easier, and when there isn't that fear, I feel happier."*

Hans' dad: *"we were very tense about him in the beginning, we were afraid."*

Hans' mum: *"...in the beginning I used to be afraid to leave him even with my mum, even she was afraid, she feared that he might choke, now everyone feels calm with him, even my dad, he used to be afraid to hold him, it took a long time for him to hold him, now when he comes he picks him up and holds him, he is not afraid anymore. Life has become easier now, once we got into a routine."* (Hans' mum & dad, 5c p. 2–3)

Going out of the comfort of their own home with the baby was challenging for some parents, who felt threatened by the risks this posed. The natural seasonal changes were sometimes viewed as threats which some parents chose to avoid particularly in the first month after discharge from NICU. Others more readily moved on to other lived spaces with their baby and experienced the outdoors sooner whilst taking the necessary precautions. Some parents experienced going out with the baby as signifying their readiness to show their child to the world.

Eric's mum said:

"...in the evening we go out, and on a day like today (cold day), I wrap him up well and go, I am not the person who stays indoors all the time and won't take him (baby) out." (Eric's mum, 6a p. 10)

Anna's parents said:

Anna's dad: *"in the beginning we were afraid to take her out because she was still very small, now no (not afraid anymore)."*

Anna's mum: *"now we just phone our friends and we go for a walk, we don't think about it twice, we go to eat at a restaurant, as long as I know I have her feeds, the insect repellent, and I know she is protected and I have everything for her."* (Anna's mum & dad, 9b p. 7–8)

Elsa's parents were initially reluctant to go out with their baby, fearing that their baby was at risk of contracting illness, but also, they feared other people's reactions to their small baby.

Elsa's mum: *"now we are more confident, we started going out, because we spent two and a half months not going out...I didn't want to go out"*

Elsa's dad: *"nowhere, last weekend and this weekend we went out."* (Elsa's mum & dad, 7b p. 2)

Elsa's mum: *"before (when talking to people) it was like I had to justify her size (small size because she was born preterm)."*

Elsa's dad: *"Exactly, I used to say, cause she (baby) was at NICU"*

Elsa's mum: *"eh, because she was a preterm"* (Elsa's mum & dad, 7b p. 4)

However, eventually these parents realised that they did not need to give any explanations about their daughter's size and they were then ready to face the world outside their home and show off their daughter with confidence.

Elsa's dad: *"now I just say, 'this is my daughter' and that's it, you know? She is my daughter."*

Elsa's mum: *"now I show her to everyone, it's like now I have opened the doors."* (Elsa's mum & dad, 7b p. 4)

Elsa's mum: *"I started to realise especially when seeing her put on weight...I said to myself, now I want to show her to the whole world."* (Elsa's mum, 7b p. 15).

Elsa's dad: *I enjoy it when we go out and people see our baby because for me, she is the most beautiful thing on earth.....she's like a trophy ((expression of pride)), I mean, I like it when people look at her and say how cute she is."* (Elsa's dad, 7c p. 27)

6.6 The fourth main theme: Living the new family

Theme 4 – Thematic structure

Main theme:

Living the new family

Sub-themes:

Unifying the family circle

Altered life perspective

As parents experienced the preterm birth of their child, they were faced with a ‘new’ reality resulting in various transitions to which parents adjusted and lived through. The fourth and last theme which emerged from the parents’ narratives, *Living the new family* reflects the new patterns parents adopted within their daily lives which incorporated their focal new relation as they transitioned to parenting their preterm baby, their new addition to their family. The two sub-themes, *Unifying the family circle* and *Altered life perspective*, help to reveal the parents’ reflections on the meaning this experience had on their lives.

6.6.1 Unifying the family circle

Every mother-father dyad in this study often talked of the relationship between them as a couple and how they supported each other through this experience. Each couple in this study expressed how their primary source of support throughout their experience was having each other by their side. Husbands sought to be with their wives for most of the time when on the unit particularly in the early days of hospitalisation and made every effort to visit the baby together with their partner daily after work. Couples described experiences where they sought to be each other’s rock which helped them cope with the situation. The mutual understanding and emotional support couples gave each other, enabled them to both be with their baby and relate to their child, despite the difficulties they faced in such unexpected circumstances. Sofia’s dad described the way he felt supported by his wife:

“We always lived the experience together in there (NICU). I used to go and feel protected by her (indicating his wife), the fact that she (wife) was there when we used to go together made me feel secure knowing that if I don’t manage to be strong emotionally then I knew there is her (wife). She (wife) is stronger (emotionally) than I am in general. (2.0) In case of crisis I step up (1.0) but usually I need a bit more emotional backup.” (Sofia’s dad, 1a p. 9–10)

The parents often used “we” and “us” when narrating their experiences which denote that experiences as being shared or held in common between them. Additionally, the couples’ interconnectedness became particularly evident in how they narrated their stories in a complementary way. Living through the same experience together, even on the neonatal unit, seemed to be an important way how parents coped with their crisis. The reciprocal understanding and the communication maintained between the couple provided them with a complementary means of coping as they journeyed through the

different transitions along their experience and seems to have enhanced their adaptation to family functioning. Sofia's dad expressed how maintaining good communication as a couple was important to move together along the different transitions throughout their experience:

"We talk a lot between us, I mean everything that we do, we do it together. I mean if she (wife) is searching on the computer, say about milestones, I am there involved in it too. I know there are many families where the mother does everything generally (in relation to child care) and the father is passive, doing nothing." (Sofia's dad, 1b p. 6)

Most parents continued to support each other in various ways once the baby was at home. When mothers had returned to work by the sixth month post discharge, the parents re-adjusted their roles and responsibilities in the family according to their working schedule. Most fathers indicated their involvement in caregiving and playtime with the baby, caring for an older child/ren and also sharing household responsibilities. Sharing parenting responsibilities in such ways contributed to the parents' coping through their home transition. This reflected effective family dynamics present in most couples, which seemed to have aided parents to cope at home. Anna's parents described how they shared the responsibility of their daughter's care between them.

Anna's mum: *"We like to take it in turns, for example if I changed the nappy now, then the next time, he (husband) does it."*

Anna's dad: *"Even if she (wife) is cooking, I take care of her (daughter)"*

Anna's mum: *"I think, not to boast but I think something which we are doing really well is that everything that I do with our daughter, he is capable of doing it too, for example, bathing her."*

Anna's dad: *"we help each other"*

Anna's mum: *"sometimes I do it (bath the baby), sometimes he does it, depending on who can do it at that point in time"*

Anna's dad: *"obviously if we are the two together (bathing the baby), it is better ((laughing))"*

Anna's mum: *"ehe, we prefer to be the two together, so we help each other"*
(Anna's mum & dad, 9b p. 8)

The main relatives who were particularly significant in the parents' lives as they journeyed through multiple transitions from the NICU to home, were the parents' own parents, the grandparents of the new baby. Parents perceived that their experience had

strengthened family cohesion not only between them as a couple but also with their close family members particularly the grandparents. None of the grandparents had visited the baby when still on the unit because the unit policy restricted their visiting. Yet, a predominant finding in this study was that grandparents were identified by all parents as being invaluable sources of support and to whom they were truly grateful. Grandparents were supportive throughout the parents' experience, from the birth of the preterm infant, through NICU hospitalisation and beyond as parents transitioned to their new life at home with the baby. Most parents received encouragement and emotional support from their own parents when the baby was still on NICU. Many grandparents also supported the new parents in practical ways particularly when the preterm baby was not the first child in the family. They helped with taking care of other grandchildren especially during the time parents were next to the baby on NICU. Hans' parents shared how the grandmother's support with taking care of their other three young children, was crucial for them to be able to go next to their baby in hospital.

Hans' mum: *"if it wasn't for my mother, we wouldn't have been able to go next to him (baby on NICU) everyday, it wouldn't have been possible."*

Hans' dad: *"to go everyday...because of the other children"*

Hans' mum: *"but she (grandmother) used to pick them up from school and keep them with her until we come back (from hospital)."*

Hans' dad: *"until we return, every day. If it wasn't for such help, we wouldn't have done it (to go next to the baby every day)."*

Hans' mum: *"I think we wouldn't have managed."*

Hans' dad: *"one of us would have had to stay here (with the other children at home)."* (Hans' mum & dad, 5a p. 29–30)

Following discharge of the baby, many grandparents also supported the parents with household chores, errands and helping with taking care of the new baby. Parents have been grateful to the support they received from their own parents which aided them to cope with their home transition. Mothers expressed how the grandparents' support with child care had been pivotal in their decision whether to go back to work or not. Parents seemed to entrust child-care to the grandparents as their first preference over alternative child care arrangements. Grandparents were described as going out of their own way to help the parents.

Sven's mum shared how her own mother supported her regularly with whatever she needed when at home with the baby:

"We have a lot of support. I have my mum who lives nearby, she comes every morning, around quarter past seven, because I have to prepare my older son for school and as she lives nearby, she comes to see if I need anything. She helps me getting the older one ready for school, or feeds the baby, she asks me if she can wash any clothes for me. I don't like to tell her to do many things, but when I need I ask her to help because I feel that her help reduces my stress (in the morning)" (Sven's mum, 2a p. 29–30)

Despite appreciating their own parents' support, sometimes parents also experienced undesirable reactions from grandparents. Parents felt that grandparents did not really understand the experience they were going through particularly when the baby was still hospitalised. Elsa's dad said:

"....relatives don't know what's going on and you can't blame them for it, because although they know that the situation is bad but they don't know what's going on. They don't know what's going on in there (NICU)...they weren't seeing what we were seeing, they weren't understanding...for me the thing that really put me down was when I showed them (relatives) a photo and they started crying and I told them, 'don't cry, that's my child, don't cry', they really put me down, crying like that as if my daughter was dying ((upset)). I knew what was going on and I knew it wasn't so bad. So then I stopped showing photos and I stopped talking and if they asked whether everything was ok, I used to say 'yes of course it is' and that's it." (Elsa's dad, 7a p. 39)

Once at home with the baby, grandparents and close relatives were often eager to see and visit the baby. The maternal grandmother in particular, was often very keen to be with the baby in the parents' home in the days following discharge. Parents were grateful to the help provided however, mothers expressed how they felt that they needed their own space so they could take control and gain their own expertise in caring for and parenting their baby. Aurora's mum explained how although she appreciated her mum's help and support with the baby, yet she felt she needed her space and preferred to get help when really needed:

"....she (grandmother) used to come once, twice, three times a week. If I am going somewhere she offers to come with me and ok she comes, then she started coming every day and I told her 'don't you think it is better for you to rest?' because then having someone preaching every day, 'why don't you do this like this? Or do this like that', then it's too much ((laughs)). It is nice to have help, but in moderation." (Aurora's mum, 3b p. 20)

As more time went by, parents felt that their close relatives interacted well with their newcomer and believed that their experience of having their preterm child, has strengthened their own relationships with their close relatives, particularly with their own parents. The child seemed to have drawn all the family together with the child

being the central focus of both the nuclear and extended families. As a result family members became more closely knit together. The preterm child was therefore acknowledged as being the new link within their family circle. Parents expressed that the new baby has brought unity within the family together with predominant feelings of joy and peace. Sven's dad shared his feelings of what having his new son at home has meant:

"Having the baby home is a big satisfaction. No words can describe it. I mean for me, the fact that he (son) is at home, he brought joy, peace and unity. I think since he came home, he brought tranquillity (into the home), peace and unity" (Sven's dad, 2a p. 12)

Eric's parents talked of the unity felt at home between them as a couple and also with other members of their extended family since having their preterm baby, who was their first-born son:

Eric's dad: *"I think (this experience) has united us"*

Eric's mum: *"exactly, we have become a family"*

Eric's dad: *"this experience has united not only us as a married couple with our son, but also our own families...we became united like a chain literally."* (Eric's mum & dad, 6a p. 29–30)

Parents who had more children other than their preterm child, became worried about the disruption in the family that the birth of the preterm baby had caused, particularly when they were not at home for a long time to be able to be with the baby on NICU and having their other child or children cared for by grandparents. Once the baby was home, mothers often became aware how their experience with the preterm child and the added attention needed, might have affected the way they related to their other child or children. Feelings of guilt were experienced by mothers who had young children whom they perceived still required their very close attention and care. Older children provided support and helped with the care of the baby once at home.

Hans' mum talked of the disruption caused in the family when being away from her other children, to be with the baby on NICU:

"...they (older children) felt lost, because before (having the baby) I used to be with them all the time, they had exams, I didn't help them at all this time. Usually I am with them all the time (to help them study)." (Hans' mum, 5a p. 17)

When there were other siblings in the family, parents were happy to unite the baby with his/her brother/s and/or sister/s once the baby was discharged home. Some mothers had

initially been preoccupied that older sibling/s would react negatively to the new baby and not readily accept the baby as a new member in their family. In view of the local visiting policy on the neonatal unit, siblings had not been part of the NICU experience and none had seen the baby when on the unit except on photographs.

Once at home mothers and fathers were very happy that other sibling/s readily accepted the newcomer, showed interest and initiated interaction with the baby from early on when the baby was home. Sven's mum described how her older son had initially been jealous of the baby when he was still in hospital but then readily accepted him once the baby was home:

"When I came home without the baby, the older son was kind of jealous of the baby, but then when the baby came home, he was not jealous of him anymore, on the contrary he really loves him and if I tell him (older son) to take care of him (baby), he takes care of him and helps me to take care of the baby too (2.0); for him it was strange that at one point I was going to the hospital to get the baby, then he couldn't even see him" (Sven's mum, 2a p. 12–13)

In view of the disrupted life experienced during the baby's hospitalisation, parents longed to regain normality and re-settle their life, within their family for all the members, in their daily living patterns. Parents particularly mothers made great efforts to re-establish normalcy at home and were grateful that by the sixth month following discharge they considered that life at home had re-settled. Kristoff's mum said:

"I think we are now more settled....our life is back to normal, the family is more settled. Well a newcomer is always going to make a change in the family but it seems that we are settled now, at least that's how I feel. Even for our older son, it seems as if the baby had come long ago, it's as if he was always here." (Kristoff's mum, 4c p. 1)

The progressive way by which parents reached out and interacted with the baby over time from the early days after birth up to the first six months following NICU discharge was described earlier in the second main theme (*Reaching out*), which emerged from the parents' experiences. Additionally, parents often expressed how the baby became the focus and priority in their life and how family-life revolved around the baby's needs. Hans' mum said:

"We are more focused on him (baby), even the others (older children) when they come from school, they don't come next to me ((laughs)), they go running straight next to him (baby)." (Hans' mum, 5b p. 7)

Aurora's dad added:

"Now everything revolves around her (baby). Whereas before we used to plan, now we do plan, but we always ask, 'but is that good for her?' Everything revolves around her...even to go out, we spend more time preparing for her than for us and making sure we don't forget anything (1.0); it's not the first time that we forgot something ((laughs))." (Aurora's dad, 3c p. 4)

Parents and other family members entered into a new life-world that included the baby. Parents recalled the early months after the baby had been discharged from the neonatal unit as times of adjustment, of getting used to living with the baby in their home, within their family. Sofia's dad said:

"She (baby) is part of our family now and whatever we do we have to keep her in mind...I mean you are not going to put her aside (2.0) everything that we do... for example I am doing a course, again I have to see how to fit it around her, but I got used to that already." (Sofia's dad, 1b p. 6)

Eugene's mum explained how the baby had become part of what she did:

"I come from work at around half past two, pick him up (from grandma) then spend the time with him, when I come here (at home) I cook, and he is next to me, and sometimes I feed him depending on what he needs, so he is part of the things that I am doing, he is there." (Eugene's mum, 8c p. 6)

As more time went by, parents expressed how they felt that they adjusted very well to having the baby at home, that the baby became central to family life and that they truly recognised the baby as part of the family. As the baby grew more, parents noted the increased interaction that the baby has shown with family members and how the baby attracted the attention of parents and other siblings in the family, as if to be a constant reminder that s/he was there now. Mothers were happy to see that all family members sought to interact with the baby and found the time to do so. Fathers were also keen to interact with the child especially as it became increasingly evident that the baby was growing and showing increased signs of interaction with those around him/her. Such paternal interactions particularly through play have been previously explored in the second theme, *Reaching out* (see section 6.4). Additionally, parents noted how since having the new baby at home, family members sought to find time during the day to spend together as a family and this made them feel more united as a family.

Hans' mum explained how every member of her family interacted with the baby on a typical day, she said:

“when we wake up in the morning, they (other children) play with him (baby) and even he (husband) plays with him before he goes to work until I prepare his milk and feed him, then he (husband) leaves and they (other children) take it in turns to play and take care of him while I do something else, I find them helpful ((laughs))....even to feed him, they all want to hold his spoon in turns...in the afternoon he (baby) sleeps and I rest with him for an hour, then I feed him again when he wakes up, they play with him again and I cook, every evening we try to eat together.....we take him (baby) out every evening...In the evening everyone gathers in the bedroom next to him (baby) until it is time to sleep.” (Hans’ mum, 5c, p. 1–2)

Hans’ dad (with tears in his eyes) said:

“This experience has united us more as a family, because there was a person, I never told her (wife) this, and he said, ‘but you have three (children)’ this was at the beginning when he (baby) had problems and we had all that trouble. I told him ‘three and ten, they are all mine’, you feel a certain pain because people may say things without meaning anything but at that time you wouldn’t want to hear such things and this stays in your head ((sad and upset))...he (baby) has united us...because having a baby like him could be the total opposite.” (Hans’ dad, 5c p. 5–6)

6.6.2 Altered life perspective

The lived experience of having a preterm child and transitioning from NICU to life at home, transformed parents into ‘new-Beings’ revealing the meaning that this experience had for them. As parents reflected on their lived experience of premature birth and parenting, they embraced a new meaning of life, they valued life from a new perspective and expressed greater appreciation of life. Parents viewed the positive healthy outcome of their baby as the true miracle of life. Anna’s mum said:

“before I used to see having a baby as a big miracle but now having gone through this I see it as an even bigger miracle because I say, how come she is so small and the organs are functioning and they grow, so it is a very big thing. I still remember when she was supposed to be born but I feel the time that she came before was like a gift because we got to know her before in reality, we had an extra gift of having enjoyed her before.” (Anna’s mum, 9a p. 15)

All parents expressed how although their experience had been bitter in many ways, yet ultimately they thought it has all been worth it, they felt lucky and looked at the bright side, that in the end the result was that they had a healthy baby who was united with the family at home. Sofia’s dad said:

“...in a way we were lucky that although we have passed through this experience still we can’t say it was a really bad experience.” (Sofia’s dad, 1a p. 11)

On reflection, many parents expressed that their lived experience of preterm birth led them to take a general positive outlook to life. Eugene's mum expressed her positivity and said:

"the experience that we passed through, turned out well and I see it as a positive experience. For me the fact that I see him ok, it has also changed my life, I feel more positive, I feel I have more energy, I mean I am not young but I feel as if I became ten years younger ((laughs)), this has given a boost to my life.... I used to feel quite discouraged (to have another baby) but this has changed my life, I mean I have become more positive, I was more overprotective over the other (son), I let go a bit because as they say when you have only one child, all your attention is focused on him." (Eugene's mum, 8b p. 15)

Many parents in this study viewed life from a more positive perspective, they became more positive beings. The new interpersonal meaning of experiencing preterm birth has clearly been unique to the different parents in the study. Some parents noted how they felt the experience was one of growth and maturity for them as a couple. Some parents, especially mothers talked about how they felt that this experience made them stronger and not afraid of what the future may hold and started to believe more in themselves and what they were capable of.

Anna's mum: "for me this experience, although it wasn't nice in the beginning because it was a shock but the fact that our daughter is alright, I cannot say that I am afraid to have more children in the future because there are those who pass through something like this and they don't want any more children. In reality I feel more encouraged to have another baby because I say, I have managed with this one, to take care of her and so on, so another baby would be easier, I mean I don't wish to pass through the same (experience) but as such now I feel I am prepared."

Anna's dad: "because before (having the baby) we didn't know anything, this is our first baby so we had to learn everything, so with another baby we would already know a lot of things." (Anna's mum & dad, 9a p. 15)

Many parents expressed that this experience taught them to be understanding and sensitive to others, particularly those going through a similar experience of preterm birth. Mothers often said how they would readily offer hope and encouragement to any other parents going through a similar experience.

Eugene's mum: "you need to be sensitive, I used to see other parents who were sad, so I wouldn't even talk, I used to stay quiet."

Eugene's dad: "you have to be sensitive to others."

Eugene's mum: "ehe, you have to be sensitive to others."

Eugene's dad: *"but as we said already, you have to pass through the experience in order to talk like this."* (Eugene's mum & dad, 8a p. 12)

Later in the same interview, Eugene's mum added:

"(the experience) makes you more sensitive to those going through a similar experience....my cousin had spent about three months with her son there, he was eight months when he was born but he was very small, there was some problem in the placenta, he was as small as the palm of my hand and that's why he spent so long (on NICU) and when I used to be there (on NICU) although he (son) spent nine days and hers spent three months, I used to say, 'now I know what she has been through', every day I said this...she has gone through the same things plus when I talk to her she says that her son has been through operations and so on...so I can understand her a bit, so this (experience) makes you aware and sensitive to others and say how lucky we are that we can see that the baby is alright." (Eugene's mum, 8a p. 33–34)

Sofia's mum expressed how she felt willing to encourage others going through a similar experience:

"Whoever I talk to, I tell them 'don't be afraid, if God forbid something goes wrong', because sometimes they (people) come to me and tell me, 'how frightening what you have been through', I tell them that obviously it is not a nice experience but the staff and the doctors, they take care of them (babies) all the time, there is good equipment, there is everything state of the art, I think that if I had been in another country I wouldn't have received such a (good) treatment, I was very pleased with the service...." (Sofia's mum, 1c p. 14)

Many parents, particularly first time fathers, became aware of the reality and responsibility that parenthood brought in their lives and how this changed their outlook to family life. Sven's dad said:

"When I was a boy, I used to dream of having a nice car, or dream that I could fly, I had a vivid imagination. Today that I am thirty-one years old and experiencing these one and a half months since he (baby) was born: going to work, having to be away from here (home), I go shopping, I go to the gas station, do errands, in my mind there is no more imagination, there is this picture of my son, it's real, that human being I can't get him out of my mind, out of my heart, I mean the happiness that I feel is beyond anything else, this person has brought me so much joy in my heart." (Sven's dad, 2a p. 35-36)

After having the baby at home for six months, Sven's dad who worked on shift basis which included night shifts said:

"I didn't have to change my work schedule because of the baby, on the contrary, I kept to the same routine; what has changed is the thought that I left my family behind at home, my own blood, so I'm often thinking of, God forbid, receiving a phone call at work with bad news, so I became more conscious of such things,

do you understand? Whereas before I didn't use to bother or if someone's wife phones (at work) I used to say, what does she need when she sees him (friend) everyday, all the time? Today that I have children, I am conscious of what a family really is." (Sven's dad, 2c p. 2-3)

Elsa's mum talked of how her view of parenting had changed, giving her a new life meaning and how she felt that her life had re-started since having the baby.

"I used to think that having children was simply because you want an extension of yourself, you don't need to go on a diet anymore and you need someone to fill up your time. Before I used to think that one could simply go in a corner and die quietly when you have a family...because your life is finished ((laughs)), it's true.....when in reality life would have just started. It's the first day of the rest of my life, it's like life starts all over again, do you understand? Now when I see a mother, I say, she is someone whom I really admire, she has gone through labour, birth, before I used to pity her, now I look up to her." (Elsa's mum, 7a p. 37).

Some fathers described how they came to realise that this experience made them aware of their need to be there for their child or children. Kristoff's dad became conscious to avoiding taking risks when at work which could put him in danger, not only him as a person but as a father and so needed to behave responsibly as a parent, take care of himself so his sons would not risk losing their dad. Kristoff's dad talked of his new meaning of fatherhood:

"...my thoughts changed because I would have never imagined that the thoughts I have today would have ever passed through my head. Before I never thought about certain things but now that I am a parent I start thinking of things that I wouldn't have thought about before becoming a parent, they wouldn't have crossed my mind. Even when it comes to risk, if I am going to do something at work, I am boarding a ship or something like that, automatically I think...ehe maybe before I was disregarding her (wife), but I knew she was an adult and that she would cope on her own, but now there are children you start saying that there are others depending on you directly; this is something I became aware of as I became a parent, I really became conscious of this whereas before I wouldn't have thought about it." (Kristoff's dad, 4c p. 4-5)

Sometimes parents also thought ahead of when their child or children would grow older and they themselves would get older. Parents expressed their wish to be there for their children and see them grow into adulthood. Until then Kristoff's mum shared how she thought that it was an important parental role to set an example of love and pass on good values to her children while instilling a sense of unity between her two sons. She said:

"...in future I want us to remain a united family, even the children I want them to be in a relationship where they can stand up for each other. Even when later on they will have their own family...I wish that they will remain close as siblings. I

wish that I can pass this on to them from when they are young...I want them to grow up into gentlemen with a strong character, that they would know how to cope, and be problem-solving. These are the kind of things which I wish to pass on to them...some might give their (children) everything (they want), but then money will not make them happy in the end.” (Kristoff’s mum, 4a p. 38-40)

6.7 Conclusion

This chapter presented the findings from the parents’ experiences of the preterm birth of their baby, when on the neonatal unit and up to six months after the baby’s discharge home from the unit. The parents’ lived experiences from the time of birth of their preterm baby and through their NICU stay emerged as having coloured and impacted their transition to home and subsequent life with their baby. Four main themes emerged together with eight corresponding sub-themes. In the first theme, uncertainty became a persisting feature of the parents’ experiences, transforming from being disturbing to accepting unknowns as an intrinsic part of their lives. In the second theme, parents constantly sought to be in close proximity with their baby following the initial disconnection experienced at birth. Through seeing, touching, holding and participating in the baby’s care, parents gradually felt a narrowing gap between them and their baby. In the third theme, parents transferred the NICU environment of routines and monitoring to their home as they sought to protect the baby with all their efforts until reassured by the child’s growth and development, when they cautiously let go of practices which their baby no longer needed. In the last theme, the parents experience the new baby as becoming the new link within their family circle of relations. The preterm birth experience has also given parents an altered life perspective of appreciation and sensitivity towards others. Over time, parents described their consciousness of time as being focused on the present, shadowed by the past but with a clearer and positive view of the future.

In the next chapter, the findings from the interviews with neonatal staff are presented.

CHAPTER 7:

FROM NICU-TO-HOME: NEONATAL STAFF VOICE THEIR EXPERIENCES

7.1 Introduction

Twelve neonatal staff were interviewed, including midwives, nurses and doctors. They all worked on the only neonatal unit in Malta. Analysis of the interviews followed similar principles to those adopted for the analysis of the data from parents' experiences. This utilised van Manen (1990) as a guide as detailed in chapter four. A modified vignette technique was utilised as discussed earlier (chapter four). The vignettes elicited a range of responses. For some staff, they confirmed what they felt they already knew about how parents experienced certain neonatal practices. Other vignettes seemed to take the staff by surprise, especially in relation to how parents experienced particular practices and situations.

This chapter presents the findings from the neonatal staff interviews. The three main themes emerged, together with their respective sub-themes; *Acknowledging good practice*, *Realising limits* and *Awakening to needed improvements in care*. These themes were evident across all three professions. In view of this, the findings are discussed collectively across the data set. Where there are specific findings within the themes that relate to a particular professional group, these are highlighted and discussed accordingly. Exemplar quotes are used to illustrate the findings, using transcription symbols and quote descriptors as discussed previously (see section 4.10 and 4.13).

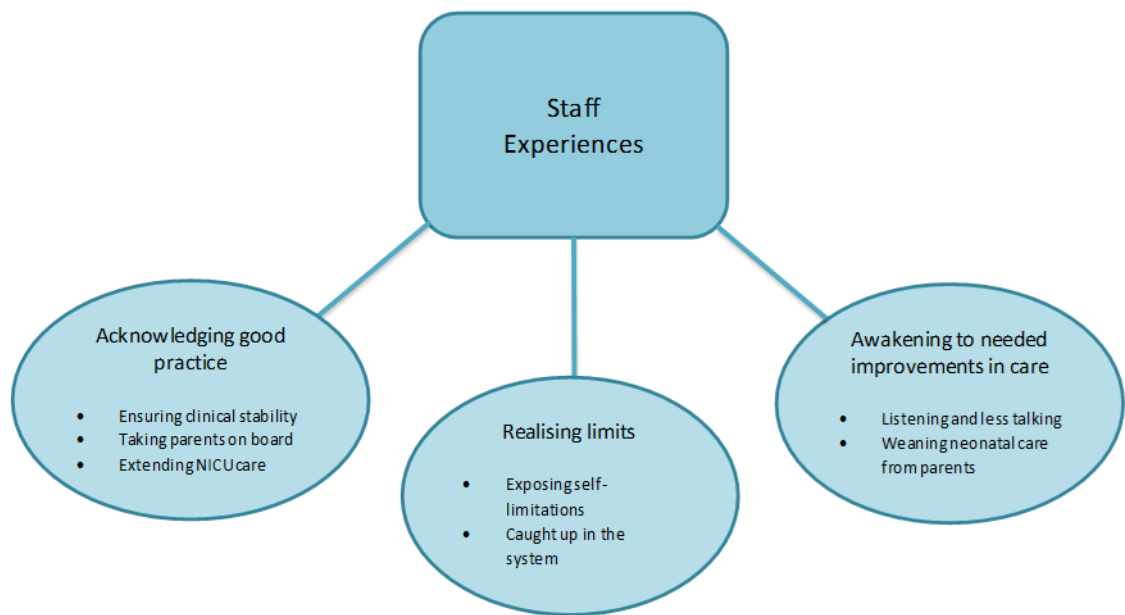


Fig. 5. Staff experiences of NICU-to-home transition

7.2 The first main theme: Acknowledging good practice

Theme 1 – Thematic structure

Main theme:

Acknowledging good practice

Sub-themes:

Ensuring clinical stability

Taking parents on board

Extending NICU care

This first main theme captures what staff perceived as being good aspects of their experiences in neonatal practice for transitions from the neonatal unit to home. At the outset of each interview, staff were asked to talk about their experience of the transition of preterm infants from the local neonatal unit to home. They tended to characterise their experiences as predominantly focused on clinical practice, and in ensuring that

preterm infants progressively gained their physiological stability. Later in the interviews, staff discussed good practice in terms of including parents as part of the neonatal care provided, and of extended practices beyond NICU hospitalisation of the preterm infant. Staff identified various experiences within their practice which they felt helped parents to transition home with their preterm infant. These data make up the first theme, *Acknowledging good practice*, which has been sub-divided into three sub-themes: *Ensuring clinical stability*, *Taking parents on board* and *Extending NICU care*.

7.2.1 Ensuring clinical stability

Having a healthy preterm baby clinically fit for discharge home was the overarching intent expressed by staff when asked to narrate their experiences of the study phenomenon. Staff, particularly doctors, emphasised the importance of having discharge criteria established on the unit, which determined what preterms needed to achieve, from a clinical perspective, in order for them to be considered fit for discharge home. Staff considered this as a positive aspect of discharge practice and felt that utilising such discharge criteria helped to achieve consistency. Dr Green described this by saying:

“We have certain discharge criteria on the unit, so for preterm babies to go home they have to be above 35 weeks, they have to be out of oxygen usually, we do send babies home on oxygen but that is in extreme circumstances. They have to be above 2 kilos in weight and most of them are feeding orally and there are no complications. So usually, even the parents when they have been here (NICU) so long, they know that those are the aims that their baby is trying to get, before eventually going home.” (Dr Green, p.1)

Within such clinical practice, doctors emphasised that their experiences and roles primarily centred on ensuring that the preterm reaches a stage where s/he achieves independence from the medical care needed on the unit. Reaching these goals was a priority for doctors and formed the basis of their decision whether to allow a preterm baby to be discharged home or not. Dr Brown expressed:

“usually the point is reached where it is evident from our point of view, from the medical point of view that the child is healthy enough to go and mature enough to go home.” (Dr Brown, p.2)

Many of the staff, including doctors, expressed that they viewed transition to home as a process which started from admission of the baby into the unit and continued throughout hospitalisation and beyond. This would suggest the need for early and

continuous parental involvement. However, some of the staff indicated that their practice on the unit towards transition home was more likely to involve parents more actively in the care of their baby only when s/he became medically stable, at a time when, having passed through the critical stages, going home became more real for both staff and parents. Against this general view, a few staff seemed to truly believe in transition as being a process and they were more likely to express the importance of involving parents in care from an early stage of hospitalisation, considering that this was positive practice which supported transition home.

Dr Brown said:

“I see discharge as part and parcel of the whole experience of NICU. If you are well prepared, when the discharge day comes, it becomes something natural. It’s not an abrupt change. I appreciate that there is an abrupt change for the parents where suddenly they have to take this ex-preterm baby with them home, and they will have to get used to certain things obviously. But, ehm, the preparation is all along the way especially the very preterm babies. The mothers, by the time they are leaving the hospital, have been feeding the baby regularly, they have been changing (the baby’s nappy) regularly, have been spending long hours with the baby (2.0) for the most part, I feel that the parents are really well prepared for that date.” (Dr Brown, p.3)

Nurse Jennifer said:

“I think our role starts on day one when the baby is admitted. You have to start preparing the parents for when the time comes for this baby to go home, you know? Like encouraging them to touch the baby, even if the baby looks very fragile. To touch the baby, to encourage them to do something for this baby, small things, bring a special soft toy, you know? Bring nice linen for the baby, special clothes for the baby. I think these things help the parents talk about when the baby will be ready to go home...so I think it starts from admission, just by simple things, you know?, just by talking to the parents and answering their questions...I think the best way to prepare them, as I said from day one that the baby is admitted and throughout the stay of the baby. It’s not like you say, this baby is a 26 weeker and still has three months here so why should I tell them what they need to do when the baby goes home and so on, but I think it is very important that you start preparing them little by little, that eventually this baby will grow, and will be more independent from all the things that are on the unit.” (Nurse Jennifer, p.2, p.6)

7.2.2 Taking parents on board

Senior midwives and nurses talked about how they experienced changes in the local practice around NICU discharge and how they felt this had improved over the years. These staff predominately expressed their satisfaction in the way that parents have

increasingly become more involved in hands-on care of their babies while on the unit compared to earlier times when parents were only allowed to visit their babies for a limited time during the day where they just looked on at the baby. Staff were grateful for such improvements in neonatal practice over the years and considered such changes as being more supportive for home transition.

Nurse Jennifer noted changes in practice which included open visiting time for parents and involving both parents in the care of the baby as much as possible. This reflected a change in culture, in which not only the mother but also the father was seen as a primary carer.

“I think in the beginning when I started to work on the NICU, this thing (going home with a preterm baby) was very difficult for the parents because at that time many parents were not allowed to participate in the care of their neonate whilst in NICU, ehm, because sort of it was the role of the nurse caring for the baby to do it. All of a sudden the mother had, you know, just to go home with this baby without knowing how to care for her fragile preterm baby. After like, I don’t know, one month, two months (the baby) being taken care of by another person, the parents were there just as visitors, to see the baby, to bring some clothes, nappies, this sort of thing. They weren’t sort of allowed that much to participate. But obviously with time these things changed, thank God. Nowadays the mothers and even the fathers are more participative in the care of their preterm baby, even from the first days.” (Nurse Jennifer, p.1)

Nurse Mandy talked about the importance of including both parents with the care of their baby on the unit:

“I think the most important thing is that the parents, both of them not just (the mother) cause we make sure that we teach both parents...on our unit we make it a point that we teach both parents, even baby bath, feeding because the mother could be sick or something, so what is important is that they are really confident in taking care of the baby on the unit.” (Nurse Mandy, p.6)

Midwives and nurses talked extensively about their experiences of teaching parents how to care for their baby in preparation for transition home. Staff conveyed how they made use of the discharge check list on the unit and that this included the different infant care skills considered important for parents to be taught prior to having their baby discharged home. They expressed satisfaction with having a discharge check list which all could follow, so that they could be consistent when teaching parents.

Nurse John said:

"I think one of the most efficient and positive things that happens around (on NICU) is having the discharge check list...it is just a simple A4 paper with basic points that they have to go through, the parents and we have to go through it with them from the day of admission till the end when they go home." (Nurse John, p.3)

Midwives and nurses elaborated on how their teaching to parents focused on basic infant care skills such as, feeding, baby bathing, nappy changing, handling and the teaching of basic life support skills to parents of preterms:

"...with regards to teaching and involving the parents in the care of the baby while still at hospital, I try to as much as possible to incorporate the parents in the baby's care with regards to treatment, baby care, bathing, playtime...we would spend the day together taking care of the baby, me and them, and obviously I would go through the procedures and I would allow them to sort of carry out the skills on their own. Me being there and sort of constantly reassuring and encouraging them (1.0) things like that really, involving them and reassuring them and giving them sort of a knowledge base, information." (Midwife Jane, p.2)

The importance of preparing parents in basic skills so they would be able to care for the baby when at home were also mentioned by the doctors but without much detail, as doctors claimed that these aspects of care were dealt with by the midwifery and nursing staff. However, doctors expressed their satisfaction in the way such training of parents was practiced on the unit. Dr Grey and Dr White said:

"I feel that most of the education really about this thing of discharge is the nurses' and the midwives' role and they do it brilliantly and they are the ones who were there (with the parents) for most of the time." (Dr Grey, p.3)

"I think they (parents) stay a long time on the unit so we get a lot of time to teach them, to show them how to do things. So while they are on the unit, sometimes for months, they are learning. The nurses and midwives do a lot, you know, so it's they who do most of the work here." (Dr White, p.7)

All the participants stated that they were reassured when the standard training was included in the parents' preparation for discharge home, and when parents could demonstrate that they could perform the basic care skills. This reassured the staff that parents were capable of caring for the baby at home. Staff felt a sense of responsibility for the baby's well-being even post discharge, and it was important for them to determine that parents showed their ability in taking adequate care of the baby's basic needs. Following practices outlined in the discharge criteria used by doctors together

with the discharge checklist used by midwives and nurses, therefore seemed to provide the passport to home not only for preterms, but also for the parents. Nurse Jennifer said:

“With the (discharge) checklist we make sure that all the most important things that parents need to know, like feeding, how the baby should sleep when he goes home, ehm, basic life support. All these things we try to make sure that before leaving the parents know. So, on the check list, whatever we teach the parents we tick so that we make sure that they know. Obviously then you recheck, we ask the parents just to make sure that they know the treatment the baby is having, all these sort of things.” (Nurse Jennifer, p.3)

Many of the staff talked of their experiences of transition as being a team effort and acknowledged that providing care towards transitioning the preterm infant from the unit to the home required consistent care from all the different professionals included in the unit. They often referred to the work collectively done by those involved as ‘the system of care’ provided on the unit. This meant that staff considered good relationships amongst the different staff on the unit and parents, as being important and fundamental to good practice. They acknowledged that everyone’s contribution in care played an important role in enhancing the transition of preterms from the neonatal unit to the home. Dr Green explained the benefits of having good teamwork on the neonatal unit particularly when staff worked hand-in-hand to convey similar and consistent messages to parents and avoid confusing them. Conflicting advice could lead to the parents mistrusting neonatal staff and ultimately be detrimental to their home transition with their baby.

“I think teamwork is very, very essential because the worst thing that can happen to a parent is to get conflicting advice. So, I think there is quite a team spirit on the unit and if people are consistent and parents are always told the same things...because parents do ask around, you know, and they want to see if people said the same thing, whether they agree, you know, and whether they are being told the same information, about what their child has, about what the prognosis is, about what long term problems, sort of they shop around. They ask the nurses, they ask the doctors, to see if we are all saying the same thing (2.0) and I think being consistent is important, you know, in not getting the parents confused, and in not losing their trust because when they get conflicting advice, now even if, we are basically saying the same thing, or if both opinions are right, I think giving conflicting advice, the parents will lose their trust in the healthcare professionals and then they start doubting everything, and then they start questioning everything, so I think that is quite a key element.” (Dr Green, p. 3–4)

Some midwives and nurses revealed how when admitting a baby, a bond developed between themselves, the baby and the parents and they felt that this helped to build a

trusting relationship with the parents particularly when continuity of care was provided by the same staff for as long as possible during the baby's hospitalisation. Staff considered that building trusting relationships with parents was good practice as it encouraged parents to voice their concerns and seek advice more freely from those staff with whom they would have built such a relationship and were more comfortable to talk to. Nurse Sonia expressed her experience of establishing relationships with parents on the unit:

"There is this thing, I don't know what it is, I find that every time I admit a baby there is a bond and it's something that cannot be helped...it helps transition because you bond with the baby, you bond with the parents. It's there, it's not something, I don't know, it comes naturally almost, they trust you completely...I think that helps the transition home, there is a trusting relationship and they ask you anything. The trusting relationship that you have, professional, I have to say, it has to be still professional but the trust I think it helps." (Nurse Sonia, p.6)

Some staff revealed that it was hard to see the babies leave, especially when they had been caring for the baby for a long time, becoming emotionally involved with the family as a result. Nurse Jennifer said:

"I think the moment of discharge is the biggest moment for us ((with tears in her eyes)). You have seen this baby coming in, a very fragile baby, 26 weeker, 30 weeker, you have seen these parents distraught all through the experience, sometimes they (parents) say it's like a rollercoaster (3.0) so I think the moment of discharge is one of the nicest things. Even as I talk now, tears come to my eyes, it (going home) is very important for the parents and us." (Nurse Jennifer, p.10)

However, staff expressed the personal satisfaction they felt with their profession when seeing these infants again after some time outside the hospital or when parents pay a friendly visit to the unit with their child. Staff enjoyed seeing how much ex-preterms change and grow over time. Midwife Alison said:

"For me, the fact that a baby has had significant problems and is able to go home, for me it's a great accomplishment. We've (staff have) been effective in making sure that the life that was created goes home and is healthy enough to go home. So for me it's an extreme sense of satisfaction, the ultimate of what we can do, particularly with preterms." (Midwife Alison, p.2)

Nurse Jennifer expressed her pleasure when she saw ex-preterms after a long time:

"When you see them after a number of years, these children have grown up now, they are teenagers, ah I say, I am getting old ((laughs)), but when you see them, the parents always remember, they tell you 'do you remember you taught me how to change the nappy or showed me how to prepare the milk?', so I think

ehe, yes, the fact that you are there to prepare them for this moment (going home), I think for a nurse or a midwife who works on the NICU is very satisfying.” (Nurse Jennifer, p.10)

Some staff also expressed how they considered their work as providing them with personal professional growth and development. They felt that they were always learning something new from different experiences which they then sought to utilise and improve their practice as they provided subsequent care to other parents and preterms. Learning from parents often served as an eye opener to staff, as they realised what really mattered to parents who experience preterm birth. Midwife Diane said:

“Every experience makes you feel much more, ehm, you feel happy that you are giving that output and you have the opportunity to learn from the parents. You give all you can give, and in the first year (of working on the unit) you learn a lot, you observe others working and build your own experience, then the parents, you really learn from the parents with every situation you feel more mature and you can give more every time.” (Midwife Diane, p.6)

Midwife Diane reinforced her thoughts about learning from the parents, in response to a vignette describing the positive feeling a father felt when he was allowed to gently touch his baby on admission to the neonatal unit:

“To let him (father) touch a little (the baby) meant a lot and that is why we learn from them (the parents) because then you say, now if I do that every time, I think it really helps, like him (father in the vignette) this helped him a lot.” (Midwife Diane, p13–14)

Many midwives and nurses expressed their experiences of their own personal practices which they felt helped to support parents better in experiencing home transition. In fact some staff talked about what they personally did in these situations which was not necessarily done by other staff but which they felt were good practices. Midwife Alison described how upon discharge she discussed with parents to see whether they had any queries about the skills they were previously taught on the unit:

“What I do when the parents are leaving, I go through the discharge checklist and I ask them specifically if they need me to explain again, like if it’s basic life support for example, (I ask them) ‘do you have any questions about it? Do you want us to do it again for you?’ I go through the list and ask them if they have any questions so you can verify as much as possible.” (Midwife Alison, p.5)

Staff recognised the distress and fears that parents experienced during their child’s hospitalisation. They were aware of the parents mixed emotions as the discharge day approached and how the moment of discharge often reached an emotional climax for

some parents after considering all that they would have gone through. Midwife Jane expressed her understanding of the parents' mixed emotions on discharge:

"...these babies sometimes spend months on the unit. If it's an early preterm, a 24 weeker or 26 weeker, they would have been there for a very long time so I understand the hesitation and resistance and sort of this new venture that they (parents) have to go home with this new baby, sometimes they are reluctant to leave as well. Although they would want to go home and start this new chapter in their life." (Midwife Jane, p.3)

Some staff recognised that even little gestures can go a long way to alleviate the distress parents experience particularly at the unexpected beginning of what often results in a long journey until the preterm baby can be discharged home. Some midwives and nurses indicated that despite the busyness of clinical practice particularly on admission of a preterm infant to the unit, they still sought to go out of their way, by sending a card with the baby's photo or footprints of the baby to the mother whom they knew was separated from her baby from birth and very often not even having had the chance to see her baby. Staff knew that these little gestures meant a lot to parents and were happy to hear that their efforts were appreciated, particularly when a vignette indicating such gratitude expressed by the parents was presented to some of the staff interviewed. Nurse Sonia expressed her happiness at knowing that such little things were appreciated by the parents:

"I love that (that a mother appreciated being sent the footprints of her baby when she could not see the baby). I'm a very creative person and I'm one of those people who love to do these things. Birthday cards when we know that the mother or the father have their birthday, usually we try and do a birthday card quickly quickly...you give them happiness with a simple thing, I mean which doesn't cost any money but the joy that you can see...it's some joy that you can give while they (the parents) are in that state in...in that big situation they're in." (Nurse Sonia, p.11)

Staff expressed how from their experiences of supporting parents through the transition home from the neonatal unit, communication with parents was a key element. Doctors recognised the importance of communication with parents particularly in keeping them informed throughout the baby's hospitalisation. Giving parents explanatory information about the child's condition and regularly updating them about the care being given featured in the doctors' experiences of communicating with the parents. Dr Brown claimed that:

“We do talk to the parents before they go home and ask them whether they have any concerns, any questions they might have...keeping good communication with the parents throughout really the stay of the baby at the NICU, updating them about the condition of their child, any deterioration, any improvement, any concerns they that they might have along the way.” (Dr Brown, p.2)

Midwives and nurses also recognised the importance of maintaining good communication with parents, not only in educating them about basic infant care but also in having the time to listen to parents, encouraging them to voice their needs and concerns. Midwives and nurses believed that two-way communication helped them to better understand and support parents while providing more empathic care which extended beyond focusing on the physical and clinical aspects of care. Midwife Jane said:

“I feel that as a midwife working on the ward, the most important thing really that I do to help this family out, is to stop and talk to them. To see what are their specific needs, wishes, concerns and that we can discuss because they might sort of feel apprehensive to go home with the baby because of fear of the unknown sort of...at the end of the day, they might need nothing, they just need to be reassured. I mean I think that if I were in that situation, if I ever were to have a preterm infant, even me being a midwife I would maybe be a little more protective of this child because I might deem him as more precious or fragile and I think as a mother I would like this push from somebody else telling me that it's going to be ok, you know?” (Midwife Jane, p.6)

Staff agreed that another good aspect of neonatal care on the unit was providing a rooming-in service for parents and babies usually for a day and night, prior going home with the baby. Staff explained that when rooming-in, parents stay in a separate room but still on NICU and take care of their baby without the direct help of staff. Staff would only provide their help should parents seek their support:

“We have a system on the unit which is, whereby parents stay with the child overnight usually, so they are on their own in a room, the baby is not being monitored, they basically take care of the baby themselves, and they know that the staff are only a door away basically, so if they need anything they're here. That helps to boost up their confidence.” (Dr Green, p.2)

All staff strongly believed that rooming-in was good practice and beneficial to parents prior to being discharged home since it helped to prepare them for what it would be like to take care of their baby on their own at home. Rooming-in was therefore considered by the staff as a very important aspect of transition reflecting a gradual shift from having neonatal staff being responsible for the baby's care to handing over the child's responsibility to the parents.

Nurse Jennifer expressed that:

“We also have rooming-in service, which I think is very important because you don’t just tell the parents, ‘listen today the baby is 2 kilos, go home’. No, you let them stay on the unit for a night, in their own room with the baby with them as if they were at home but with the help of the nurses who are nearby in the unit because the room is within the unit. So, they can call, they can come out with the baby if they need help, we try to mimic the home environment. So they are there, they have their own things, they sterilise their own bottles, they make their own milk, they breastfeed if they are breastfeeding, so I think this thing (rooming-in) helps a lot and it is one night or two nights as they wish...it’s a very very good thing to do.” (Nurse Jennifer, p.8)

The staff perceptions regarding the benefits that rooming-in offered were informed by the positive feedback they receive from parents who had positive rooming-in experiences. Introducing such a vignette from parents’ experiences during the interviews with staff, reinforced their perception of the benefits rooming-in offers to parents. Having parents experiencing rooming-in seemed to reassure the staff that the parents were able to take care of the baby on their own. Midwife Alison expressed how staff still felt responsible for the child’s well-being following discharge from the unit and so they needed reassurance that parents could safely care for the baby:

“We (staff) want the baby to be safe when he goes or she goes home, so whether the parents like it or not it’s our responsibility to make sure that the baby is safe and cared for.” (Midwife Alison, p.10)

7.2.3 Extending NICU care

Many of the staff conveyed that their experiences with preterm infants and their parents did not stop with NICU discharge of the baby. They sought to keep an open service to parents primarily by encouraging them to phone the unit at any time of day and night should they feel that they required further help or advice from the staff on the unit. This indicated that the staff felt it was important not to disconnect the parents abruptly from the care received on the unit. Staff were aware that once at home, parents are likely to encounter difficulties for which they might need advice. They noted that parents expressed relief when they were told that they could phone the unit if they needed. Nurse Sonia said:

“We always give them our (telephone) numbers, the numbers of the ward and we tell them to phone anytime that they want and that helps. Sometimes they call for little things, sometimes they call for bigger things however it helps because it sets their minds at rest and we tell them that if we cannot understand

what they are saying they can come over and we'll see what they need, so the service even though they're home it's still open, so it helps." (Nurse Sonia, p.5)

Staff claimed that they frequently received calls from parents whose preterm infants had been discharged home, asking for advice. The staff felt that it was reassuring for the parents to talk to someone on the unit whom they had met before and who had taken care of their baby. Midwives and nurses who attend to parents' calls, recalled that the most common concerns necessitating parents to phone the unit were primarily about changes in the baby's sleeping and feeding patterns. They felt that parents needed the reassurance that changes in such behaviours were often reflecting the baby's adaptation to the new home environment. All staff felt that providing support to the parents in this way following discharge was an important and good aspect of their practice. Nurse John said:

"We receive several calls especially in the next three, four days post discharge. They (the parents) call over, 'the baby hasn't stopped crying, the baby isn't drinking, what shall I do?' these kinds of concerns, they are minimal things because all parents pass through such situations when their babies cry, when they don't want to feed." (Nurse John, p.6)

All the staff also expressed the importance of having a community neonatal service to further provide support to parents at home following discharge of their preterm baby. Midwives and nurses who had experience with providing this service explained how this practice was not formally organised as part of the health service but it stemmed from the felt need amongst staff on the unit to further support parents once at home. Those midwives and nurses who were interested in providing this service were doing this extended role, on voluntary basis without being compensated in any way. This meant that these staff have gone the extra mile to provide further support post discharge of preterm infants. Nurse Sonia explained how the service functioned:

"We are approximately five people (staff) doing it (community neonatal service) here, we are from different areas of Malta and we take our area according to where we live. It is offered to babies with complications, NG (nasogastric) tubes, babies that are less than 30 weeks of gestation as well and what we do is first we go after one week, then we revisit after two weeks, then sometimes we do a third visit after the fifth week after they go home. In the meantime we offer our telephone numbers, personal numbers and they phone us at any time they want, days and nights. It's on a voluntary basis...it's not a formal service, it's on voluntary basis we don't get anything for it or anything." (Nurse Sonia, p.2)

There was unanimous agreement amongst all staff about the benefits this service offered to parents and the importance of having it more formally organised in future. Those providing community care talked about the benefits parents have expressed about this

service as staff gave advice, listened to parents' concerns and reassured them about the care they were providing to their infants. Through community care, staff came across occasional situations which had not become evident during the babies' stay in hospital, like nurse Mandy who encountered postnatal depression when visiting a mother at home after NICU discharge:

"I had been nursing this baby and you know, when they stay a long time on the unit you even get friendly with the mother, and on the unit the mother was confident of taking care of the baby and the husband was too, and then when I went home for the home visits she was very happy to see me and she started talking with me and she started telling me that she doesn't want anything to do with the baby ((surprised expression))...and it ended up being a case of postnatal depression. I mean she ended up having treatment, so me going there, I think it was good, ok it was difficult cause you're in the parents' home, you're an outsider there and I had to have aids from outside. The problem was that the father, the husband wouldn't (accept it), he was saying that the mother was ok but she was telling me that she was going to kill the baby so what am I going to do? Am I going to leave the baby in that house?" (Nurse Mandy, p.5)

Narrating these experiences made staff realise, even more than before, the importance of having this service for these parents and babies. Parents may need help and support at odd hours and staff responsible for community care have been there ready to go out of their way and answer these cries for help. The staff involved in providing community neonatal care expressed their satisfaction at being part of this, despite the difficulties they experienced particularly since they provided the service voluntarily on their off duties. Nurse Mandy described a particular incident where her help was needed when least expected:

"Once on Christmas day, I had one of the relatives (of an ex-preterm baby), she phoned me, she told me 'we have a problem, we need you, can you come?' I told them 'yes I come', I mean she lived five minutes away from my home so it wasn't a problem really, but I had others who phoned me at six in the morning and I had to go even on a Sunday, so I mean we make sure that the nurses and midwives who are in the group (providing community neonatal care) are in a position that if the need arises they go (to the parents), they cannot tell them (parents) 'I cannot come', you know?" (Nurse Mandy, p.4)

Doctors' experiences of follow up were more focused on the formal service provided to all ex-preterm infants post NICU discharge at neonatal outpatients department within hospital. Having this service has also been described by doctors as a positive aspect of

their practice especially since the same group of doctors who would have cared for the baby on NICU, followed up the baby post discharge:

“seeing familiar faces...they (parents) always look for familiar faces when they come for follow-up. I think that is good, you’re always going to be there, a doctor, you know, they always want to see familiar faces, people who know them.” (Dr White, p.5)

The doctors’ experiences of follow-up care focused on the medical checks done to monitor the baby’s health, growth and development:

“usually discharge is to home with their parents with an appointment at neonatal outpatients usually within a few weeks, and then obviously we follow them up from neonatal outpatients about any problems they might have, development and medical check-up at that point.” (Dr Brown, p.1)

Generally staff perceived that the outcome of their work was positive, for both babies and parents. They seemed to believe that transitions to home from the neonatal unit were without problems. Dr Green said,

“I think on the whole, the transition to home is, you know, very smooth and quite good, and the system has worked over the years. I think the parents are quite happy with the system as well...most of the transitions are very, very similar and they are quite smooth, straightforward.” (Dr Green, p.2)

Additionally, neonatal staff reported that they were often praised for their good work and deeply thanked by parents. Acknowledgment of good practice, added to the staff’s satisfaction in their profession and to their sense of fulfilment in their practice of neonatal care. When vignettes which included aspects of practice which were positively perceived by the parents were introduced during the interviews, staff expressed further acknowledgement of their good practices as parents seemed to have reinforced these by talking positively about them.

7.3 The second main theme: Realising limits

Theme 2 – Thematic structure

Main theme:

Realising limits

Sub-themes:

Exposing self-limitations

Caught up in the system

Through the course of each interview with the different staff, all those interviewed identified limitations within their specific area of practice which they came to realise could hinder transition from the neonatal unit to the home for parents of preterm infants. Some staff were able to reflect on their own personal practices and could identify limitations within their own practice or those within their particular profession. Additionally, all staff were able to identify practices which they felt were limited by the organisation of care within the neonatal department and also at ward management level on the neonatal unit.

The vignettes from the parents' experiences introduced to the staff during the interviews also brought to light practices which were perceived unfavourably by the parents. When staff were faced with such vignettes, they were surprised and even shocked at hearing how some practices had a negative effect on the parents' experiences because they had never realised these situations before. Some of the negative vignettes reinforced the staff's pre-existing awareness of limitations in practice and so parents confirmed what staff already knew. This second theme, *Realising limits* has been divided into two sub-themes; *Exposing self-limitations* and *Caught up in the system*.

7.3.1 Exposing self-limitations

Contrary to what has been discussed in the first theme, where midwives and nurses indicated their satisfaction with having a discharge checklist, later in the interviews staff revealed that, despite having this tool which all staff should utilise with parents, they

were aware that this was often not used as intended by individual staff on the unit. The main concern expressed was with the lack of appropriate documentation when using this tool and consequently this made continuity of care vis-à-vis parents' education of basic care skills more difficult. Nurse John said:

"Discharge planning (using the discharge check list) unfortunately sometimes it gets skipped or forgotten or we don't use it at all." (Nurse John, p.3)

Midwives and nurses were upset when this form was overlooked and forgotten or it was incompletely filled up with many items on the list left empty. These situations made it difficult for staff to determine what would have already been taught to parents with the result that important topics for education could be completely missed whereas others could be repeated over and over again unnecessarily by different staff. Some midwives and nurses indicated that when this form was commenced and put with the baby's records, ideally from admission, it was likely that those staff providing care from then on would follow the example and continue with the right documentation on the tool. Staff realised that ultimately these limitations in practice negatively affect the hospital-to-home transition from the unit. Nurse Mandy exemplified a situation where appropriate documentation was lacking:

"Although they (staff) do the discharge planning (according to the discharge check list) but there is nothing written so for example, last week we had a baby going home, so for example on Monday one of the nurses showed her (the mother) and talked to her about feeding and baby bath. She (nurse) didn't write anything, the next day another nurse showed her baby bathing and feeding again, and unfortunately the parents are not going to tell you 'it was shown to me yesterday' because they like to see if I'm going to tell them the same things and it was done about three times. Then for example on the fourth day there was the same nurse (she said), 'but I showed them' but 'you didn't' write anything', so I think one of the problems is documentation." (Nurse Mandy, p.11)

Midwives and nurses were also concerned that when the discharge checklist was not properly used throughout the hospitalisation of the baby in the teaching of basic care skills to the parents, important educational elements were left to the very end prior discharge, and so were provided in a rushed way or omitted totally. Midwives and nurses showed their awareness that this was not sufficient practice on their part. They believed that this was not supportive to transitioning home since parents' mixed emotions at the time of discharge were likely to influence their ability to adequately understand extensive information provided all at once in a hurried manner at discharge:

"The last thing we do, which I think we do it a bit too late and it's done rushed, quite rushed, is the basic life support, which is done only once and it's done

either two days before they leave or just before they leave, which then questions might start popping up and they don't have anyone to answer (their questions). We should do that a bit earlier." (Midwife Carla, p.2)

A vignette indicating inadequate information where a parent expressed a lack of clear explanations to the questions she asked when her baby was on the unit, was presented to some of the staff interviewed. Their reactions to this parent's experience indicated their awareness that adequate information-giving was sometimes overlooked. Revealing this to the staff via the vignettes was disturbing for them, causing them to reflect on their practice. Nurse Sonia's reaction was particularly striking:

"that hurts, it means that we didn't give the service that we should give...we missed the opportunity to teach her (mother) something, somehow there was this missing with that parent, which I don't think it's nice of us let's say that. I think we failed her to an extent which to me, it hurts if we failed somebody like this. I mean we are here to give a service, a good one I mean we are supposed to be professionals. Most of us do the job from our hearts and it seems somewhere there we got lost ((disappointed and worried expression))." (Nurse Sonia, p.13)

Doctors revealed how they sometimes lacked contact with the parents and communication with them was limited. They identified that not keeping parents adequately informed about the care being given could be detrimental to home transition. Additionally, doctors recognised that lack of adequate communication with parents was a personal self-limitation in their practice, yet they also attributed this to lacking adequate time particularly when the unit was busy. Doctors felt that they dedicated less time to those babies and parents approaching discharge while they tended to spend more of their time dealing with the care of the more intensive babies. Dr Brown said:

"definitely it's lack of communication...maybe ourselves too might be at fault when we are too busy, when we have the NICU with 20, 25 patients so we don't really have the time to spend with each and every individual parent. Ehm, so yes I think communication or lack of it, is the main cause of any problems that might arise." (Dr Brown p.4)

There also seemed to be a lack of clarity between doctors in terms of who should provide information regarding the regular updates in the child's condition and care. Having consultant-led teams of doctors, it seemed ambiguous as to which information should be provided by the consultant and which information is provided by the doctors on duty. In principle, doctors expressed that any significant changes in the child's condition or care and results of major investigations should be provided to parents by the consultant but in practice this was not always done and doctors on duty, sometimes felt uncomfortable when parents asked them about something they knew the parents

should have been informed about by their consultant. On the local unit parents were required to make an appointment if they felt they needed to talk to the consultant. However, staff were aware that parents did not always know about this and the lack of adequate communication resurfaced. Staff were aware that some parents may be voiceless, they would not really ask for information and there was a risk that parents would end up not receiving what everyone believed was their right to know. Dr White said:

“This strikes me a lot, that the parents sometimes feel that either we don’t explain enough to them... sometimes you go to speak to them and she (mother) says, ‘no I don’t know anything’ and you know, then you say, ‘did you meet the consultant’ and they say, ‘no, not really’ and I say ‘why don’t you make an appointment?’...so these things make me unhappy because I think there should be regular...the parents should be regularly met by the consultant and given the information..... It’s not done regularly so the parents have a right you know, to be informed about their babies and they should be given the information regularly.” (Dr White, p.4)

7.3.2 Caught up in the system

Staff from the three different professions attributed many limitations in their practices relating to home transition to the organisation in which they worked. They felt ‘thrown’ into a system which made them feel restricted in changing and improving practice. This was felt to be a result both of the organisation of care within the neonatal department, and also at ward management level on the neonatal unit. Most of the staff felt that parents of preterm infants lacked appropriate psychosocial and emotional support. They believed that the psychosocial impact of preterm birth and the possible repercussions this could have even in the long term on the parents, was underestimated. Doctors, midwives and nurses felt that their care practices predominately focused on the clinical aspects of care and although midwives and nurses provided some emotional support to parents, yet all professionals felt that this was not enough. Dr Grey expressed the implications of having a preterm birth:

“I think the other thing that they need, that these parents need is psychological (support), from the psychological aspect as well, I mean we are accustomed to having a pregnancy which lasts forty weeks and at the end of approximately nine months you have your baby, your baby is born and maximum after four days you go home and take the baby with you. Now having the preterm baby, I mean I have never experienced this myself, I have never experienced a delivery, I mean I don’t have children but I feel sometimes that some mothers also feel that they have done something wrong to sort of like ehm (1.0) bring about this preterm

delivery, so there is that element of guilt, so having a preterm baby I think is a trauma for the parents, then there is all that anguish of whether the baby is going to have a brain haemorrhage, if the baby is ventilated and in an incubator, he is unwell, sepsis and so on and so forth and I think that causes quite a psychological toll on the parents and it doesn't necessarily mean that they would have gone over that when the baby is well enough to be discharged home and in fact I have heard and I've seen parents who had a preterm baby, who is well but they are still obsessed with this baby that something is going to happen to this baby and I don't feel that psychologically they are supported, but I think psychological support in neonatology is the same like all over the hospital basically that it is very difficult to give patients psychological support that they need so I think there is a big lacuna over there, the psychosocial field is a big problem.” (Dr Grey, p.6–7)

Staff believed that parents needed professional psychosocial support because they lacked the adequate training to provide this:

“Something else which hinders (home transition) and which I think can be improved over the unit is psychological support which we don't have much. We have just a little bit, obviously we (staff) try to do our best in supporting the parents as nurses and midwives, but we are not psychologists so we cannot go into much detail about helping the parents.” (Nurse John, p.5)

Staff considered that parents of preterm infants needed such support not only throughout the baby's hospitalisation but also when they go home with the baby:

“the doctors take care of the medical aspect that other things like the social aspect, the psychological aspect you know, which are so important, we don't take care of. Not we don't take care of, we don't take care of enough I feel, so we've had babies who have gone home after we took care of them here for I don't know, months, two three months and then they go home and they die. So we had one case in time where the baby went home, she didn't even last a week at home, she wasn't even a week at home. She got unwell, the mother tried to walk to the hospital cause she had no, she didn't realize that the child was so unwell and she tried to walk cause she had no transport and in her panic she tried to walk to the hospital and the baby died. So we don't want these things to happen. I mean this is a rare situation, but we need to support them socially as well, socially, psychologically, it is very important. It's not just the doctor seeing them regularly medically and checking the heart and so on, not just that, we need the support, if she needs support then the social workers need to support her.” (Dr White, p.12)

The lack of professional psychologists on the neonatal department was considered as the main limitation and staff believed that this was not only a neglected area of practice but also that it was not being identified as an important aspect of neonatal care within their department. Dr White said:

"I think at the moment there is not enough psychological support because we don't have enough psychologists, I feel that is the problem. We have a psychologist but she can't cope with all the work that there is." (Dr White, p.3)

Midwives and nurses were also upset with aspects relating to the allocation of care on the unit by ward managers. On the local neonatal unit, midwives and nurses worked with a patient (baby) allocation system and they felt that the allocation of those preterms approaching discharge home was not being adequately managed. Ward managers often allocated these babies to the more junior members of staff because the clinical care required was no longer intensive and so staff lacking experience in providing intensive care would be able to care for such babies. On the other hand, during the stages requiring intensive care, preterm babies were allocated to more experienced senior staff. Midwife Carla claimed:

"Usually the preterms, when they are about to go home, they are just 'cot-care' so they (ward managers) give them to (be taken care of by) the new ones, just graduated, to learn how to nurse just a small baby so us, the senior ones, we are always with the worst ones (critical babies) and you hardly get the time to speak to them the parents (of those babies approaching discharge). In fact they (parents) tell you, 'you don't do (care for) my baby anymore?', because at the beginning, when they were preterms and ventilated, and not so good (critical stage), we (senior staff) used to do them (take care of them) all the time, and they (parents) get used to you. But then, as they get better, you know, they go to the younger ones (junior staff), so they are not so hard to do (so difficult to care for them anymore), because they are just 'cot-care' and feeding, you know? Things like that, but they don't, but the young ones (junior staff) don't have the experience to speak to them (parents) like we do, you know?...that would help a lot I think if we (senior staff) were able to keep looking after them but that's the system, the young ones (junior staff) have to learn." (Midwife Carla, p.5-6)

This situation was considered by staff as underestimating the importance of care towards home transition. Staff maintained that the days prior to discharge as a time when parents needed more than before advice, reassurance and answers to their concerns. However, junior staff may not have the knowledge and experience to provide the advice needed and to be able to answer the parents' queries appropriately. This made senior staff worried that important opportunities for parent education were being missed. Being 'thrown' into such an organisation was experienced by staff as limiting their possibility to fulfil their educative and supportive role to parents. Nurse Sonia explained:

"They (junior staff) don't have enough experience in the way to talk to the parents...I think this hinders a lot. New staff has to learn, they are still in their

learning phase so they cannot have expertise. They can give (advice) on certain things, but there are other things they are not sure about, they are lacking experience...and for me I think it gets complicated whenever there are new staff discharging a baby. So I think it is one of the major things that hinders transition... The managers have to think of it as, not he's a good (medically healthy) baby, he's going home, he can stay with a junior, no. He's a good baby, he's going home and parents need good advice." (Nurse Sonia, p.7, 13)

Another related concern expressed by senior midwives and nurses was the frequent turnover of staff on the unit where new staff often started working on the unit while others left. This necessitated the senior staff to spend more of their time in teaching new midwives and nurses who went to the unit. Senior staff claimed that frequent staff turnover as well as busy times where the unit got overcrowded with babies, were primary reasons which kept them away from being with the parents of preterm infants and from giving their utmost to these parents. Nurse Sonia expressed her frustration at experiencing regular turnover of staff on the unit:

"I think the big turnover of staff, new staff all the time, I think it's one of the things that hinders (the transition to home)...the turnover of staff shouldn't be in the NICU, the big turnover of staff it shouldn't be I think in the NICU and it comes from way above (management), I'm saying it because you have people (staff), you teach them for six months, one year, then they leave literally. When they are getting hold of NICU care literally, they leave and you don't see them anymore and that's, I mean sometimes if we are lucky they come back but mostly we are unlucky, they don't come back, it's the truth." (Nurse Sonia, p.7)

Midwife Diane expressed how increased workload and shortage of staff on the unit affected the care provided to parents:

"Sometimes even the workload, sometimes you feel so tired of so much work that maybe most of the time you are not giving your 100% to the parents, to the baby you are giving 100% but to get the parents involved, to think about them as going home soon and to help them adapt to the situation, ehm that's what I think." (Midwife Diane, p.6)

Midwife Alison also expressed her concerns when the unit got very busy:

"The problem right now is that there are a lot of babies and few staff, so it's just periodic right now cause usually we're ok. Most of the time it's one nurse or midwife with one or two babies, and when it's that case it's not a problem to help the parents learn, to help them towards transition home but when you have more than two babies it's very difficult especially if they are more intensive...obviously when you have a lot of work to do, it's very difficult to give them (parents) the time they need." (Midwife Alison, p.7)

Although all staff believed that providing parents of preterm infants with a rooming-in service prior to discharge home was beneficial, yet different staff expressed conflicting opinions about the practice. These reflected the experiences they had encountered personally. Staff perceptions differed primarily about whether rooming-in should be optional or mandatory for parents prior to discharge home. Some of the staff felt strongly that rooming-in should be mandatory for all parents. Dr Grey, describing a negative experience, expressed her concerns when parents do not room-in. She had an experience where parents, who had not roomed-in, made a mistake when administering medication to their baby at home despite having had instructions by staff before discharge. This resulted in the baby's condition being adversely affected, needing re-hospitalisation and intensive care. She said:

“it has transpired that these parents, this was their first child, had been offered to room-in but they had refused, and sort of that made me think....I know you need to respect autonomy, the parents' autonomy and you can't push what they don't want but I know the person who had told them had said it in the correct way, but I think that made me realise that sometimes we need to be a bit more pushy because at the end of the day we as professionals are also responsible for these babies' wellbeing. Now this baby could have had brain damage had he had a prolonged fit and...it could have been life threatening and that was when I think I felt that we need to be more sort of like eh proactive and maybe this rooming-in should be the norm for everybody, that is, you have to room-in (it should) not (be) an option.” (Dr Grey, p.4–5)

The responsibility that some staff felt towards the baby's well-being and safety when s/he went home seemed to reflect the fears which accompany these bad experiences, confirming staff in their opinion that rooming-in should not be optional, despite knowing that such a decision would be a top down ('leaping-in') mode of caring and so over-ride the parents' autonomy to decide whether they feel the need to room-in on the unit before discharge home or not. Rooming-in provided reassurance for staff that the parents were capable of caring for the baby on their own (whether this was actually true or not). However, some staff were upset at authoritative attitudes of their colleagues who would not consider that parents had other lives outside the unit and who portrayed negative attitudes towards those parents who did not wish to room-in. Midwife Jane felt that pressuring parents to do what staff thought was best, instead of trying to understand the parents, was unlikely to have any benefit. Midwife Alison felt angry that parents' reasons behind their decision whether to room-in or not were often not considered:

“some (parents) need it (rooming-in), some don't need it as much. Some (staff) don't realise that most people have lives outside the unit, it's not just taking care of the baby. From the staff I've heard a lot of comments about it, like 'they

(parents) don't know they have a baby here (on NICU)?' but I understand these parents' point of view...sometimes when they (parents) show that they're not really ready for it (rooming-in) or they don't really want it, they are pressured into it. So they do have a choice but it's only on paper, you know?" (Midwife Alison, p.9)

As previously indicated, some staff held a strong belief that rooming-in was beneficial for parents and this was probably informed by the positive feedback staff were used to having from parents. However, when vignettes from parents' experiences indicating negative perceptions regarding rooming-in were presented to them, most of the participants were taken aback or even shocked, because they had never encountered these negative comments from parents. These vignettes acted as eye openers for staff as they came to realise that rooming-in was not always positive for parents as they had previously thought. In fact, many of the staff acknowledged that the negative experiences described in the vignettes were real and made them start thinking of possible ways how the rooming-in service could be improved. Midwife Diane and midwife Carla said:

"My goodness ((shocked))! The thing is, we had a lot more things (in the rooms) but they were stolen (and not replaced) so we give them some plastic things but obviously it's not home and most of the time they have to bring a lot of things with them, even the sterilizer so it is then like 'home'...the thing is that maybe these parents were a bit forced to be there too." (Midwife Diane, p.14)

"We offer them (parents) a night or two (to room-in), mostly everyone stays a night cause it is really boring in there, they get fed up. It's just like a bedroom but you have nothing, no TV, you can't maybe cook." (Midwife Carla, p.4)

Staff also recognised that a limitation in their practice stemmed from organisational policies. This reflects their 'thrownness' in an NICU world of regulations which related to the lack of importance given to siblings and close relatives to the care provided to preterms when on the unit. At the time of data collection, the unit visiting policy did not allow siblings or any other relatives to visit the baby during the hospital stay. All the different staff reflected that such a system worked against family-centered principles of care and limited the transition home of preterms. Staff expressed that although this approach was taken on the unit to avoid increased sources of infections for the babies on the unit, yet they believed that the benefits of including siblings and close relatives especially grandparents, outweighed the perceived added infectious risk. Dr Brown said:

“If there are sibs (siblings) in the family, or even grandmothers and grandfathers, ehm, I must admit that from the medical point of view we ignore them, they do not exist. For us it’s the baby who is sick and we need to treat him. That should be our primary concern but on the other hand, if there is a two year old boy at home who has been left by his mother because the mother is always coming to the hospital, I think he, this sibling, and the grandparents which are really part of the extended family for many families in Malta, have been kind of neglected in the whole process. Our concern about infectious diseases and so forth is real and we should not allow the NICU to become like the village square with people coming in and out at will but I think we should be giving more opportunity to siblings and grandparents.” (Dr Brown, p.6-7)

In Malta, grandparents are the primary sources of emotional and social support for parents with newborns, and staff acknowledged that denying grandparents’ involvement in the care on the unit would make it more difficult for them to support the parents of preterm infants after discharge. Also staff expressed concern that grandparents were likely to have difficulties when they came to care for the preterm baby, usually soon after discharge from the hospital when both parents return to work. Grandparents lacked experience in caring for a preterm baby who was usually still considered a very small baby at discharge. Additionally, staff also expressed their concerns for the child’s wellbeing when grandparents care for the preterm at home without having received any instruction related to basic care skills:

“Something which we are not doing here right now and I wish that we would have is, considering that the siblings come in as well with the parents and close family...the people who will be helping the mother and the father at home...We had a child, I think she was 4 or 3 (years old) and they (her parents) were showing her a picture every day, a picture of her (preterm) sister. The problem was that first she (preterm) was with the CPAP, eventually they removed the system and she (sibling) literally told them ‘she’s not my sister’, ‘she’s not the one with the tubes and all’ and we had to sort of convince this three year old that it’s still her sister so then I think that if she at least once per week she came and visited her sister, she wouldn’t have had this problem. And this happens also with the grown-ups, I mean they (preterms) leave here as normal babies however they are of a lesser weight (compared to a term baby). Some people have never seen such small babies, and they (relatives/grandparents) have to handle them. When the mummy goes to work, when the mummy goes out shopping, when the mummy takes a bath, whatever and I think that for me it’s painful that they cannot come in...because they are part of the family. They will be living with these kids, and I think, I mean they will have a big role in their life however in the most important time of their life they won’t be there, (if) at least maybe in the last week, two weeks before discharge they can come over and start caring for them once per week, twice, two hours, I don’t know but it helps the transition.” (Nurse Sonia, p.3-4)

7.4 The third main theme: Awakening to needed improvements in care

Theme 3 – Thematic structure

Main theme:

Awakening to needed improvements in care

Sub-themes:

Listening and less talking

Weaning neonatal care from parents

Having acknowledged limitations in their current practice, staff identified various ways in which neonatal practice could be improved to better support parents through their transition from the neonatal unit to the home. In their reflections to improving the current practice, staff showed how, despite lacking a formal family-centered care policy on their unit, they were generally aware of important elements which would improve existing practices and move closer to the ideal of family-centered care both on the neonatal unit and beyond. This third main theme, *Awakening to needed improvements in care*, which emerged from different staff experiences in neonatal care, elicits what staff felt was needed to improve transitions from the neonatal unit to the home. This theme is sub-divided into two sub-themes; *Listening and less talking* and *Weaning neonatal care from the parents*.

7.4.1 Listening and less talking

Different staff attributed the lack of adequate communication with parents as a major limitation of neonatal practice which hinders the parents' transition home with their preterm baby. After having attributed various reasons as to why communication was not always adequate in their practice (theme 2, section 7.3), staff also reflected on the importance of having good two-way communication between parents and the different neonatal staff. Staff felt it was their responsibility that when 'caring-for' parents, they needed to be available to parents, needed to maintain constant communication with the parents and ensure that time was found during their practice to listen and talk with parents regularly. Different staff acknowledged that preparing parents for discharge and transition to home should not be left towards the very end of hospitalisation as

sometimes tended to happen, but should be ongoing starting from admission. Maintaining good ongoing communication with the parents from as early as possible during hospitalisation of the preterm infant was believed by many of the staff, to be the start of the process of transition home for parents:

“I don’t think the preparation for the discharge should be done on the day of the discharge but throughout really the stay of the baby at the NICU, in keeping good communication with the parents updating them about the condition of their child, any deterioration, any improvements, any concern that they might have along the way. I feel that is part and parcel of the preparation for discharge.”(Dr Brown, p.2)

Some doctors, after having identified that their communication with parents was often lacking, realised that they needed to do their own part with improving their communication with parents. They became aware that many parents were voiceless, and that they did not readily ask doctors for information or make an appointment to talk with doctors:

“We (doctors) need more communication with the parents, the consultants to meet them (parents) more regularly, not wait for them to ask for an appointment, it would have to be a regular appointment.” (Dr White, p.7)

“Parents need daily updates from doctors too (not only from nurses and midwives) without having parents chasing for information.” (Dr Grey, p.17)

Different staff revealed that a lot of information was given to parents during the course of their child’s hospitalisation, however they realised the need to be careful and not overwhelm parents. They noted that it was important to follow their pace and provide them with information according to their needs. Information thus needs to be ongoing, and not delivered in haste and as a pile of undifferentiated knowledge at the end of hospitalisation:

“There are parents who can handle so much information and it actually empowers them but then there are parents who are actually overwhelmed and it can actually become counterproductive because then they start panicking...I always feel that it takes longer to gauge what amount of information a patient (parent) needs then to actually pass on the information but that would be ok with somebody who can take it but it wouldn’t be ok to overwhelm somebody with all that information, somebody who can’t handle it. I think the first thing is to gauge what information is needed because patients come in all forms and sizes, shapes and sizes ehm and you realize this, there are parents of preterm babies who don’t need...they need some support but they can handle washing the baby, giving the baby the bottle and so on and so forth and then there are parents who, it takes them a long time to get used to things so I think you need to follow the parents pace.” (Dr Grey, p.10)

"I think with some talk and if you (staff) listen to them (parents) and give them time so you would know what they need to learn...they will be much more comfortable and reassured once they go home." (Midwife Diane, p 6)

Similarly, Midwife Carla identified the need for staff to talk more *with* parents:

"Us (staff) being able to listen to parents and being there, not just nurse him (the baby) and that's it. You sit down with them and talk with them, because they do have a lot of questions about their child." (Midwife Carla, p.5)

Many respondents suggested the need to have more staff working on the unit so that the busyness of practice does not take time away from being with the parents. As Dr Grey said:

"I think one of the major problems that we have right now is the overcrowding, ehm we have a lot of babies, so that means you have less time to spend with each individual patient, from the medical side and I think it affects the nursing care as well because if you are looking after two babies it's one thing, if you are looking after three and four, it's another thing...you cannot spend half an hour chatting with the parents, can you? So you have less contact time...maybe having more people on board (staff) would be ehm a good idea because if you have more staff it means you have more patient contact ehm and this is both from the medical and the nursing point of view." (Dr Grey, p.16)

In view of the great deal of information and training given to the parents, staff realised that parents may find difficulty recalling some of the information later and they suggested the need to provide repeated teaching to parents to help them retain the information given. Some staff also suggested that education to parents could be provided as group teaching for parents on the unit during the day through lectures and demonstrations, which could also serve for parents to build support networks between them:

"having lectures and demonstrations and these things (would help). We do teach them things like basic life support but perhaps, we could, if we have resources to do it, rather than having one nurse telling them once about how you would, you know, perform basic life support, it would be done more regularly perhaps (repeated teaching). We could have lectures during the day, something like that." (Dr White, p. 6)

Providing parents with written information which they could easily refer to when they are at home was also suggested as a possible way of improving the practice of information giving to parents and in overcoming problems with recalling information previously given when on the unit. Neonatal staff also believed that parents would benefit from receiving more specific education about preterm infants so that they would be more prepared in what to expect especially relating to growth and development in

their babies, particularly when this did not follow the expected trends associated with a term baby. Dr Brown said:

“Something else that can be definitely done is to give them a written piece of literature about dosages of medicines, any complications, when to call a doctor, which symptoms are important, what is the dosage of paracetamol, or any painkillers, whether you should use colic drops, or when do you expect the child to start teething problems and so forth...during a discussion you (staff) can give a lot of information but probably they will forget 95% of it. Having the same information written down on a paper, parents can easily refer to...so a discussion with parents, not just on the last day but throughout their stay on NICU and some written information specifically for ex-preterms and not for just any other baby. Most of the information will apply to all babies, obviously, but ex-preterms have concerns of their own.” (Dr Brown, p.5–6)

Following the staff initial focus on physical and clinical aspects of care, the lack of adequate psychosocial and emotional support given to parents of preterm infants emerged as the interviews unfolded. This either happened spontaneously or was triggered by the introduction of vignettes from parents’ experiences. However, all staff agreed that psychosocial and emotional care needed to improve to better support parents in coping with their preterm birth, through hospitalisation and transition home with their baby. Many of the staff felt that psychosocial care needed to be an organised service on their unit, provided by adequately trained professionals and offered to all parents. Having a more multidisciplinary approach to care including psychologists and social workers who would work regularly with NICU parents was suggested by staff so that a more holistic approach to transition home would be implemented. Midwife Jane reflected on the need for more psychological support to parents of preterm:

“I think they should be supported much more. The fact that we give them CPR training and we make sure that they come to give the baby a bath and that they feed the baby, but I think there is a lot more underneath the surface sort of. Those are the basic skills you know, but I think psychologically we need to take care of the parents much more.” (Midwife Jane, p.8 para 42)

Dr White emphasised that psychosocial support should be offered on regular basis to all parents:

“we need to do regular counselling so we look out, see if there are mothers (and fathers) who have problems, psychological problems, how they are coping, if they are coping. So this would be a sort of screening and has to be done regularly and then those who need are offered (further) psychological help.” (Dr White, p.3)

Some staff felt that parents are unlikely to ask for psychological or social support themselves. Yet, staff realised that there are various reasons why parents need psychosocial and emotional support. Even the parents' past life experiences could have an impact on the way they respond and cope with their preterm birth, hospitalisation of their baby and beyond. So, staff believed that if *all* parents were invited to talk about their situations with the right professionals, they could be supported to cope better according to their unique experiences. As Dr Grey said:

"It is not necessarily because you go out from the unit with a healthy baby, it doesn't mean that it doesn't have its consequences you know, it just doesn't stop there, it goes beyond that...a full-time psychologist is what these parents need because those people who need it (psychological support) the most are those people who are not aware that they need it because denial is a very strong coping mechanism (3.0) that is all I can say." (Dr Grey, p.20)

Midwives and nurses, in particular, noted from their experiences that parents who spent a long time with their baby on the unit tended to cope better with their transition home than those parents who spent shorter periods of time next to their baby on the unit:

"You see the difference between the people (parents) who, the time they spend here with the kids and those people who don't stay here as much. Those who can come here for feeding and changing times only, or come for two hours a day, there is a big difference from those who stay more with their baby, how they cope then at home. The ones who stay here more (longer), they know how to handle the baby, they are more relaxed. In fact, these people, most of them they want to skip the phase of rooming-in and they are capable of skipping it because you can see it. You can see it, you say 'these are ready for home, these aren't so much.'" (Nurse Sonia, p.8)

Nonetheless, staff also recognised that it may not be feasible for some parents to be on the unit for long hours due to other commitments particularly when having other young children at home. Although, as noted previously, many Maltese families are supported with childcare from close relatives, and particularly grandparents, staff recognised that organised social support for childcare provided within the hospital, while the parents are on the NICU, could better support and encourage parents to spend more time on the unit. These findings suggest that staff are extending their focus from the clinical needs of the baby to looking more widely at the needs of the parents and their families and recognising the importance of parents' contact to the child's wellbeing. Dr Grey said:

“I think parents should be encouraged to spend more time in hospital, now I know that some parents have other siblings and that might be a problem because I know that with changing generations now most grandparents work as well, so that is going to be a problem, child care...maybe something could be done...I mean these are really families in need as well, not financial needs, but they have other types of needs, social support, so child care facilities could be provided for them.” (Dr Grey, p 5)

Many of the staff believed that it would be beneficial for parents if they could encourage parents to talk among themselves and support each other when on the neonatal unit. Staff also suggested that parents could be encouraged to build their own support networks if staff could organise talks and group discussions for parents while on the unit. These could focus on common topics of interest like growth and development in preterms. Nurse Jennifer said:

“you (staff) can make them (parents) meet other parents and the setting of the unit (open ward) helps, because they can talk with other parents, we can encourage them to talk to each other just for their own encouragement because parents can encourage each other quite a lot. And when you are passing through an experience sometimes you want somebody who is passing through the same experience to talk to.” (Nurse Jennifer, p.3)

Additionally, different staff identified that parents needed a parent-to-parent support group which is formally organised where parents who have had preterm infants can support each other even post NICU discharge. This could better support parents go through home transitions so that they do not feel alone. It appeared from the interview data that some staff had already been taking the initiative to set up a parents’ support group. However they felt frustrated by the organisation of care in which they worked which seemed to make it difficult to pursue such an initiative. Dr White explained:

“...once they are at home they feel alone and you know, there is also a need for a support group which we are trying in fact to set up so at the moment we are trying to set up a support group for parents who had children, who have children on the unit, and parents who would have taken their children home...so they can talk to each other and their experiences are shared and like that their problems are halved...we’re in the process of setting it up. I mean we (the support group) wanted to meet in the hospital but when you meet in the hospital you need to involve a lot of administrative people so that was proving to be an obstacle, believe it or not ((upset)). So now we might be trying to meet outside the hospital but we thought perhaps it would be easier if we could meet within the hospital because of the parents who are on the unit.” (Dr White, p.3-4)

Many of the staff indicated their disagreement with having a visiting policy which excluded close relatives, namely grandparents and siblings and indicated that they felt that this should be revised as they claimed that siblings and grandparents also had transitions to go through. For siblings, life would have changed considerably since the birth of the preterm baby and their transition to accepting the baby at home was then made more difficult if they would have only seen their new sibling in a picture for weeks since birth. Respondents felt that grandparents too, being the primary sources of support with childcare in Malta, need to be involved in the care of preterm during hospitalisation of the infant so that their transition to care for the baby when at home while parents are at work would not be problematic. Hence, staff become aware of the relational basis of the parents' lives to the world and those who are significant for them. Midwife Diane said:

“from my experience in Belgium and in England and even in Scotland, they (neonatal staff) used to emphasise that the relatives should come, the close relatives, the close family and the sisters or brothers (siblings) cause for two months, you know that your mother just had a baby and you never (see her), when they are going to be at home, it is going to work really bad for them (siblings). The transition is for everyone, it's for the parents, for the siblings and for the grandparents, you know and I think we have to work on that and we have to find some way or another and do something about it.” (Midwife Diane, p.8)

Staff felt it was in their interest to ensure that when the baby goes home s/he is safely taken care of not only by the parents but also by any other relatives caring for the child. Staff maintained that they were willing to work towards implementing changes to their current visiting policy and identified how including other relatives in the care of preterms on the unit was important:

“we should start getting the relatives in, at least the grandparents because here in Malta they are of a big help the grandparents because usually most of the couples, most of the mummies go back to work soon so the grannies need to know how to look after such a small baby because a two kilos is a very small baby...so we should involve them...even the siblings, we should get them a bit inside (the unit).” (Midwife Carla, p.4)

7.4.2 Weaning neonatal care from parents

Neonatal staff repeatedly indicated that the transition to home commences on admission of the baby to the unit, continues through hospitalisation of the infant and beyond after discharge. This means that different staff believed that transition to home was not a

time-specific event which occurred at the point of discharge from NICU. Staff perceived that home transition needed to reflect a more gradual shift for parents where their unique needs are better recognised and incorporated into neonatal care. *Weaning neonatal care from parents* reflects the needed changes in neonatal practices which staff perceived were necessary so that parents are better supported especially at the time around NICU discharge and after going home.

Providing parents with a rooming-in service prior to discharge home has already been identified as a positive aspect of neonatal practice in this study (theme 1, section 7.2). However, different staff recognised that this service had its' own limitations. Although in principle parents could be offered to room-in for more than one day and night prior to discharge, in practice there seemed to be the standard practice for rooming-in to be limited to such duration with little consideration as to whether parents may need more time:

“...if they would be able to spend more time ehm rooming-in, and not just for one night because one night comes and goes and sometimes a baby might sleep well the first night and then the second night he won't sleep so well or he won't feed so well.” (Dr Grey, p.5)

A gradual shift from the unit to the home would therefore need to reflect more the parents' needs and so consider changing this practice to facilitate parents to room-in with their baby until they feel confident to go home which may mean that parents could spend more time rooming-in than was currently practiced. Dr Grey continued by saying:

“...they could sort of spend more time over there (rooming-in), I think it would be a good transition because you don't go from intensive care with full monitoring directly to home...that is why I said that rooming-in is not a standard night for everybody because one family might need one night and they are ok and another family might need two, three nights...so I think it is getting to know the parents well before.” (Dr Grey, p 6)

In principle, rooming-in on NICU is referred to as being the practice where parents experience being with and caring for their baby in a home-like environment away from their own home. However, neonatal staff became aware that rooming-in facilities on the unit had not quite provided parents with such a service, particularly when they heard the vignettes from parents' experiences. These stories indicated the lack of facilities in the rooms and how these limitations made the room-in experience a negative one for some parents. Many of the staff therefore realised that rooming-in practice needed better planning and management. The rooms available needed to provide a more homely environment for parents which would more truly be 'a home away from home'. Staff

realised that parents need to be comfortable when rooming-in and this experience should not cause them more stress. Having almost bare rooms was not inviting for parents to live in and staff recognised that even simple facilities and features like the décor in the rooms would help to make parents feel more comfortable.

“The rooms for rooming-in, they’re literally like a jail, like a jail room. The window is there ((indicating with a stretching of her arm)), a wall is like a meter away from the window so they have literally no light. It doesn’t have a feel of home. Rooming-in it’s supposed to be, alright, that you care for the baby but at the same time I think it should be more comfortable, you know, you’re not just locked in the room.” (Midwife Alison, p.11-12)

Some of the staff believed that when parents refused to room-in, they needed to explore the reasons behind their decision. Family issues, as in not allowing other siblings to room-in with the parents, could be one main reason why some parents refuse to room-in since that would create problems with childcare for them during the time they spend rooming-in on NICU. Adopting more family-friendly rooms which provide a service that truly reflects a homely environment, where it would be possible for parents to get other siblings while rooming-in with the baby, is a change in the practice which would be more inviting to parents to experience rooming-in on the unit prior to going home with their prematurely born baby. Midwife Carla claimed:

“...mostly everyone stays a night cause it is really boring there, they get fed up. It’s just like a bedroom and you have nothing, no TV, you can’t maybe cook. It should have been planned a bit better like a small flat so at least they can stay two or three days and be more comfortable. They could get the siblings in as well, to stay with them for a while cause mostly it’s just the couple, they stay or the mother and maybe a grandparent cause the husband can’t stay (to care for other child/ren at home).” (Midwife Carla, p.4)

Providing neonatal community service to parents of preterm infants post NICU discharge had been clearly described by all staff as being beneficial in supporting parents in a gradual transition from NICU to home, where the neonatal care provided by midwives and nurses was not terminated abruptly for parents, but continued as needed following discharge home. This was believed to support parents in experiencing their spatial shift from the neonatal unit environment to their home. However, it became clearly evident that at the time of data collection, this service was ad hoc and not adequately organised. There was no clear agreement between staff on how the service operated, especially whether it was care offered post NICU discharge to all parents of preterm infants or not and how visits were organised with the parents. Yet, there was

consensus between the staff that this was an aspect of care which needed to be addressed and improved primarily by being formally organised and not a voluntary service provided by a few dedicated midwives and nurses to a very limited number of parents of preterm infants. Staff claimed that over time this service had been badly affected by staff shortages, which resulted in the service almost dying-out:

"I can say that in the last three years, we only had a few parents who had these visits, most probably because we knew that there were some problems with the parents, social problems or maybe we saw them very anxious. I think this service should be more spread to other parents (be)cause maybe sometimes we think that they are very good and it's ok to let them go home but they might show then that really they are not (ok). Ehm maybe I saw this (neonatal service) six times in three years, not more than that...I think it should be more widespread and our nurses and midwives (neonatal staff) should go there (home visits)." (Midwife Diane, p.9)

Many of the staff expressed their interest in working towards implementing an adequately organised service which best meets the needs of parents of preterm infants:

"...parents like this thing that you (staff) go to their house, the way you tell them you prepared really well for this baby, the house is cosy for the baby all these sort of things, and they are doing it very well, I think you give them a lot of encouragement. So this thing (community neonatal service), we should keep on encouraging and keep on improving, improving the system." (Nurse Jennifer, p.5)

Some of the staff suggested that community neonatal care could better support parents. Extending neonatal care to include not only care provided post discharge but also include care like home visiting prior to having the baby discharged home, to support parents in preparing their home environment to receive their baby. Midwife Diane asked,

"Why don't we go before (discharge home) and explain to the parents things (which they can prepare) that maybe they are not thinking about?" (Midwife Diane, p.10)

Community neonatal care which provides a twenty-four hours support system for parents where continuity of care and carer are practiced as much as possible, was what staff believed would be best. In doing this, parents are not just sent home with their baby, but they are supported and encouraged in building their self-esteem and confidence, whilst providing them with the advice and reassurance needed. Midwife Jane said:

“I think it would be beneficial if the parents are visited at home by a member of the staff, possibly a nurse or midwife who would have cared for the baby (on the unit) so there is sort of continuity, you know, to see how they have adjusted, if they have any concerns, if the baby has had any problems, if they as a family have any problem...I think that would be ideal so that they’re not just thrown back into their house...it would be nice to go see how the family is working as a unit together in their own environment, I think that would be good.” (Midwife Jane, p.7)

Staff indicated that they appreciated and needed the parents’ feedback about the services they were providing so they could improve their practice according to the parents’ needs. Yet, staff recognised that improving the service was not without challenges and that the organisation in which they worked needed to support their initiatives.

Nurse Mandy expressed her concern when staff lacked feedback from parents:

“Sometimes even I worry, ‘are we doing it the right way?’ not just discharge, even going to the community, we don’t get feedback...it’s good (to get feedback) to improve our care.” (Nurse Mandy, p.15)

Nurse Jennifer emphasised the importance of having feedback from parents:

“Some parents come and visit (the unit), especially on the birthday (of the child), they come back just to visit but it would be good to have their experiences too because we (staff) view things differently. Parents, the way they view things, they might think of something differently how things should be done and I think we should consider a lot their opinion because at the end of the day we are working for these babies. We want them to go to their homes, in a good environment where their parents are better carers than we (staff) are in NICU. That is what we want, because they grow up in their family.” (Nurse Jennifer, p.11)

7.5 Conclusion

This chapter presented the findings from 12 neonatal staff members’ experiences of their role in the transition of preterm infants from the neonatal unit to the home. Three main themes emerged together with seven corresponding sub-themes. In the first theme, staff revealed the multiple ways in which they perceived that their practice supported the parents’ transition to home with their preterm infants. Subsequently, as staff reflected deeper on their roles in practice, they identified various practices which were likely to hinder a smooth home transition for parents and these were captured in the second theme. Finally, the third theme revealed what neonatal staff perceived that was

needed to better support parents as they take their preterm infant home from the unit. These themes reflect opposing realities in the staff experiences, particularly captured in what they say *is* practiced and what *should* be practiced.

There have been no prior studies of staff and parents' views and experiences of transition from NICU care that have re(viewed)the findings through the lens of Heidegger's philosophical ontology. The next chapter of this thesis undertakes a Heideggerian interpretive analysis to uncover the underlying phenomenon that frame and influence the meaning of NICU transition for the study participants.

CHAPTER 8:
APPLYING A HEIDEGGERIAN INTERPRETATIVE LENS TO
NICU-TO-HOME TRANSITION

8.1 Introduction

Following the analysis and presentation of the lived experiences of parents of preterm infants and of neonatal staff about the transition of preterms from the NICU to home, I sought to delve deeper into what the findings from both participant groups may mean. The participants' narratives brought forth many shades of their lived realities. As the interviews progressed more layers were peeled off, indicating an evolving process of revealing further experiential realities. Interestingly both participant groups started their narrations with similar introductions, an initial public appearance of acknowledging that experiences of neonatal care and practices were positive and that the system was working well. However, as participants reflected deeper on their experiences and got underneath the initial superficial layer, they revealed more of the phenomenon, providing greater depth in the meaning and understanding which would otherwise have remained hidden. It became evident that across the two data sets, the experience of neonatal care practices had complementary but also contrasting realities between parents and staff. It is these oscillating realities across parents' and staff experiences which will be further interpreted through Heidegger's philosophical notions in this chapter.

After dwelling in the data of both participant groups, the resultant question was, *'how is it that both parents and staff experience practices which facilitate and others which are likely to hinder home transition?'* Hence, the discussion which follows seeks to interpret further the meaning of the phenomenon revealed in this study, which is *'Parents and staff experience home transition of the preterm infant through both enabling and inhibitive neonatal care practices'*. This interpretive discussion is divided according to two philosophical themes which emerged: *'Staff-parents solicitude'* and *'The technological beings'*. Excerpts and paradigm cases from the participants' data are used to highlight the resonance of these themes with Heidegger's philosophy. Although the participants' quotes used in this chapter have been used in previous chapters, they are

used here to elucidate a philosophical interpretation and not the first level analysis as presented in chapters six and seven.

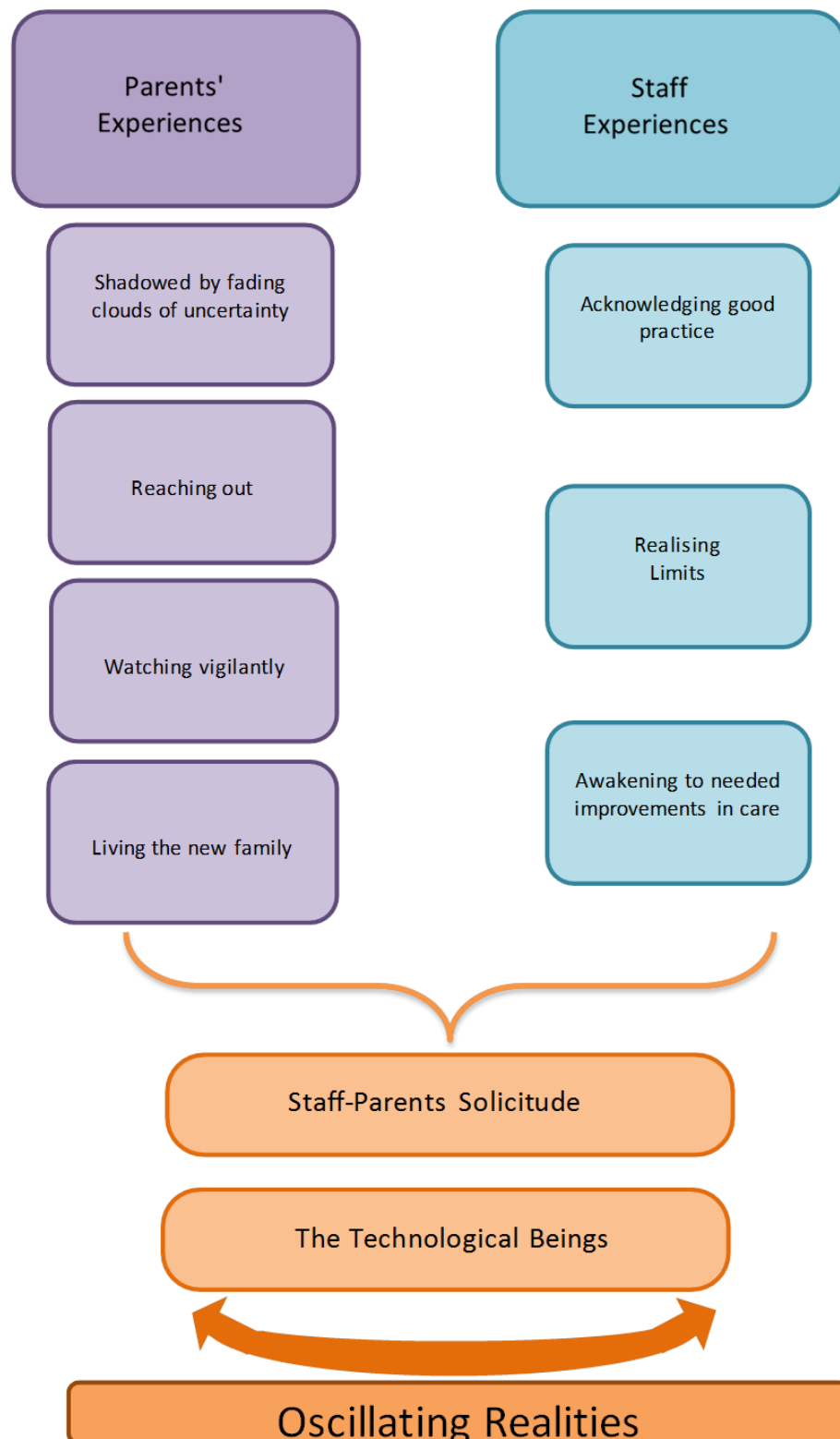


Fig.6 Overview of hermeneutic interpretive findings of NICU-to-home experiences

8.2 Staff-parents solicitude

Heidegger (1962), in his concept of care describes the way one Dasein relates to other Daseins as solicitude (*Fursorge*), which means ‘caring-for’ (Healy, 2011). According to Heidegger, solicitude is a state of Dasein’s Being (Heidegger, 1962) referring to the type of care shown to other human beings through our involvement with other people, as we encounter them within-the-world. In this study, neonatal practices can be interpreted through the relation of care between neonatal staff and parents. We may think of neonatal practices as a form of solicitude where staff demonstrate their involvement with parents through different modes of solicitude. According to Heidegger (1962), solicitude has two distinct forms or two extreme possibilities: ‘leaping in for’ or ‘leaping ahead of’. This section focuses on interpreting the data in terms of how solicitude could be seen to vacillate as neonatal staff cared-for parents by both ‘leaping in’ for them and also by ‘leaping ahead’ of parents.

The ‘leaping in’ mode of caring for the other, takes others for granted, diminishing the others’ freedom of choice, taking over and choosing for the other. In such solicitude others can become dominated and dependent as this takes over the possibilities of others and directs and controls them (Steiner & Reisinger, 2005). Heidegger calls this mode of solicitude as ‘inauthentic’ caring because it treats the other as less than the owner of his or her ‘mineness’, leading him/her away from the ownership of his own being-one’s-self (Fould, 2014).

In neonatal care a ‘leaping in’ mode of solicitude was revealed on several occasions both in the parents’ narratives and those of the staff. When ‘leaping in’, staff restricted the parents’ participation in caring for their baby when on the unit, took away decision making from the parents and often, by virtue of their expertise in neonatal care, staff decided what was best for babies and parents. It has been shown that on the unit, staff decided when the baby would be discharged home and what the parents needed to know before the baby was permitted to go home. Staff expressed their responsibility to direct their care at forming functional and competent parents who acquired skills to be able to deal with their baby. In doing so, staff often functioned as gatekeepers, ‘leaping in’ and setting limits for what and how parents should parent their child and acquire the characteristics of a ‘good parent’. Dr Brown explains how the decision to discharge the baby from the unit was based on a medical perspective:

“usually the point is reached where it is evident from our point of view, from the medical point of view that the child is healthy enough to go and mature enough to go home.” (Dr Brown, p.2)

In this study, an everyday routine ‘fallen mode’ of being resonates with leaping-in solicitude which parents often experienced on the neonatal unit and was reflected in routine ways of being-with and practices adopted by neonatal staff. Hence in their ‘everydayness’, staff tended to be absorbed in such activities, including their dealings with parents on the neonatal unit. According to Heidegger (1962), the ‘they-self’ pursues its everyday indifferent mode of ‘being-with’ and is related to our everyday ‘absorption in’ our life activities where we do not become fully engaged with our particular responsibilities. Being in a ‘fallen mode’ relates to behaving in a predetermined way with each other, by conforming and not attempting to achieve a unique perspective (Heidegger, 1962).

There were several routine practices on the unit: the use of standard discharge teaching, checklists and discharge criteria used with all parents of preterms, the visitation policy on the unit and the practice of rooming-in at the end of the preterm’s hospitalisation. It became evident that these ‘standard’ practices did not address the unique and holistic needs of parents and so, often negatively impacted the parents constraining their possibilities to experience adequate parenting on the unit. These practices are further discussed with the next theme relating to the Heideggerian concept of *machination*. Nurse Jennifer explains about the routine use of a discharge checklist with all parents. She said:

“With the (discharge) checklist we make sure that all the most important things that parents need to know, like feeding, how the baby should sleep when he goes home, ehm, basic life support. All these things we try to make sure that before leaving the parents know. So, on the check list, whatever we teach the parents we tick so that we make sure that they know.” (Nurse Jennifer, p.3)

Additionally, in this study staff often conceptually took the role of professional parents to the preterm babies in their care. They may not have always trusted the parents with caring for the preterm and adopted a paternalistic attitude and took ownership of the baby. This reflected the power imbalance in relationships between staff and parents, which restricted the parents’ possibility to experience the sense of parenthood that they wished. Elsa’s parents expressed their frustration on the neonatal unit as they felt that

their role as parents was often overlooked by staff who ‘leaped in’ and whose behaviour restricted them from connecting to and parenting their child, unlike other staff who gave them more opportunity to express their parenthood on the unit.

Elsa’s dad said:

“I used to tell her (wife) that this baby is my daughter, but here (on NICU) she’s not....I walk in there, to see my daughter...but in there she is not my daughter”
(Elsa’s dad, 7a p. 5)

Elsa’s mum added:

“some (staff) are too much of a mother themselves. They are mothers, I know most of them are.....and they start mothering the baby themselves. I wanted to try (to feed her) myself, to try myself as much as possible but it’s like some didn’t give me that chance because they became overprotective on her.... they got attached maybe, I mean I don’t blame them but it’s like I didn’t have the opportunity to start realising that I need to start taking over.....by all means they do a very good job but at times they are too much a mother themselves. Some tell you to try, they give you a chance, but not all of them.” (Elsa’s mum, 7a p. 5–6)

In contrast, solicitude which ‘leaps ahead’ liberates the other to exist for herself or himself and so frees others to their own possibilities and potentiality-for-Being. The emphasis is on empowering the other rather than suppressing and disabling the other (Heidegger, 1962). Heidegger calls solicitude which ‘leaps ahead’ as ‘authentic’ caring where the other is seen as self-governing and whose ‘mineness’ is acknowledged (Heidegger, 1962).

Parents in this study also narrated experiences where they felt that some of the staff took the ‘leap ahead’ and gave them the possibilities and the power to choose, when their preterm baby was on the neonatal unit. This became particularly evident when parents felt that they were encouraged to participate in the care of their baby. As neonatal staff supported them in their transition from the neonatal unit to their home, they leaped ahead of parents, they encouraged parents to look past their present situation to their future, helped them realise their own potentials and their possibilities. Many parents described actions of the staff who supported them in pursuing their possibility to parent their child when on the unit. These neonatal staff went beyond their ‘fallen mode’ of the ‘they-self’ and leaped ahead by choosing to move away from the routine practices on the unit and supported parents by enabling parenting, ultimately leaving a positive

impact on parents in their experience of home transition. Anna's dad expressed how staff had involved them in hands-on care of the baby:

"....at NICU they (staff) taught us practically everything what we needed to do, how to change the nappy, wash her and everything, and they supervised over us doing these things, we have learnt....they taught us everything." (Anna's dad, 9a p. 5)

When people show others that they have possibilities, that they have choices, they are bringing to light the other's essence as a human being, as in the case of parents who are encouraged to appreciate and embrace their own possibilities (Steiner & Reisinger, 2005). Hence, one may argue that the question, whether to 'leap in' or 'leap ahead' lies in whether Dasein's actions towards the other affirm or deny the other's freedom to choose and pursue own possibilities.

Kristoff's mum shared her experience with how staff behaved differently. She recounted her difficulty with how she would breastfeed her baby following discharge and many of the staff readily 'leaped in' and told her how she should feed her baby, until one particular midwife took the 'leap ahead' and sought to empower the mother to feed her baby by acknowledging the mother's previous experience of breastfeeding with her older child. This 'authentic' caring empowered the mother and gave her the confidence she needed when breastfeeding her baby. She said:

"What I feel had confused me was how I was going to feed the baby when I go home. There (on NICU) he was fed every three hours for eight times a day and with the other child I always breastfed him on demand. So when we came for discharge I asked them (staff), 'how am I going to feed him?' ... I got confused and everyone started giving me their opinion, and if I spoke to six, the six of them told me differently. Some were telling me that he is still small and to try and force him to drink every three hours, wake him up, so I got confused what I should do ((confused expression)). Then there was a midwife and I asked her, because I was asking everyone to get everyone's opinion, and this one asked me 'What did you do with your other son?' I told her that I breastfed him on demand, and she said 'then do that and just keep an eye on his weight' and she also said 'try to give him a bottle of expressed breastmilk before he sleeps so that you are sure that he has had his amount' and that is what I did when I came home and I started going to breastfeeding clinic to check that his weight was good and that was working (for me)." (Kristoff's mum, 4a p. 17-18)

At the outset of each interview with the staff, whether midwives, nurses or doctors, a sense of comfort with what was considered the norm in everyday practice in neonatal care was expressed. According to Schalow (2013), the norm provides a comfort-zone, a

sense of being comfortable, for the most part, of where we are without asking questions. In fact, staff in this study were clearly unaccustomed to questioning themselves as neonatal carers and their practices on the unit. As indicated earlier, staff commenced their stories by identifying the good aspects of their roles and practices. However, as the interviews progressed they moved along a continuum between being unquestioning and acknowledging that their practices were providing parents with adequate support for home transition, to becoming more inquisitive as they went under the surface and reflected deeper on their practices. Staff expressed various feelings on how neonatal practices had an impact on parents' experiences. Being faced with situations which have adversely influenced the parents' experiences of neonatal care, rattled the staff's comfort zone and made them realise that it was not all good for parents and the situation needed to be improved. When faced with a situation where a mother expressed her frustration at having had many unanswered questions when on the neonatal unit, Nurse Sonia suddenly became aware of 'everyday' practices on the unit and how these impacted parents negatively. Nurse Sonia said:

*"that hurts, it means that we didn't give the service that we should give....we missed in the opportunity to teach her (mother) something....somehow there was this missing with that parent, which I don't think it's nice of us let's say that. I think we failed her to an extent which to me, it hurts if we failed somebody like this. I mean we are here to give a service, a good one I mean we are supposed to be professionals. **Most of us do the job from our hearts and it seems somewhere there we got lost.**" (Nurse Sonia, p.13).*

Many staff participants in the study started to question their everyday Being in neonatal care. Self-questioning relates to the structure of care which reflects the individual's 'can-be' or 'potential-to-be' (*Seinkonnen*). The 'can be' is the dynamic whereby the individual directs him/herself 'ahead' towards new possibilities. The self is not simply 'who' it is 'now', but is and becomes its own possibilities (Schalow, 2013). Heidegger (1962) suggests that there is always a possibility to become, that is, Dasein is not finite but constantly becoming through a reflective process of its situation. Through their reflections on practice, staff realised that their solicitude with parents, was often not supporting them adequately on the unit and towards their transition home with their preterm infant. They identified the need to care for parents by demonstrating more attitudes and behaviours which 'leap ahead' of parents. Staff recognised the need to move forward towards care where parents are more listened to, where the unique needs of different parents would be identified and addressed through more individualised

approaches of solicitude. Thus, they could see their potential-to-be neonatal staff who could improve practice and better support parents in their transition, in their potential to parent their new baby. Having become aware that much more could be done to better support parents in their transition home, staff identified a new ‘potential-to-be’ in terms of improving themselves and their practices and care for parents more by ‘leaping ahead’ than by ‘leaping in’.

Midwife Diane described how her experiences with different parents on the unit help her experience such a dynamic shift in care, enabling parents to pursue their new parenting role:

“you really learn from the parents, with every situation you feel more mature and you can give more every time.” (Midwife Diane, p.6)

8.3 The technological beings

Heidegger (1976) was one of the early philosophers of the 20th century to address his concern for technology and through his philosophy warns about the dangers technology can bring about (Todres, Galvin & Dalhberg, 2007). Heidegger was concerned with the ‘essence’ of technology and not with viewing technology as tools and products to use (Thomson, 2011). According to Heidegger, we have to confront the danger of technology in order to be receptive to a ‘wake up call’ and of a ‘turning’ and thereby a potential transformation at the heart of our technological way of existing (Schalow, 2013). Heidegger (1977) coined the term ‘machination’ which refers to the technological progress and the resultant dominance of technological and calculable ways of thinking and of handling objects. Machination reduces anything to numeric measurement, calculation and control (Thomson, 2011).

The following discussion draws on Heidegger’s concept of ‘machination’ to interpret parents’ and staff experiences of technology and how this has led them to become technological beings at the expense of abandoning the humane ‘Being’ in neonatal care. In this regard, technology refers not only to the equipment used to monitor the preterms’ wellbeing but also to standard routines and practices adopted on the unit. Technical practices were particularly reflected in fixed regimes of infant feeding, the use of standard discharge criteria and discharge checklists, discharge teaching and the practice of rooming-in. Technological interpretations also relate to elements pertaining to

systems of care within the organisation, as in the allocation of care on the neonatal unit and the visiting policy adopted. This discussion does not imply that such use of technology is unnecessary in the intensive care setting but in congruence with Heidegger's thoughts, the problem lies in *how* technology was used and thus the impact this had on the study participants.

Heidegger sees technology as a way of disclosing and revealing 'Being' and as transforming beings who are involved in technology (Moran, 2000). In his exposition of the essence of technology, Heidegger applied the concept of 'enframing' (*Gestell*). He argues that technology is fundamentally 'enframing', which is an all-encompassing view of technology, not as a means to an end, but rather as a mode of human existence. According to Heidegger (1977), all that has come to presence in the world has been 'enframed', such that what is revealed in the world, what has shown itself as itself (the truth of itself) required first an 'enframing', literally a way to exist in the world, to be able to be seen and understood (Moran, 2000). Hence, 'enframing' names the fundamental, ontological process of 'revealing' and 'to enframe' refers to the process of an 'opening up' as a "*gathering together of that setting-upon that sets-up man, [that] challenges him forth, to reveal [to himself] the real*" (Heidegger 1977, p. 302). Carnevale (2005) argues that 'technological enframing' reveals the world only insofar as it reveals the world as a resource, a thing to be manipulated, controlled and used, what Heidegger (1977) describes as a 'standing-reserve'. According to Heidegger (1977), human beings are 'standing-reserve', being challenged to set upon all things, including ourselves, so that they may be ready to be ordered about and becoming something technological.

Heidegger (1977), claims that 'machination' is underpinned by three influences which include: 'massiveness', 'calculation' and 'acceleration' (Thomson, 2011). These concepts reveal how these influences became evident in the participants' experiences of NICU-to-home transition. The insights gained from these interpretations show how technological practices had negative impacts where parents of preterm infants have been objectified into becoming 'standard' parents, where their unique personhood has often been overlooked with the result that the holistic nature of parenting has received little consideration. Technical care has featured as the priority of care, yet this meant that other psychosocial and emotional supportive care were marginalised rather than being considered complementary parts of a holistic approach to neonatal care. Nurse John expressed how staff believed in the use of technical aspects of care on the neonatal unit:

“I think one of the most efficient and positive things that happens around (on NICU) is having the discharge checklist...it is just a simple A4 paper with basic points that they have to go through, the parents and we have to go through it with them from the day of admission till the end when they go home” (Nurse John, p.3)

Heidegger (1977) claims that technology has rendered ‘beings’ to be perceived as lineated and homogenous resources (Thomson, 2011). Such ideology lies in what Heidegger (1977) names, ‘the outbreak of massiveness’ and resonates with this study where through ‘enframing’, the parents are turned into a ‘standing-reserve’, similarly and uniformly equated with every other parent, through specific policies and practices. On the neonatal unit, the ‘enframing’ of parents occurred in multiple ways. The standard discharge teaching and checklists used, for instance, relate to parents as standardised and homogenous resources. Various clinical standards, procedures and policies have been established on the unit which dictate how ‘good parenting’ should be established. These practices reflect how parents (the ‘resources’) were controlled based on objective ‘truths’ (Thomson, 2011). *“The demand for rules is a symptom of the technological approach to the world, an approach that tries to manage and control the behaviour of all entities, including human beings” (Polt 2003, p. 169).*

Nurse Jennifer described what care on the unit focused on and shows how all parents were controlled into becoming able to do care-giving tasks for their baby:

“With the (discharge) checklist we make sure that all the most important things that parents need to know, like feeding, how the baby should sleep when he goes home, ehm, basic life support. All these things we try to make sure that before leaving the parents know. So on the checklist, whatever we teach to the parents we tick so that we make sure that they know” (Nurse Jennifer, p 3)

Standard discharge practices adopted by the staff on the unit, reflected repeated cycles of the same events with all parents without extending beyond the stage following discharge of the baby. Staff too reported being overcome by technological practices and got stuck in repeated cycles of preparing all parents for home transition using the same tick-box checklists and so fitting all parents into the same cycles of discharge procedures, based on a clinical perspective, lacking in the recognition of parents’ individualised needs. Ultimately, staff indicated their discomfort with repetitive and routinised care. In a return to an authentic position as caregivers concerned with the wellbeing of individual babies and families, as noted above and in chapter seven, some

of them had chosen to use their own time to offer a highly personalised post-discharge support outreach service.

Heidegger (1977) claims that the ‘outbreak of massiveness’ relates to standards whose quantifiable ‘truths’ manipulate and dominate the ‘standing reserves’ through the processes of calculation and acceleration. ‘Calculation’ refers to calculable objective measurements of progress and success. According to Vallega-Neu (2003), “*all ‘beings’ are determined and organised by guiding principles and rules, everything is regulated through calculation*” (p. 59). This concept resonates with calculations made which are considered indicative of the preterm’s progress and ultimately achieving the desired measurements for the baby to be considered fit for discharge home. The discharge criteria used on the neonatal unit stipulated the measurement of having the baby weighing 2 kilograms and a gestation of 35 weeks, as being the requirements needed for the baby to achieve in order to be discharged home. These calculations have created boundaries and impositions of when parents could take their baby home and emphasised the clinically-centered discharge practices with no consideration of the parents’ psychosocial and emotional readiness to take their baby home.

Dr Green described this by saying:

“We have certain discharge criteria on the unit, so for preterm babies to go home they have to be above 35 weeks, they have to be out of oxygen usually, we do send babies home on oxygen but that is in extreme circumstances. They have to be above 2kilos in weight and most of them are feeding orally and there are no complications. So usually, even from the parents’ point of view, they can, by the time they’ve been here (NICU) so long, they know that those are the aims that their baby is trying to get, before eventually going home” (Dr Green, p.1)

In this study, parents and staff spoke of awaiting the timings and measurements stipulated by protocols in neonatal practice. Time was utilised to determine aspects of care as in, the rigid calculation and timing of feeding the baby, irrespective of the baby’s indicative need to feed. Routinised, strict amounts of three-hourly feeding regime adopted on the unit made parents feel compelled to continue to follow these regimes even at home indicating that parents were not really confident in determining feeding cues in their babies themselves. In this case, machination became the only way of Being that was possible for some parents, even in the home setting. In this case, technology was not a physical thing, but a mind-set. One could argue that the effects of calculations undermined the parents’ self-capabilities ‘to be’ parents as they often surrendered their child to the expert care of the neonatal staff and their technological

control. Anna's mum described how she was dominated by rigid feeding routines on the unit, which stayed with her even when her baby was home:

"I kept to the same feeding routine she (baby) had there (on NICU), I feed her every three hours, and if she doesn't wake up (after 3 hours), I wake her up and feed her" (Anna's mum, 9a p. 10)

The extensive use of technology to monitor the wellbeing of babies has also made parents become dependent on such monitoring as part of the process of becoming 'good' parents and so were controlled and manipulated to rely on monitoring and routinised care adopted on the unit, even when their baby was discharged home. These insights resonate with Heidegger's criticisms of technology in terms of how a 'will to will' is represented (Thomson, 2011) and how the powerful dominance of technological practices on the NICU stayed with the parents beyond the hospitalisation of their baby. Parents in the study expressed how this constant monitoring and surveillance of the baby's wellbeing on the unit stayed with them for much beyond discharge, where they continued to closely monitor their baby in a similar manner.

Elsa's dad said:

"I know that over there she (baby) had constant surveillance, I know that she had that special plate (apnoea mattress), I know that the things that she had were constantly monitoring her and I realised that after we left there (NICU), that I have to constantly monitor (the baby at home too)" (Elsa's dad, 7c p. 39–40)

Eric's parents explained:

Eric's dad: *"the first thing that we bought (when we came home) was the baby monitor"*

Eric's mum: *"ehe, the baby monitor for the cot...because there (on NICU) he used to have it, so like this our minds are at rest for sure."* (Eric's mum & dad, 6a p. 9-10)

'Acceleration', another concept related to the 'outbreak of massiveness', refers to the speeding up of processes to achieve the desired outcomes (Thomson, 2011). Having the preterm infant being discharged home from the neonatal unit seemed the ultimate desired outcome for both parents and staff. However, towards the end of NICU hospitalisation, some parents felt rushed and the last phase on the unit was 'accelerated'. Informing parents to room-in with their baby was sometimes a last minute thing which often took parents by surprise. Various aspects of discharge teaching were similarly left to the very end when a lot of information was given to the parents over a short span of

time. The readiness of the parents to take their baby home was not really considered and discharge was the staff's decision based on the baby reaching medical stability and on whether staff believed that parents were capable of performing care-giving tasks to the baby.

Elsa's dad described how at the end of hospitalisation, once the decision was made that the baby was fit to go home by the staff, he felt being rushed to the NICU door and take the baby home:

"I think the door of NICU closes a bit too fast (on the parents), this is something I felt...when we left it felt very scary. It was like 'ehe she is being discharged today, good, ok thanks, bye' It was literally, 'thanks, bye'...it was abrupt, you know, there had been all that caring then when it came to leave...it was very impersonal when we left...it was too abrupt....there was too much coldness when we left, you know?, 'eh ok, ok, bye bye' (father imitates the sound of a door slamming shut)." (Elsa's dad, 7c p. 37)

Heidegger (1977) argues that 'machination' turns Being into 'present-at-hand' where concern is based on the presenting facts and concepts, without any concern for the history, value or usefulness of others (Thomson, 2011). In this study, the essence of Being a parent has been concealed by the essence of technology. When their child was born prematurely, parents experienced the loss of their child as it was taken away to intensive care, the birth itself felt unreal and NICU technology and practices often took over their possibility of parenting their child. The baby did not feel their own until they took him/her home. Their Being has been 'forgotten' and care focused on technical aspects directed at producing parents capable of doing tasks for their baby, missing out on the more holistic nature of parenting, particularly the psychosocial and emotional aspects of preterm parenthood. Sven's mum expressed how the birth of her baby felt unreal and that having her baby taken away to intensive care was experienced as the loss of her child:

"...I took it really badly the way it happened, sort of at one point he (baby) is inside me and all of a sudden they (staff) took him away, not even giving me a chance to cuddle him. It's like I didn't realise I just had a baby of my own ((surprised)). I felt as if they had taken something from within me. They (staff) are not to blame, because it was for the best of the baby, but for me it was traumatic." (Sven's mum, 2a p. 1)

Neonatal staff often became inauthentically absorbed in routine technological everyday processes with little regard for the parents' Dasein, resulting in parents becoming depersonalised of their own Being. Staff had been adopting technological practices and procedures, lacking consideration for the need to question these practices (the essence

of inauthenticity). It is only after reflecting on such practices that staff started to recognise the need to engage with parents at a more emotional and affective level, listening to parents and adopting practices to address their unique and holistic needs. This would better support them in their transition from the neonatal unit to their home with their preterm infant. Staff indicated good ambitions to develop more family-focused care that promoted and facilitated home transition. However, so far care seemed to be driven by management constraints and medical-technical aspects which staff often found themselves ‘thrown’ in despite becoming aware of the constraints certain practices created for parents and in effect, hindering an effective home transition with their baby.

Having been dominated and controlled by medical-technical care, staff started to realise how this overlooked other important aspects of care. Doctor White said:

“the doctors take care of the medical aspect than other things like the social aspect, the psychological aspect you know, which are so important, we don't take care of. Not we don't take care of, we don't take care of enough, I feel.” (Dr White, p.12)

According to Heidegger (1962), ‘thrownness’ is a basic characteristic of Dasein as ‘Being-in-the-world’ and refers to the certainty that we as beings find ourselves thrown into a context without having a choice (Healy, 2011). Heidegger (1962) claims that “..... ‘thrownness’ is meant to suggest the facticity of its being delivered over” (p. 174). These terms refer not only to how the world we live in impacts on us, but also as encountering our world by always being ‘attuned’ to it (Healy, 2011). According to Heidegger (1962), a fundamental basis of our ‘thrownness’ is the inauthentic state of ‘fallenness’. Heidegger refers to ‘falling’, as a state in which we get caught up in the ‘public self’, without accessing our ‘authentic-self’ (Moran, 2000). Staff and parents were ‘thrown’ into the systems of care adopted on the unit which focused primarily on the medical care of the preterm infant, perceiving a total pathological perspective to prematurity, including parents’ normal responses to this life crisis.

Heidegger (1962) warns that it is only when the situation in which we flee is revealed that we begin to understand and interpret our ‘being-in-the-world’. Similarly, staff need to reflect on the practices and policies in which they have been ‘absorbed in’ and question the meaning such care reveals. Staff expressed different feelings about the organisation of care adopted on their unit and often felt powerless. However, they indicated their desire to a different model of individualised and family-centered care

organisation that would optimize health and address the unique needs of the whole family where the child, parents and any other family members who parents wish to include in neonatal care.

Staff ultimately realised that care needed to include more psychosocial and emotional support for parents, which primarily required them to listen to parents and explore with them their reactions to their preterm birth. Providing medical-technical care aiming at a favourable outcome of a healthy preterm baby does not rule out the effects that prematurity has on the parents.

Midwife Jane said:

“I think they (parents) should be much more well supported. The fact that we give them CPR training and we make sure that they come to give the baby a bath and that they feed the baby, but I think there is a lot more underneath the surface sort of. Those are the basic skills, you know, but I think psychologically we need to take care of the parents much more” (Midwife Jane, p.8)

Dr Grey, in her reflection on the care given, acknowledged that discharge of a healthy baby did not abolish possible long term consequences from premature birthing. She said:

“It is not necessarily because you go out from the unit with a healthy baby, it doesn’t mean that it doesn’t have its consequences you know, it just doesn’t stop there, it goes beyond that” (Dr Grey, p.20)

Heidegger’s (1977) concept of machination reduces parents’ experiences of parenting their preterm into one narrowed ‘standardised’ perspective of producing ‘good’ parents who could perform care-giving tasks for their baby, rejecting variations amongst parents’ history, uncertainties and their unique concerns and needs. ‘Massiveness’ enframed parents into controlled technological beings where neonatal care prioritised the technical elements of care and overlooked other important elements where the essence of truth remained largely concealed. Recognising and accepting such concealment potentially directs efforts at finding ways to engage with the changes needed to be addressed in neonatal care and genuinely understand the meaning of parenting the preterm infant and better support them in neonatal unit to home transition. Every parent needs to be acknowledged as a distinctive being with individually determined history, responses to the preterm birth, needs, values and beliefs. In neonatal care, technology needs to be balanced with an authentic ‘Being-with’ and so enabling parents to truly experience their identity and role as parents to their preterm infant in the neonatal care setting.

8.4 Conclusion

This study has brought to light oscillating realities in the experiences of parents of preterm infants and neonatal staff of the transition from the neonatal unit to the home in Malta. The philosophically based interpretations presented in this chapter have sought to provide deeper meaning of such fluctuating experiences and why this could be so. I have drawn on Heidegger's philosophical concepts where the effectiveness of transition-to-home experiences reflected different modes of solicitude between staff and parents, and the technological influences of practices on the neonatal unit. Utilising Heidegger's underpinnings helped to uncover insightful meanings and significances of the phenomenon for those who experience it and enabled understanding in a new light.

In Malta, neonatal care on NICU leading to home transition seems to be complex and driven by medical-technical aspects of care and management constraints. In theory, staff know how they ought to behave and practice in order to facilitate the parents' transition from the NICU but narratives revealed that the reality differed in various ways. Staff have not always demonstrated behaviours and practices supportive to home transition. However, they have shown good ambitions to develop care that better promotes and facilitates the parents' and preterm infants' transition from the NICU-to-home.

Putting aside the medical-technical aspects of neonatal care would be unthinkable in today's care of preterm infants. However, the consequences of overlooking psychosocial and emotional support of parents experiencing preterm birth and premature parenting may not be clear as yet. The findings and interpretations revealed in this study serve to highlight the lack in adopting a holistic and family-centered approach to neonatal care.

Parents' stories and staff experiences indicated that neonatal care needs to focus on 'Being-with' parents through solicitude which leaps ahead of parents where neonatal staff respond appropriately to the parents' unique situations. Practising everyday repetitive routinized caring, where staff acted in the 'they self' has clearly not been effective in addressing the unique and individual needs of parents. Authentic caring on the neonatal unit, potentially supports transition experiences of parents of preterm infants from the unit to their home. 'Attuned' individualised neonatal care can enable parents in their transition towards effectively parenting their preterm infant both on the neonatal unit and ultimately at home. Establishing healthy parent-staff relationships based on respect and trust, can therefore facilitate positive home transitions. Findings

generated through this lens suggest that creating a family-focused neonatal health care service has not yet been achieved in Malta.

The next chapter discusses the key findings of the study in relation to the wider literature. Congruence to previous findings is identified, while new and insightful findings that emerged from this study are highlighted. The study's strengths and limitations are also discussed.

CHAPTER 9

DISCUSSION

9.1 Introduction

This chapter discusses the key findings of the study in the light of other literature in this area. As previously indicated in chapter two and appendices D and E, few directly relevant research studies were identified at the outset of this study, or as the study progressed. Consequently, in this chapter comparison of the findings includes other studies that explored neonatal care practices and experiences more broadly. Findings from this study relating to parents, and, to a lesser extent, neonatal staff reinforce but also extend reported findings in other existing research. This chapter concludes by exploring the strengths and limitations of the study.

9.2 Concurrence with and extension to current literature: staff findings

9.2.1 Focus on clinical and / or psychosocial aspects of care

The results of this study resonate with earlier findings that the initial primary concern for neonatal staff in terms of transition out of the NICU is the medical stability of the infant, and the need to provide parent education to prepare parents in caring for their baby on their own when at home (Mancini & While, 2001; Meck et al, 1995; Sheikh et al, 1993). In previous studies, and in the current case the content of this education was largely driven by what staff perceived as being important for parents to learn and know prior to discharge (Drake, 1995; Sheikh et al, 1993). This included the use of discharge checklists and the tick-box approach to preparing parents for home transition. The views and experiences of medical staff, in the initial stages of each interview, seemed to concur with the rather instrumental views expressed by the nursing staff. In this study staff based the discharge appropriateness of the infants upon their clinical decisions and generally lacked consideration for the parents' readiness to take their baby home. Redshaw and Hamilton (2005) in a national UK survey on neonatal unit organisation and policy, also found that many neonatal units had rather prescriptive criteria for discharge based on a weight or gestational age cut-off, the baby's maintenance of body

temperature, growing and feeding orally well and when staff thought that parents were able to cope.

Additionally, in this study, unlike others in this area, further probing, and the use of vignettes revealed that, as staff narrated their experiences, they started to reflect deeper on their practice and were able to move from the primary focus of care directed at meeting the needs of the baby, to recognising that parents of preterm infants needed to be better supported psychologically and emotionally. Recognising the lack of attention being paid to non-clinical issues, particularly in the provision of psycho-social support, and the effects on a family's journey through neonatal care and their experience of the transfer from NICU to home, have been the predominant concerns which led to the nationwide POPPY study across neonatal units in the UK (Staniszewska et al, 2012).

Nurses, midwives and doctors in this study, recognised the need to have more contact with parents and be with them, not only to provide the physical care and teachings, but also to actively listen to parents, get to know them, identify their needs and concerns. Similarly, nurses in Fegran and Helseth (2009) perceived that understanding parents' situations and needs was crucial when adopting family-centered care. Additionally, the importance of identifying parents' needs was addressed in the development of a model of FCC where there was a strong parental involvement from generating principles to defining indicators for implementation in a family-centered model of care (Staniszewska et al, 2012). The authors (Staniszewska et al, 2012) of this project argue that involving parents as valid research partners helps develop care which is relevant and appropriate to parents' needs.

9.2.2 Rooming-in

Rooming-in prior NICU discharge is considered an essential part of family-centered caregiving (Griffin & Abraham, 2006). Although previous studies have investigated mothers' views of rooming-in (Bennett & Sheridan, 2005; Costello & Chapman, 1998), there have been no earlier studies of the views of neonatal staff in this area. In this study, rooming-in was explored in depth by the staff participants. They reflected beyond the benefits usually attributed to this practice, as they also expressed the difficulties and their concerns with this practice on the unit, and ultimately how it could even hinder rather than facilitate home transition for parents. They noted, particularly, that although

the service was portrayed as being optional, in practice the decision ultimately rested on doctors and ward managers, with parents not having much say or choice in the matter. Influenced by negative experiences of re-admissions of preterms where rooming-in was not done, doctors were more in favour of rooming-in being mandatory for all parents of preterm infants, despite knowing that this denies parents' collaboration in decision-making.

On the other hand, some other staff, particularly midwives and nurses recognised that an autocratic attitude does not address the parents' unique needs for rooming-in. They perceived that rooming-in was unlikely to be beneficial for parents who were forced to do what they felt they did not really need. This controversy between staff may be explained by the sense of responsibility which many staff, expressed for the baby's wellbeing and safety not only when on the unit but also when at home. Consequently, rooming-in was perceived by many of the staff, as confirming the parents' abilities to manage the infant's care before they hand over the baby to them completely.

Such findings have brought forth issues of collaboration and decision-making, while highlighting issues of power of staff over parents. Collaboration between neonatal staff and family members in the management of the infant's care is one of the cornerstones of FCC (Feldman, Ploof & Cohen, 1999; Harrison, 1993; Saunders et al, 2003) which helps families become more involved in decision-making and so become empowered to influence care processes in their infant's recovery (Bowen, 2007).

Additionally, the staff in this study also identified that the rooms used for rooming-in were not adequately equipped and uncondusive to a home-like environment which such rooms were supposed to offer. Redshaw and Hamilton (2010) also found that despite the fact that almost all neonatal units in the UK had rooms for rooming-in, yet many had inadequate facilities and that this may contribute to parents feeling unimportant. In their attempt to make it better, many staff in this study identified ways of improving the conditions for rooming-in care, making it more family-friendly, by improving facilities and décor in the rooms. Findings suggest that where there are rooming-in facilities, attention should be paid to how the practice and facilities for rooming-in are utilised. They should be used to increase parents' overall capacity to maximise their sense of Being, Being-parents as primary caregivers without the restrictions and impositions which became evident in this study. This issue is further explored in terms of the parents' views below.

9.2.3 Staff-parent relationships and information-giving

The importance of communication and ongoing information-giving to parents throughout their NICU stay has been repeatedly identified as being key to family-centered care but is still often not adequately practiced on neonatal units (e.g. Cooper et al, 2007; Irlam & Bruce, 2002; Ramezani, Shirazi, Sarvestani, & Moattari, 2014; Staniszewska et al, 2012). Communication with parents on neonatal units has only been sparingly explored from staff perspectives, and doctors in particular, have not featured in the existing studies.

The findings in this study resonate with previous studies where workload, frequent turnover shortage of staff and lack of continuity of care were identified as limiting the staff contact and communication with parents on neonatal units (Cooper et al, 2007; Higman & Shaw, 2008; Johnson, 2008; Valizadeh et al, 2013). Trajkovski et al (2012) add that such identified barriers reveal nurses' difficulties in implementing FCC into the relational aspects of their daily practices. These resource issues have been seen as barriers to establishing trusting relationships with parents, which is one of the essential components to the practice of family-centered care on neonatal units (Fegran, Fagermoen & Helseth, 2008; Higman & Shaw, 2008).

This study also adds a more nuanced analysis and reveals that the trusting relationships that staff were predominately concerned with, were from their own perspective of being trusted by the parents. They were less reflective about the need for them to trust parents reciprocally, to be good parents to their babies. This differs from the mutual trusting relationship between staff and parents and vice versa which has been advocated in previous literature (Fegran et al, 2008; Higman & Shaw, 2008). Indeed, staff participants disliked the tendency for parents to evaluate and judge the information they were given by asking around various staff to try to identify the most consistent information. Staff saw these actions as destructive to parent-staff relationships, as fostering a climate of mistrust, and as something which needs to be avoided, rather than as a genuine attempt by parents to find the information and advice that they trusted best.

Although family-centered theory focuses on building trusting relationships between staff and parents (Fegran & Helseth, 2009; Shields et al, 2006), yet the mutuality of such relationships is still questionable (Corlett & Twycross, 2006) since intensive care units are still environments where nurses and physicians maintain most of the control (Moore, Coker, DuBuisson, Swett & Edwards, 2003). The dilemma of how much

control is given to parents has also been previously identified by nurses who experienced ‘power struggles’, and control was described in terms of finding a ‘middle ground’ (Higman & Shaw, 2008). Trajkovski et al (2012) also identified that nurses experience tensions in practice where they often want to involve parents but yet retain control in neonatal care. Such findings indicate that staff need to understand their own professional power-relations and how these could influence trusting parents, and that, in order to achieve mutuality, power and trust must be balanced. Positive and trustful staff-parent relationships enable parents to connect to their infants whereas a negative relationship may lead to disconnection (Flacking et al, 2006; Lupton & Fenwick, 2001).

Essentially FCC places the needs of the individual infant in the context of the family, thereby redefining the relationship between parents and staff (Davis, Mohay & Edwards, 2003; Heerman, Wilson & Wilhelm, 2005). One of the core principles promoted in FCC is the need for a partnership between parents and health professionals (Shields et al, 2006) where ‘the expert’ role of the staff shifts to one of guidance (Lee, 1999). This necessitates staff willingness to create a balance of power that facilitates a mutually satisfactory collaboration where the parent-staff relationship is based on respect for the family’s strengths, individuality and diversity, combined with honest and open communication (Malusky, 2005). Such collaboration between neonatal staff and parents is considered essential for implementing FCC in NICUs (Saunders et al, 2003).

9.2.4 Visiting by relatives and siblings

Including siblings and relatives in neonatal care is advocated as being important in supporting the whole family, and aiding family life adjustment to the baby at home post discharge. It is also consistent with a family-centered care philosophy (Gooding et al, 2011; Griffin, 2006; Levick, Quinn, Holder, Nyberg & Munch, 2010). Although neonatal staff in this study concurred with these benefits in principle, they also expressed concerns with an increased risk of infection with more liberal visiting. This attitude was also reported by Meyer, Kennally, Zika-Beres, Cashore and Oh (1996). Visiting siblings and relatives should not be a treat to an increased risk of infection if they are adequately informed about hand hygiene and show no signs or symptoms of acute illness or communicable disease (Meyer et al, 1996). There seems to be a dearth of research investigating such visiting issues particularly from staff perspectives. This may explain why neonatal units across different countries vary extensively in their

visiting policies with regards to welcoming visiting by relatives and siblings (Greisen et al, 2009).

Staff in this study, were aware that locally close family relatives, particularly grandparents, played a very important role in supporting parents of preterm infants both during hospitalisation and beyond. Previous studies have noted the importance of including grandparents on neonatal units in terms of emotionally supporting the family (Gooding et al, 2011; Griffin, 2006; Levick, Quinn, Holder, Nyberg & Munch, 2010). However, staff in this study also considered that grandparents' visiting on the unit was important for them to be able to learn infant care-giving skills, as they were concerned with the wellbeing and safety of preterms once they go home, if they were to be taken care of by inexperienced grandparents. This observation extends the discussion of trusting and being trusted in the previous section. The baby is seen as the responsibility of the staff (not the parents) and the staff need to be able to hand him/her over to caregivers they can trust to perform (clinical) caring duties adequately. Nurses in Trajkovski et al (2012) were also identified as having a sense of responsibility towards the baby where their primary concern was the health and well-being of the infant and reported putting the baby first and being the baby's advocate.

9.2.5 Extension of neonatal care into the community

Participants recognised that the parents' need for advice, information and reassurance do not stop at discharge from the neonatal unit, as previous studies have also noted (Drake, 1995; Meck et al, 1995). They talked about a neonatal community service which had been practiced by some midwives and nurses locally, who voluntarily offered post-discharge care to some families. All staff, including the doctors, believed that this service was beneficial for families in principle, and that it had the potential to improve parental confidence, coping and competence with infant care, which reflects the findings of previous research (Brett et al, 2011; Cleveland, 2008; Griffin & Abraham, 2006; Redshaw & Hamilton, 2010). Staff also believed that community care provided continuity of care by staff known to the parents on the neonatal unit which has been found to be valued and appreciated by parents (Langley, Hollis & MacGregor 1999; Staniszewska et al, 2012). This supports findings from Lopez, Anderson, & Feutchinger (2012), who, after evaluating transition care programmes, identified that nurse involvement in continuity of care at home was a key element perceived to ease the

transition from hospital to home for families, as nurse guidance and care were maintained. Evaluation of FCC interventions involving educational packages and additional support at time of discharge also indicated reduced parental stress associated with taking their baby home, improved parent-baby interactions and an improved home environment for the baby (Brett et al, 2011). FCC initiatives which extend to post-discharge have been linked to assisting parents in practical and emotional issues at home (Brett et al, 2011).

However, although having such a community neonatal service might be read as a purely supportive service, some of the data from the current study raise subtle questions about whose interests are actually being served. Many respondents felt that their sense of responsibility for the baby extended even to post-discharge. Thus, they saw neonatal community care not only as extending post-discharge support to parents, but also for them to see (trust) that the safety and wellbeing of the baby was maintained in the home environment. This is a new finding, and it resonates with some of the parental accounts of feeling under continued (self) surveillance, and of a responsibility to the NICU for the wellbeing of their baby after transition home. This issue is explored further below.

9.3 Concurrence with and extension to current literature: parents' findings

9.3.1 Coping through hope

It is well documented that the premature birth of an infant and its subsequent hospitalisation in NICU is a source of stress for parents (eg. Olshtain-Mann & Auslander, 2008; Lawhon, 2002; Redshaw, 1997). In this study, as in others, the parents experienced shock, fear and helplessness (eg. Griffin & Pickler, 2011; Hutchinson et al, 2012; Jackson et al, 2003; Lee, Norr & Oh, 2004). However, most prior studies have focused on mothers. In the current study, the emotions of fathers were also captured, and, in many cases, were very strongly expressed. These emotional responses were accentuated by profound and shifting uncertainties as to the wellbeing of their infant. Other studies have identified many uncertainties which parents of preterm infants face (e.g. Bissell & Long; Hutchinson et al, 2013; Jackson et al, 2003), but this study is one of the few to adopt a longitudinal design, allowing for an understanding as to how these complex emotions shift over time. This included the crisis of the preterm birth itself, followed by the process of settling into the rhythms of the NICU, the new unknowns

generated by the homecoming of the infant, and the shift from an initial focus on the uncertain survival of the baby to the possibility of future repercussions due to prematurity.

These findings revealed that hope helped parents to cope, at each unfamiliar new stage in the process and ultimately led them to have a positive outlook on life. However, staff in this study, do not seem to have identify with such means of parental coping, which highlights that staff need to be active listeners in their practice so they become aware of what the parents' means of coping are and be able to facilitate and strengthen these as they support the parents. Although the importance of becoming progressively hopeful and looking forward to a positive future as the child's condition improved has also been expressed by Swedish parents (Jackson et al, 2003), the role of effective and trustworthy information and advice was particularly evident in this study. Information-giving and communication in the interactions between staff and parents, have similarly been valued by parents in Stainszewska et al (2012) and ultimately have been identified as being key elements of FCC in neonatal units.

However as in other studies, participants also reported that staff did not always adequately inform parents about their baby's condition and progress (Mancini & While; Rabelo et al, 2007). Furthermore, parents in this study indicated that the information they received about their child was a means for them to get to know and connect with their baby. Such findings resonate with those found by Finlayson et al (2014), who also identified that mothers sought to establish their maternal identity on the neonatal unit by actively seeking information from staff. The inclusion of staff and parents in this study allows for triangulation of parents and staff views of the information-giving process. Staff frustration with parents who sought information from a range of their colleagues, as reported above, may miss the point that this range-seeking behaviour is crucial for parents to build confidence and hope in their child's prospects for the future. Additionally, staff may overlook the important significance that their communication and information-giving has for the parents-child relationship. Brett et al (2011) when reviewing interventions on neonatal units which implemented family-centered principles in care, found that the effectiveness of these interventions ultimately emphasised the importance of communication with, supporting and providing information for parents of preterm infants.

9.3.2 Making the unreal real

At birth, expectant parents usually have great anticipations to meet and hold their baby for the first time. However, with a preterm birth parents revealed that they were faced with the opposite, the baby was drawn away from them as it was taken to intensive care. Parents in this study very vividly expressed feeling distant and disconnected from their baby at birth. Additionally, mothers felt empty and disembodied as the baby was taken away from them. Hutchinson et al (2012) found similar disconnected feelings of emptiness in parents of preterm infants. However, this study allowed for a more detailed analysis of the meaning of these feelings. Parents talked about the sense that the birth of their baby was unreal. Some mothers tried to cope with this situation by putting their sense of becoming a parent and celebrating the birth of their baby “on hold”. Finlayson et al (2014) found that mothers in their study expressed “not feeling like a mother” or not “being the mother”. They added that mothers experienced a state of limbo or liminality characterised by a sense of disorientation occurring when pre-motherhood did not resolve into motherhood since mothers were unable to take their baby home, the place where they could provide a nurturing maternal environment (Finlayson et al, 2014).

A component of FCC involves promoting and supporting parent-infant relationships (Levin, 1999). Early physical and emotional closeness between parents and their infant is believed to be crucial for bonding and the formation of positive attachment relationships (Flacking, Thomson, Ekenberg, Lowegren & Wallin, 2013). Once on the neonatal unit, parents in this study expressed how they craved connection to their baby both physically and emotionally. They longed to touch and hold their baby and to participate in care-giving. Similar findings have been expressed by mothers in Staniszewska et al (2012) who highlighted the importance of early mother-infant interactions in getting to know their baby, in developing a relationship with their child and their parenting role.

However, as in the current study, parents on neonatal units encounter many barriers which keep them away from drawing closer to their baby. The technology and equipment surrounding the baby, the incubator, and the critical condition of the baby have been identified as inhibiting the parents’ contact with their baby, which concurs with other studies in this area (Jackson et al, 2003; Hutchinson et al, 2012). In this particular study, it was possible to explore what parents did to try to get closer to their

baby, to make him/her real, and, in the process, to regain their sense of being parents. Fathers, especially, sought to create both current realities, and future memories, by taking photographs of the baby throughout the hospital stay on NICU. Photographs also helped parents capture the changes in their baby and ultimately have a more complete story of their early life, as well as providing a means of sharing the birth and the baby with family and friends, who could not see and hold the new family member. However, in the parents' experience, this need to create a parental record was seen by staff to be disruptive, to the point of being prohibited by some. These restrictions suggest that staff may not understand that the taking of photographs in the early stages of the life of the preterm was freighted with meaning, beyond the simple visual account. Staff could see the baby all the time on the unit, whereas the parents could not. For the parents, if the life of the baby was not captured visually, it had never happened for them, leaving them no real memories to hold on to. In this case, far beyond the usual impulse to take frequent pictures of term newborns, the imperative to keep a record was essential for the maintenance of hope, as discussed above.

Parents' interaction with their baby gradually changed from being a visitor on the unit to a more hands-on and participative role in their infant's care. However, the degree to which this happened depended on practices, behaviours and attitudes of the neonatal staff. In previous research, health professionals have similarly been found to play an important role in encouraging and supporting parents to participate in providing care for their infant, and in understanding and responding appropriately to their infant's cues (Browne & Talmi, 2005; Kaaresen, Ronning, Ulvund & Dahl, 2006; Melnyk et al, 2006). Additionally, staff have been recognised as having a vital role in supporting parents in the process of building their relationship with their infant and enabling them to gradually increase their caring responsibilities (Staniszewska et al, 2012). Flacking et al (2012), after reviewing the literature on closeness and separation in neonatal intensive care argue that developing a nurturing unit culture which facilitates parent-infant closeness, requires the removal of all restrictions with regard to parents being on the unit and including them as empowered players in their infant's care.

Positive outcomes of being involved hands-on in the baby's care on the unit, have been identified by parents in previous studies (e.g. Brett et al, 2011; Burnham et al, 2013; Griffin & Pickler, 2011; Rabelo et al, 2007) and have been shown to increase the parents' sense of competence and confidence in care-giving and their readiness for discharge home (Bissell & Long, 2003; Burnham et al, 2013; Griffin & Pickler, 2011).

Additionally, from their review, Brett et al (2012) identified that enhancing parents' coping and improved confidence in infant care may also lead to improved infant outcomes and reduced length of stay at the neonatal unit. FCC acknowledges that discharge home begins from admission. However, this necessitates that parents are encouraged and supported to be involved in their child's care from the beginning which would increasingly prepare them for hospital discharge (Griffin & Abraham, 2006).

Once home, many mothers in this study expressed how they interpreted being home as the birth-made-real. Having the baby home also meant that parents could claim their child as being their own, and could parent their child away from the gaze of the public health-system without restrictions (Deeney, Lohan, Spence, & Parkes, 2012). However, this was not an unalloyed feeling of freedom to be parents, as the next section illustrates.

9.3.3 The process of transitioning

The perceived benefit of skills transference with discharge teachings (e.g. Broedagaard & Wagner, 2005; Burnham et al, 2013; Mancini and While, McKim, 1993; Meck et al, 1995; 2001; Sheikh et al, 1993; Smith et al, 2012) was favourably expressed by all parents in this study who felt that the discharge teaching and participation in infant care-giving activities whilst on the unit helped them in feeling confident and competent in care-giving as they transitioned home. However, despite such favourable outcomes attributed to learning infant care giving skills, parents also revealed that discharge teachings had not included information about changes in the infants' behaviour, interacting with the baby, and signs of illness and development, which parents expressed concerns about once at home. Missed information-giving resonates with previous studies (Mancini & While, 2001; Meck et al, 1995; Sheikh et al, 1993; Staniszewska et al, 2012). The need for a more individualised approach and for support and information beyond discharge became evident, as in previous studies (e.g. Drake, 1995; McKim, 1993; Olshtain-Mann & Auslander, 2008; Sheikh et al, 1993; Sneath, 2009; Staniszewska et al, 2012).

A key element in this process, as has been discussed above, was the ritual of rooming-in. Some of these parents confirmed benefits associated with rooming-in, reporting that this was a positive experience in terms of having had the opportunity to care for their

baby on their own, and that it prepared them for what it would be like at home. Other studies reported similar results (Bennett & Sheridan, 2005; Costello & Chapman, 1998; Staniszewska et al, 2012). However, other parents in the current study reported a more negative impact. They questioned the imperative to room in (almost as if this was a test they had to pass before they were judged to be fit to be ‘allowed’ to take their baby home). They questioned the benefit of spending a day and night in a room with their baby doing what they had been doing on the neonatal unit (and not doing what they were likely to be doing at home with their baby). The room layout, décor, and lack of facilities were felt to be limiting and not at all home-like. Indeed, the experience was stressful for some parents, and especially fathers, who felt restrained in a small, enclosed environment where it was necessary to bring various belongings from home.

Rooming-in on neonatal units has only been sparingly studied and such adverse outcomes have not become so overtly evident before. However, findings from a key study which explored the issues of space and place on neonatal units (Flacking & Dykes, 2013) resonate to an extent with the experiences of rooming-in revealed in the current study. The availability of rooming-in for parents in this study may be linked to what Flacking and Dykes (2013) refer to as the “hotel room” in their study. However, the opportunity for parents to occupy such rooms with their baby varied across the two studies since the “hotel room” has been described as providing an opportunity for parents to be with their baby long term at sometime during the stay at the NICU (Flacking & Dykes, 2013) whereas in the current study this facility could only be utilised towards the end of the hospital stay for a limited time, usually one or two day/s and night/s.

Flacking and Dykes (2013) identified that the design, facilities and the feeling of “at-homeness” in the “hotel room” varied across the different neonatal units studied where the more “homely and warmer” rooms were more likely to be described as “enabling a family-life”. The authors argue that an atmosphere of hospitality was evident in the feeling of “at-homeness” as parents felt welcomed and a warm atmosphere was conveyed when attention was paid to the interior design, reflecting a de-institutionalisation of the environment (Flacking & Dykes, 2013). Ultimately, the authors (Flacking & Dykes, 2013) conclude that the design and availability of facilities help facilitate connection and closeness between parents and their baby where they experience a sense of ownership of their baby with an impact on parent identity and that the earlier and the longer parents can stay with their baby in close proximity, the more

they will be attuned to the baby's signals and be 'in charge' of their baby's care. Findings from Flacking and Dykes (2013) help explain the negative impact experienced by parents in the current study where the availability, the non home-like design and lack of facilities in the spaces used for rooming-in hindered the parents' connection with their baby as they could not bear to live in a room which did not meet their needs. Ultimately, findings suggest that it should not be assumed that where rooming-in is practiced, it only offers benefits to the parents. The underlying intent and rationale for, and practice of rooming-in requires further, more comprehensive research from a range of perspectives particularly when this is the last contact that parents have with the neonatal unit and the staff prior discharge home.

Finally, taking the baby home from the constant surveillance on the unit was often experienced with mixed emotions by the parents in this study. Leaving was a joyous moment for most parents, but it also meant they lost the security of the staff and all the monitoring used to surveil their baby's wellbeing. They also became ultimately responsible for the wellbeing of another (vulnerable) human being. Other researchers have similarly found that mixed parental feelings were common at NICU discharge (Jackson et al, 2003; De Souza et al, 2010; Rabelo et al, 2007). However, the anxiety felt by parents in this study at discharge centered predominately on the risk of ill-health of the baby once at home and not on their ability and confidence in taking care of the baby, as has been found in such previous studies. Consequently, as in other similar studies, many participants sought to monitor and protect their baby at home by adopting similar practices to those on the neonatal unit (de Souza et al, 2010; Griffin & Pickler, 2011; Jackson et al, 2003).

The longitudinal nature of this study extends earlier findings in revealing how letting go of the technical and routine practices adopted on the unit, posed difficulties for most parents in the study. This was reflected in their continued adoption of similar practices even at home for months after discharge. Additionally, parents indicated that regular check-ups at their private paediatrician reassured them of adequate growth and development of their baby, gave them peace of mind, and confirmed their parenting abilities, which in turn, increased their confidence in parenting. Staff may not realise the influence that 'machination' has on parents and they need to understand how this becomes a mind-set for parents particularly because of the predominant focus on technical and standard care on the unit. These findings support earlier studies which have identified that parents continue to need support and information after discharge

from the neonatal unit and that home support interventions have had beneficial outcomes (Brett et al, 2011). Additionally, the POPPY model of FCC in neonatal care has clearly identified how neonatal services can continue to support parents following discharge from the neonatal unit (Staniszewska et al, 2012).

9.3.4 Partner-to-partner support

Each mother-father dyad in this study provided each other mutual emotional support. Sharing the same experience with their own child seems to have provided the parents' understanding of what each partner was experiencing. The interconnectedness between partners supported each others' emotional well-being and seems to have enhanced their adaptation to family functioning throughout their experience. This mutual support has not been so evident in previous studies. Yet, advocates of family-centered care emphasise that both parents should be included in the baby's care (e.g. Redshaw & Hamilton, 2010; Brett et al, 2011).

Coping with home transition was facilitated when both partners supported each other and shared their responsibilities at home, including the care of the baby and that of any other siblings. This finding seems to differ from what is generally documented in the literature where gendered roles with the family usually associate the child's care with the mother (Bain et al, 2003; Dermott, 2008). This study indicates a shift from the traditional father who is not really involved in child care but perceived as the more distant parent, family breadwinner and authoritative figure, towards an expectation of equal co-parenting (Deeney et al, 2012).

9.3.5 Grandparents' support

Malta is characterised by its small geographical area, which means that, although newly formed families through marriage or co-habitation, move away from their respective family of origin, and go and live in a different location on the Maltese Islands, they still live in relatively close proximity to the families of origin. This local feature is reflected in the maintenance of family ties, with good relationships and frequent contact between nuclear and extended families. Such a Maltese cultural characteristic featuring the

interconnectedness of familial relationships emerged very clearly in this study's findings.

The supportive role of grandparents to parents of preterm infants is not well documented in the literature and only a few previous studies have indicated that grandparents were important to parents' emotional wellbeing in the context of preterm birth (Golish & Powell, 2003; McKim et al, 1995). In previous studies there seems to be a lack of in-depth exploration of how grandparents were perceived as being supportive by parents. In contrast, this study demonstrates the multiple ways in which grandparents supported the participants. However, it also revealed that, in their attempt to support the parents, grandparents may not have realised that sometimes they caused more pressure and distress on the couple. Without prior experience of prematurity, and not being involved in NICU care, grandparents may have found it difficult to understand what the parents were experiencing and in some instances this seemed to limit their empathic support to the parents. When at home, parents felt that they needed to make up for the time they had been away from their baby and be together at home. Consequently, the regular help offered by some grandparents was interpreted as invading the parents' space of being alone with the baby in their own home. This created inner conflict in parents, especially mothers who perceived regular and often daily help as more than they actually needed, and viewed grandparents as overstepping their boundaries. The involvement of grandparents on the neonatal unit, and in the early days after the return home of a preterm infant, seems to be a neglected area of research which requires in-depth exploration. Family-centered care advocates that care of the infant is given in the context of its family, valuing the importance of including not only parents but also other relatives, such as the grandparents. Yet, it is evident that across neonatal units, including the one in the current study, restrictive visiting policies often inhibit relatives from being included in neonatal care (Redshaw & Hamilton, 2005; 2010).

9.3.6 Re-making family and parental identity

By the time of the final interviews for this study, participating parents seemed to have created a new life and identity out of their experience, which has not been reported in other studies. By this point, the parents focused on positive transformations rather than on negative attributes in their lived experiences of premature birthing. They interpreted having the preterm child as unifying the family and strengthening family cohesion, not

only between them as a couple but also with other family members, especially their own parents. The participants viewed and valued life from a new and positive perspective, experiencing a sense of added strength and capability to face the future, but also becoming more sensitive and understanding of others in similar situations. These new interpersonal meanings of experiencing preterm birth indicate the parents' acceptance of the unexpected events and situations surrounding the premature child and how this has helped them to move on through hope and increasing confidence as they transitioned to life at home. Parents' focus on these positive perspectives could be vital in supporting and promoting parenting and family wellbeing in such unexpected circumstances of premature birthing and parenting.

9.4 Limitations of the study

In this study careful attention was given to ensure trustworthiness all along the research endeavour, however potential limitations of the study need to be addressed. Primarily, the interpretations offered in this work relate to my interpretations of the findings which does not exclude that other interpretations could result from the same data collected. Being a novice researcher in interpretive phenomenology, my interpretations could be limited by my lack of expertise, however I had a research supervisory team with whom I checked my interpretations. I also presented preliminary interpretations and findings to peer groups and sought feedback on the veracity of my work.

Additionally, having left recruitment of parent participants in the hands of neonatal unit staff, could have introduced recruitment bias if particular parents were selected to take part in the study and not others. This could have resulted in parents with particular characteristics to be more readily selected, while others were not invited to participate. However, the varied background characteristics of the parents in the sample suggests that, in fact, such recruitment bias may have not been so influential when selecting parents for this study.

Another limitation pertains to the inclusion criteria set for the participants' eligibility to the study, which in turn excluded others from participation. In each separate group of participants, parents and staff, the relative similarity in many of the participants' characteristics resulted in relatively homogeneous samples for each of the groups. Consequently the findings are not representative of all parents having preterm infants or all neonatal staff. The findings from the parents are particularly limited to their

experiences in the context of having a preterm infant with a healthy outcome. Parents with different characteristics and those experiencing more complex health or psychosocial issues, such as: single mothers, teenage mothers, parents with a previous preterm birth experiences, preterms with medical needs post NICU discharge and so on, are likely to have different experiences which are not represented by the sample of parents in this study. Similarly for the staff, since the sample consisted predominately of female participants, a gendered bias could have influenced the findings since experiences might have differed if more males were included. Nonetheless, having a sample where male participants were outnumbered reflected the population of neonatal staff on the local neonatal unit which consisted predominately of female staff across all of the three professions included. My prior relationship with staff on the neonatal unit may have influenced their responses in this study and social desirability bias in particular, could have been introduced in the study.

The small purposive samples used in this study may be viewed as a limitation, however such sampling is considered appropriate in phenomenology which does not intend to generalise the results but rather to capture a detailed understanding of the meaning of the participants' experiences. Given that rich data was obtained and saturation was reached with the samples recruited, larger samples were not considered necessary. Although the findings are only reflective of the participants, yet attention was given to detailing the context and characteristics of the participants and the settings, so that a degree of transferability of the findings may be considered with caution to others who hold similar characteristics.

Collecting data from one neonatal unit may be regarded as a limitation to this study, however doing otherwise was not an option since this was the only unit available on the Maltese Islands. Another possible limitation could be attributed to interviewing both parents together as a couple in joint interviews, where the voice of each parent could have been unequally heard. Additionally, each of the parents could have refrained from expressing their views and feelings frankly in front of their partner. Despite having had both parents in each couple living their experience with the same preterm child they shared, yet each of the parents lived their experience from their own perspective. Taylor and de Vocht (2011) argue that the presence of one's partner in a joint interview influences the experience of participants, and influences the descriptions they provide. Combining the two approaches to interviewing parents, that is, one-to-one interviews with each parent and also joint interviews with both parents together, would provide

richer understanding of the phenomenon. Each approach would complement the other in elucidating different aspects of the couple's experiences enabling the researcher to elicit individual as well as shared meanings (Taylor & de Vocht, 2011).

The use of vignettes may be seen as a limitation in terms of its compatibility with interpretive phenomenology because these stories were not really experiences emergent from the staff being interviewed, which is considered the norm in interpretive phenomenology. The vignettes could also have influenced the staff to respond according to what was presented in these stories. However, in this study the vignettes were used only as a tool for reflection and so to aid the staff to reflect further on their experiences. Additionally, the vignettes were used at the end of the interviews, when the staff participants had narrated their experiences freely and had nothing to add.

9.5 Strengths of the study

This study provided a rich description of the lived experiences of parents of preterm infants and of neonatal staff of hospital-to-home transition in Malta and contributed to a body of knowledge that is sparse in nature. Key gaps identified in previous literature, which often studied the phenomenon from very focused perspectives, have been addressed. This study explored lived experiences from multiple perspectives; from both mothers and fathers, together with midwives, nurses and doctors. This has not been previously done in one phenomenological study. The use of hermeneutic phenomenology proved to be appropriate to let the voices of all be heard, and to illuminate and interpret the lived experiences of the two participant groups.

The longitudinal design for eliciting parents' experiences offered the opportunity to observe experiential shifts over time as the same sample of parents was followed through three different time-frames up to six months post-discharge. This was reflective of the concept of transition where their coping, adjustment and experiential meanings, as they evolved through time, could be elicited. The period of follow-up was longer than that investigated in most previous studies giving a clearer reality of parents' individual daily life within their family.

This study had a high participation and retention rate since all participants, both parents and staff invited to take part in the study willingly accepted to share their stories. Additionally, all parents kept their commitment to the study through the three time-

frames of data collection and none of the parents dropped out at any point in time. This suggests that the study phenomenon was considered of interest to the participants. The interviews gave both parents and staff the chance to voice their feelings and to reflect upon their lived experiences together with an opportunity to look into the future, reflecting on new possibilities of Being. Both parents and staff positively interpreted their participation in these interviews indicating their need to be heard.

In phenomenology it is considered important for the researcher to have a degree of experience, interest and familiarity with the phenomenon studied. I believe that having these characteristics was an asset to this study which enhanced the interview process and my ability to relate to and hear each participant, facilitated communication and my understanding of the participants' experiences. In this study, many of the parents, especially mothers expressed how they appreciated the opportunity to tell me, a midwife researcher, their stories which for them turned out to be a helpful and healing experience.

The modified vignette technique used with neonatal staff helped to sensitise them to a glimpse of the influences that helpful and sub-optimal neonatal care practices have on the parents' experiences which often extend beyond discharge from the neonatal unit. Consequently, these vignettes aided them to reflect deeper into their experience of neonatal practice. It is hoped that presenting the findings from the parents' participants to neonatal staff would make them receptive to the recommended changes in practice which emerged from the findings.

Another strength of this study was interviewing both parents together. Throughout the interviews, I encouraged both mothers and fathers to express themselves freely and explained that I was interested in the experiences of both. Parents told their stories in an engaged way, which resulted in rich narratives bringing to light their shared meanings of preterm birth. These revealed the interconnectedness between the couple and the significance of their support to each other in coping and adjusting to their new parenting role as they lived through their NICU experience but also post discharge home. Studies where both parents' experiences in the whole process of preterm birth are very few, especially those exploring parents' experiences from as early as the preterm birth itself and extending to months after discharge home of the infant.

As the researcher of this study, I have taken steps and provided a clear audit trail of the research process to establish trustworthiness of the study.

9.6 Conclusion

This chapter integrated the study findings with those found in previous studies. Resonance between this study's findings and those documented in earlier literature, have been discussed. However, key findings in this study have also extended what had been found previously and provided more depth and knowledge of the study phenomenon. Findings predominately emphasis the inconsistent practices in the delivery of daily practices on the neonatal unit and reveal the resultant impact that such variations have on the experiences of staff and also parents. Generally staff showed an awareness of FCC principles but were also aware that such principles were not really adopted in practice. Ultimately, they identified that family-centeredness needed to be more comprehensively embraced on the neonatal unit. Parents' experiences revealed how their sense of parenting was affected by the care received on the unit, which extended to beyond home transition.

In the following concluding chapter, implications for practice, which emerged from the findings of this study will be discussed. The study's contributions to knowledge are highlighted and suggestions for further research are put forth.

CHAPTER 10:

CONCLUSION

10.1 Introduction

This thesis has provided a detailed account of the study whose aim was to explore the experiences of parents of preterm infants and of neonatal staff pertaining to the transition from the neonatal unit to home in Malta. The meta-narrative review has uniquely identified the prevailing narratives and the changing imperatives in neonatal parenthood research around this topic over time. This hermeneutic phenomenological study was guided by the philosophy of Martin Heidegger and van Manen's methodical steps guided the research method. Longitudinal interview data at three different time-frames was obtained from nine mother-father dyads after their preterm infant was discharged home from the neonatal unit. Twelve neonatal staff from different professions were also interviewed. Findings were interpreted through current related literature and through a Heideggerian perspective.

This final chapter reviews the key findings of the study while contributions to knowledge which emerged from this study are highlighted to indicate the importance of the new insights gained from this study to this current area of practice and beyond. The implications for practice and suggestions for future research are also presented. Personal reflections which provide a glimpse of the journey that I travelled during the process of this phenomenological research conclude this thesis.

10.2 Review of key findings and contributions to knowledge

Findings from the neonatal staff reinforce previous data particularly in terms of the child-centered and clinically-focused NICU discharge care practices. Some of the difficulties expressed by parents in parenting their preterm child on the neonatal unit and through their home transition resonate with previous literature. However, the findings of this study extend our knowledge in this area of neonatal care specifically in relation to the meaning-making of home transition experiences for both parents and staff, as they reflected deeply into their experiences. New insights which emerged from

the findings include how parents coped with the life of uncertainty which they faced due to the preterm birth. Hope helped parents to cope not only through the initial critical phase of the baby's life but also extended to after homecoming where they moved ahead to the future with a positive approach. Parents also sought to make reality out of what started as an unreal and unexpected situation. Taking photographs of the baby helped them to view the birth of the baby as being real, as a means of capturing the baby's life-story from when on the unit and creating long-term memories. Some parents' experiences extended from the more widely perceived benefits of rooming-in with their baby, to revealing adverse outcomes particularly when they felt that their needs were not adequately addressed. New insight is also evident in how the practices adopted on the unit, to monitor and protect the baby ('machination') influence parenting which extends beyond the neonatal unit. The interconnectedness between the couple reflected in the strong mutual support between parents extends previous knowledge of the benefit of having both parents included in neonatal care. Most mothers and fathers in the study articulated how sharing family responsibilities helped them to support each other and enabled them to cope with home transition. The strong family-ties with extended family members, namely the grandparents uniquely features in this study identifying an important role grandparents can play in supporting parents of preterm infants. Experiencing preterm birth has elicited new meaning for parents in this study. They felt transformed in various ways, perceived a new identity and looked at life from a more positive perspective. Their experience of preterm birth and the preterm child were deemed as strengthening cohesion between family members, including with those of the extended family.

New insights from the staff findings are particularly evident in how, through in-depth reflection they extended from recognising the good practices on the neonatal unit to acknowledging limitations which staff perceived as hindering adequate supportive care to parents through their home transition from the neonatal unit. Additionally, staff identified ways how their practices needed to be improved and extended. Particular issues around power and control on the neonatal unit brought to light difficulties which neonatal staff experienced with trusting parents and their extended sense of responsibility for the baby's wellbeing even post discharge. Staff findings identified controversies in the practice of rooming-in on the neonatal unit. Opinions differed around collaborating with parents to decide whether they needed to room-in or being

more autocratic, as often happens, where parents are not given any options and just told to room-in. Since many of the staff felt a sense of responsibility for the baby which extended beyond discharge, rooming-in was perceived as a means to confirm the parents' ability to care for their baby on their own before they handed over the baby to them completely. Additionally, staff felt they needed to ensure the safety and wellbeing of the baby once at home by involving grandparents in neonatal care and equip them with infant caregiving skills. Likewise, staff felt that extending neonatal care into the community ensures that babies were well cared for at home.

10.3 Implications for practice

In this study, staff identified the need to practice in a more family-centred approach and this suggests that it would be beneficial if staff would get together in experiential discussions to voice their views prior to implementing any family-centered care guidelines or policy. They need to challenge themselves in critically exploring the primacy of parenting and the role of parents on NICU. Group research discussions where staff can become more research aware of the latest evidence-based practice on neonatal units could make them more receptive to changes in practice. Furthermore, reconciling the differences and exploring possibilities for change requires staff to look, listen and learn from parents. Staff and parents could initially meet separately and their views are shared with their peers. Consequently, ideas may be shared between parents and staff in face-to-face joined meetings which would enable constructive discussion. This approach, where the views of service users together with staff are included in the improvement of services reflects an experience-based co-design which has been effectively used in various settings (Pearch, Barasitser, Smith & Greenhalgh, 2010) including in a large national study across neonatal units in the UK addressing family-centered care (POPPY) (Staniszewska et al, 2012). Having clear guidelines and policies for practice may be an important step in having a consistent awareness amongst staff of what family-centered care should entail.

This study enabled staff participants to reflect on their neonatal practices as they started to identify how parents could be better supported on the neonatal unit and also as they transition to their home with the baby. This suggests that staff need to be supported in order to become more reflective practitioners starting from pre-registration training to post-registration, through continuous professional development. This would help them

to examine their own practices regularly together with their manners and behaviours, since these can all impact on the parents' experiences. Sharing of experiences between staff can also help them to reflect on their practice, identify how practices could be improved and also provide peer emotional support. According to Ironside (2006), helping students to challenge their assumptions, think through and interpret situations they encounter from multiple perspectives is the basis of narrative pedagogy. Additionally, Ironside (2006) found that practising interpretive thinking helps engage teachers and students in pooling their wisdom, challenge their preconceptions, engage with others and see new possibilities for providing care.

The findings of the study indicated that communication between staff and parents on the neonatal unit was not always satisfactory and both participant groups identified that this needed to improve. This suggests that staff need to re-examine their interpersonal skills where their openness to communication and active listening skills are paramount. Parents need to feel safe in exposing themselves and their needs. This depends on how welcoming staff are to sit down with the parents. Parents are unlikely to start talking about themselves in a new alien environment with unfamiliar people if they are not given the attention and opportunity to express what often remains unsaid. Staff need to show an open disposition and get to know the parents from early on so they can identify the parents' background and situations surrounding their preterm birth and incorporate their unique needs into their care. This would help to shift the existing child-focused care perspective to recognising the parents-and-baby as a whole. This should aid staff to see parents and their babies as experiencing Beings, who seek to be understood, cared for and supported. Therefore, neonatal staff need to adopt care where they truly are 'being-with' and engaging with the parents.

Engaging with parents at a more emotional and affective level may be a new step towards the practice of family-centered care in a meaningful way which has been identified by the staff, including the doctors, as needing improvement in practice. Staff indicated that they felt inadequately trained to provide the necessary emotional care to parents and identified that qualified professionals are needed to address such parents' needs. This suggests that staff training in emotional intelligence can better equip neonatal staff to improve their abilities in identifying and addressing the psychosocial and emotional needs of NICU parents. Additionally, this would help them to determine whether parents require any further specialised support. A multidisciplinary team of counsellors, psychologists and social workers who are accessible to provide care on the

neonatal unit and who are specialised in working with NICU parents is also necessary. Additionally, prior to resorting to additional professional support, neonatal staff need to identify, facilitate and strengthen the parents' existing support. Therefore, it is suggested that grandparents or any other relatives identified as supporting the parents, are included in neonatal care from an early stage during hospitalisation of the preterm infant.

Findings of the study also suggest that facilitating parent-infant interaction needs to be better addressed so that parents spend less time on the unit as spectators and their parent-infant relationship commences as early as possible. Facilitating and encouraging early parent-baby encounters contribute to a growing love and care between parents and baby, however individual timing is crucial as each parent is unique. An empathic and supportive approach would facilitate the parent-infant relationship from early on. Thus, parents should be encouraged and assisted to participate in their infant's care and that this is gradually paced according to their readiness.

Parents in this study expressed that taking photographs of their baby while on the unit, had important meaning and significance in terms of making the baby 'real' and even for long-term memory making. Thus, within education it must be ensured that staff are made aware that taking photographs is an important part of Being-a-parent to the preterm infant. Staff need to understand that taking photos has meaning and significance for parents, and that it reflects the way they make sense of early parenting that baby. Having such understanding, staff may then facilitate and encourage parents to take regular pictures of their baby when on the unit. Staff awareness and sensitivity to the meaning that photography has for parents, can be introduced in undergraduate programmes and also as part of on-going professional development post-registration.

The importance and impact of communication and information-giving has emerged from both staff and parents' findings. Consequently, as both parents and staff suggested, more efforts need to be directed towards improving communication with the parents where comprehensive, consistent information is freely and regularly provided by neonatal staff, including the doctors, without requiring parents to actively seek to obtain such information. Commencement of information-giving should start early in the parents' NICU experiences and constantly provided along hospitalisation but also beyond. The findings revealed that the parents' informational needs continue well beyond discharge.

This study uncovered how ‘machination’ translated into parenting the prematurely born child, extending even long term at home. This suggests that on neonatal units, technical and routine practices should be gradually withdrawn as the healthy preterm infant approaches discharge from the neonatal unit so that by this time the parents are confident that their baby is no longer vulnerable and needing such monitoring and fixed practices at home. Encouraging and facilitating parents in assessing the infant’s health status without relying on monitors is also recommended. This would help parents build on their intuitive strengths and empower them in caring for their infant.

Both staff and parents expressed that instructions and discharge teachings on the unit, may not always be sufficiently provided, particularly when left towards the end of hospitalisation and given only once in a hurried manner. Such findings suggest that information and instructions should be repeated several times along the hospital stay. The use of simple language, unhurried manner and information tailored to the specific needs of the baby and parents are also indicated to help parents recall and understand the information and not become overwhelmed with information at discharge, which they would then be unlikely to remember. Moreover, parents also indicated that once at home and along their transition experiences, they had concerns relating to changes in the baby’s behaviour, growth and development. In order to address parents’ ongoing concerns and informational needs, information should be available in printed material, on a website or utilising audio-visual aids, which can help parents access the information when needed. A parents’ information pack could be helpful to complement the verbal information given on the unit.

Findings identified that rooming-in facilities as being uncondusive to a homely environment which suggests the need for such facilities to be improved. Additionally, findings also suggest that rooming-in needs to be made more available to parents, not only in terms of the physical facilities but also in the ideology behind this practice, where the emphasis should be on supporting parents prior to discharge. Staff need to understand the issues which have been identified as being troublesome for parents and the unique needs of different parents need to be supported. These suggestions would apply to any neonatal unit which provides rooming-in prior discharge if parents are to be truly supported to have positive parenting experiences during rooming-in.

Findings also suggest that other facilities on the unit need to be dealt with, so that parents can be encouraged to spend as much time next to their baby on the unit as

possible. Having a parents' area where they can have time for breaks when on the unit and possibly interact with other parents, and comfortable seating next to the baby's cot or incubator are a few facilities which would be more supportive to NICU parents on any neonatal unit. Parents in the study also identified the need to have access to parking areas which are closer to the neonatal unit to avoid the distress and fatigue experienced by parents from walking a long distance from the main visitors' car park to the unit. Hospital parking fees incur a large expense for parents' whose preterm infant is hospitalised for many weeks. This suggests that free parking permits could be issued for parents for the duration of their child's hospitalisation. Parking and distance problems need to be considered widely, particularly considering the negative impact these have left on parents in this study. Many neonatal units across the world may have similar issues which need to be adequately addressed to minimise the burden experienced by parents, particularly with limiting their time to be with their baby on the unit as they spend a long time walking to the unit.

Both parents' and staff findings revealed that continuity of care was lacking on the unit and consequently related problems were identified. Such findings suggest that for each infant and his/her parents, continuity of care would be provided by a small group of neonatal staff throughout the hospital stay. This may make mutual-trusting relationships between parents and staff easier to establish and a balance between power and trust may be achieved. A co-ordinator of care would also be beneficial. A neonatal nurse or midwife who works on the unit should be allocated to every family to help ensure continuity of care across different disciplines, and enhances communication and documentation between all those providing care. Additionally frequent turnover of staff should be prevented and the neonatal unit should have adequate staffing levels.

Parents and staff in this study recognised the value of having peer parent support. Findings suggest that staff and parents' initiatives need to be facilitated by the organisation of care in setting up and organising such parent-to-parent support groups. All parents should have access to peer support from as early as possible, ideally from prior the preterm birth if this is anticipated to happen and subsequently ongoing throughout the hospitalisation of the baby and extends to after discharge, which would further aid parents' transition to life at home. Regular get-togethers and meetings could be planned to occur during the day, in the evening or on weekends, depending on the needs of the families. Facilities for the group to meet in a parents' area located in the

neonatal unit could facilitate parents on the unit to attend the group. Thus, the organisation of care should support the availability of facilities and arrangements.

The visiting policy on the neonatal unit restricted parents from being with their baby whenever and for as long as they desired. Unlimited access and an open visitation policy are therefore indicated to ensure that parents are able to be near their infant where both parents and infants can connect together. Additionally, sibling visitation should be encouraged for children who are prepared in advance and who are supervised by an adult. Facilities which offer child-minding services within the hospital for siblings would facilitate parents to be next to their baby, especially when child-minding support from family or friends is not available.

Being aware that parents have ongoing concerns and the need for them to be better supported in the community following NICU discharge, staff highlighted the importance of a community follow-up neonatal service. Parents clearly indicated their need for continued guidance, support and reassurance following discharge as they all resorted to private services at their own expense. Such findings suggest that community follow-up neonatal care is formally set up to provide continuity of care and support the parents' needs as they transition home from the neonatal unit. Follow-up care should be provided through a system whereby NICU midwives and nurses rotate through a home visiting programme to facilitate continuity of care after discharge. Additionally, this service should be provided for free to all parents following NICU discharge so that parents from any socio-economic status would have access to this follow-up care. Telephone support could also be provided as part of follow-up care where staff-initiated calls can be made to parents to enquire about their coping and adjustment with parenting their child at home and to see if they have any concerns. Through such follow-up services, staff can foster parents' self-efficacy by recognising and commending their parenting competencies. Many parents indicated that taking part in the study interviews and talking about their experiences, particularly what they had gone through when on the neonatal unit, acted like a healing exercise suggesting that parents could benefit from being given the opportunity to voice their experience. This could be included as part of follow-up care since it may help parents come to terms with their preterm birth experiences and consequently be a means of moving on.

The government social policy can also be amended to become more family-friendly and better support the needs of parents of preterm infants. Fathers should be more

recognised in the Maltese family and paternity leave needs to be improved to make up for the time fathers spend in hospital with their baby, particularly since the support between the couple has been found to be so important in the parents' coping. Fathers have also indicated their struggles with work and their need to interact with their child and despite wanting to be involved in child rearing, they often felt that they were missing out. Mothers of preterm infants could also benefit from extending the current duration of maternity leave to make up for the time the child spends in hospital since Maltese mothers often end up returning to work soon after the child leaves the neonatal unit with possible detriments on the mother-infant relationship, and their coping and adjustment to life at home with the baby. Governments worldwide should seek to optimise social policy so that the needs of contemporary families are supported internationally.

10.4 Suggestions for further research

In this study, the literature has been reviewed through a meta-narrative approach. This was useful in uncovering the chronologic storyline of the nature of knowledge in previous research on NICU-to-home transition, which helped me understand the historicity within the participants' narratives in this study. In future hermeneutic research in this particular field of neonatal care, it could be useful to undertake a hermeneutic review of the literature (Smythe & Spence, 2012). When reviewing literature hermeneutically, the researcher's thinking and search for meaning-making within literature could subsequently further help bring to light what is often disguised and hidden in the data from the hermeneutic study that would follow (Symthe & Spence 2012).

The study, reported in this thesis, can be considered a catalyst to trigger future studies in exploring parents' and staff experiences with different characteristics to those held by the participants in this study. It is hoped that this study provides a base for future inquiry into the experiences of other specific groups of parents and their children were NICU and transition-to-home experiences are likely to differ to those revealed in this study. Thus, further research needs to be done with parents who have multiple preterm births, those with preterm infants having chronic illnesses or abnormalities and parents of varying backgrounds in terms of socioeconomic status, those not in a stable relationship and ethnic diversity. Such further research could provide a broader

understanding of parents' experiences and identify needs specific to particular groups of parents and their children.

It would also be useful if further studies explore the experiences of preterm birth and the subsequent hospital-to-home transition from other perspectives, namely those of the grandparents and possibly also the siblings. This would be helpful in providing a wider view on family coping and adaptation with preterm birth and changes in the current service delivery could reflect the needs of the family more broadly as well. Additionally further research into the exploration of variations in family dynamics, stability and cohesion could provide more insight into how different types of families with preterm infants could be better supported in ways which address their unique needs.

There is a dearth of research exploring the study phenomenon from neonatal staff perspectives and this study can only be considered a start. More studies are needed to further reveal the meaning of caring from the perspectives of staff who care for preterm infants and their parents. Further exploration is needed from the different professionals included in this study particularly from the doctors' perspectives. Although midwives and nurses on neonatal units may be the ones who are in most contact with preterm infants and their parents, recommended changes in practice towards more family-centered care need to be embraced by all those providing care to preterm infants and their families in order to be effective.

Conducting a similar study using quantitative research may offer a wider exploration of larger groups of participants, both parents and staff. This may be more appealing and convincing to the organisation and policymakers to support the recommendations for changes which emerge, particularly when financial implications are considered. The study phenomenon could also be studied using ethnographic research where the inclusion of observations would be an additional means of data collection and supplement the experiences revealed through interviewing. Participatory action research which involves different staff and parents could be done to identify and implement needed changes in neonatal practice.

This study explored the parents' experiences up to six months post NICU discharge and so addressed a key gap in previous literature which have more commonly explored the study phenomenon up to the first few weeks after discharge home. Future research could adopt a similar longitudinal design but extends to after the first six months post

discharge to better understand how parents' experiences might change over a longer period of time and so any additional long-term needs would be identified.

Further research also needs to target specific findings which emerged from this study as contributing to new knowledge. The areas of memory-making with the use of photographs needs more in-depth exploration to reveal further the meaning that different photos that the parents take of their preterm infant has for them, even in the long-term. The process of 'machination' on the neonatal unit that influences parenting, is another area of future research, which needs to explore further how parents disentangle themselves from the influence of routine practices and monitoring over time and how they learn to trust themselves and confidently be parents. Another area which warrants additional study is to explore what really motivates staff to adopt changes in practice, like the community neonatal outreach. Grandparents (or other supportive relatives) also need to be targeted to explore what their experiences of preterm birth in the family are and what meanings they attribute to their experiences of being grandparents to a preterm child. The transformed-Beings that parents revealed that they have become because of the preterm birth can also be studied further to identify any additional transformative changes which parents attribute as a consequence of the preterm birth over time as the child grows more, beyond the first six months following NICU discharge. All these issues for further research have not been asked before and emerged from the findings of this study in interesting ways because a Heideggerian analysis has been utilised.

10.5 Concluding thoughts

During the course of this study, the pre-understandings I held at the beginning developed and transformed, as the issues and context around such pre-understandings were increasingly revealed through the participants' narratives. My belief that there was a lack of a FCC policy that guides practice on the unit, but that, despite this, staff increasingly sought to embrace FCC principles in practice, was reinforced by the staff narratives. However, the study also revealed that characteristics of FCC were inconsistently practised by neonatal staff and that such inconsistencies in practice between different staff were readily identified by parents when on the unit. In addition, parents preferred to be cared for by staff who adopted a more family-centered approach

in their practice. As they reflected on the vignettes, staff themselves recognised that practises on the unit suffered from inconsistencies and they became increasingly aware that such care does not adequately support parents when on the unit and in their journey to home transition.

My pre-understanding that care on the unit focused predominately on clinical wellbeing of the infant with psychosocial and emotional care receiving less attention, was also confirmed through this study. The data revealed that staff participants also believed this, and that it was an area of practice which they were not happy with and which they sought to improve. Additionally, neonatal staff became increasingly aware through the time of the study that discharge practices focused on the baby's physiological wellbeing and that the parents' readiness for discharge home was not really elicited as parents were not really involved in the decision for discharge.

My prior belief that staff assumed that parents who demonstrate eagerness to take their baby home are well prepared for the transition and that this might not reflect reality for many parents, was, again borne out of the data collected. The parents' narratives revealed in-depth their realities of parenting their preterm child both on the unit and over the long-term at home, helping in understanding of their true experiences, and revealing some of the misconceptions/ assumptions which staff, including myself, may have had about this area of transition prior to the data collection.

Undertaking this study has helped me to learn and develop in many ways. Primarily, I feel that I developed my research skills particularly those related to my chosen research approach and philosophy: interpretive phenomenology. Working iteratively through the research process helped me not only to enhance the trustworthiness of the study but also to improve and refine my research skills as the study progressed.

A particular skill which I strongly feel that I developed through the course of this study was that of active listening. Prior to commencing this study, I already valued the importance of active listening as an interpersonal skill predominately because of my midwifery experiences. However, this study helped me to develop and value the importance of having the skill of active listening in terms of making me, the researcher, a phenomenological tool influencing the experiential narratives that research participants decided to offer. I have learnt that showing an open disposition and listening with an intent to understand rather than being ready to respond, offered participants the opportunity to reveal their experiences in-depth. I feel that listening to participants with such interest helped them to increasingly engage into the study and

this enabled them to reflect deeper on their experiences. This made me realise how both parents and staff lack such an opportunity to voice their experiences in everyday life and that they may readily do so if only someone shows them that they are ready to listen.

Developing active listening skills during this study, links to development in my professional career as a midwifery lecturer. Experiencing first-hand how much can be learnt by listening to others, I now increasingly seek to adopt a teaching approach which helps to develop the skill of active listening in the midwifery students that I teach. I believe that incorporating opportunities in the classroom where students are encouraged to voice and reflect on their experiences, would be a useful way how students not only learn directly from each others' unique experiences but also to value the experiences of their colleagues and develop the skill of active listening which they can then utilise in the clinical setting.

Personally, this study has also helped me to realise and value the uniqueness in each participant's experience and I feel this has made me become more sensitive towards others. I was particularly struck by how parents of preterm infants experienced particular situations when on the neonatal unit which were significantly influential on their experiences, even in the long term. Consequently, I became increasingly aware how particular situations or practices, which may be insignificant to the staff, can have a profound impact on parents. This made me more aware that how people relate to each other, often unconsciously, can have a profound impact on one another. Surely, this does not only apply to neonatal care but even more broadly in our daily lives, in any encounter we have with others.

Notwithstanding the many challenges encountered as I pursued my PhD studies, this phenomenological inquiry gave me an extremely rewarding and fulfilling experience with an opportunity to learn and grow with the participants. It gave me a deeper sense of the meaning of being human, of being-in-the-world of both parenting a preterm infant and of caring for preterm infants and their parents in neonatal practice, and for this I am truly grateful to all participants who willingly entrusted me with their stories.

This study has advanced our understanding of what being parents of a preterm infant on the neonatal unit and through home transition means, and also what Being-staff providing neonatal care means. These experiential findings have provided insight into how parents can be better supported both when on the unit and following discharge

home and so promoting the wellbeing not only of the child but of the whole family, which in turn would extend to the health of society as a whole and future generations.

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APPENDIX A: LIST OF DATABASES

Databases searched for literature review:

Ovid Medline

PsycINFO

CINAHL

Cochrane Database of Systematic Reviews

Academic Search Complete

BMJ Journals

EBSCOhost databases

BIOMED Collection

JSTOR

Sage Journals Online

Joanna Briggs Institute

APPENDIX B: QUALITY ASSESSMENT OF QUALITATIVE STUDIES

<p>For each study, questions are answered using Y=Yes, N=No and UC=unclear</p> <p>Each study is graded using the following grading system (Walsh & Downe, 2006):</p> <p>A: No, or few flaws. The study credibility, transferability, dependability and confirmability are high.</p> <p>B: Some flaws, unlikely to affect the credibility, transferability, dependability and /or confirmability of the study.</p> <p>C: Some flaws that may affect the credibility, transferability, dependability and /or confirmability of the study.</p> <p>D: Significant flaws that are very likely to affect the credibility, transferability, dependability, and /or confirmability of the study.</p>					
Aim: Clear?	Participants: appropriate for question?	Design: appropriate for aims and theoretical perspective?	Methods: appropriate for design?	Sample: size and sampling justified?	Does the data analysis fit with the chosen methodology ?
Reflexivity: present?	Study: ethical?	Does the data presented justify the findings?	Is the context described sufficiently?	Is there sufficient evidence of rigour?	Quality grade

APPENDIX C: QUALITY ASSESSMENT OF QUANTITATIVE STUDIES

<p>For each study, questions are answered using Y=Yes, N=No and UC=unclear</p> <p>Each study is graded using the following grading system:</p> <p>A: No, or few flaws. The study validity, reliability and generalisability are high.</p> <p>B: Some flaws, unlikely to affect the validity, reliability and generalisability of the study.</p> <p>C: Some flaws that may affect the validity, reliability and generalisability of the study.</p> <p>D: Significant flaws that are very likely to affect the validity, reliability and generalisability of the study.</p>					
Introduction	Methods				Results
Aim /purpose: Clear?	Research tool: is the questionnaire used sufficiently described?	Sample selection: are the sample, size and sampling clearly described and justified?	Data collection: Is there sufficient description of how data was collected?	Analysis: Is the method of data analysis described clearly and justified?	Are results clearly presented and address the aim/purpose of the study?
Discussion			Ethics	Quality grade	
Are results adequately summarized with reference to the study objectives and placed in context of previous work?	Are strengths and limitations of the study stated?	Are issues of validity, reliability and generalizability sufficiently addressed?	Are ethical considerations reported?		

APPENDIX D: CHARACTERISTICS OF QUANTITATIVE STUDIES

Author/s Year Country	Study aim	Research methodology/ design	Sampling characteristics	Data collection	Data analysis	Main findings
Sheikh, O'Brien & McCluskey-Fawcett 1993 USA	To gather staff reports concerning the information available as part of standard discharge teaching in NICU, to identify the importance nurses place on particular discharge teaching topics and to identify who among the NICU staff is considered responsible for teaching certain topics	Survey	34 nurses and 45 parents (mothers)	Questionnaire	Descriptive and Inferential statistics	Mothers and nurses generally agreed on the content and importance of various discharge teaching topics however there was less agreement on what was currently included in discharge teaching. The responsibility of teaching different topics was variable across staff.
McKim 1993 Canada	To assess the kinds and amount of information and support received and the mothers' perceived needs for information and support during the first week after NICU discharge	Survey	A convenience sample of 56 mothers	Questionnaire	Descriptive and Inferential statistics	Mothers having a difficult first week had indicated specific information needs. The more preterm and the greater the severity of illness in the baby and having longer hospitalization, more likely to have a difficult first week at home.
Drake 1995 USA	To investigate the effectiveness of the card sort method in assessing parents' learning needs prior to their infant's	Survey	A convenience sample of 7 nurses and 10 parents (mothers).	Questionnaire	Descriptive statistics	Nurses and parents discharge teaching priorities differed but both ranked CPR teaching and signs and symptoms of illness as priorities.

	discharge from the NICU					
Meck, Fowler, Claflin & Rasmussen 1995 USA	To identify mothers' perceived supportive NICU experiences, to identify information needs mothers have prior or following discharge, and to determine the extent to which recollections of information needs vary across time.	Survey	36 mothers	Questionnaire	Descriptive statistics	Mothers have discharge teaching needs which have not been met through tradition discharge teaching.
Mancini & While 2001 UK	To assess parents' views of discharge planning of their baby	Survey	A convenience sample of 16 parents (mothers)	Questionnaire	Descriptive statistics	Generally satisfied with discharge teaching received, but mothers identified various topics with which they were less satisfied with the information received.
Bain, Findlay & Greig 2003 Scotland	To determine parents' perceptions of their preparation to take their baby home from NICU and to identify important areas of teaching in this preparation	Survey	Cohort sample of 374 parents (mothers)	Questionnaire	Descriptive statistics	Although most mothers were satisfied with the teaching, various concerns and teaching which could be improved have been identified by mothers.
Smith, Young, Pursley, McCormick & Zupancic 2009	To quantify and compare the family' and the nurses' perception regarding the family's discharge preparedness	Survey	Cohort sample of 867 family-nurse pairs	Questionnaire	Inferential statistics	Generally families rated their discharge preparedness higher than the nurse's rating. Families felt prepared for discharge if confident with: paediatrician

USA	and to determine which elements contribute to a family's discharge preparedness					selection, infant's health and maturity and their home environment.
Smith, Dukhovny, Zupancic, Gates & Pursley 2012 USA	To investigate specific post NICU discharge outcomes and issues for families	Survey	287 parents (mainly mothers)	Questionnaire	Inferential statistics	After discharge mothers identified various processes that helped prepare them for the transition to home but also identified how discharge transition could be improved.

APPENDIX E: CHARACTERISTICS OF QUALITATIVE STUDIES

Author/s Year Country	Study aim	Research methodology/ Design	Sampling characteristics	Data collection	Data analysis	Main findings
Jackson, Ternestedt & Schollin 2003 Sweden	To study how mothers and fathers of preterm infants describe their experiences of parenthood during the infant's first 18 months of life	Phenomenology	Sample of 7 consecutive sets of parents (mothers and fathers)	Interviews	Giorgi's (1985,2000) method	Internalization of parenthood was a time-dependent process with 4 syntheses of experience – alienation, responsibility, confidence and familiarity
Bissell & Long 2003 UK	To elicit the concerns and feelings experienced by parents during the baby's transition from the NNU to home	Qualitative approach	Volunteer sample of 10 mothers, 5 fathers	Interviews	Colaizzi's (1978) method	Themes identified before discharge – attitude, concerns, readiness and understanding. At 6 weeks after discharge, themes – attitude, changing concerns, adaptation and acceptance.
Lee, Norr & Oh 2004 Korea	To describe the emotional adjustment and concerns regarding infant care expressed by Korean mothers of premature infants	Qualitative descriptive study	Purposive sample of 47 mothers	Interviews	Content analysis (Miles & Huberman, 1994)	5 themes identified – self-blame, concerns about the infant, reluctance to express negatives, fear of stigmatizing responses to the infant by others, and delayed joy in mothering.
Rabelo, Chaves, Cardoso & Sherlock 2007	To investigate the feelings and expectations of mothers of preterm babies at discharge.	Qualitative descriptive study	11 mothers	Interviews	Thematic analysis	Mothers experienced excitement and happiness at discharge but many reported being anxious and insecure on how to care for their

Brazil						preterm babies.
de Souza, Pinheiro-Fernandes, Clara-Costa, Cruz-Enders, de Carvalho & da Silva 2010 Brazil	To explore maternal experiences with premature children in a domestic environment	Qualitative descriptive study	Purposive sample of 24 women	3 Focus groups	Content analysis	4 themes identified – hospital discharge, preparing the family for discharge, caring for premature baby at home and life changes arising from the premature birth.
Griffin & Pickler 2011 USA	To describe mothers' experiences during the first month after their preterm infant's hospital discharge	Descriptive phenomenology	Purposive sample of 10 mothers	Interviews	Colaizzi's (1978) method	5 theme clusters – dealing with an unexpected pregnancy outcome, experiencing the reality of taking care of a baby alone, struggling to adjust to the maternal role, enhancing maternal inner strength and changing the maternal lifestyle.
Hutchinson, Spillett & Cronin 2012 USA	To explore the parents' experiences during their infant's transition from NICU to home	Grounded theory	Purposive sample of 9 mothers and 3 fathers	Interviews and field notes	Constant comparative method (Strauss & Corbin, 1998)	Model of parental progression in 4 phases – premature parental onset, parental incomplete, parental involvement and parental completion
Burnham, Feeley & Sherrand 2013 Canada	To identify what parents need to feel ready for the discharge of their infant from NICU	Descriptive qualitative	20 parents	Interviews	Qualitative content analysis	4 themes – information needs, hands-on experience, cues from the infant and from the NICU environment and tailoring to infant / family situation
Valizadeh, Namnabati, Zamanzadeh & Badiie	To identify the factors that influence infant's transition from NICU to home	Qualitative	Purposive sample of 12 nurses and 4 physicians	Interviews	Qualitative content analysis	3 themes – cognition of infant's needs, effectiveness of training and organizational context

2013						
Iran						

APPENDIX F: DETAILED NARRATIVE FINDINGS OF STUDIES IN LITERATURE REVIEW

Thematic findings of quantitative studies

- **Content and perceived importance of discharge information**

Sheikh, O'Brien and McCluskey (1993) were the first researchers who sought to determine what the content of standard NICU discharge teaching included for parents being discharged home with their preterm infant from a US midwestern teaching hospital. Subsequently other researchers, included here, have also aimed to identify what NICU discharge teaching included in other NICUs and have cited the earlier findings by Sheikh et al (1993) in their work (Smith et al, 2009). Sheikh et al (1993) asked 34 nurses and 45 mothers about the nature of the information discussed with parents as part of standard discharge teaching. Mothers responded to a questionnaire between four and six weeks after the infant's discharge home. Forty-three items were presented to participants which were divided into eleven categories, namely; feeding, bathing, sleeping, crying, playing, baby's unique characteristics, monitoring baby's health, taking care of baby's health, medical care, learning about prematurity and with family and friends. Nurses generally agreed that parents were receiving extensive information included in the categories listed in the questionnaire however some of the items within different categories were discussed with the parents less than others. More than half of the nurses in the study indicated that some topics were not discussed with the parents. These included; how to tell if baby is sleepy, how much baby might cry, tricks to keep baby involved in play, what to do if someone living at home gets sick, how baby's medical records are transferred and how relatives and friends might react to the baby. Staff and mothers did not always agree as to whether information on the various topics was actually discussed as part of standard discharge teaching.

Notable differences between staff and mothers were found in nearly every category presented in the survey. More than half of mothers did not recall receiving instructions about all of the items listed in the following categories; sleeping, crying, playing, learning more about prematurity and with family and friends. Other items where more than half of mothers did not recall receiving instructions about include; what to do if the baby is not eating enough, how long a baby should sleep at one time, baby's response to handling, how to recognise differences between normal breathing patterns and those that indicate illness and how to distinguish between spitting up and vomiting. The data reported indicated that staff and mothers had different perceptions about the topics discussed as part of standard discharge teaching in NICU. Consistently, for all but two items, the percentage of staff reporting a topic was discussed was higher than the percentage of mothers who recalled receiving information about the same topic. In five items there was a discrepancy of 50% or more between staff and mothers. These included topics relating to recognising signs of illness, feeding and crying. Other large discrepancies between staff and mothers were in topics that are unlikely to arise naturally in the NICU and included; how to encourage baby to interact with mum, what to do when baby cries, normal and delayed growth and development and suggestions on ways to encourage baby's growth and development.

Two years later, Meck, Fowler, Claflin and Rasmussen (1995) studied a purposive sample of 36 mothers whose infants were discharged from an NICU of a midwestern university medical center in the US, about their NICU experience including the discharge teaching they received. The Retrospective Transition Interview (RTI) designed by the authors, was used twice with each mother, first at one month after the infant's discharge and again at around six months post-discharge. There were no significant differences between the answers in the first questionnaire and the second about the discharge teaching mothers said they had received. Nearly all mothers recalled receiving information relating to the baby's health and medical care, such as when to schedule a doctor's visit, how to contact the NICU staff, how to take the baby's temperature, and, when applicable, how to use a heart and apnoea monitor; or routine care such as bathing

and feeding. In contrast, many reported not receiving information about developmental issues such as playing, crying and sleeping and information relating to prematurity and family roles. Information on parent support issues, such as contacting parents of other premature infants and handling extended family reactions to the baby, were reported by only two mothers. The lack of information received by mothers in Meck et al (1995) are therefore similar to those identified previously by Sheikh et al (1993).

The content of discharge teaching and how this has been perceived by mothers was studied again six years later by Mancini and While (2001) who asked a convenience sample of 16 mothers of preterm infants about their satisfaction with the discharge teaching they had been given on NICU. This was asked on the day prior to discharge of the baby and again 6 weeks post-discharge. Mothers were asked to rate the six educational topics identified by the researchers; safety issues, feeding, hygiene, giving medications, recognising signs and symptoms of infection and developmental issues and indicate whether they were very satisfied, satisfied or not satisfied with the information they received about each topic. Generally mothers expressed satisfaction with the information regarding infant care which they had been given prior to discharge. However, they were less satisfied with information relating to infant development and recognition of ill health. Levels of satisfaction with the discharge teaching received pre-discharge showed some deterioration six weeks after discharge where more than half of the mothers indicated that information relating to safety issues, hygiene, feeding and giving medication could be improved. The most common concerns expressed by mothers at both pre-discharge and post-discharge were feeding issues, followed by signs and symptoms of infection which was particularly cited prior discharge. Such concerns may indicate the lack of adequate information received or recalled by mothers.

In a large survey, Bain, Findlay and Greig (2003) studied a purposive sample of 374 mothers across all twenty-one NICUs in Scotland who answered a questionnaire two weeks after their infant was discharged home from NICU. Mothers were asked about the teaching of essential skills during their baby's stay in the NICU and about the information given to them at time of discharge. They were also invited to comment on topics that were not taught but they felt should have been and on any information, written or verbal, that might have been helpful to them after discharge. The majority of mothers indicated that they were satisfied with most of the teaching of essential skills they received, with 86% feeling that they were taught what they needed to know. The main difference in the findings related to the advice and instruction given to mothers of babies being breastfed compared to those bottle feeding. Less than half of the bottle feeding mothers received teaching in terms of sterilising bottles, preparing feeds, how to increase their baby's feeds and how to recognise hunger. On the other hand, over 90% of breastfeeding mothers reported receiving advice and instruction on expressing milk, storage and defrosting of breast milk and 71% were able to recognise their baby's readiness to feed. Mothers in this study also identified some aspects of baby care on which teaching could be improved. These included CPR, developmental care at home, temperature control, giving and stopping medications, and basic childcare for fathers. A lack of written information given to parents of preterm babies was identified in this study and more than half of the mothers reported not receiving written information relating to immunisations given to their baby in NICU, medication and oxygen therapy and that they would have liked more verbal and written information on constipation, colic, vomiting and demand feeding.

In the study mentioned earlier by Sheikh et al (1993), the authors also aimed to identify the importance nurses and mothers placed on particular discharge teaching topics. Results showed that staff and mothers generally agreed on the importance of different topics listed in the survey. Items in the categories of feeding, monitoring baby's health and taking care of baby's health were rated by both staff and mothers as most important topics amongst those presented. Items in the categories of sleeping, crying, playing and interaction with family and friends were rated by both staff and mothers as lower in importance. Drake (1995) used the card sort technique as a teaching aid in the NICU to determine the priorities of learning needs identified by a convenience sample of ten parents and seven nurses according to the importance they attribute to different discharge topics and subsequently nurses' and parents' responses were compared.

Near the infant's day of discharge, the nurse and parents ranked a set of seventeen cards where fourteen cards were labelled with a discharge teaching topic and three left blank for participants to add any other topic. The nurse sorted the cards according to her assessment of the parents' needs for education and parents sorted the cards according to their own importance of the different topics relating to their learning needs. Subsequently a discharge teaching plan was initiated according to the parents' card sort assessment. The nurses' and parents' rankings indicated the importance of different discharge topics and thus teaching priorities.

All parents ranked, what to do if baby stops breathing, as the most important of all topics. Other topics which the parents ranked high included: identifying that the baby is sick, taking the baby's temperature, and knowing if the baby will have any long-term problems. The topics which the parents ranked lowest in importance included; using a car seat for the baby, getting help with the baby at home, and taking the baby out in public. Only one parent wrote on the blank cards and topics related to relationships between other siblings and the father with the baby and the availability of a support helpline for any needed advice when at home. The nurses often ranked cards differently from the parents. Out of fourteen labelled cards, nurses matched parents only between 21% to 43% of the time. However, both parents and nurses ranked CPR and signs and symptoms of illness as being very important. Both nurses and parents, ranked car seat usage as low in importance while parents ranked temperature taking as a high priority but nurses ranked this as a low priority.

Meck et al (1995) in their study found that after one month post NICU discharge, generally all mothers rated all 49 discharge teaching items listed as being important or very important, regardless of whether they recalled receiving information mentioned in each item. The items which mothers rated as being most important included: giving medicine, scheduling follow-up care, and operating heart and apnoea monitors. Items of less importance to mothers were related to basic infant development such as breastfeeding and sleeping patterns. With regards to the mean ratings of importance, only four of forty-nine items were significantly different at seven months post discharge. 'Encouraging baby's interaction' increased in importance while 'how much and how often to feed baby', 'if baby sleeps through feeding' and 'when to schedule doctor visit' declined in importance.

Across the ten year span of the literature included in this sub-theme, it is evident that generally there seems to be agreement on the basic content of discharge teaching in NICUs and that generally mothers were satisfied and discharge teaching met most of their needs. Yet, it has also become evident that mothers do not always recall receiving information about specific topics which may indicate that such teaching had either not been provided or that it had been forgotten by the mothers which questions the effectiveness of the discharge teaching provided if mothers cannot recall receiving such information later on when at home. Where mothers recalled receiving various information they could also identify various topics where discharge teaching could be improved. Collectively such findings indicate that mothers often have unmet informational needs where the importance of the different topics is subjective according to their unique needs and to the time post-discharge when particular topics become more useful as the child grows such as the identified needs to learn more about developmental issues and interacting with the baby through play. This could explain why the importance attributed to different discharge topics, have not always been agreed between staff and mothers.

- **Discharge preparedness perspectives**

As indicated in the discussion above, findings in Sheikh et al (1993), suggest that although nurses believed that parents are receiving extensive information, mothers' responses suggested that in many cases, they felt that they were not adequately prepared for their baby's discharge home. The mothers and /or staff perceived preparedness at the time of discharge from NICU was the focus of two of the surveys in this review. Meck et al (1995) directly asked thirty-six mothers at one and six months post discharge to recall whether at the time of discharge they had felt prepared to care for their preterm baby at home. At one month post-discharge, thirty-four (94%) mothers reported that they felt prepared to care for their child at home but ten mothers (28%) said that it was difficult to leave the NICU. Results collected at six months after

discharge differed to those at one month where twenty-eight (79%) mothers reported that they recalled feeling prepared to care for their child at the time of discharge and six mothers (18%) recalled that they experienced difficulty to leave the unit. Variations in the results between the two timings have not been explained by the authors, however they indicated that recollection difficulties may have influenced the results as it may have become more difficult for the mothers to remember how they felt as more time passed from the day of discharge.

Fourteen years later, Smith, Young, Pursley, McCormick and Zupancic (2009) studied issues around NICU discharge preparedness. The researchers sought to quantify and compare the family's and the nurse's perception regarding the family's discharge preparedness and to determine which elements contributed to a family's discharge preparedness. Families rated their overall discharge preparedness on fourteen individual questions with a 9-point Likert scale on the day of discharge. Independently, on discharge day the discharging nurse evaluated the family's discharge preparedness using a similar 9-point Likert scale. This large survey was completed by 867 family-nurse pairs, comprising 58% of the target population of infants discharged from NICU after a minimum of a 2-week hospitalisation at the Beth Israel Deaconess Medical Center in the US. Families were considered discharge 'prepared' if they rated themselves and the nurse rated their technical and emotional preparedness as ≥ 7 on the Likert scale. Most families (87%) were prepared for discharge as assessed by both families' and nurses' assessment.

According to the family's self-reported technical discharge preparedness, prepared families were more confident with several things; bottle feeding, baby care skills, expectations of infant bowel/bladder function, preparation of a bed for the infant, recognition of signs of illness in the infant, selection of a paediatrician, arrangement for help at home and understanding special programs for preterm infants. In terms of emotional discharge preparedness, families were more likely to be prepared at discharge when confident with their baby's breathing and heart rate, their infant's health and maturity and their readiness for their infants to come home.

It is interesting to note that discharge preparedness was associated with the infant, but not maternal or discharging nurse characteristics. When controlling for other significant factors, being confident with their child's health and maturity, having their home environment ready for their infant to come home and confidence with selecting a paediatrician, were statistically significant in families who felt prepared for discharge. Generally families rated their discharge preparedness higher than the nurse's ratings. It is likely that families and nurses used different evaluation criteria to rate their NICU discharge preparedness. The discharging nurses often did not have a long-term relationship with the family and was less likely to be familiar with the infant or family.

The two main surveys included in this sub-theme suggest that although many of the participants felt prepared for discharge home from the NICU with their preterm infants, yet some parents still felt inadequately prepared to leave the unit. These findings question the long-term implications that such feelings can have on the family once at home and this is possibly what future research needs to target. It has also been shown that discharge preparedness perspectives differ between staff and parents and so questions the value of having nurses assessing parents' discharge preparedness particularly when the nurse is unfamiliar to the family (Smith et al 2009). It could be argued that parents' assessment is more likely to reflect how prepared they feel at discharge.

- **Parental post NICU discharge outcomes**

McKim (1993) studied a convenience sample of fifty-six mothers of preterm infants discharged home from one hospital in Newfoundland, Canada. Mothers were asked to recall their first week at home with the baby following NICU discharge. A questionnaire was answered while mothers waited for their visit at their first perinatal follow-up clinic around 6 months post discharge. Findings indicated that almost half (48%) of the mothers had a difficult first week post-discharge. The more premature the baby, the greater the severity of illness, the longer the

hospitalisation, having had infants with apnoea in hospital, and those mothers not visited by the community health nurse in the first week, were more likely to have required specific informational needs which were not met. Subsequently these mothers claimed that they had a difficult first week at home. When mothers were asked why they found the first week difficult, their replies centered on the infants' prematurity indicating lack of adequate information, uncertainty and lack of confidence when caring for their baby at home.

Smith et al (2009), followed up their study in 2012 by investigating specific discharge outcomes and issues for families following NICU discharge (Smith et al, 2012). In the first five to six days following discharge. A structured telephone questionnaire was used to elicit the data from 287 families, mainly mothers, who shared their views about the processes that helped prepare them for the transition to home. These included extensive instructions in infant care and recognising ill-health, spending time at the infant's bedside while in NICU and becoming familiar to his/her needs, receiving written instructions and initial supplies for the first night at home. Despite these positive NICU discharge outcomes, parents also talked about how they perceived that their discharge transition could have been improved. Parents identified how this could be done by having a discharging nurse familiar with the family and / or infant, providing more and consistent information, having clear explanations about discharge criteria and process and informing the family about any changes in the discharge plan as early as possible. Those families who had been previously identified to be 'unprepared' for NICU discharge (Smith et al, 2009) were more likely to have difficulties post-discharge associated with infant feeding, handling changes in the baby's behaviour including irritability and sleeping pattern.

The findings from the above surveys shed some light on how parents feel once at home and that parental post-NICU discharge outcomes seem to be influenced by various factors, and not only by the teaching and instructions received prior discharge. However, it is clear that these data lack depth and the lack of detail in the participants' responses makes it difficult to depict clearly the context within which the participants constructed their perspectives.

Thematic findings of qualitative studies

• Premature parental beginnings

The earliest qualitative study included in this meta-narrative is that by Jackson, Ternestedt and Schollin (2003) done in Sweden, who have looked at parenting the preterm infant from hospitalisation through transition home, as being an evolving process overtime and not made up of discrete isolated events. The first sub-theme identified in the included literature first appeared in this study (Jackson et al, 2003) where seven consecutively selected sets of parents of preterms were interviewed at four different time-frames, both during hospitalisation of the infant and progressively after discharge until the child was eighteen months old. Using descriptive phenomenology, each set of parents (mother and father) were interviewed together by one of the researchers and the findings of their narratives reflect gender similarities and differences between mothers' and fathers' experiences. *Premature parental beginnings* are partly evident in Jackson et al's (2003) findings in their first phase of parenthood which they described as being 'alienation'. This reflected the parents' feelings and emotions at the time of the preterm birth and early NICU hospitalisation. Mothers described the time of the infant's birth as being unexpected and felt disconnected from the events. At this time, mothers expressed mixed emotions about both parenthood and their relationship with the baby. On one hand they expressed happiness about the baby and on the other, grief about the unexpected premature birth. Mothers' main concern related to the fear that their baby would die though they progressively felt hopeful of having a positive future for their child and family. Fathers felt unprepared for the sudden preterm birth and experiences of unreality were predominant especially in those fathers who had not been present at the birth of their baby. Similar to mothers, the fathers' main concern was their fear of losing the baby.

The next study where the sub-theme, *premature parental beginnings* emerged, is that of Lee, Norr and Oh (2004) done in Korea who described the emotional adjustments and concerns of 50

Korean mothers of premature infants from hospitalisation through six weeks after discharge. Unlike the previously mentioned study (Jackson et al, 2003), Lee et al (2004) did not include fathers in their sample. Shortly after NICU hospitalisation mothers expressed strong emotions of self-blame and guilt about the premature birth. Such emotions were strongly influenced by Korean cultural belief that negative pregnancy outcome reflects a mother's failure to provide a positive prenatal environment. In view of this, mothers struggled to identify a reason for the premature birth. Mothers blamed themselves and felt that others blamed them for the premature birth and subsequently tried to identify their failure. Similar to other parents, Korean mothers expressed their concern for their infant's current condition, health and future development. However, mothers repressed their negative thoughts and earlier fears and did not verbalise their feelings. These early stresses fostered silence and denial in Korean mothers. Despite cultural variations, ten American mothers who participated in a descriptive phenomenological study by Griffin and Pickler (2011) expressed similar initial psychological responses following the unexpected premature birth and their emotional reactions included fear, guilt, relief and uncertainty.

The next study published (Hutchinson, Spillet & Cronin, 2012) was also done in America where nine mothers and three fathers had been interviewed both during NICU hospitalisation and after discharge home using a grounded theory approach. From their findings, the authors described a model of parental progression in four phases where the initial phase is referred to as 'premature parental onset' and is characterised by the parents' initial reactions to the premature birth where fear, emptiness and concern about death of their baby were commonly expressed. The second phase of the parental progression model described by Hutchinson et al (2012) is 'parental incompleteness' which is also reflected in *premature parental beginnings* as parents described their reactions to their first visit to the NICU. The parents' reactions here related predominately to their inability to hold the baby resulting in experiences of emptiness, an inability to bond with the baby, being upset, disappointed, guilty and sad. Parents were further saddened when the mother was discharged home without the baby particularly because parents had not as yet felt like a mum or dad. The data in this study often referred to parents' experiences which included mothers' and fathers' experiences together without differentiation. However, the number of mothers in the study was three times more than that of the fathers and in reality much of the findings were likely to represent maternal experiences.

- **Adapted early parenting**

In the studies reviewed, this sub-theme emerged in the early parents' experiences with their preterm infant on the NICU. This is a phase where parents constantly sought to adapt to parenting their baby in an unfamiliar environment and in ways which they had not expected to be parenting their newborn baby. Mothers' narratives in Jackson et al (2003) indicated how they had been affected by the physical NICU environment and seeing sick infants being cared for on the unit. The open layout in which most infants were cared for on neonatal units also affected mothers as this meant they were initiating parenting in a public space and expressed that they would have liked to be in a private area with their baby. Mothers felt that they needed to actively participate in the care of their infant however they often stepped back for various reasons. As discussed above, mothers felt that the environment itself created a barrier against their participation. They also felt uncertain about what was expected of their parental role particularly when it seemed that the baby belonged to the health care system and they were just 'borrowing' the child. On the contrary, fathers in this study expressed confidence in the competence of the staff in taking care of their baby and were not seeking to actively engage in participating in the baby's care as expressed by the mothers (Jackson et al, 2003). However, de Souza et al (2010) found that where mothers' participation was limited to basic infant care and fathers' participation just included being present during visiting times, has not been positively experienced by parents as this made it impossible for them to understand this new reality and establish their real role in parenting their infants.

In subsequent studies, further *adapted early parenting* has also been characterised by the parents' early involvement in caring for their preterm infant while on NICU. Hutchinson et al (2012) showed how being able to hold the baby for the first time was a major event experienced

by the parents. This brought mixed feelings of ambivalence, nervousness and joy. As the infant's health became more stable, parents experienced increased participation in their infant's care. However, such progressively increased involvement was not always straight forward due to some infants having setbacks in their health status resulting once again in limited care by parents until the infant's condition stabilised again. In Canada, Burnham, Feeley and Sherrand (2013) explored the perceptions of 20 parents of preterm infants, both mothers and fathers, about what they needed to feel ready for NICU discharge. Parents' hands-on experience with caring for their infant was identified as an important means for parents to feel ready for discharge. The parents' progressive involvement helped them to overcome the fear and nervousness they felt when handling the baby. This helped them to gain confidence in their caregiving abilities and reassured them that they could manage caring for their infant. Such findings had been previously expressed by mothers in other studies (Griffin & Pickler, 2011; Rabelo et al, 2007) where learning and practicing providing care to their preterm infants while in NICU, helped mothers to get to know their baby and bond with the infant during the NICU hospitalisation.

Parents in Burnham et al's (2013) study also expressed how NICU staff played an important role in helping them adapt to parenting their infant on the NICU and in turn increased the parents' readiness for discharge. Parents appreciated when they were encouraged and involved in the infant's care. Such experiences gradually made parents get ready to go home. Learning through observation, demonstration and practicing under supervision were positively experienced by parents as they learned infant care skills in the security of the NICU. Similarly, mothers in the previously mentioned study by Griffin and Pickler (2011) also experienced positively the learning they received from the NICU staff. Burnham et al (2013) also found that parents' perceptions of their infant's readiness for discharge influenced their own feelings of readiness about taking their infant home. Parents described how observations and cues from their infant and the NICU environment affected their perceptions of their infant's readiness for discharge. Spending time in the NICU allowed parents to witness their infant's progression throughout hospitalisation and when they could see that their infant was healthy, they were reassured that their infant was ready to go home. When the infant was off monitoring, and moved to a less intensive area on the NICU, hearing NICU staff saying that their baby is doing well and will be going home and ultimately rooming-in with the infant were positive indicators to parents reflecting their infant's readiness to go home. On the contrary, parents who had not identified such cues particularly from the NICU environment, especially when the baby was not moved to a less acute part of the unit and the baby was continuously monitored until the day of discharge, parents' perceptions of their infant's readiness for discharge were decreased.

In some studies, the parents' experiences of *adapted early parenting* extended to the time leading to NICU discharge of the infant. Bissell and Long (2003) found that the parents in their study felt well prepared to go home with their baby and in turn expressed positive feelings of excitement and looked forward to go home. Parents identified several factors which aided their readiness for home particularly when feeling that they understood their baby, that there was no further teaching and parenting skills to learn from the hospital and felt confident to manage on their own and believing that the baby was well. Parents' attitudes reflected a positive acceptance of the baby and the situation and articulated the desire they felt to go home. Despite such optimism, these parents expressed various concerns with some identifying specific concerns pertinent to their baby's health and development. Feeding, weight gain, temperature control, and safety were the more common concerns expressed around providing care to the infant. However, parents also expressed practical and organisational concerns when their baby gets home. Such a concern was particularly expressed by mothers who had twins or other siblings, or were single parents with no external support. Such mothers believed that having routine and being organised would be essential for their survival at home. Emotional support and role integration were concerns predominately expressed by fathers who felt that the support that they had given to their partner was an important part of their role as fathers however they were concerned on how they would be able to provide similar support once at home.

In Rabelo et al (2007), mothers indicated that the preparation for discharge they received included instructions about practical aspects of caring for the baby. However, they highlighted the need for repeating instructions at the moment of their child's discharge, and particularly the information which specifically related to their premature baby. Having written information and instructions have been identified by such mothers as a way of enhancing the transition from NICU to home (Rabelo et al, 2007).

Burnham et al (2013) also found that prior to being discharged home with the infant, parents identified what they needed in order to feel ready for NICU discharge. They strongly expressed a need for information, including information about routine infant care, how to monitor the baby's well-being at home, about any specialised supplies or equipment they might need at home, information about post-discharge follow-up and preparation for unexpected events. Parents were particularly concerned about potential repercussions their infants could face as a result of being born preterm, as well as how to recognise and manage signs and symptoms of illness. Their perceptions of what they required to feel ready for discharge indicated that they had not received enough information about what was important to them. They highlighted that information specific to preterm infants was lacking, and they considered that receiving information tailored to meet their specific NICU experiences and needs was very important.

Mixed feelings at NICU discharge have been expressed by mothers in some studies (de Souza et al, 2010; Rabelo et al, 2007). In one study, this was a mixture of crying, happiness, relief but also fear (Rabelo et al, 2007). Other mothers expressed a range of mixed feelings once they learnt that their infant would soon be discharged home (de Souza et al, 2010). These mothers viewed such news as a celebration of overcoming the hurdles they experienced with their baby in hospital and welcomed the day to take their baby home. However, they also expressed insecurity and anxiety related to the termination of support from the NICU staff and their increased responsibility. After learning that their infant was about to be discharged, Korean mothers in Lee et al (2004), experienced changes in their previous emotional responses and began to express feelings of 'joy in mothering'. Mothers often felt that it was a dream come true and expressed gratitude to the NICU staff. Feelings of guilt and self-blame declined, mothers continued to express concern for their infant with a shift from being concerned about the infant's survival to providing the physical care to their still fragile infant at home. Suddenly mothers seemed overwhelmed with taking on the responsibility of their infant's care and felt that they suddenly became very busy.

- **Unreal-reality parenting**

After leaving the NICU environment, the included studies indicated that parents experience a shift from a sense of not being a 'real' parent, to the shock of the reality of parenting in their home environment. In the first few weeks following discharge, Jackson et al (2003) found that mothers felt a new sense of responsibility and were insecure when caring for the baby at home because they did not feel prepared enough for the baby's discharge and their new responsibility. Mixed feelings of fear, responsibility, happiness and relief to be home became evident in mothers in this study. However, mothers were often worried about their baby and they sought to monitor the child in a similar way that staff used to monitor the baby's condition. Fears that the baby would die, re-surfaced for mothers and such anxiety caused them constant fatigue and lack of sleep. Mothers described these experiences as a continued feeling of unreality and that such situations made it difficult for them to bond with the baby. Fathers also felt insecure in providing care to their baby and this resulted from feeling unprepared to take the baby home, not being involved in the discharge decision, and having missed practical guidance in infant care when the baby was in NICU. Fathers claimed becoming tired from constantly checking on their baby, yet most fathers were pleased about having the baby home because this led them to participate in the baby's care and made them feel a new responsibility which made their parental role more real.

In another study (Bissell and Long, 2003), parents generally expressed positive thoughts about being at home with their baby in the first few weeks after discharge, although they commented on their sleepless nights and the hard work they experienced at home. However they accepted

such life changes and equated them with the reality of parenting the baby at home. These parents also expressed how the nature and levels of concern changed once they were home. Their worries about prematurity and the infant's condition were quickly dissipated as parents began to gain confidence in the care and make decisions for their baby at home, making them feel in control and take on full responsibility. Bissell and Long (2003) also found that the first few weeks at home were a period of adaptation for the parents which they perceived as a gradual learning process through which they adapted to life at home with the baby using their own practices and adaptations of parenting skills. Despite the unavoidable additional work they experienced, parents positively perceived a preference to such a life at home with the baby as they could spend more time together as a family, in their familiar home environment. Once at home parents also experienced adaptation to changing patterns in the baby's behaviour and in meeting the unique needs of their baby.

Lee et al (2004) found that in the first few weeks at home with the baby, Korean mothers expressed increasing positive feelings and joy in motherhood and increasing competence in caring for their infant. Fatigue from caring for their baby round the clock, was commonly experienced but being the infant's mothers, felt obliged to care for the baby. Often these mothers felt isolated and lacked support at home because their husbands were at work most of the day and relatives lived far away. After the first few weeks at home, mothers still expressed continued concerns about the baby health and practical care. Concerns about infant breathing, feeding, bathing, sleeping patterns, and medication were commonly experienced. Mothers also continued to express distress and anxiety related to the infant's prematurity and possible future problems.

The next study which looked into the mothers experiences with the baby at home in the first four weeks (de Souza et al, 2010) predominately revealed the difficulties mothers faced as they cared for their infants at home. The weight of taking on the responsibility for the care of the baby without support from NICU staff burdened the mothers. The negative feelings expressed related to concerns and fears of not knowing how to care for the baby, difficulties with feeding and uncertainties about the baby's functional stability. Maternal fatigue from constantly checking on the infant, which has been expressed in previous studies, has emerged again in this study. Dealing daily with curiosity visits from friends and neighbours distressed mothers as their comments constantly compared the baby to a term baby. Mothers also felt insecure at home particularly due to the lack of specialised care available close to their home. The busy daily demands of caring for the baby often meant that mothers stopped skin-to-skin care and breastfeeding once at home. Despite such negative feelings, mothers expressed that adapting to the new daily routine at home also brought positive aspects relating to mother-family and baby triad particularly where each family member shared in the responsibilities at home. Mothers in this study (de Souza et al, 2010) felt overwhelmed by the life changes resulting from having a preterm infant. They still did not view their baby as being normal and sought to dedicate themselves entirely to care and protect their baby whom they still viewed as being fragile and vulnerable. Despite the trauma and difficulties mothers experienced, they felt grateful of having their child at home and being able to enjoy their motherhood role.

Griffin and Pickler (2011) also explored mothers' experiences in the first few weeks following their preterm infant's hospital discharge. These mothers recalled the day of hospital discharge with ultimate positive feelings following the ordeal they had gone through. Similar to what other parents have expressed in previous studies mentioned above, these mothers also had positive, negative and mixed feelings (happiness, optimism, excitement and unconditional love, worry, nervousness and frustration) in the first few days at home. Mixed feelings included fluctuations between these positive and negative feelings. This was also a time when mothers felt the reality of parenting setting in, where some expressed that they had gone through the transition smoothly, while others faced difficulties particularly attributed to the infant's behaviour as in feeding, sleeping and crying. Mothers sought to adapt from their previous life to a new lifestyle that included the responsibility of mothering a preterm infant. Such lifestyle adaptations included making changes which fitted around the baby's schedule, using prior knowledge and advice from others to mother the baby, protecting the baby and recognising

maternal role and responsibilities although these were often very tiring especially in the early days at home.

Griffin and Pickler (2011) also found that mothers sought to develop their inner strength to promote their well-being and aid them to transition smoothly to life at home following NICU discharge. Mothers recalled different kinds of self-support which helped them cope with the new maternal lifestyle, including writing, crafting, praying and napping. Communicating with others was useful to help mothers as they felt relieved when they shared their distress. Mothers also found that accepting support from others helped them to increase their inner strength during the transition. Help from partners, family members or other social networks provided support with infant care and household work. Healthcare support was sought by phone or by using emergency services. Adjusting to a new lifestyle that included the baby meant that mothers disconnected from their previous social networks, avoided negative influences and got in a closer relationship with their own mother. Ultimately mothers claimed that the baby had given more meaning to their life (Griffin & Pickler, 2011). In Hutchinson et al (2012), parents truly felt like parents to their child when the infant was home as they made arrangements in their lives and established routines for caring for their infant.

In Burnham et al (2012), once at home parents particularly expressed concerns when the baby slept, especially with the noises made and the normality or otherwise of the breathing pattern, resulting in frequent monitoring. After the first few months at home, Jackson et al (2003) found that both mothers and fathers experienced increased confidence in parenting their baby, although they still felt some concern for the child. Mothers' experiences reflected adjustment at home with life becoming increasingly normal and routine and felt more confident being a mother. Those mothers whose baby gained weight and looked normal compared to full-term infants tended not to worry any more about acute changes in the baby's health. However, those with the smallest infants experienced continued difficulty bonding with their baby who still looked small, fragile and not like a normal baby and the fear of losing the child still prevailed. On the whole, mothers felt they were overprotective of their baby and did not allow others to care for their baby causing an everyday strain in their life. Mothers also sought reassurance and support from health services and frequently went to check that their baby was in good health.

As indicated earlier, in the most recent published qualitative study (Valizadeh et al, 2013) a shift was evident in the focus compared to studies published earlier, where the participants were neonatal staff, and the aim was to identify factors that influence the transition from NICU to home from their perspectives. None of the previously discussed qualitative studies elicited the responses from neonatal staff when exploring this phenomenon. This qualitative study was done in Iran and interviews were used to collect data from purposively sampled participants, sixteen nurses and four physicians. Qualitative content analysis was used for data analysis and three main themes emerged; cognition of infant's needs, effectiveness of trainings and organisational context. The neonatal staff responses as indicated in the identified themes reflected their medical perspective of providing care to neonates on the NICU and how this care affected the well-being of babies at discharge. The different issues captured in the three themes ultimately affected the babies' transition from NICU to home in terms of having babies with differing complications at discharge. The neonatal staff knowledge and their understanding of infants' medical needs were considered a positive factor, which enhanced a safe transition. However, the ineffective training offered to staff without organised evaluation and follow up, and a deficiency within the organisational context, including inadequate equipment, shortage of staff and lack of protocols and regulations on the NICU, together with unclear roles and duties between staff, were identified as barriers affecting infants' NICU-to-home transition. Some aspects of the findings of this study can be specific to the NICU setting where the study has been conducted. It is notable, however that the focus of data remained on the medical care provided to the babies. The staff did not talk about other aspects of care, such as parental involvement, which could be equally important in the safe transition of babies from NICU to home. Having retrieved no other qualitative studies with a similar scope and with neonatal staff as participants, the data cannot be compared to other literature. This highlights the need for further research to study this phenomenon from the staff perspectives.

APPENDIX G: PARTICIPANTS' INFORMATION LETTERS

Information letter for parents

Rita Pace Parascandalo

Department of Midwifery, Faculty of Health Sciences

University of Malta

Tel: 23401176 Email: rita.pace-parascandalo@um.edu.mt

Information sheet about a research study entitled 'NICU-to-home transition of preterm infants: Neonatal staff perspectives and parents' experiences.'

Date

Dear parents,

I am a midwife and full-time assistant lecturer at the Department of Midwifery, Faculty of Health Sciences, University of Malta. I am currently reading for a PhD with the University of Central Lancashire, Preston UK. My research study will include the exploration of the transition of preterm infants from the NICU-to-home from neonatal staff perspectives and parents' experiences.

Since you are being identified as parents of a preterm infant who has received neonatal care in the local NICU, you are being invited to participate in this study. Your participation will include three interviews together (mother and father) with myself at three different times following your baby's discharge home. These interviews will be done at one month, three months and six months after discharge from the NICU. Each interview will be audio-recorded and should take approximately one hour. Your participation in the study is on voluntary basis, you may choose to accept, refuse and / or withdraw from the study at any time. All information you provide will be kept confidential and used only for the purpose of the study. Personal data shall not be disclosed to third parties and may only be required by the University or the supervisory team for verification purposes. Data will be anonymised and all efforts shall be implemented to ensure that your identity will not be revealed in the final report of the study. Participating in this study allows you the right to access, rectify and erase any information which you provide as necessary.

Your support for this research project is greatly appreciated because through your participation can help identify potentially better practices which would ease the transition from the NICU-to-home for future parents having preterm infants. Should you require further information regarding this study, I can be contacted on rita.pace-parascandalo@um.edu.mt or 2340 1176. If you are interested in being part of this study, please inform a member of staff at the NICU. If you indicate your interest in the study, I will contact you in the first few weeks after discharge

home to give you any other details you require and should you be willing to participate in the study, we will negotiate to meet for our first interview when and where it is convenient for you.

Best regards,

A handwritten signature in dark ink, appearing to be 'Rita Pace Parascandalo', written in a cursive style with a long horizontal flourish extending to the right.

Rita Pace Parascandalo

Informazzjoni għall-ġenituri

Rita Pace Parscandalo

Department of Midwifery, Faculty of Health Sciences

University of Malta

Tel: 23401176 Email: rita.pace-parascandalo@um.edu.mt

Informazzjoni dwar l-istudju bit-titlu 'It-tranzizzjoni bejn l-NICU u d-dar ta' trabi li jitwiellu qabel iż-żmien: Perspettivi ta' l-istaff u l-esperjenzi tal-ġenituri'

Data

Għeżież ġenituri,

Jiena 'midwife' u nghallim fid-Dipartiment tal-'Midwifery' fil-Fakulta tax-Xjenzi tas-Saħħa fl-Universita' ta' Malta. Bhalissa jiena qiegħda nagħmel studju fil-livell ta' Dottorat fl-Universita' ta' Central Lancashire fi Preston l-Ingilterra. Qed nagħmel studju fuq it-tranzizzjoni mill-NICU għad-dar ta' trabi li jitwiellu qabel iż-żmien mill-perspettivi ta' l-istaff u esperjenzi tal-ġenituri.

Peress li inthom ġejtu didentifikati bħala ġenituri ta' tarbija li twieldet qabel iż-żmien li giet ikkurata fl-NICU lokali, inthom qed tiġu mistiedna tiehdu sehem f'dan l-istudju. Il-partecipazzjoni tagħkom tinkludi tlett intervisti flimkien (l-omm u l-missier) miegħi fi tlett okkazzjonijiet differenti wara li t-tarbija tiġi mibgħhuta d-dar. Dawn l-intervisti isiru wara l-ewwel xahar, wara t-tielet xahar u wara s-sitt xahar li t-tarbija tkun ilha d-dar. Kull intervista tiġi rekordjata u tiegħu madwar siegħa. Il-partecipazzjoni tagħkom hija fuq bażi volontarja, tistgħu tagħzlu li taċċettaw, tirrifjutaw u / jew li tiegħu milli tiehdu sehem meta tridu mingħajr konsegwenzi. Kull informazzjoni li inthom tagħtu tinżamm kunfidenzzjali u tintuża biss għall-iskop ta' l-istudju. Informazzjoni personali ma tingħatax lil terzi persuni. Din l-informazzjoni tista' tintalab biss għall-verifika mill-Universita' jew mit-tim li qed jissupervizjani f'dan l-istudju. L-informazzjoni ser tiġi anonimizzata u kull sforz ser titiehed biex l-identita' tagħkom ma tiġiex żvelata fir-rapport finali. Il-partecipazzjoni tagħkom f'dan l-istudju tagħtikom d-dritt li taċċessaw, tirrangaw jew tneħħu xi informazzjoni li inthom tagħtu skond il-bżonn.

L-appoġġ tagħkom għal-dan l-istudju huwa apprezzat ħafna għaliex l-partecipazzjoni tagħkom tista' tgħin biex tidentifika prattika potenzjalment aħjar li fil-futur tista' tgħin it-tranzizzjoni bejn l-NICU u d-dar għall-ġenituri bi trabi li titwiellu qabel iż-żmien. Jekk tixtiequ aktar informazzjoni rigward dan l-istudju tistaw tikkuntatjawni fuq rita.pace-parascandalo@um.edu.mt jew 2340 1176. Jekk inthom interessati tkunu parti minn dan l-istudju, jekk jogħġbokom infurmaw li xi membru ta' l-istaff ta' l-NICU. Jekk inthom tindikaw dan l-interess tagħkom f'dan l-istudju, jien nikkontantjakom fl-ewwel f'tit ġimghat wara li t-tarbija tagħkom tiġi d-dar biex nagħtikom aktar informazzjoni li tkunu tixtiequ. Jekk inbagħad inthom tiddeċiedu li tixtiequ tippartecipaw fl-istudju, aħna flimkien niftehmu biex niltaqghu għall-ewwel intervista meta u fejn tixtiequ inthom.

Filwaqt li nirrigrazzjakom, nselli ghalikom

A handwritten signature in black ink, consisting of a stylized 'R' followed by a long horizontal stroke.

Rita Pace Parascandalo

Information letter for neonatal staff

Rita Pace Parascandalo

Department of Midwifery, Faculty of Health Sciences

University of Malta

Tel: 23401176 Email: rita.pace-parascandalo@um.edu.mt

Information sheet about a research study entitled 'NICU-to-home transition of preterm infants: Neonatal staff perspectives and parents' experiences.

Date

Dear,

I am a midwife and full-time assistant lecturer at the Department of Midwifery, Faculty of Health Sciences, University of Malta. I am currently reading for a PhD with the University of Central Lancashire, Preston UK. My research study will include the exploration of the transition of preterm infants from the NICU-to-home from neonatal staff perspectives and parents' experiences.

Since you are being identified as a doctor/midwife/nurse who works closely with preterm infants and their parents in the local NICU, you are being invited to participate in a one-time interview to discuss your perspectives of the transition of preterm infants from the local NICU to home. The interview will be audio-recorded and should take approximately one hour. Your participation in the study is on voluntary basis, you may choose to accept, refuse and / or withdraw from the study at any time. All information you provide will be kept confidential and used only for the purpose of the study. Personal data shall not be disclosed to third parties and may only be required by the University or the supervisory team for verification purposes. Data will be anonymised and all efforts shall be implemented to ensure that your identity will not be revealed in the final report. Participating in this study allows you the right to access, rectify, and erase any data which you provide, as necessary.

Your support for this research project is greatly appreciated and your participation could help improve the current neonatal services which would help ease the transition of the NICU-to-home experiences for parents of preterm infants. Should you require further information regarding this study, I can be contacted on rita.pace-parascandalo@um.edu.mt or 2340 1176. If you agree to participate in this study, please use my contact details above to let me know when it is convenient for you so we can meet for such data collection.

Best regards,



Rita Pace Parascandalo

APPENDIX H: PARENTS' AND STAFF INTERVIEW GUIDES

Interview guide for parents at one month following discharge from the NICU

Demographic information

Baby's characteristics:

Gestation of baby at birth: _____

Baby's birthweight: _____

Baby's gender: Female _____ Male _____

Duration of NICU stay: _____

Baby's medical needs at discharge: _____

Baby's age at interview: _____

Parent's characteristics:

Parents' age: Mum _____ Dad _____

Parents' occupation: Mum _____ Dad _____

- What can you tell me about your experience with this baby?
 - Tell me about the preparation you received from the NICU for discharge home with your baby.
 - How did this experience affect you?
- What has your experience with your baby at home been like this month since being discharged home?
- Would you like to share any other experience?

Interview guide for parents at 3 months following discharge from the NICU

- What has your experience with your baby at home been like since we last met?
How do you compare your experience during this time to the first month following discharge?
- Would you like to share any other experiences?

Interview guide for parents at 6 months following discharge from the NICU

- What has your experience with your baby at home been like since we last met?
How do you compare your experience during this time to the first three months following discharge?
- Would you like to share any other experiences?

Gwida għall-intervista mal-ġenituri wara l-ewwel xahar li t-tarbija tkun d-dar mill-NICU

Informazzjoni demografika

Karatteristiċi tat-tarbija:

Ġimghat tat-tqala meta twieldet it-tarbija: _____

Piż tat-tarbija mat-twelied: _____

Sess tat-tarbija: Tifla _____ Tifel _____

Tul taż-żmien fl-NICU: _____

Bżonnijiet mediċi wara li t-tarbija ġiet id-dar: _____

Eta' tat-tarbija meta qed issir l-intervista: _____

Karatteristiċi tal-ġenituri:

Eta' tal-ġenituri: Omm _____ Missier _____

Xogħol tal-ġenituri: Omm _____ Missier _____

- X'tgħiduli dwar l-esperjenza tagħkom b' din it-tarbija?
Kif affettwatkom din l-esperjenza?
Għiduli dwar il-preparazzjoni li ingħatajt mill-NICU biex tiġi d-dar bit-tarbija.
- X'kienet l-esperjenza tagħkom bit-tarbija id-dar dan l-aħħar xahar mindu ġiet mill-NICU?
- Tixtiequ taqsmu xi hsiebijiet ohra dwar l-esperjenza tagħkom li jistgħu ikunu relevanti għal dan l-istudju?

Gwida għall-intervista mal-ġenituri wara it-tielet xahar li t-tarbija tkun d-dar mill-NICU

- X'kienet l-esperjenza tagħkom bit-tarbija id-dar mindu ltqgħjna l-aħħar?
Kif tikkomparaw din l-esperjenza matul dan iż-żmien ma' l-ewwel xahar li it-tarbija ġiet d-dar?
- Tixtiequ taqsmu xi esperjenzi ohra?

Gwida għall-intervista mal-ġenituri wara is-sitt xahar li t-tarbija tkun d-dar mill-NICU

- X'kienet l-esperjenza tagħkom bit-tarbija id-dar mindu ltqgħjna l-aħħar?
Kif tikkomparaw din l-esperjenza matul dan iż-żmien ma' l-ewwel tlett xhur li it-tarbija ġiet d-dar?
- Tixtiequ taqsmu xi hsiebijiet xi esperjenzi ohra?

Interview guide for neonatal staff (pilot study)

Demographic information:

Doctor _____

Midwife _____

Nurse _____

Male _____

Female _____

Length of experience in NICU: _____

- From your experience, how do you describe your role in the transition of preterm infants from the NICU to home? / What can you tell me about the discharge practices of preterm infants at this NICU?

What do you think helps / hinders the transition of preterm infants from the NICU to home? / What changes do you suggest to the current practices to ease the transition for parents of preterm infants from the NICU to home?

- Would you like to share any other experience?

Interview guide for neonatal staff (Main study)

Demographic information:

Doctor _____ Midwife _____ Nurse _____

Male _____ Female _____

Length of experience in NICU: _____

- From your experience, how do you describe your role in the transition of preterm infants from the NICU to home? / What can you tell me about the discharge practices of preterm infants at this NICU?

What do you think helps / hinders the transition of preterm infants from the NICU to home? / What changes do you suggest to the current practices to ease the transition for parents of preterm infants from the NICU to home?

- Would you like to share any other experience?
- What are your thoughts and feelings about the following parents' experiences on the neonatal unit?

Vignettes from parents:

- *Learning on the NICU:*

Father: 'what we didn't know about was the warmth factor, we were heating up the room too much...you don't know certain things so I expected that someone should have told me these things so I would be prepared'.

- *Contact with baby:*

Mother: 'the staff really welcomes you, I mean I appreciated a lot that whoever was with him (baby) on admission sent me his footprints, I mean so I could see his footprints, so you appreciate that a lot since you are not seeing the baby (directly)'.

- *Rooming-in:*

Father: 'rooming in is a good idea because at least you know what you are going in for and if you have a problem there is whom you can ask, and not you come home maybe something happens in the middle of the night and you would not know what to do'.

- *Information giving:*

Mother: 'something that used to make me feel uncomfortable was that every time I asked something, they (staff) say that it is normal and (that it) happens in a lot of children. But why does it happen? it is like there is a big question mark on a lot of things'

- Would you like to add anything else?

APPENDIX I: EXAMPLES OF VIGNETTES

Selected vignettes from parents' interviews

Positive vignettes

- *Learning on NICU:*

Mother: 'I feel that we were prepared more than other parents in reality although we had not been to antenatal classes'

Mother: 'they taught me a lot of things, how to wash the baby, how to feed him, so in a way it was beneficial cause being the first baby, you wouldn't know anything, so they taught me a lot of things'

Mother: 'since they had taught us a lot of things there (NPICU), once we were home we immediately got into a routine'

- *Contact with baby:*

Father: 'I felt bonded with him from the beginning, even that thing of having asked one of the nurses or midwives, if I could put my hand in and touch him a little with my finger and they told me that I could. I felt that feeling that he is my son'

Mother: 'the staff really welcomes you, I mean I appreciated a lot that whoever was with him (baby) on admission sent me his footprints, I mean so I could see his footprints, so you appreciate that a lot since you are not seeing the baby (directly)'

Mother: "The NICU staff did their best and after a few days they removed him (baby) from the incubator and gave him to me to hold so I start feeling a bit of a bond. He was still in the incubator and it was really nice for me, a surprise. When we went there (on NICU) she (staff) told me 'of course you can hold him'. I told her that up till then I wasn't feeling anything towards him, it was like I didn't have a baby, I didn't feel a bond towards him, he was still without a babygrow, naked with just a blanket. That was the nicest day for me because when I held him for the first time I felt an instant bond and joy. From then on the bond started to get progressively stronger."

Mother: "As soon as they (staff) put him in the cot and I could handle him, I took the initiative and began changing him when it was the time to do it, every three hours. So there was contact, but only when he was taken out of the incubator."

- *Rooming-in:*

Father: 'rooming it is a good idea because at least you know what you are going in for and if you have a problem there is whom you can ask, and not you come home maybe something happens in the middle of the night and you would not know what to do'

Mother: 'it was good to be on our own and take care of the baby there (rooming-in) and knowing that the staff were there to help'.

- *Information giving:*

Father: 'even at the beginning you go in (NPICU) and you see the nurse coming to talk to you, to explain (about the baby), so you feel comfortable'

Mother: 'they just told me that anything could happen, they told me that the baby is in a sort of ITU for babies....it was a shock because you would have thought that there is still quite some time for her to be born, then all of a sudden you just see her there in that state, it was a shock...but the fact that they gave me hope but at the same time they told me what could happen, that was of great help'

Father: 'the nursing staff were really friendly and they used to explain everything, anything new and so on, they used to explain it to us'

Father: 'after about one hour I went (to NPICU) again, I found the baby in an incubator everything ready, and the doctor who was caring for him came instantly. He explained exactly how he (the baby) was, he told me that everything was ok, that he had to spend some time in the incubator, anyway he explained the whole process and it was quite safe for me then, that I could put my mind at rest.'

Negative vignettes

1. Learning on the NICU:

Father: 'what we didn't know about was the warmth factor, we were heating up the room too much...you don't know certain things so I expected that someone should have told me these things so I would be prepared.'

Mother: 'we didn't know certain things about a preterm baby. It was different then our first child (who was born at term). The sleeping pattern, his irritability was different...no one told us about such things.'

Father: 'when you come home you realise that there were things which we weren't told about...we had to learn from our own experience'.

2. Contact with baby:

Father: 'we didn't use to just open the incubator ourselves, we had to ask the nurse, I mean they used to come immediately, so don't get me wrong, once you tell them, they just come instantly eh, but that thing that you had to ask them...(once he is in the cot) this thing stops so you can just go and pick the baby up and you can say this baby is mine. So we were very eager for the baby to be in the cot'.

Mother: "I used to see the morning go by slowly until it was time to go to NICU, because in the morning I couldn't go before 11 o'clock. Sometimes they (staff) even let me in later (than 11 o'clock), because of the doctors' round. I used to feel very bad in the morning."

Father: "When he (baby) was in the incubator we used to open the ports next to him and we used to stroke him a bit. We used to enjoy it when he opened his eyes, because he was with his eyes closed for most of the time, when he used to grab my finger and feel him pulling...then it was much better (in the cot), we could hold him, we could see him better, because as long as he was enclosed in the incubator, there was a certain distance between us and the baby...it was a moment we were waiting for. When he was in the

incubator, we used to see other babies in the cot, and we used to say, ‘when is our baby going to be in the cot?’ we were looking forward to that (to have the baby in the cot).”

Father: “I used to tell her (wife) that this baby is my daughter, but here (on NICU) she’s not...I walk in there, to see my daughter...but in there she is not my daughter.”

3. *Rooming-in:*

Father: ‘Rooming-in for me did not make much sense or really how it was in our experience. It was more of a hassle, a trauma. For me that night was traumatic’.

Mother: well, you are not in your own bed there, that is already uncomfortable, you are in hospital, the room is absolutely bare, not even a teaspoon.

Father: for me it was really uncomfortable to live there myself, let alone, to live there with my daughter. You might say I am thinking of myself before thinking of my daughter, but my daughter she was already there (in NICU) but for me it was all new, there was nothing not even for me to do a cup of tea, no mug nothing’.

Mother: ‘I don’t know why we did rooming in, I mean because ok they (staff) tell you so they see how you (parents) get along on your own, but I don’t know really what difference it would have made if I came home not having done it (rooming in)....we were pressured to do it. Pressured to do it on that same day, they (staff) didn’t allow me to do it say, on the next day’.

4. *Information giving:*

Mother: ‘something that used to make me feel uncomfortable was that every time I asked something, they (staff) say that it is normal and (that it) happens in a lot of children. But why does it happen? it is like there is a big question mark on a lot of things’

Father: ‘they (staff) said that we could phone NICU to see how the baby was, so we used to phone about *our* baby, ok, and then they tell you we can’t give you information (over the phone)’

Mother: ‘Maybe what I wished at the beginning when she was still having the very intensive care, was to have regular meetings with the doctors because although they (the doctors) were available 24 hours, I used to feel uncomfortable telling them (the staff) that I wish to talk to a doctor every day.’

Mother: ‘I knew that a file (baby’s records) was being written about her (the baby) but I had no access to that information, that thing really kills me.....how I wish I could read that book (medical records), so I would know exactly what my daughter has been through, cause I was not there 24 hours. I really wish I have access to that’.

Mother: ‘the doctors never talked to us, in six weeks that we were there, we always talked with the nurses and midwives....the consultant or the doctors in his team never spoke to us....as such we never felt the need for them to talk to us because the nurses and midwives used to tell us everything, how she (the baby) was doing, her progress, the equipment , test results, we got to know everything from them’.

APPENDIX J: TRANSLATIONS VERIFICATION LETTER

L-UNIVERSITÀ TA' MALTA
L-Imida MSD 2080 - Malta
IL-FAKULTÀ TAL-ARTI
ID-DIPARTIMENT TAL-ISTUDJI
TAT-TRADUZZJONI, IT-TERMINOLOĠIJA
U L-INTERPRETAR



UNIVERSITY OF MALTA
Msida MSD 2080 - Malta
FACULTY OF ARTS
DEPARTMENT OF TRANSLATION,
TERMINOLOGY AND
INTERPRETING STUDIES

9th May, 2015

To whom it may concern

Translation from Maltese to English

Ms Rita Pace Parascandalo, an assistant lecturer in the Department of Midwifery, Faculty of Health Sciences, University of Malta, is currently reading for a Ph.D. Part of her research involved translating from Maltese into English some extracts from interviews recorded verbatim. She then had these translated texts examined by a Maltese teacher and eventually she sent them to me for a final inspection.

This document, therefore, attests that the translation (Maltese to English) of the selected passages of the collected data from parents of preterm infants by Ms Rita Pace Parascandalo as part of her doctoral research, has been duly inspected. The target text in English is deemed to be an acceptable version of the source text in Maltese; that is, the source text is equivalent to the target text.

Prof. Charles Briffa
Department of Translation, Terminology, and Interpreting Studies
Faculty of Arts

APPENDIX K: THEME TABLES

First and second level analysis of parents' data

Theme 1 - Shadowed by Fading Clouds of Uncertainty

Parents' voices	Key words	Ideas Concepts /	Sub-theme	Theme
<p><i>"...I was at work and I went to the doctor there and as soon as he found it (blood pressure) high again and I phoned her (obstetrician) she immediately told me to go directly to hospital. At that moment, I was shocked to tell you the truth and at work they (colleagues) just stared at me, I just started to cry. We had just finished preparing the hospital bag the day before because I used to tell him (her husband), that there is no rush, there were ten more weeks to go and he (husband) had told me to prepare it cause you never know what might happen. Then, when I went into hospital, I thought I would stay maybe for three days and go back home. I used to ask the doctor, when she thought I would be going home and she used to say that if I do go back (home) she wouldn't suggest that I go back to work, however she used to say that she couldn't tell me (if I would go home) and it would depend on the blood pressure. But it (blood pressure) remained high, although I was having the pills, it was still high, so they couldn't give me a date (for discharge) because they were taking blood tests every day to check how things were. Then, when they saw that things were becoming worse...in the morning she (doctor) came and she said she would speak to the consultant for his decision. And she came back and told me that at two o'clock we would do it (an emergency Caesarean Section). It was so sudden that there was no time for me to prepare myself for the event that was going to happen on that same day. I phoned him (husband) immediately and told him to come quickly because it (the birth) was happening on that day." (Eric's mum, 6a, 21–22)</i></p> <p><i>"When she (wife) called me, I just couldn't believe it, I froze (pause), I didn't know what to do, so many thoughts passed through my mind (pause), then I just left work and went to hospital." (Eric's dad, 6a, 22)</i></p>	<p>Shock</p> <p>Wanting to go home</p> <p>Disbelief</p>	<p>Uncertain</p> <p>unexpected preterm birth</p>	<p>Disturbing uncertainty</p>	<p>Shadowed by fading clouds of uncertainty</p>

<p><i>"My waters broke...but what I know is that the week before (the birth) I had fallen down the stairs and I landed with a blum sitting down...I really hurt and my bones were aching but I told him (husband) 'I didn't hurt my tummy' and it was like at that moment instinctively I told him (husband) 'no, don't worry cause I didn't hurt my tummy'...but I sprained my ankle and I was really in pain for two days...so I don't know if this (the fall) could have triggered it (the preterm labour)...I don't know if it was because of this (fall) because he (baby) was born the week after."</i> (Eugene's mum, 8a, 4)</p>	Uncertain cause of preterm birth is	Trying to find a reason for the preterm birth	Disturbing uncertainty	Shadowed by fading clouds of uncertainty
<p><i>"I was worried because the baby was 31 weeks, then I said 'thank God that he made it to 31 weeks' because I began to realise the difference when a baby is born at 31 weeks and one born less than 31 weeks and the consequences there could be. Between 30 weeks and 31 weeks I had learnt from my reading that there is a big difference. I didn't know anything in this field before, but having arrived to 31 weeks, I said 'thank God he (baby) made it to 31 weeks'. At least there could be problems related to 31 weeks and not 28 or 27 weeks and the fact that they told me that the baby cried and started breathing, he had responded well, they bagged him and he responded well, that was a relief because from what I read I said 'than he mustn't be bad considering the complications he could have had'. Then they passed by me with the baby, I saw him and they took him to NICU straightaway. I wasn't interested to go near the baby then, I knew he was in good hands, I was more concerned about my wife, until she comes out of there (theatre) (1.0). Then the consultant came to talk to me about the complications my wife has having, he was telling me about the hysterectomy (2.0); but when I knew that she (wife) was ok, out of theatre, then I went to see the baby."</i> (Kristoff's dad, 4a, 7-8)</p>	Concerned for baby and wife	Fear	Disturbing uncertainty	Shadowed by fading clouds of uncertainty
<p><i>"When I went there (NICU) for the first time I got a <u>shock</u> out of this world, when I saw my daughter like that (2.0)((eyes welling up)), obviously I wasn't expecting her to be like that...I spent one minute, two minutes <u>maximum</u> and I left in a state of shock."</i> (Sofia's dad, 1a, 1)</p>	Unexpected first sight	Shock	Disturbing uncertainty	Shadowed by fading clouds of uncertainty
<p><i>"When we (mum and dad) went to see our daughter (in NICU), at that time they (neonatal staff) didn't fill us with many hopes but didn't make us lose hope either. They just said that there was a chance that anything could happen, they told me that our daughter was in like an ITU for children....it was a bit of a shock because you start thinking that there was</i></p>	Anything could happen	Uncertain survival	Disturbing uncertainty	Shadowed by fading clouds of uncertainty

<i>still quite some time before she is born and then all of a sudden you see her there in such a state, it was a bit of a shock...but the fact that they filled me with courage but at the same time informing us what could happen, that was of great help.” (Anna’s mum, 9a, 1–2)</i>				
<i>“(with tears in his eyes)) Listen, I really thought of the worst (2.0) I said to myself ‘we have lost our son’ (2.0). She (wife) was talking to me (on the phone) and she started crying and she stopped talking and a doctor talked to me, I don’t know who she was, and I thought my son died and they don’t want to tell me...then the doctor said ‘It is better that you come (to NICU)’ and I asked ‘but what happened?’ and she repeated ‘it is better if you come’. As if she didn’t want to tell me. I wanted to ask whether he (baby) was still alive and she (doctor) didn’t say that he was still alive, just that I should go immediately and I asked her again, ‘but did something happen?’ and she said ‘no, but <u>come!</u>’ Probably she was saying so because she was afraid that I could have an accident on the road cause I needed to drive to the hospital.” (Hans’ dad, 5a, 6–7)</i>	Thinking of the worst	Fear of pending loss	Disturbing uncertainty	Shadowed by fading clouds of uncertainty
<i>“I didn’t sleep at nights, always waiting, fearing they (neonatal staff) would call....that something happened, the mobile phone always left switched on because you never know what could happen.” (Eugene’s dad, 8a, 24)</i>	Sleepless nights	Doubting what could happen	Disturbing uncertainty	Shadowed by fading clouds of uncertainty
<i>“As a parent I think that something that used to make me feel uncomfortable to ask a question, they (staff) used to say ‘That is normal, it happens in a lot of things, either it happen?’ It is like there is a big question mark on a lot of things, either tested or because they (staff) don’t know exactly the cause or maybe because too technical for us and so they don’t tell us...they (staff) often said, ‘babies...’ that is always echoing in my head.” (Sofia’s mum, 1a, 5)</i>	Feeling uncomfortable when answers not definitive	Unresolved uncertainty	Disturbing uncertainty	Shadowed by fading clouds of uncertainty
<i>“What I feel had confused me was how I was going to feed the baby when I go home. There (on NICU) he was fed every three hours for eight times a day and with the other child I always breastfed him on demand. So when we came for discharge I asked them (staff), ‘how am I going to feed him?’... I got confused and everyone started giving me their opinion, and if I spoke to six, the six of them told me differently. Some were telling me that he is still small and to try and force him to drink every three hours, wake him up, so I got confused what I should do ((confused expression)).</i>	Confused	Conflicting advice	Disturbing uncertainty	Shadowed by fading clouds of uncertainty

<i>Then there was a midwife and I asked her, because I was asking everyone to get everyone's opinion, and this one asked me 'What did you do with your other son?' I told her that I breastfed him on demand, and she said 'then do that and just keep an eye on his weight' and she also said 'try to give him a bottle of expressed breastmilk before he sleeps so that you are sure that he has had his amount' and that is what I did when I came home and I started going to breastfeeding clinic to check that his weight was good and that was working (for me)."</i> (Kristoff's mum, 4a, 17–18)				
<i>"I think the NICU door closes a bit too fast (on the parents), this is something I felt...when we left it felt very scary. It was like 'ehe she is being discharged today, good, ok thanks, bye' It was literally, 'thanks, bye'...it was abrupt, you know, there had been all that caring then, when it came to leave...it was very impersonal when we left...it was too abrupt....there was too much coldness when we left, you know?, 'eh ok, ok, bye bye' ((father imitates the sound of a door slamming shut))."</i> (Elsa's dad, 7c, 37)	NICU door closes fast	Hospital discharge unannounced and unexpected	Disturbing uncertainty	Shadowed by fading clouds of uncertainty
<i>"Obviously what is mostly on my mind, is that she (baby) reaches the milestones according to her age and in fact every time we go to the doctor I <u>make sure</u> that I ask the question, 'what should she be doing in the next weeks?' so that I am on the alert to know what she is supposed to be doing."</i> (Sofia's mum, 1b, 3)	Fearing delayed development	Knowing there could be repercussions	Embracing reality	Shadowed by fading clouds of uncertainty
<i>"In my heart I say that if there had to be something (wrong) with him (baby) I must be able to take care of him, I don't think much about this but this is how I reason, after all whatever happens happens."</i> (Eugene's mum, 8c, 4–5)	Feeling capable	Accepting the reality	Embracing reality	Shadowed by fading clouds of uncertainty
<i>"I appreciate it when I see changes in his developments, two days ago he started to sit down and holds on and when I call him he tries to come to me although he doesn't walk yet...and also he waits for me with that smile, as I go in (into a room) on tiptoe and when he sees me he smiles and giggles...now there is something new each day."</i> (Hans' dad, 5c, 3–4)	Happy to see improvements	Uncertainties resolving	Embracing reality	Shadowed by fading clouds of uncertainty
<i>"Someone who had a baby at forty weeks and spent only three days in hospital and went home, had only three days chance to learn and I had six weeks chance to learn...this is something positive, cause I spent <u>six</u> weeks learning at NICU."</i> (Anna's mum, 9c, 17)	Feeling privileged	Learning on NICU	Embracing reality	Shadowed by fading clouds of uncertainty

<i>"Since we came home it is much better now, before she wouldn't sleep the whole night, she used to wake up every two hours. During the day she used to cry for most of the time, you have to lift her up all the time. Now she wakes up in the morning, drinks, sleeps for another two hours, so she gives me time to do more things, and it is easier to go out with her too...it's a matter of getting used to her and her routines." (Aurora's mum, 3b, 2)</i>	Getting used to baby and her routines	Settling at home	Embracing reality	Shadowed by fading clouds of uncertainty
<i>"I think that when one thinks far ahead one would be missing the present. Thinking too much on what might happen, makes you miss the present." (Kristoff's dad, 4a, 29)</i>	Living in real time	Appreciating the moment	Embracing reality	Shadowed by fading clouds of uncertainty
<i>"The glass is still half full...we're trying to get out the positives from what we have gone through, otherwise we despair. We shouldn't say that things could have turned out worse either, things have turned out as they did, <u>this</u> has been our story, we accept reality and walk on forward." (Kristoff's dad, 4a, 23)</i>	Being positive	Accepting what has happened Looking positively to the future ahead	Embracing reality	Shadowed by fading clouds of uncertainty

First and second level analysis of staff data

Theme 2 – Realising limits

The voices of neonatal staff	Key words	Ideas / Concepts	Sub-theme	Theme
<i>“The last thing we do, which I think we do it a bit too late and it’s done rushed, quite rushed, is the basic life support, which is done only once and it’s done either two days before they leave or just before they leave, which then questions might start popping up and they don’t have anyone to answer (their questions). We should do that a bit earlier.” (Midwife Carla, p.2)</i>	Hurried teaching Just before discharge	Inappropriate parent education Feeling inadequate	Exposing self-limitations	Realising limits
<i>“that hurts, it means that we didn’t give the service that we should give...we missed the opportunity to teach her (mother) something, somehow there was this missing with that parent, which I don’t think it’s nice of us let’s say that. I think we failed her to an extent which to me, it hurts if we failed somebody like this. I mean we are here to give a service, a good one I mean we are supposed to be professionals. Most of us do the job from our hearts and it seems somewhere there we got lost ((disappointed and worried expression)).” (Nurse Sonia, p.13)</i>	Missed teaching	Feeling inadequate Hurt Feeling a failure Lacking professionalism	Exposing self-limitations	Realising limits
<i>“definitely it’s lack of communication...maybe ourselves too might be at fault when we are too busy, when we have the NICU with twenty, twenty-five patients so we don’t really have the time to spend with each and every individual parent. Ehm, so yes I think communication or lack of it, is the main cause of any problems that might arise.” (Dr Brown p.4)</i>	Lack of communication Being busy	Less time for parents	Exposing self-limitations	Realising limits
<i>“the doctors take care of the medical aspect that other things like the social aspect, the psychological aspect you know, which are so important, we don’t take care of. Not we don’t take care of, we don’t take care of enough I feel...we need to support them socially as well, socially, psychologically, it is very important. It’s not just the doctor seeing them regularly medically and checking the heart and so on, not just that, we need the support, if she needs support then the social workers need to support her.” (Dr White, p.12)</i>	Medical focus Lacking psychosocial support	Going beyond the medical care	Caught up in the system	Realising limits
<i>“Usually the preterms, when they are about to go home, they are just ‘cot-care’ so they (ward managers) give them to (be taken care of by) the new</i>	Not intensive anymore	Inadequate allocation of	Caught up in the system	Realising limits

<p>ones, just graduated, to learn how to nurse just a small baby so us, the senior ones, we are always with the worst ones (critical babies) and you hardly get the time to speak to them the parents (of those babies approaching discharge). In fact they (parents) tell you, 'you don't do (care for) my baby anymore?', because at the beginning, when they were preterms and ventilated, and not so good (critical stage), we (senior staff) used to do them (take care of them) all the time, and they (parents) get used to you. But then, as they get better, you know, they go to the younger ones (junior staff), so they are not so hard to do (so difficult to care for them anymore), because they are just 'cot-care' and feeding, you know? Things like that, but they don't, but the young ones (junior staff) don't have the experience to speak to them (parents) like we do, you know?...that would help a lot I think if we (senior staff) were able to keep looking after them but that's the system, the young ones (junior staff) have to learn." (Midwife Carla, p.5-6)</p>	<p>Reduced contact with parents Lacking experience in advice giving</p>	<p>care Lack of continuity</p>		
<p>"I think the big turnover of staff, new staff all the time, I think it's one of the things that hinders (the transition to home)...the turnover of staff <u>shouldn't be</u> in the NICU, the big turnover of staff <u>it shouldn't be</u> I think in the NICU and it comes from way above (management), I'm saying it because you have people (staff), you teach them for six months, one year, then they leave literally. When they are getting hold of NICU care literally, they leave and you don't see them anymore and that's, I mean sometimes if we are lucky they come back but mostly we are unlucky, they don't come back, it's the truth." (Nurse Sonia, p.7)</p>	<p>New staff to teach</p>	<p>Staff turnover</p>	<p>Caught up in the system</p>	<p>Realising limits</p>
<p>"The problem right now is that there are a lot of babies and few staff, so it's just periodic right now cause usually we're ok. Most of the time it's one nurse or midwife with one or two babies, and when it's that case it's not a problem to help the parents learn, to help them towards transition home but when you have more than two babies it's very difficult especially if they are more intensive...obviously when you have a lot of work to do, it's very difficult to give them (parents) the time they need." (Midwife Alison, p.7)</p>	<p>Few staff Many babies</p>	<p>Increased workload Less time for parents</p>	<p>Caught up in the system</p>	<p>Realising limits</p>

APPENDIX L: PERMISSION LETTERS

Prof XXXXX

Chairman Department of Paediatrics

XXXX Hospital,

Head, Department of Paediatrics

Faculty of Medicine and Surgery

University of Malta.

2nd April, 2011

Dear Prof XXXX,

I am a midwife and assistant lecturer in midwifery at the Department of Midwifery, Faculty of Health Sciences, University of Malta. I am currently reading for a PhD with the University of Central Lancashire (UCLan), Preston UK. My research study focuses on the NICU-to home transition of preterm infants being explored from neonatal staff perspectives and parents' experiences. This research project is being supervised by three supervisors from UCLan with Prof Soo Downe as Head of Studies, and locally supervised by Dr Rita Borg Xuereb. My supervisory team has approved this research project and finds no objection to the nature of the study. The study will involve data collection from doctors, midwives and nurses working on the NICU and parents whose preterm infants have received care in this unit. Data collection will seek to explore the current practices relating to discharge management of preterm infants from the NICU and how such practices are reflected on the parents' experiences of caring for their preterm infants at home in the first six months following discharge from the NICU. In this regard, I kindly ask for your permission so I will be able to collect such data. Your support for this research project is greatly appreciated. Should you require further information regarding this study, I can be contacted on rita.pace-parascandalo@um.edu.mt or 2340 1176.

Yours sincerely,



Rita Pace Parascandalo

Assistant Midwifery Lecturer

Department of Midwifery

Faculty of Health Sciences

University of Malta

Dr XXXX

Consultant Neonatologist

Head, NICU

XXXX Hospital

2nd April, 2011

Dear Dr XXXX,

I am a midwife and assistant lecturer in midwifery at the Department of Midwifery, Faculty of Health Sciences, University of Malta. I am currently reading for a PhD with the University of Central Lancashire (UCLan), Preston UK. My research study focuses on the NICU-to home transition of preterm infants being explored from neonatal staff perspectives and parents' experiences. This research project is being supervised by three supervisors from UCLan with Prof Soo Downe as Head of Studies, and locally supervised by Dr Rita Borg Xuereb. My supervisory team has approved this research project and finds no objection to the nature of the study. The study will involve data collection from doctors, midwives and nurses working on the NICU and parents whose preterm infants have received care in this unit. Data collection will seek to explore the current practices relating to discharge management of preterm infants from the NICU and how such practices are reflected on the parents' experiences of caring for their preterm infants at home in the first six months following discharge from the NICU. In this regard, I kindly ask for your permission so I will be able to collect such data. Your support for this research project is greatly appreciated. Should you require further information regarding this study, I can be contacted on rita.pace-parascandalo@um.edu.mt or 2340 1176.

Yours sincerely,



Rita Pace Parascandalo

Assistant Midwifery Lecturer

Department of Midwifery

Faculty of Health Sciences

University of Malta

Dr XXXX

Consultant Paediatrician

Department of Paediatrics

XXXX Hospital

2nd April, 2011

Dear Dr XXXX,

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Yours sincerely,



Rita Pace Parascandalo

Assistant Midwifery Lecturer

Department of Midwifery

Faculty of Health Sciences

University of Malta

Ms XXXX

Director Nursing Services

XXXX Hospital

2nd April, 2011

Dear Ms XXXX,

I am a midwife and assistant lecturer in midwifery at the Department of Midwifery, Faculty of Health Sciences, University of Malta. I am currently reading for a PhD with the University of Central Lancashire (UCLan), Preston UK. My research study focuses on the NICU-to home transition of preterm infants being explored from neonatal staff perspectives and parents' experiences. This research project is being supervised by three supervisors from UCLan with Prof Soo Downe as Head of Studies, and locally supervised by Dr Rita Borg Xuereb. My supervisory team has approved this research project and finds no objection to the nature of the study. The study will involve data collection from doctors, midwives and nurses working on the NICU and parents whose preterm infants have received care in this unit. Data collection will seek to explore the current practices relating to discharge management of preterm infants from the NICU and how such practices are reflected on the parents' experiences of caring for their preterm infants at home in the first six months following discharge from the NICU. In this regard, I kindly ask for your permission so I will be able to collect such data. Your support for this research project is greatly appreciated. Should you require further information regarding this study, I can be contacted on rita.pace-parascandalo@um.edu.mt or 2340 1176.

Yours sincerely,



Rita Pace Parascandalo

Assistant Midwifery Lecturer

Department of Midwifery

Faculty of Health Sciences

University of Malta

Ms XXXX

Manager Midwifery Services

XXXX Hospital

2nd April, 2011

Dear Ms XXXX,

I am a midwife and assistant lecturer in midwifery at the Department of Midwifery, Faculty of Health Sciences, University of Malta. I am currently reading for a PhD with the University of Central Lancashire (UCLan), Preston UK. My research study focuses on the NICU-to home transition of preterm infants being explored from neonatal staff perspectives and parents' experiences. This research project is being supervised by three supervisors from UCLan with Prof Soo Downe as Head of Studies, and locally supervised by Dr Rita Borg Xuereb. My supervisory team has approved this research project and finds no objection to the nature of the study. The study will involve data collection from doctors, midwives and nurses working on the NICU and parents whose preterm infants have received care in this unit. Data collection will seek to explore the current practices relating to discharge management of preterm infants from the NICU and how such practices are reflected on the parents' experiences of caring for their preterm infants at home in the first six months following discharge from the NICU. In this regard, I kindly ask for your permission so I will be able to collect such data. Your support for this research project is greatly appreciated. Should you require further information regarding this study, I can be contacted on rita.pace-parascandalo@um.edu.mt or 2340 1176.

Yours sincerely,



Rita Pace Parascandalo

Assistant Midwifery Lecturer

Department of Midwifery

Faculty of Health Sciences

University of Malta

Ms XXXX

Midwifery Officer

NPICU

XXXX Hospital

2nd April, 2011

Dear Ms XXXX,

I am a midwife and assistant lecturer in midwifery at the Department of Midwifery, Faculty of Health Sciences, University of Malta. I am currently reading for a PhD with the University of Central Lancashire (UCLan), Preston UK. My research study focuses on the NICU-to home transition of preterm infants being explored from neonatal staff perspectives and parents' experiences. This research project is being supervised by three supervisors from UCLan with Prof Soo Downe as Head of Studies, and locally supervised by Dr Rita Borg Xuereb. My supervisory team has approved this research project and finds no objection to the nature of the study. The study will involve data collection from doctors, midwives and nurses working on the NICU and parents whose preterm infants have received care in this unit. Data collection will seek to explore the current practices relating to discharge management of preterm infants from the NICU and how such practices are reflected on the parents' experiences of caring for their preterm infants at home in the first six months following discharge from the NICU. In this regard, I kindly ask for your permission so I will be able to collect such data. Your support for this research project is greatly appreciated. Should you require further information regarding this study, I can be contacted on rita.pace-parascandalo@um.edu.mt or 2340 1176.

Yours sincerely,



Rita Pace Parascandalo

Assistant Midwifery Lecturer

Department of Midwifery

Faculty of Health Sciences

University of Malta

Mr XXXX

Data Protection Officer

XXXX Hospital

30th May, 2011

Dear Mr XXXX,

I am a midwife and assistant lecturer in midwifery at the Department of Midwifery, Faculty of Health Sciences, University of Malta. I am currently reading for a PhD with the University of Central Lancashire (UCLan), Preston UK. My research study focuses on the NICU-to home transition of preterm infants being explored from neonatal staff perspectives and parents' experiences. This research project is being supervised by three supervisors from UCLan with Prof Soo Downe as Head of Studies, and locally supervised by Dr Rita Borg Xuereb. My supervisory team has approved this research project and finds no objection to the nature of the study. The study will involve data collection from doctors, midwives and nurses working on the NICU and parents whose preterm infants have received care in this unit. Data collection will seek to explore the current practices relating to discharge management of preterm infants from the NICU and how such practices are reflected on the parents' experiences of caring for their preterm infants at home in the first six months following discharge from the NICU. In this regard, I kindly ask for your permission so I will be able to collect such data. Your support for this research project is greatly appreciated. Should you require further information regarding this study, I can be contacted on rita.pace-parascandalo@um.edu.mt or 2340 1176.

Yours sincerely,



Rita Pace Parascandalo

Assistant Midwifery Lecturer

Department of Midwifery

Faculty of Health Sciences

University of Malta

Mr XXXX

Chief Executive Officer

XXXX Hospital

30th May, 2011

Dear Mr XXXX,

I am a midwife and assistant lecturer in midwifery at the Department of Midwifery, Faculty of Health Sciences, University of Malta. I am currently reading for a PhD with the University of Central Lancashire (UCLan), Preston UK. My research study focuses on the NICU-to home transition of preterm infants being explored from neonatal staff perspectives and parents' experiences. This research project is being supervised by three supervisors from UCLan with Prof Soo Downe as Head of Studies, and locally supervised by Dr Rita Borg Xuereb. My supervisory team has approved this research project and finds no objection to the nature of the study. The study will involve data collection from doctors, midwives and nurses working on the NICU and parents whose preterm infants have received care in this unit. Data collection will seek to explore the current practices relating to discharge management of preterm infants from the NICU and how such practices are reflected on the parents' experiences of caring for their preterm infants at home in the first six months following discharge from the NICU. In this regard, I kindly ask for your permission so I will be able to collect such data. Your support for this research project is greatly appreciated. Should you require further information regarding this study, I can be contacted on rita.pace-parascandalo@um.edu.mt or 2340 1176.

Yours sincerely,



Rita Pace Parascandalo

Assistant Midwifery Lecturer

Department of Midwifery

Faculty of Health Sciences

University of Malta

Dr XXXX

Superintendent

XXXX Hospital

30th May, 2011

Dear Dr XXXX,

I am a midwife and assistant lecturer in midwifery at the Department of Midwifery, Faculty of Health Sciences, University of Malta. I am currently reading for a PhD with the University of Central Lancashire (UCLan), Preston UK. My research study focuses on the NICU-to home transition of preterm infants being explored from neonatal staff perspectives and parents' experiences. This research project is being supervised by three supervisors from UCLan with Prof Soo Downe as Head of Studies, and locally supervised by Dr Rita Borg Xuereb. My supervisory team has approved this research project and finds no objection to the nature of the study. The study will involve data collection from doctors, midwives and nurses working on the NICU and parents whose preterm infants have received care in this unit. Data collection will seek to explore the current practices relating to discharge management of preterm infants from the NICU and how such practices are reflected on the parents' experiences of caring for their preterm infants at home in the first six months following discharge from the NICU. In this regard, I kindly ask for your permission so I will be able to collect such data. Your support for this research project is greatly appreciated. Should you require further information regarding this study, I can be contacted on rita.pace-parascandalo@um.edu.mt or 2340 1176.

Yours sincerely,



Rita Pace Parascandalo

Assistant Midwifery Lecturer

Department of Midwifery

Faculty of Health Sciences

University of Malta

APPENDIX M: ETHICS APPROVAL

Ethics approval from the University of Central Lancashire



2nd September 2011

Soo Downe/Rita Pace Parascandal/Kevin Hugill/Victoria Hall-Moran
/Rita Borg Xuereb
School of Health
University of Central Lancashire

Dear Soo, Rita, Kevin, Victoria & Rita

**Re: Faculty of Health & Social Care Ethics Committee (FHEC)
Application - (CA number 191)**

The Faculty of Health Ethics Committee (FHEC) has granted approval of your proposal application 'NICU-to-home transition of preterm infants: neonatal staff perspectives and parents' experiences' on the basis described in its 'Notes for Applicants'.

Within a month of the anticipated date of project completion you specified on your application form, we shall e-mail you with a copy of the end-of-project report form. This should then be completed and returned to Research Office within 3 months or, alternatively, an amended end-of-project date forwarded to Research Office. Completion of an end-of-project form is required under the University's ethics research governance procedures.

Please also note that it is the responsibility of the applicant to ensure that the ethics committee that has already approved this application is either run under the auspices of the National Research Ethics Service or is a fully constituted ethics committee, including at least one member independent of the organisation or professional group.

Additionally, FHEC has listed the following recommendation(s) which it would prefer to be addressed. Please note, however, that the above approval will not be affected should you decide not to address these recommendation(s).

Should you decide to make any of these recommended amendments, please forward the amended documentation to the Research Office for its records and indicate, by completing the attached grid, which recommendations you have adopted. Please do not resubmit any documentation which you have *not* amended.

Yours sincerely

Denise Forshaw
Chair
Faculty of Health Ethics Committee

Ethics approval from the University of Malta

To be completed by Faculty Research Ethics Committee

We have examined the above proposal and advise

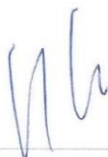
Acceptance

Refusal

Conditional acceptance

For the following reason/s:

Signature



Date

15/6/2011

To be completed by University Research Ethics Committee

We have examined the above proposal and grant

Acceptance

Refusal

Conditional acceptance

For the following reason/s:

Signature



Date

8/7/11

APPENDIX N: CONSENT FORMS

CONSENT FORM

The aims and details of the project on 'NICU-to-home transition of preterm infants: neonatal staff perspectives and parents' experiences' have been explained to me by Ms Rita Pace Parascandalo.

I know that the information collected will remain confidential, and that it will be used only for scientific purposes. I also know that a written report of the study will be drawn up, and that I will not be identified in any way in this report. I know that all the information collected, including any audio-recordings will be password protected and destroyed on completion of the study.

I therefore give my consent to participate in this research project as I sign below whilst being witnessed and countersigned by the researcher.

I am aware that I am under no obligation to do so, and that I can withdraw my consent at any moment without giving any reason.

In case of any difficulty during the study, I can contact:

Ms Rita Pace Parascandalo (Researcher)
Telephone number: 23401176 / 99455084
E-mail: rita.pace-parascandalo@um.edu.mt

Signature:.....

Name of participant:

.....

Telephone number:

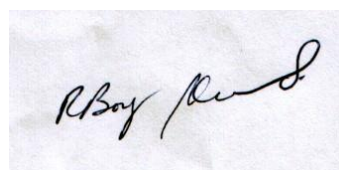
Signature:

Name of person responsible for the study:

Prof Soo Downe

Dr Rita Borg Xuereb

Signature:



Formola ta' kunsens

L-iskop u d-dettalji tal-proġett 'NICU-to-home transition of preterm infants: neonatal staff perspectives and parents' experiences' ġew spjegati minn Ms Rita Pace Parascandalo.

Jiena naf li l-informazzjoni miġbura ser tinżamm b'mod kunfidenzjali, u li ser tintuża biss għal skopijiet xjentifiċi. Naf ukoll li ser isir rapport bil-miktub tar-riżultati, u li meta jsir dan, naf li bl-ebda mod ma nista' niġi identifikat. L-informazzjoni miġbura, inkluża '*audio recording*' ser tiġi protetta minn '*password*' u meqruda meta jispicca l-istudju.

Għalhekk qed nagħti l-kunsens tiegħi lill-persuna responsabbli għal din ir-riċerka billi niffirma hawn isfel waqt li tixhed dan u tiffirma r-riċerkattriċi ukoll.

Naf li ma għandi l-ebda dmir nagħmel dan, u li nista' nirtira fi kwalunkwe punt, mingħajr ma nagħti raġuni.

Jekk ikolli diffikulta' waqt l-istudju, nista' nistaqsi għal:

Ms Rita Pace Parascandalo (Riċerkattriċi)
Numru tat-telefon: 23401176 / 99455084
E-mail: rita.pace-parascandalo@um.edu.mt

Firma :

Isem tal-partecipant:

.....

Numru tat-telefon:

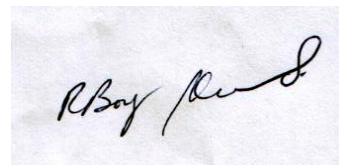
Firma:

Isem tal-persuna responsabbli għall-istudju:

Prof Soo Downe

Dr Rita Borg Xuereb

Firma:



Response to FHEC Application - CA No.191 (Version No.2)

Recommendation	Applicant Response
1. That the consent form is altered to reflect witnessed consent with the researcher signing at the same time.	Recommendation adopted