

**THE EXPERIENCE OF THE NEONATAL
INTENSIVE CARE UNIT (NICU) AND NICU
SUPPORTIVE INTERVENTIONS.**

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Abbreviations

APIP – Avon Premature Infant Project

COPE – Creating Opportunities for Parent Empowerment

CPAP – Continuous Positive Airways Pressure

CBD – Central Business District

dB – decibel

LBW – low birth weight

NA – not applicable

NHMRC – National Health and Medical Research Council

NICU – Neonatal Intensive Care Unit

NIDCAP –Newborn Individualised Developmental Care and Assessment Program

NUPS –

NVIVO – 9

NVIVO – 10

PSS – NICU - Parental Stress Scale – Neonatal Intensive Care Unit

RANZCP – Royal Australian and New Zealand College of Psychiatrists

1 Abstract

Parents of babies born prematurely begin their journey of parenthood in the stressful and highly medicalised environment of the neonatal intensive care unit (NICU). This environment influences a range of factors including parental stress, staff behaviour and communication, and baby growth and development. This thesis examines the experience of parents and nurses in an inpatient neonatal intensive care unit. The reactions of parents to supportive interventions are considered, including experiences with a professionally facilitated support group.

Data for this research were collected through interviews with both parents and nurses and with a parental survey that included the PSS-NICU (Parent Stress Scale – Neonatal Intensive Care Unit; Miles, Funk & Carlson, 1999). Qualitative data were analysed thematically and multiple regression analysis was used for the parent survey results.

This thesis comprises four studies. Parents were interviewed during their baby's NICU admission and then after their baby's discharge. Over 13 months during the research period any parent with an infant in NICU was invited to complete the Parent Stress Scale-NICU. Nurses who were employed in the same hospital neonatal intensive care unit were interviewed about their supportive role for parents in the nursery and their experience of parents in the nursery.

The overarching Research Questions were, "What is a parent's general experience of having a baby in Neonatal intensive care" and "What is their experience of the

emotionally supportive care provided to them?” In addition, further specific research questions were addressed in each study.

In Study 1, parents described the emotional experience associated with having a baby as an inpatient in the NICU. The research questions for this study were: “What are the parental experiences of the NICU?” and; “Do parents feel the support that they received, including that from the formal support group, met their needs?” Themes that emerged were about pregnancy and the baby, parenting, nurse interactions and support. In particular, fear and guilt centred upon having given birth early; parents felt challenged to meet the needs of an ill, and potentially dying baby, as well as experiencing the feeling of powerlessness. Support through information sharing with professionals, sharing the experience with other parents and seeking family support were discussed by parents as helpful for managing the experience.

In Study 2, parents related their experiences after their baby’s discharge from hospital. The research questions for the study were: “What are parents’ reflections afterwards, on their experiences as a NICU parent?”; “How do they describe their relationship with the baby after discharge from the hospital?”; and “How helpful was the pre-discharge support group?” Themes included anxiety and concern about the baby’s readiness for discharge and risk of further illness. Parents were unsure if they felt sufficiently prepared to care for their baby at home. All participants reflected that the support group and friendships with other NICU parents were key to ‘surviving’ the NICU experience.

The parent interactions with neonatal intensive care nurses are ongoing throughout their baby's time in the NICU. To address the role of the NICU nurses in parent support, the nurses' views on the NICU experience were explored in Study 3. Views were sought on how they perceived the experience for themselves, for parents, and what they saw as the emotional supports that assist parents. The research questions for the study were; "How do participants view their role in the neonatal intensive care unit (NICU)?", "How do participants provide support for parents in the NICU?" and "What elements obstruct and assist the NICU staff in providing emotional support for parents?"

Participants viewed their role as an enjoyable yet difficult one, requiring seniority, training and experience. They provided support to parents by communicating, listening, providing individualised support and by encouraging parental involvement with their baby. Constructive elements that contributed to the provision of support included a positive NICU environment and providing a parent support group. More obstructive elements were a lack of physical NICU space, little time available for nurse to parent conversation and language, and cultural barriers between nurses and parents.

Parents' experiences of the NICU were further explored using the PSS-NICU, and these results are the focus of Study 4. The Parent Stress Survey – Neonatal Intensive Care Unit (PSS NICU), demographic and support-related responses were collected from 73 parents of NICU babies in South Australia over a 13-month period. The highest PSS NICU scores were concerned with separation from, and little contact with, their baby. The majority of parents (53%) attended the NICU parent support

group, 42% of parents had more than one session with the NICU social worker and 42% of parents would have preferred more professional support.

Multiple regression analyses demonstrated parental age, infant gestational age at birth and having a twin birth were all significantly associated with having a higher PSS NICU Sight and Sound score. Infant gestational age at birth and having a twin birth were significantly associated with a higher PSS NICU Baby Look/Appearance and Behaviour score. Support group attendance was significantly associated with a high score in the PSS NICU Relationship and Parental Role subscale. Identifying these elements of parent experience of stress suggest that changes to the delivery of parent support would be beneficial. In particular, support should be provided to older parents and parents of very premature babies and twins, as they have the highest stress scores. Further research into what drives attendance at support groups, helpful aspects of support, and further development of support resources are discussed.

Together, the four studies that comprise this thesis show that an admission to the NICU requires professionally facilitated and family based emotional support for the parents during and after the baby is in hospital. This professional support should be emotionally supportive as well as educational and informative, and be provided in a flexible form. Support and training is also needed for nursing staff to provide the intense and ongoing emotional support that parents require.

2. Statement of Originality of this work

I certify that this work contains no material which has been accepted for the award of another degree or diploma in my name in any university or tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name for any other degree or diploma in any university or tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint award of this degree.

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3 List of Publications contained in this thesis

1. Turner, M., Chur-Hansen, A., Winefield, H. (2012). Examining the Experience of Parents and Staff in a Neonatal Intensive Care Nursery. *Neuropsychiatrie de l'Enfance et de l'Adolescence*, Supplement. 60, S190.
2. Turner, M., Chur-Hansen, A., Winefield, H. (2013). The Emotional Experience and Supports for Parents with Babies in the Neonatal Nursery. *Advances in Neonatal Care*, 13, 438-446.
3. Turner, M., Chur-Hansen, A., Winefield, H. (2014). The Neonatal Nurses' View of their Role in Emotional Support of Parents and its Complexities. *Journal of Clinical Nursing*, in press. doi: 10.1111/jocn.12558
4. Turner, M., Chur-Hansen, A., Winefield, H. Mothers' Experiences of the NICU and a NICU Support Group Program – submitted to the Journal of Infant and Reproductive Psychology April 8th 2014. Currently revised from first submission and under review.
5. Turner, M., Chur-Hansen, A., Winefield, H. The Assessment of Parental Stress and Support in the NICU using the PSS NICU (Parental Stressor Scale – Neonatal Intensive Care Unit). Submitted to, Journal of Pediatric Nursing, May 28th 2014. Currently under review.

3.1 Conference Presentations related to this thesis -

1. 2008 RANZCP (Royal Australian and New Zealand College of Psychiatry),
Child and Adolescent Psychiatry Conference Port Douglas, Queensland,
AUSTRALIA

PAPER TITLE: One finger to bond with – the assessment of a therapeutic support
group for parents of babies in neonatal intensive care

Date – 12 to 16 October 2008

Author –Turner, M.

2. AAIMH (Australian Association of Infant Mental Health) Conference - Angels
in the Nursery – Supporting Parent-Child Relationships, Adelaide AUSTRALIA.

PAPER TITLE: One finger to bond with – the establishment of a therapeutic support
group for parents of babies in neonatal intensive care and special care baby nurseries.

Date – 9 November 2008

Author – Turner, M.

3. 2009 RANZCP (Royal Australian and New Zealand College of Psychiatry)
Congress – Living in Interesting Times, Adelaide, AUSTRALIA.

PAPER TITLE – The Parent and Nurse experience of the neonatal intensive care
nursery.

Date - 26 May 2009

Author - Turner, M., & Chur-Hansen, A.

4. RANZCP Child and Adolescent Psychiatry Conference, Child 2009,
Queenstown, New Zealand.

PAPER TITLE - Further down the Road - One Finger to Bond With, The Neonatal Nursery Support Group 1 year on..

Date - 7 September 2009

Author – Turner, M., & Chur-Hansen, A.

5. 2009 Joint Conference AAIMHI and the Australasian Marce Society. The infant, the family and the modern world. Intervening to promote healthy relationship. Melbourne, Australia.

PAPER TITLE - Supporting the Intensive Care Parent – Research into the Neonatal Nursery Support Group at the Womens and Childrens Hospital, South Australia.

Date –1 October 2009

Authors – Turner, M., & Chur-Hansen, A.

6. 18th European Congress of Psychiatry. Improve the Quality of Psychiatric Treatment and Research In Europe. Munich, Germany.

PAPER TITLE – Supporting the neonatal intensive care parent – research into parental supports and perceptions of the intensive care experience in Australia.

Date – February 27 to March 2 2010

Authors – Turner, M.

7. RANZCP 2010 Congress, Auckland New Zealand – A Shared Endeavour, Tatau Tatau,

PAPER TITLE -The experience of the neonatal nursery for parents and staff

Date – 3 May 2010

Author – Turner, M., Chur-Hansen, A., & Winefield, H.

8. IACAPAP (International Association for Child and Adolescent Psychiatry and Allied Professions.) Beijing, China, 2010 – Improving child mental health: Increasing Awareness and new Pathways for Care.

PAPER TITLE - Infants and the Experience of their Parents in the Neonatal Intensive Care Unit.

Date – 3 June 2010

Authors – Turner, M., Chur-Hansen, A., & Brock, P.

9. RANZCP 2014 Congress – Evolving Landscapes in Mental Health, Perth, Australia

PAPER TITLE - The Emotional Experience of Parents and Nurses in a South Australian Neonatal Intensive Care unit (NICU)

Date – 13 May 2014

Authors – Turner, M., Chur-Hansen, A., & Winefield, H.

10. Australian Childhood Foundation, 2014 Trauma Conference - Childhood Trauma: Understanding the Basis for Change and Recovery at the Melbourne Convention Centre.

PAPER TITLE - The Emotional and Traumatic Experience of Parents and Nurses in a South Australian Neonatal Intensive Care unit (NICU)

Date – 6 August 2014

Authors – Turner, M., Chur-Hansen, A., & Winefield, H.

3.2 *Poster presentations related to this thesis*

1. IACAPAP (International Association of Child and Adolescent Psychiatry and Allied Professions) World Congress, Paris, France,

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Presented – 22 July 2012

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2. European Conference of Developmental Psychology, Lausanne Switzerland
September 3 – 7, 2013.

Title - Stress and Support in the Neonatal Intensive Care Unit.

Authors - Turner, M., Chur-Hansen, A., & Winefield, H.

Poster Presented – 6 September 2013

These posters, in A4 format, are included in this thesis in the appendices.

Chapter 1 - Introduction

1. Overview of this Thesis

This thesis extends the knowledge base about the experiences and supportive needs of parents of babies in neonatal intensive care units (NICU).

The introductory chapter outlines the gaps in NICU research that were noted and for which this research was designed to address. Examining the previous relevant research, there was a lack of data on parents' experiences of the supports offered to them while their baby was in NICU. Their response to how these supports were delivered, and whether they were helpful or more distressing, was unknown to a large extent. Through nurse and parent qualitative research and accumulation of Parental Stress Scale NICU, (PSS NICU) survey quantitative data, this research shows that emotional support for parents, in particular an open parent support group, is important in assisting parents through their NICU journey.

These data are analysed with both framework analysis and quantitative analysis. The method of framework analysis (Pope & Mays, 2006) and an explanation of how it can be used to examine the experience of being a parent and nurse in the NICU, are discussed in the latter part of this chapter. The ethical and methodological considerations affecting the conduct of research with this vulnerable population are also introduced.

Chapters two to five inclusive, are four research papers with each focussing on a different element of the research. Chapter two presents the results from participant

interviews during their baby's NICU inpatient admission. Chapter three presents results from participant interviews after their babies were discharged from hospital. Chapter four is a research paper based on NICU nurse interviews addressing their experience of working in the NICU. Chapter 5 is a research paper examining provision of parent support, and quantitative analysis of the Parent Stress Scale – NICU surveys completed by parents of the NICU in this study. Chapter six provides a conclusion to the thesis drawing together the parent and nurse qualitative data and the PSS NICU quantitative data together with, a review of these findings as well as a discussion of the limitations of this research.

2 Rationale for this thesis

This chapter considers the role of the neonatal intensive care unit (NICU) and its effect on parents as well as the provision of support for parents in the NICU. A review using a range of publication databases including Academic Search Premier; Cinahl; PubMed; Scopus and PsycINFO were used to source literature on the NICU field. The literature describes a wide range of studies discussing parents in the neonatal intensive care unit, but few were focussed on examining the parent NICU experience related to the emotional supports provided. As medical advancements continue, the age from which a baby is deemed 'survivable' is getting younger and younger. Now, babies from 23 weeks gestation, 17 weeks before their due date, can enter the neonatal intensive care unit and spend over 100 days being cared for before their parents can take them home. While these NICU medical technologies have advanced, the evidence base for supportive systems for the psychological needs of NICU parents appear to have fallen behind. Despite this, the provision of support is often a recommendation in research into assisting parents in the NICU, but how this is

provided, what kind of support is offered, and who provides it, are frequently omitted (Kara et al., 2013) with a varying level of evidence available to support these decisions (Brett, Staniszevska, Newburn, Jones, & Taylor, 2011).

This study sought to explore this gap in knowledge about the supportive system for the parents and to provide an evidence base for structuring future supports. This research considered the experience of the parents and the support, including parent group support; from a number of perspectives. These included: the experience of the parent of a baby as an inpatient in the NICU; the experience after being discharged home with their baby; the experience of the nursing staff in the NICU units and their view of the support provided to parents, and a quantitative view with parents able to indicate their level of stress related to various parts of the NICU experience using the PSS NICU. The data from the PSS NICU were analysed alongside parental demographic and support experience data and relationships between stress and these variables were determined.

Together; this outlined the areas of emotional support that are important to parents and staff and by comparing these findings to the current content of the hospital support group, recommendations could be made for clinical changes to parent support services.

3 The NICU

Neonatal intensive care units provide care for babies who are born unwell, premature or who require observation after birth. NICU units are a very busy part of a hospital with most functioning at full capacity, with babies requiring intense nursing and medical care and interventions, most days of the year. In Australia there are

approximately 23 neonatal intensive care units and approximately 68 special care neonatal nursery units (Abdel-latif, Keckskes, & Bajuk, 2013). In 2011, 301,810 babies were born in Australia. Babies are full term when they are born between 37 and 40 weeks gestation. A number (8.3%, or 25,113) of these babies are born prematurely at less than 36 weeks gestation, and more than 2,600 are born prior to 32 weeks (Li, Zeki, Hilder, & Sullivan, 2013). In 2011, 3300 of these babies required an admission to the special care baby unit or the neonatal intensive care unit. Pre-term births occurred in 57% of twins and 97% of higher - order multiple births (Li, Zeki, Hilder, & Sullivan, 2013). As well as the life and death challenges for the neonate. Psychological distress and depressive symptoms are often the after effects of a NICU experience for mothers of these premature babies (Davis, Edwards, Mohay, & Wollin, 2003; Segre, Chuffo-Siewert, Brock, & O'Hara, 2013). Post-traumatic stress disorder has also been identified in mothers of premature neonates post partum (Shaw et al., 2006; Ukpong, Fatoye, Seni, & Adewuya, 2003). The experience of fathers has not attracted a great deal of attention in previous research, nor has the extended family experience been studied.

3.1 Care of Premature Babies in the NICU

The earliest studies about the emotional or psychological aspects of neonatal intensive care began in the 1980's. This was a time when new medical interventions such as new ventilation techniques and surfactant medication to improve lung maturity were increasing the chance of neonate survival. Over the last twenty years there has been a steady increase in the survival rates of premature babies. Much of this change has been due to the large range of new medical procedures and equipment available to treat this group of babies. Along with this, there has been a steady stream of research

and increase in knowledge about pregnancy, the physical relationship between mother and foetus, as well as delivery and the premature baby. While this has provided enhanced medical care, it has also provided a unique situation for parents who, from the minute of birth, have a critically ill child due to their prematurity.

The survival rate in a recent study in NSW shows that survival at 22 weeks was 0% and rose to 98.8% at 31 weeks (Abdel-latif, Keckskes, & Bajuk, 2013). The majority of deaths of these babies occurred within the first four days of life. For the babies who live, a number will suffer from chronic illnesses, such as those that occur after surviving severe prematurity. These illnesses are known to have a negative impact on the relationship between a child and their parent (Franck, Cox, Allen, & Winter, 2005; Aagaard & Hall, 2008).

In 1991 Kratochvil, Robertson and Kyle, reviewed parents with eight year old children who were premature at birth. Forty percent of these parents felt that there was an ongoing adverse effect on the parent-child relationship due to the separation and experience of having a premature baby. Further studies that examined the infant parent relationship with parents and their premature infants showed that avoidance of negative experiences is a frequent coping style used by parents in the NICU. This can lead to a maladaptive relationship with their child (Greco et al., 2005) and such parents are at risk of developing Acute Stress Disorder (Shaw et al., 2006, 2013). However there is a paucity of research examining the parent experience of support in the NICU, which may be an important factor in mitigating poor relationships between mother and baby.

3.2 Parents in the NICU

The environment of the neonatal intensive care unit is not the environment that most parents imagined for their first encounters with their baby. Some parents find this an overwhelming and confusing time (Arnold, et al 2013) and for a number of parents this time is a loss of innocence as parents question their beliefs in safety, medical care and the roles of power amongst parents and staff (Davis & Stein, 2004 p. 33). The noise, chaos and large numbers of staff in a unit often cause parents to feel a lack of both control and input into their baby's admission (Zelkowitz et al., 2008; Singer et al., 1999).

An admission to a neonatal intensive care unit has a variety of adverse effects upon the psychological wellbeing of the parents and the parent - infant relationship (Zelkowitz & Papageorgiou, 2005). Researchers such as Eidelman and Feldman (2006), have found that premature infants are at higher risk for difficulties with mother-infant interactions as well as other cognitive delays. Maternal traumatic experience and premature birth (Muller-Nix et al., 2004; Forcada-Guex, Borghini, Pierrhumbert, Ansermet, & Muller-Nix, 2011), which are often associated with premature delivery, are two of the most important factors in predicting a poor maternal – child relationship post discharge. The long lasting effects of parental anxiety in the NICU may also affect the parent-infant relationship until the infant reaches 2 years of age (Zelkowitz et al., 2008), and this may be a cause of maternal post-traumatic stress disorder (Forcada-Guex, Borghini, Pierrhumbert, Ansermet, & Muller-Nix, 2011; Jubinville, Newburn-Cook, Hegadoren & Lacaze-Masmonteil, 2012). Parental divorce is also higher in the NICU parent population (Manning, 2012).

Research in children's intensive care units (with children over the age of 1 year) shows emotional strain on the parent - child relationship. In particular Miles et al., (1989a) found that the most stressful experiences were seeing their child in pain, seeing their child frightened and sad, and the inability of the child to communicate with the parent. Grief as a NICU parent over the pre-term birth can affect the on-going parenting relationship with the baby, after discharge. Resolution of this maternal grief has important implications for emerging attachment security for infants born prematurely (Shah, Clements, & Poehlmann, 2011). On the other hand, there have been positive outcomes documented from being a NICU parent. Being involved in the day-to-day care of babies in neonatal intensive care can help parents learn the parenting role (Skene, Franck, Curtis, & Gerrish, 2012) and increase their emotional sensitivity toward their baby (Coppola, Cassibba, & Costantini, 2007; Coppola & Cassibba, 2010). Providing support to parents of babies in intensive care has additional physical benefits for the baby as it can improve the baby's physical outcomes and shorten their length of stay in hospital (Nearing, Salas, Granado-Villar, Chandle, & Soliz 2012).

3.3 The NICU nursery

The neonatal intensive care unit approach to the emotional care of parents and babies has changed over the last ten to twenty years. There have been a number of techniques developed to encourage parents to have more physical contact with their children as well as encouraging reading to, and conversation with, the baby. More and more NICU centres are trying to address the needs of family by modifying their nursery's physical structure and supports as well as the way in which they provide care for the babies. These changes can enable older children to visit their newborn

siblings and have grandparents play a role in caring for their new grandchildren. Family-centred care, which acknowledges the importance of parents as partners in care, is widely viewed as a desirable and essential part of neonatal nursing (Fegran & Helseth, 2009).

The NIDCAP (Neonatal Individualised Developmental Care and Assessment Program) – is a system developed by Dr Heidelise Als and her team at the Childrens Hospital Boston, USA. It uses individualised care for each baby in a nursery. NIDCAP is a specific, family - centred care model, upon which a number of less structured forms of developmental care are based, depending upon the needs of each nursery. It is underpinned by the understanding that ‘the quality of the experience before term may influence brain development significantly’ (Als, 2004, p. 202). It is well described by Westrup, (2007, p. 445): “NIDCAP is a multidisciplinary process involving not only medicine and nursing, but also family and organizational psychology. The aim of family-centred developmentally supportive care is, above all, to alter the focus from the traditional task- or procedure-oriented emphasis on care to processes and relationships, including increased involvement of families.”

NIDCAP is not instituted in the nursery described in this dissertation. However this nursery has recently introduced family-friendly principles, as have many other nurseries. In general this entails the parents being more involved in the medical and nursing decision making around their baby and including them in the day-to-day cares of the baby. Research has shown that for this to be effective, the managers of each neonatal unit need to implement training in using COPE (Creating Opportunities for Parent Empowerment), or other supportive programs, to facilitate parent involvement

(Roets, Rowe-Rowe, & Nel, 2012; Zimmerman & Bauersachs, 2012). It is also suggested that as well as a supportive program for parents, that NICU staff need to reflect upon what support they give individually (Franck & Axelin, 2013).

3.4 Support Groups

Group support is used in a number of circumstances when parents or children have medical or emotional challenges such as intellectual impairment (Hastings & Beck, 2004), cancer (McGrath, P., 2001) and eating disorders (Pasold, Boateng, & Portilla, 2010). The aim of these groups is to provide the appropriate support for the specific needs of the population attending. Parents of children with eating disorders, who attended a group to provide emotional support, described the group as helpful in understanding the behaviour and complexities of their child's illness (Pasold, Boateng, & Portilla, 2010). Another positive aspect of this group is that it also gave parents an environment where they could learn from other parents and share their experiences. These support groups facilitate the meeting of other parents and the forming of relationships with those in a similar situation (McGrath, P., 2001).

Providing professionals to facilitate the group separates this from a participant led self-help group, where the facilitation is from participants in the group (Rootes & Aanes, 1992). In professional facilitator run support groups, such as the one that is the focus of this research, the facilitator 'helps the group explore issues through discussion, provides educational or teaching materials, and takes care of practical matters of running the group' (Martin & Smith, 1995; pg 391). This allows all parents to be group participants and receive emotional support rather than take on the responsibility of managing group dynamics and structure. The challenge of running a

parent support group is often poor attendance (Smith, Gabard, Dale, & Drucker, 1994). Ensuring that the group meets the needs of those attending, as well as providing a counselling professional such as a psychologist, psychiatrist or social worker as facilitator can increase the attendance at the parent group (Smith, Gabard, Dale, & Drucker, 1994).

3.5 Support groups in the NICU

Group support for NICU parents has been initiated in a number of hospitals throughout the world (Kaaresen, Ronning, Ulvund, & Dahl, 2006; Melnyk et al., 2006). The various methods of NICU support groups include structured closed groups, open groups, groups run by volunteers and groups run by parents (Bracht, Ardal, Bot, & Cheng, 1998). The most researched support program for NICU parents is the COPE program developed in the USA. COPE (Creating Opportunities for Parent Empowerment) was developed by Bernadette Melnyk, a Professor of Nursing in Arizona. Her initial investigations into NICU parents showed that low birth weight (lbw) infants experience varied adverse physical/mental/behavioural outcomes persisting beyond school age as compared to non low-birth weight infants (Melnyk et al., 2006). Parents of these preterm infants experienced high stress levels and are usually inadequately prepared for their experiences as compared to parents of term infants. The NICU parents experienced increased rates of parental depression, anxiety and dysfunctional parenting as compared to families of babies not requiring NICU.

3.5.1 COPE (Creating Opportunities for Parent Empowerment)

COPE addresses a range of issues including the appearance and behavioural characteristics of premature infants; how parents can participate in their infants' care, meet their infant's needs, make interactions with their infant a more positive experience, and aid in their infant's development. Activities are done that assist parents in implementing the new skills outlined in the COPE booklet and CD's given to parents, these activities include recognising their infant's alert states and stress cues, and identifying special characteristics of their infants. Families involved in COPE have lower parental stress, increased confidence in parenting skills, more developmentally sensitive interactions with their babies, and less depressive and anxiety symptoms than do comparison mothers in a control group (Melnyk et al., 2001). Melnyk also showed that babies weighing less than 1500 grams went home on average eight days sooner if their parents completed the COPE program (Melnyk et al., 2006). Roman et al. (1999) outlined the use of parent-to-parent support at Butterworth Hospital in Michigan USA. The provision of the COPE program to this group improved maternal mood states, maternal-infant relationships and improved the home environment.

In Norway, a study completed by Kaaresen, Ronning, Ulvund, & Dahl (2006) reported on the result of eight sessions by specially-trained nurses with NICU parents. This intervention reduced parenting stress levels to those comparable with their peers without NICU babies. The follow up study also showed decreased stress levels in parents two years after completing the sessions (Kaaresen, Ronning, Tunby, Nordhov, & Ulvund, 2008). Research completed by (Forcada-Guex, Pierrehumbert, Borghini, Moessinger, & Muller-Nix, 2006) as well as that of Singer et al., (1999) emphasised that the main clinical goal should be to support a healthy parent-infant relationship in

the NICU and this should occur in the first few months of life. To achieve this, neonatal intensive care units should ‘aim to provide a varied, flexible and sustainable programme of support options’ (Nicolau & Glazebrook, 2008, pg. 196), for parents. Recent research completed by Kyno et al., (2013) showed through qualitative analysis, that there were benefits to providing an early intervention support program to parents of premature babies in Norway. Parents considered the group to be both emotionally supportive and educational (Kyno et al., 2013), indicating that support through a support group may be the most appropriate channel for this assistance to be delivered to neonatal intensive care unit parents.

3.6 The Hospital NICU Support Group

This research is the first to interview parents about their experience of a support group in the NICU while the baby is both an inpatient, and at two to four months post discharge. There have been no research articles, to date in CINAHL, SCOPUS, PsycINFO, Academic Search Premier and PubMed that have used qualitative interviews with both patients and nursing staff to rigorously examine the issue of parent emotional support. The support group began in April 2008 and was continuing at the time of writing this dissertation (September, 2014). At the time of the research, the group was co-managed by a senior neurodevelopmental physiotherapist and the author. The group was offered to all primary carers of babies who were in the hospital Neonatal Intensive Care Unit. The most common patients in the NICU were babies born between 23 and 30 weeks who required mechanical ventilation and frequent blood transfusions, as well as complicated medical care. The Special Care Baby Unit (SCBU) subsection of the NICU catered for babies born from 30 weeks to 35 weeks, and also for babies born at term who had a variety of genetic disorders

and/or physical malformations. Babies were moved through the unit from the Neonatal Intensive Care Unit to the Special Care Baby Unit as they gained weight and required less medical intervention. Most babies transitioned from the NICU to the SCBU when they reached 30 weeks gestational age. There were a number of other transitions; from a closed, heated isolette to an open cot when the baby weighed 1800g. A change to ventilation was also another progression, moving from full mechanical ventilation to continuous positive airway pressure (CPAP) and eventually to using intranasal oxygen. Parents could attend the support group at any stage of their baby's admission.

The parent support group ran every week for 75 minutes and was available to parents who had a baby or babies in either the NICU or the SCBU. The content was tailored to those attending the session by determining the age and medical state of their baby at the beginning of the session. The group activities were based on information giving as well as the common supportive and reflective elements used in therapeutic group work.

A new element, which has not been documented in previous NICU parent groups, was the use of true-to-life weight and size dolls for parents to use to practice holding, feeding and wrapping a baby. This allowed parents who were unable to hold their children the experience of holding something of a similar weight, shape and size as their baby. These dolls were brought to each session and were used particularly when speaking about baby cues, containment of a baby when distressed and baby cares. There were 10 dolls in total, the right size and weight for each of the average 23, 24, 26, 27, 28, 29, 30, 32, 34 and 36 weeks gestation. These were made by Zoe Jarman,

Tummy Bear Australia Pty, Ltd. (<http://www.tummybear.com.au>) using a pattern by Sandi Eding and Judi Ward.

Topics addressed in the group sessions are below, in order from Week 1 to Week 10 with flexibility dependent on attendees' needs and requests:

Week 1	The stress of the NICU on you, your baby and your partner
Week 2	Being with your baby and feeding your baby
Week 3	Learning to touch/contain or hold baby
Week 4	Learning about baby cues
Week 5	Use of voice, reading and narrative with your baby
Week 6	The move from NICU to SCBU
Week 7	The anxiety of the long admission and anxiety of going home
Week 8	Going home, baby carriers, baby slings, external support groups
Week 9	Common premature baby development, corrected age, play and interaction with your baby
Week 10	Explaining prematurity to everyone else

Figure 1 – Premature baby dolls, in different skin tones, as used in the Parent Support Group.



3.7 Nurse Interactions

Few studies have focussed on nurse interactions in the Neonatal Intensive Care Unit. The relationships between nurses are complex. Bullying and hostility are recognised as issues in labour wards, mother and baby units, as well as neonatal intensive care units (Reynolds, Kelly, & Singh-Carlson, 2014). This horizontal hostility and disruptive staff behaviour contributes to negative patient outcomes within the nursery (Reynolds, Kelly & Singh-Carlson, 2014; Veltman, 2007). Although nursing staff are present twenty four hours a day in the NICU, their contributions to parent stress and parent coping (both positive and negative), seem to have been often overlooked. Holditch-Davis and Miles (2000) and Hurst (2001) reported that nurses could have a major role in reducing parental stress. Determining the sources of this stress, such as by researching stress using the PSS-NICU, can help NICU nurses use specific interventions to target and reduce the parent's stress (Turan, Basbakkal, & Ozbek, 2008). This seems apparent given their exposure to, and direct contact with, an infant and its parents for hundreds of hours.

4. Studies of Parental Stress in the NICU

The early studies of parental stress associated with a child's hospital admission were completed in the general wards of the hospital and later the intensive care unit. These results were extrapolated to the NICU until the 1970's where the first research into parental stress related to NICU admission was performed. This research was focussed on the early approaches in the NICU of highly restricted parent visiting hours and low survival rates of very early premature babies (Kaplan & Mason, 1960; Fanaroff, Kennell, & Klaus, 1972).

One of the first studies addressing emotional support for parents was Barnard et al., 'Helping Parents with preterm infants; Field test of a protocol' published in *Early Child Development and Care* in 1987 which examined an early supportive intervention. This was followed in 1990 with a paper examining how to care for parents in the NICU (Kenner, 1990). Kenner found, through research with babies discharged from the NICU that the parents experienced a range of intense emotions including stress, anxiety, fear and confusion. She suggested that nursing support could help mitigate these feelings and contribute to a 'healthy, functional family unit', (pg. 78). Miles, Funk and Kasper in 1991 found that there was a lack of qualitative research to further delineate parental stress and suggested that further research both during and after NICU admission would help better understand parental stress.

This then built a foundation for a larger area of research on the parental experience in the NICU and parents' coping mechanisms. Further research considering types of support, the definitions of support and the parents' view of support were suggested (Coffman, Levitt, & Deets, 1990). One of the most significant factors in the NICU experience is the parent relationship (Reis, Repel, Scott, Brady-Fryer, & Van Aerde, 2010; Manning, 2012) and communication (Tandberg, Pettersen Sandtro, Vardal, & Ronnestad, 2013) with nursing staff. Although this has been recognised, little research into the nurses' training and ability to provide good communication and support has occurred. Further qualitative studies have contributed to understanding of a parent's experience in the NICU (Arnold et al., 2013) but few have assessed what supports parents request and what is offered in a nursery.

To complement qualitative work there are a variety of quantitative tools for assessment of parental stress in the NICU. The PSS-NICU has been used in a large number of studies including Sisk, Lovelady, Dillard, & Gruber, (2006); Kim (2000); Franck, Cox, Allen, & Winter, (2004) and Turan, Basbakkal, & Ozbek (2008) although the tool has been used in only one previous Australian study (Mannix, 2012). The PSS-NICU was originally adapted from the Parental Stressor Scale: Pediatric ICU (PSS:PICU) developed by Carter and Miles (1989) and Miles and Carter, (1982, 1984, 1989). The PSS NICU, (Miles, Funk, & Carlson, 1993) was developed by Dr. Margaret S. Miles, Professor, Department of Children's Health, The University of North Carolina, to measure parental perception of stressors arising from the physical and psychosocial environment of the neonatal intensive care unit. It is a tool that has also been assessed for validity and reliability in the USA, Italy (Montirosso, Provenzi, Calciolari, & Borgatti, NEO-AQUA Study Group. 2012) and Great Britain (Franck, Cox, Allen, & Winter, 2005) and has been recommended for use in research and clinical practice.

Although the Parenting Stress Index is used frequently it has not been validated for use with a premature and ill infant study population. It currently is only suitable for infants older than one month, corrected age. The NUPS scale (Neonatal Unit Parental Stress) scale was developed by Reid, Bramwell, Booth and Weindling (2007). Although this scale may be useful it has very little documented use. The scale was not publicly available at the time when required for this study and therefore could not be considered for use in this research.

Other quantitative tools that are available are for assessing service delivery satisfaction such as the NIPS (Neonatal Index of Parent Satisfaction) and the Neonatal Intensive Care Unit- Parent Satisfaction Form (Conner & Nelson, 1999). Although these tools appear to be appropriate for use in the NICU they assess parent satisfaction with service delivery of medical care and do not assess parental stress or the parent-infant relationship while in the NICU.

5 Theoretical Background to the research

Three theories are of particular relevance to this thesis. These are the theory of attachment between parent and child, theories of grief and loss, and the theory of group support.

5.1 The theory of the first relationship: parent and child

Attachment theory (Bowlby, 1969) is the central theory of this century that describes our first relationship with our mother (or other primary caregiver). This first relationship is often viewed as the most important relationship that a person will ever have, no matter whether it is for a few moments at birth or for a lifetime. This was preceded by research and theories of previous researchers. Melanie Klein, Sigmund Freud, Mary Ainsworth, Donald Winnicott and Anna Freud, as noted child psychotherapists, viewed the mother-child relationship as a template for future relationship. Melanie Klein developed object relations theory, which places the mother-child relationship at the core of development of personality (Klein, 1932). Donald Winnicott later introduced the concept of ‘the good enough mother’. This mother is able to use her maternal instincts to protect the infant and provide care as well as adapt their care to the infant’s needs (Winnicott, 1953). In this description of

the mother-child relationship, the child and mother were seen as a dyadic unit rather than two separate people. This relationship was seen as more important than the individual experience of the baby, with an emphasis on the 2-way communication that exists between mother and child.

John Bowlby, (1969/1982, 1973, 1980, 1988) proposed that attachment bonds involve two behavioural systems—an attachment system and a care giving system. First, individuals come into the world equipped with an attachment behavioural system that is prone to activation when they are distressed and this functions as a method of protection and survival (Bowlby, 1969; Bretherton, 1987). The attachment system thus solidifies enduring emotional bonds between individuals. Mary Ainsworth demonstrated the intensity of this relationship using the Strange Situation (Ainsworth, 1970) in which she identified types of attachment behaviour between mother and child. These categories of secure attachment, insecure ambivalent attachment and insecure avoidant attachment (Ainsworth, 1970) describe the different attachment relationships that are still used today. This was the first research-based evidence found to support Bowlby's theory of attachment. According to Bowlby, (1980) an individual who has experienced a secure attachment "is likely to possess a representational model of attachment figures(s) as being available, responsive, and helpful" (Bowlby, 1980, pg. 242).

Although there are developmental changes in the expression of the attachment system across the lifespan, it has been argued that the basic function of the attachment system remains constant (Hazan, & Zeifman, 1999, pg. 345). This function is to provide safety and security to those in the relationship, an essential experience for a baby. Attachment theory (Bowlby, 1969) describes that it is in this first relationship that our

future well-being is determined. We use what we have learnt from this relationship in all of our future relationships particularly with our family and spouses. It is because of the value and meaning of this first relationship that it is imperative to protect its development. Schneider, Atkinson and Tardif (2001) and Mikulincer and Shaver (2012) showed that the effect of parent infant attachment continues to influence ongoing friendships and relationships throughout life.

5.2 Attachment and Prematurity

Research findings in the early mother – premature infant bond highlight the need to better understand these early attachment relationships. The mother – infant attachment relationship begins in pregnancy and is linked to the attachment behaviour seen after delivery and into childhood (Condon & Corkindale, 1997). The mother-preterm infant relationship is complex (Korja, Latva, & Lehtonen, 2012) and in the NICU up to one third of very preterm babies show disorganised attachment (Wolke, Eryigit-Madzwamuse, & Gutbord, 2014). The NICU experience lessens mothers' self-confidence and self esteem and contributes to their struggle to build strong attachment relationships with their baby. Factors such as early separation from their baby, limited physical contact with their baby and other negative first experiences in the NICU all interfere in the mother's ability to form an emotional bond with their baby (Borghini et al., 2006; Kersting et al., 2004). Very little is known about the attachment relationship with a father and premature baby. The few studies that have been completed have found that fathers have elevated levels of stress and anxiety (Miles et al., 1992) and are at risk of depression (Mackley, Locke, Spear, & Joseph, 2010) and look for ways to control some aspects of their experience in the NICU (Arockiasamy, Holsti, & Albersheim, 2008). Their presence in the nursery is

important although techniques to include them in the NICU environment are yet to be defined (Nagorski Johnson, 2008).

Touch is an important part of communication with an infant and is the beginning of attachment and communication between mother and infant (Duhn, 2010). The gradual increase in touch over time is the way in which an infant builds its understanding of their parents and the world, while its other senses are maturing (Reynolds et al., 2013). Research into the effects of physical contact with parents in the NICU has shown that the benefits to infants from this contact include physical, emotional and relational benefits. Babies with regular skin-to-skin contact gain weight faster; have more stable blood pressure and heart rate and breast feed sooner (Morelius, Theodorsson, & Nelson, 2005; Korja et al., 2008).

When the attachment relationship begins in a rapid, unplanned, premature way that is associated with illness and a long admission to intensive care it is unsurprising that mothers, fathers and babies struggle to build this relationship. Even when sensitive parenting is in place one-third of very-preterm babies struggle to form a strong attachment due to their neurodevelopmental problems (Wolke, Eryigit-Madzwamuse, & Gutbord, 2014).

The physical state of the baby makes it difficult for the baby to also engage in the attachment relationship. Assessment and clinical treatment of premature babies and in particular exposure to painful procedures, is physically difficult for a very preterm infant to manage (Holsti et al., 2006). Due to their raised heart rate and physical distress during physical intervention these premature babies have difficulty feeling settled and calm to be able to engage with their parents. Babies with extreme

prematurity are unable to hear and experience touch as a term baby can and are also unable to give the physical feedback of shared gaze and shared experiences that are used to build attachment.

5.3 The Theories of Grief and Loss in relation to premature birth

Grief has been described as the emotional core of the experience of delivering prematurely (Davis & Stein, 2004, p 21). Parents who have not been able to enjoy a normal pregnancy, delivery or home-coming often grieve over the loss of these experiences. There is a large range of losses that a mother, in particular experiences: the loss of trust in your body to maintain a pregnancy, losing the type of labour you wished for and the pride of showing your family the healthy baby that you have grown (Davis & Stein, 2004, pg 45).

When an infant dies in the neonatal intensive care unit many parents recall a lack of support from their nurses and physicians (Gold, 2007). They describe feeling alone and unsupported. Parents also recall behaviours or comments that were offensive or upsetting and these can be recalled years after their infant's death during their process of bereavement (Raphael, 1984). These comments may have been made when the staff were unaware of a baby's death or avoided the family after a baby's death (Gold, 2007). Although many people only consider grief and loss when a death of a friend or relative occurs, people grieve for a wider range of other reasons. Bowlby (1980, pg. 85) outlined three stages of grief when a child is separated from their mother: protest, despair and detachment. He used this model to look at grief and loss. Bowlby identified four phases in grief work: (i) numbing; (ii) yearning and searching; (iii) disorganisation and despair; and (iv) reorganisation. This view allowed a focus upon

the relationship between parent and child and its role in grief and loss. Grief and mourning occurs in children and adults whenever attachment behaviours are activated but the attachment figure, such as parent who is not present in the NICU, continues to be unavailable (Bowlby, 1973).

Parents generally feel excluded from the team on the NICU and spend much of their time trying to increase their participation with their baby's cares (Wigert, Johansson, Berg, & Hellstrom, 2006). This distance between professionals and parents in the nursery contributes to the challenges faced in building the baby-parent relationship. NICU parents have been shown to be more anxious, less sensitive in interactions with their babies and often relinquish their hopes for their children to "catch up" to term infants developmentally, with accompanying symptoms of psychological distress (Zelkowitz et al., 2008). It is important to consider this in research, where many parents are grieving the loss of a normal pregnancy, delivery and infant.

5.4 The Theory of Group Support

Formalised and structured group support has a history dating back to 1935, when Alcoholics Anonymous began, to decrease alcoholism that appeared untreatable by doctors (Oka & Borkman, 2000). In developed countries this method of support expanded and the self-help group, (where help is self-generated or given by non mental health trained professionals), movement began (Vattano, 1972). In 1983 the World Health Organisation European Office produced an international report (Hatch & Kickbusch, 1983) on self-help, and the growth of support groups. Self-help groups and Internet based professional and self-help groups have steadily increased.

The popularity of the support group can be understood by applying Festinger's social comparison theory (Festinger, 1954). This postulates that people will join a group in uncertain and stressful times to seek out others' opinions about feelings and thoughts (Davison, Pennebaker, & Dickerson, 2000). In particular when people have an experience that sets them apart from their immediate social circle they move toward others who have the same experience. Parents with children with special needs in general use a support group as a way to receive reassurance and to share information (Schier, Korn, & Michel, 2001). Those in a support group can also help members find their own resources that were previously unknown and strengthen each other's resolve to move through their distress (Nugent, Hughes, Ball & Davis, 1992). This was the basis for offering a support group for parents in the NICU on which this dissertation is based, to draw together parents who share this experience, and provide professional support to facilitate this. Determining the facilitator role in each group is important. As in Matloff and Zimmerman (1996), this group required a facilitator who was not providing core medical or nursing care to the parent or baby. This approach allows reflection on those providers and an accepting space for parents to speak honestly about their experiences.

5.5 The Theory of Social Support

Relationships play a significant role in our day-to-day interactions, including mediating coping with stress. An increasing interest in the role of social and interpersonal relationships in preventing or lessening the effect of emotional distress took place in the 1970's (Caplan, 1974; Cassel, 1976; Cobb, 1976; Heller, 1979; Henderson, 1977; Kaplan, Cassel & Gore, 1977). There are four types of support described by House (1981). *Emotional support* is associated with sharing life

experiences including the provision of empathy, love, trust and caring. *Instrumental support* involves tangible aid and services that directly assist a person in need. Close friends, colleagues and neighbours provide such support. *Informational support* involves the provision of advice, suggestions, and information that a person can use to address problems. *Appraisal support* involves the provision of information that is useful for self-evaluation purposes: constructive feedback, affirmation and social comparison. The potential protective effect of these supportive interactions and relationships is also referred to as a buffer. This buffer is thought to lessen the negative effects that the distress may have on the person.

Support groups are based on the theory that these positive social connections assist people in staying well or recovering faster. Social support, as shown by the range of supportive behaviours above, is a dynamic concept with a range of variables thereby making it hard to quantify and research. Vaux (1992) outlined the important interactions between the provider and recipient of social support. Research indicates that psychosocial group support programs can increase social support and decrease psychological distress in cancer patients but may be most effective for patients in distress and/or with limited social resources (Goodwin et al., 2001; Helgeson, Cohen, Schulz, & Yasko, 2000; Lepore & Helgeson, 1999).. The element of fellowship when in a group of those with a shared experience may also be one of the larger benefits from participation (Locke & Nekich, 2000)

However the potential benefits from a support group must be weighed against the potential for higher functioning participants being exposed to participants who model poor coping (Taylor & Dakof, 1988). Another consideration in providing appropriate

support is to assess the participants' need for support and the view of what they are offered. Providers of support or supportive programs have previously described giving more support than recipients feel they are receiving (Antonucci & Israel, 1986; Sarason et al., 1990). This mismatch of support may lead to inappropriate supportive methods being offered and little benefit gained by the participants.

6 Choice of Research Method

Qualitative methods were used in this research project as they allowed the voice of the parent to be heard through direct analysis of the parents' interviews (Britten, 1995). A major feature of qualitative methods is their ability to describe and display phenomena as experienced by the study population in fine detail and in the study participants' own terms. They therefore offer the opportunity to better understand phenomena, to see what they are about or what lies behind them (Ritchie & Lewis, 2003, pg 31). Qualitative research also allows associations that occur in people's thinking or acting to be identified (Ritchie & Lewis, 2003, pg 32).

Qualitative research has been the main method used to investigate the psychological and emotional experiences of parents in neonatal intensive care units throughout the world (Field, 1990; Franck, Cox, Allen, & Winter, 2004, 2005; Holditch-Davis & Miles 2000; Muller-Nix et al., 2004; Turan, Basbakkal, & Ozbek, 2008; Wigert, Johansson, Berg, & Hellstrom, 2006). All of these studies have involved interviewing parents with either semi-structured or open format. A qualitative approach has allowed a better understanding of their personal experiences and allowed accurate recording of this verbatim. A number of techniques have been used to assess these data sets. Despite these qualitative studies few have addressed the parents' view of NICU support.

Bracht, Ardal, Bot & Cheng (1998) evaluated a support group similar to the one described in this thesis. Although they described the group schedule and described the evaluation of the group they did not describe any methodology, did not describe the questionnaire that was used and did not comment on the results. Hurst (2006) developed a stress survey for use in their research but did not describe this in detail and did not provide a copy in their article. Other studies including Nottage (2005) evaluated the use of services of parents in NICU but did not use their interview data to consider why parents use particular services or which parents were likely to attend a support group. To address these gaps in the research base parents' experiences of NICU/SCBU were evaluated in this thesis, including their experiences of the support group, with sound methodology. For the interview data, framework analysis was used.

6.1 Framework Analysis

When considering the NICU environment and its complexities it is important to allow the voices of the parents and nurses to be the source of information. Analysis of these data was through framework analysis. Framework analysis has five stages: familiarisation, identifying a thematic framework, indexing, charting, mapping and interpretation. Researchers at the UK National Centre developed Framework analysis to be used in Social Research (Ritchie & Lewis, 2003). This type of analysis develops a hierarchical thematic framework that is used to classify and index data according to key themes and concepts. The framework identifies a series of main themes subdivided by a succession of related subtopics. Once judged to be comprehensive each main theme is charted by completing a chart, matrix or table. Each cell of the

table or matrix contains relevant summaries from the data set. These charts are used to examine the data for patterns and connections and allow interpretation of the data using both inductive and deductive analysis.

A strength of framework analysis, over other methods of analysis of interview data is that it includes an examination of relationship amongst themes (Green & Thorogood, 2004; Pope & Mays, 2006). The advantages of thematic analysis have been identified by Braun and Clarke (2006) as flexibility, the ability to offer a thick description, the ability to have participants as collaborators as well as the results being accessible to the general public. However the disadvantages are that the data often cover a broad range of themes and could be interpreted differently by others. This requires a number of researchers to be available to read and analyse data at the same time to ensure quality. The data can also be voluminous and complex, requiring a detailed audit trail to be kept to ensure that appropriate themes are identified (Ward, Furber, Tierney, & Swallow, 2013).

6.2 Quantitative Analysis

The present research project incorporates quantitative research, using the Parent Stress Scale -NICU (Miles, 1993). Quantitative and qualitative methods are combined to provide a richer understanding of the experience of parents in the NICU. The qualitative research allows a deeper understanding of the experience of the NICU and the role of support systems and the quantitative research was able to identify predictive factors about which NICU parents experience the most stress, which elements of the NICU cause stress, and which parents seek more support. Combining

these two methodologies allows triangulation of the data and a deeper understanding from professional and parent perspectives.

6.3 Mixed Methods Research

Mixed method research is the combination of qualitative and quantitative research to examine a research question. The aim is to use different strategies and research approaches so that there is added strength to the results gained (Johnson & Turner, 2003) and minimise the weaknesses that a single research method may present when considering a complex research area (Johnson & Onwuegbuzie, 2004). Mixed methods research also tries to eliminate gaps in the data collection and minimize pre existing assumptions of the researcher (Pope & Mays, 2006). The way that this is achieved is that the variation in data collection leads to greater validity. Research questions are answered from a number of perspectives. In the present research the mothers were interviewed twice, nurses were interviewed and then parent and baby data was collected in a quantitative manner using the Parent Stress Scale Neonatal Intensive Care Unit (PSS – NICU).

This research utilizes this approach and brings these results together in triangulation which is an ‘attempt to map out, or explain more fully, the richness and complexity of human behavior by studying it from more than one standpoint’ (Cohen & Manion, 1994, pg 112) and has been recommended for use in primary health care research (Creswell, Fetters, & Ivankova, 2004). Therefore locating the factors through the thematic analysis in interviews was able to complement the PSS NICU data and deepen the understanding of participants and their NICU experiences.

7 Research Questions

This dissertation examines the NICU/SCBU experience of parents, the relevance of the support group to the parents who attend and to also examine its effect, if any, on parental stress experienced. This project also examines the views of the NICU nursing staff on their role in supporting parents and the parent experience that they see in the NICU.

The overarching Research Questions are, “What is a parent’s general experience of having a baby in Neonatal intensive care” and “What is their experience of the emotionally supportive care provided to them?” In addition, the following questions are addressed in this thesis: What are the most stressful factors for a parent in Neonatal Intensive Care? Do parents in neonatal intensive care want more support than is currently offered? Do parents find the NICU support group helpful? Are there predictive factors that can be identified in parents who attend support groups? What experience in NICU is the most stressful for parents? Do nursing staff feel that parents benefit from the NICU support group? Do nursing staff feel that they are suitably trained to psychologically support parents in the nursery? How do nursing staff see parents managing stress in the nursery? Do nursing staff feel that parental stress interferes with the parent’s relationship with the baby? How should a ‘best practice’ NICU parent support group be structured?

8 Contribution of this Research

Parents who have children in the neonatal intensive care unit are exposed to a foreign and highly stressful environment. This has driven a range of research studies to identify and address the difficulties that these parents face. Unfortunately many of the studies have lacked a rigorous methodology.

The selection of parents in previous studies has been varied and has often excluded parents of babies with serious health conditions,(Jackson, Ternstedt & Schollin 2003). Some research only assessed babies with a singular diagnosis (for example, Singer et al., 1999); or included singleton babies only and not multiple births (for example, Davis, Edwards, Mohay, & Wollin, 2003). Other studies have required the baby to be medically well and stable (for example, Basso, 2006), which is very unlikely in the NICU. Wigert, Johansson, Berg, & Hellstrom (2006) interviewed parents between 6 months and six years post discharge from the NICU. This type of timeframe, with such rapidly moving technology improving neonatal outcomes every year, fails to capture a comparable group of parents and cannot account for myriad variables. Hughes, McCollum, Sheftel & Sanchez (1994) evaluated coping styles in parents of NICU babies but did not assess the type of supports that were used by parents. Many studies have indicated that further research needs to be completed for the effect of parental support to be known (Nearing, Salas, Granado-Villar, Chandle & Soliz, (2012), Melnyk et al., 2006, 2010; Jotzo & Poets, 2005). The elements of these that I have addressed in my research in particular, are the analysis of mothers' views after discharge with their baby, using a prospective rather than a retrospective design and the recording of social characteristics of participating parents.

9 Ethical Considerations

This research followed the NHMRC National Statement on ethical conduct on human research (NHMRC, 2007) to ensure that the rights and safety of participants were recognised and protected. All participants were given a verbal and written explanation of the research with each given information sheets, consent forms and

contact details for the researcher and the human ethics committee of the hospital where this research was conducted. Emotional distress, of both parent and nurse participants was considered and plans made to address this possibility were included in the research protocol. Those parents who found the survey or interview distressing were able to access the perinatal psychiatry team at the hospital by requesting an appointment (this option was not taken up by participants in this research), or they were able to attend the support group or receive support from nursery staff. Participants were also able to complete only a part of the survey if they did not wish to complete particular items. The telephone number for the mental health crisis service was provided at the end of the survey for parents and was included in information cards for all parents and nurses interviewed.

Nurse interviews all occurred over the telephone at the nurses' request, to ensure privacy for the interview. Parents were interviewed in an office away from the NICU. As the author of this research and PhD thesis was involved in provision of clinical care of parents in the parent support group and the delivery of mental health care for all referred postnatal mothers; she did not conduct the interviews for any participants in this research study. This minimised the influence that the researchers view of the research and support group had on the answers of the participants.

9.1 Reflexivity in theory

Reflexivity is an important but challenging element of the qualitative research process (Mauthner & Doucet 2003). The practice of reflexivity should occur across the whole research process including the interpretation of data, the researcher's role in the analytical process and in the opinions that we bring to the research (Devine & Heath,

1999; Henwood & Pidgeon, 1997; Olesen, 1994). By doing this researchers are able to see how their personal and professional histories influence their research and their interpretation of others and be mindful of this in their analysis of the research.

9.2 Reflexivity in Practice

As the author of this thesis was also a practitioner within the same health service where this research occurred, a range of areas were reflected upon to ensure that personal viewpoints and bias affected the research as little as possible. This research was driven by both a professional and personal interest in the supportive therapies offered to parents of premature babies. After providing a consultative service for a short time as a psychiatrist I was overwhelmed with referrals. The NICU physiotherapist expressed difficulty running a NICU parent group without a co-facilitator. At that time a decision was made to offer a NICU support group with each of us as co-facilitators. This group was aimed to cover both supportive themes as well as practical hands on physiotherapy techniques. To determine whether the topics that were being covered in the group were appropriate according to the parents, research into the parent experience of the group and the NICU was required. It was from this support group and the staff in the NICU that my research participants were drawn.

I was surprised that, in general, the parents in the NICU were not seen as a vulnerable population by the hospital. There was a view from many medical staff that having a baby in the NICU was 'not a big deal' and that by offering support we were making 'a mountain out of a molehill'. Beginning the group and the research was a frustrating experience and many obstacles were placed in the way to provide this support. Out of

this I was driven to look for and produce research to show the distress of parents, where it occurs and the ways in which these families should be supported.

I have been mindful that these powerful clinical and emotional drivers have an effect on the way that I have undertaken the research, the results of the analyses, who I chose as a supervisor and how I structured my research and who I located to perform the participant interviews.

Having had this first early experience within the NICU I am aware that I am more likely to be alert to and therefore to find negative experiences and negative views of the nursery than positive. The stories I have heard of many parents in the support group that describe their distress and detachment from their child are often in my mind as I read transcripts from participants. This has reminded me to keep a balance of views and ensure that I am not missing positive comments about the NICU experience or support. I have tried to distance myself from these experiences as I read the transcripts and have not listened to the recordings to avoid recognising voices from the NICU. I have learned from these interviews that there are both positive and negative parts of the NICU experience. Initially with so little support from my own team of mental health professionals I was driven to believe that I alone saw the need. However I had omitted the dedication of the staff in the nursery as well as the families that surrounded many of these babies and parents. The nursery staff saw their roles as key and I, not having worked in the nursery as a medical doctor, did not see their dedication and training. Through this research I have been able to reflect on my views about this and better understand their role in the NICU.

As a doctor I also brought my own views and experiences of nurses. There is a long history of conflict and competition between these two groups of health care providers, and in particular there is a culture of division between doctors and nurses (Rosenstein, 2002). My own experiences as a doctor and the relationships that I have had with nurses and the nurses' relationships with other doctors were also issues that I was mindful about. My awareness of this enabled me to look at their interviews and better understand their struggles and responses to how they worked in a complicated and busy ward with many cultural and institutional structures and barriers.

Presenting my research to a variety of professional audiences, including psychiatrists, neonatologists, nurses, psychologists and social workers has enabled me to reflect on weaknesses and strengths in my research and to consider their responses. Feedback from these sources, in general, echoed the results that I found in this research, and that this complex time in a mother and infant's life requires a deep understanding on the part of professionals. Now as my research is being brought together I have learnt through the reflexive process about my previous thoughts and opinions. By being mindful of these and through collecting and analysing the data I am confident that I have been able to represent the participants' experiences, and the support needs for NICU parents in a trustworthy and rigorous way.

Chapter 2 – Mothers’ Experiences of the NICU and a NICU Support Group Program

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I was responsible for the conception of the research upon which this paper is based. I produced the first draft of the manuscript and submitted the final manuscript. All of the data analysis and literature search were completed by me. As the primary author, I have been the party responsible for responding to reviewers and editors based on discussions with and consent from my supervisors ACH and HRW.

Dr Melanie S Turner date -

Professor Anna Chur-Hansen and Professor Helen Winefield (Supervisors).

Professor Anna Chur-Hansen and Professor Helen Winefield were the supervisors of my doctoral candidature. As co-authors and supervisors their role was to guide and assist me by reading paper drafts and making suggestions. The interview

transcriptions were checked by ACH and HRW for accuracy and the initial stage of coding of one interview to ensure consistency and to improve rigour in my findings. We, Anna Chur-Hansen and Helen Winefield, hereby certify that this statement of contribution is accurate, and give our permission for this paper to be incorporated into the doctoral thesis of Melanie Turner for submission for the degree of Doctor of Philosophy from the University of Adelaide.

Anna Chur-Hansen.....date.....

Helen Winefield.....date.....

1 Abstract

Aim – to understand both the maternal experience of the NICU and the mothers' view of a NICU Parent Support Group.

Background - Mothers of babies who are born premature have their first experiences of parenting while their infant is in the neonatal intensive care unit (NICU). This presents multiple challenges and a range of stresses related to their role as a mother and concerns about their baby's survival and growth. Thus, various supportive interventions have been trialled with this NICU parent population. However the focus of this support and how it should be delivered lacks research as an evidence base for practice. Mothers' experiences of the NICU and a professionally facilitated NICU support group at a city hospital were explored in this qualitative research..

Method - Nine mothers in 2010 were interviewed while their babies were NICU inpatients. Interviews were recorded, transcribed and analysed thematically.

Results - The NICU admission resulted in participant mothers facing challenges in getting to know their baby, forming their parenting role while in the NICU, and a reliance upon, but resentment toward, nursing staff. Positive feelings about their baby's strengths were also apparent. The parent support group was an important part of managing the experience of the NICU and was reported to meet the emotional support needs of these NICU parents.

Conclusion - The implications and recommendations for NICU based emotional support are discussed. In particular modifications to support group structures to ensure professional staff involvement and a balance between education and emotional care are reviewed.

Keywords – neonatal, parent support, NICU, support group, mother's experiences.

2 Background

2.1 The Experience of the NICU

An admission to a neonatal intensive care unit (NICU) is known to have adverse effects upon the psychological wellbeing of the parents and the parent-infant relationship (Balakrishnan et al., 2011; Padden & Glenn, 1997). Previous research has identified maternal stress, anxiety and depression in mothers of premature babies in the NICU (Zelkowitz et al., 2008; Shaw et al., 2006). While in the nursery mothers may express feelings of exclusion from the care of the baby (Wigert, Johansson, Berg, & Hellstrom, 2006) and feel less confident and increasingly incompetent in their role as a parent (Flacking et al., 2012; Miles, Funk, & Kasper, 1992).

A range of post-NICU discharge maternal mental illnesses has been identified including depression, anxiety and posttraumatic stress disorder (Holditch-Davis, Robin Bartlett, Blickman, & Shandor Miles, 2003). These, coupled with, maternal traumatic experience and premature birth are important factors in predicting a poor maternal – child relationship (Muller-Nix et al., 2004; Forcada-Guex, Pierrehumbert, Borghini, Moessinger, & Muller-Nix, 2006; Forcada-Guex, Borghini, Pierrhumbert, Ansermet, & Muller-Nix, 2011; Zelkowitz et al., 2008). As well as these complexities, premature infants are also at higher risk for cognitive delays (Eidelman & Feldman, 2006) and developing anxiety (Rogers, Lenze, & Luby, 2013), further adding to stress within the family unit (Howland, 2007).

2.2 Supportive Programs for Parents in the NICU

NICU units have instituted a range of supportive programs to improve outcomes for mother, father and baby. The goal of a support system in the NICU is to facilitate a

healthy parent-infant relationship in the NICU and in the first few months of life (Forcada-Guex, Pierrehumbert, Borghini, Moessinger, & Muller-Nix, 2006; Singer et al., 1999) and to provide this support in a varied, flexible and sustainable way (Nicolau & Glazebrook, 2008). Roman et al., (1999) and Preyde and Ardal, (2003) found that the provision of a parent-to-parent support group improved maternal mood states, anxiety, maternal-infant relationships and improved the home environment.

Kaaresen, Ronning, Ulvund and Dahl (2006) report that after eight individual nurse to parent sessions post NICU discharge, parenting stress levels were reduced to one comparable with their peers with babies not in NICU. A follow up study (Kaaresen, Ronning, Tunby, Nordhov, & Ulvund, 2008) also showed decreased stress levels in parents two years after completing the sessions. Bracht, Ardal, Bot and Cheng, (1998) examined a support group with a format based on education and emotional support from professionals. Participants attending this group had less intense negative emotions than prior to attending. Evaluations of structured one-to-one intervention programs (Zelkowitz et al., 2008; Kaaresen, Ronning, Ulvund, & Dahl, 2006) and programs involving recorded and written material (Melnik et al., 2006) have shown some positive effects on parent stress. These support programs may have most benefit if started soon after premature delivery (Young-Mee & Nam-Hee, 2007; Zelkowitz et al., 2008).

3 This Research: The NICU Support Group.

This research examined the emotional experience of NICU mothers and their experience of the NICU support group offered in one NICU unit. The NICU parent support group commenced in 2008, 24 months prior to the collection of the data for

this study, to address the on-going need for perinatal mental health support for NICU parents.

3.1 The NICU parent support program

The program was designed to provide a weekly, no cost, supportive environment for parents to share their experiences with other parents as well as ask questions and receive education, information and support from NICU professionals. This support group addressed two of the three intervention approaches identified in Benzies, Magill-Evans, Alix Hayden and Ballantyne (2013), these were; parent support and parent education, including information giving, demonstration, engagement and feedback. Two staff facilitated the group, a child and adolescent psychiatrist (the first author) and a neurodevelopmental physiotherapist. The combination of these two staff enabled the psychological care of the parents and babies to be managed as well as the detailed parental care of the baby from a developmental point of view. Premature babies are at higher risk of neurodevelopmental disabilities (Moster, Terje, & Markestad, 2008) and the physiotherapy input at this early inpatient stage allowed early identification and treatment of movement and coordination disorders in the baby. This also enabled parents to be encouraged to handle and perform 'cares' for their baby. Previous parent groups at this hospital had been run in an ad hoc manner and had a variety of success, but all having ceased within 6 months of commencement. The curriculum for this group was based on a list of topics prepared by the two facilitators.

These topics were derived from feedback from NICU staff, parents and perinatal mental health staff when the first author approached these groups. Topics that were

covered were, managing stress; being with your baby; feeding your baby; touching and holding your baby; baby cues; your voice and baby; moving from NICU to another unit; managing anxiety; taking baby home; developmental milestones and explaining prematurity to others. This group differs from the COPE model (Melnik et al., 2006) as it is given in a face-to-face method. The group also differs from the Avon Premature Infant Project (APIP) conducted in Bristol in the United Kingdom. APIP investigated a parent support program offered to parents of babies born at younger than 32 weeks and after discharge from hospital. This support was home visiting with research nurses. This is in contrast to the parent support approach considered in this paper. The parent support group expanded on the APIP criteria by offering the support group to parents of inpatients of any gestational age, including over 32 weeks gestation. In this circumstance both staff were trained in two complementary but separate areas, providing co-facilitation of a group. Early neurodevelopmental mother child intervention, such as that taught in the NICU parent support group, has been shown to have a positive effect on the developmental outcome of low birth weight babies (Gianni et al., 2006).

This parent support group created an educational, safe and supportive space for parents where the facilitators paid attention to parent dynamics and allowed parents to be participants receiving both information and emotional support. To facilitate the sharing of information parents were provided with written information produced by the health service managing the NICU. This included material on premature baby development, common parent questions and information about the neonatal intensive care unit, feeding and talking to your baby, as well as the website addresses and general information from and website details of, Bliss UK <http://www.bliss.org.uk/>;

Austprem <http://www.austprem.org.au/>, and Little Aussie Prems

<http://www.lilaussieprems.com.au/>.

True-to-life weight and size premature baby dolls were used for parents to practise holding, feeding and wrapping a baby. These dolls were brought to each session and were used particularly when speaking about baby cues, containment of a baby when distressed and baby cares. There were 10 dolls in total, the average size and weight for 23, 24, 26, 27, 28, 29, 30, 32, 34 and 36 weeks gestation. This allowed parents who were unable to hold their baby to have the experience of how much they may weigh and of their size. The program was promoted through flyers throughout the nursery, recommendations from nursery staff at the bedside, the group being listed in each baby's calendar and record sheet at the end of each cot as well as recommendations from other NICU parents. A number of other individual supports were available to parents with all referrals made through the NICU staff. These included lactation consultant input, perinatal mental health team input from a trained mental health nurse and the NICU team social work support.

4 Method

Aims - The research questions for this study are: "What are the maternal experiences of the NICU" and, "Do parents feel the support that they received, including that from the formal support group, met their needs?"

4.1 Design

A cross sectional interview study design was implemented in this research, with each mother participating in an interview and completing a short informational survey at

the beginning of the interview, which included demographic information and gestational information. Two direct questions were asked of support in the survey; whether the participant would like more professional support and whether they felt supported by their family. A qualitative research method was chosen for this study as it offered an accessible and theoretically flexible approach to analysing qualitative data (Braun & Clarke, 2006). This type of research is based on individual or group interview data and has been the main method used to investigate the experience and coping mechanisms of parents in neonatal intensive care units (Holditch-Davis & Miles, 2000; Jackson, Ternstedt & Schollin, 2003; Muller-Nix et al., 2004; Turan, Basbakkal & Ozbek, 2008).

4.2 Participants

Potential participants were parents of infants who were at any stage of their inpatient neonatal intensive care stay (from 23 weeks to 40 weeks gestational age babies), who had attended at least one NICU parent support group and spoke fluent English. These parents were provided with a consent form and information sheet explaining the research. An interviewer who had no clinical contact or role within the health service completed all interviews. Nineteen parents who had attended the Parent Support Group were invited to participate: 16 women and 3 men. All of the men declined and all asked that we speak instead to their partners.

4.3 Data Collection

Interviews were conducted at the hospital where the NICU was situated; they ranged in duration from 45 to 70 minutes and were digitally recorded with participant consent and later transcribed. Research interviews were semi structured and employed open-

ended prompts. Participants were asked three prompt questions about their experience being a NICU parent, how they would describe their relationship with their baby, and whether the NICU support group sessions addressed issues relevant to them.

Following the conventions of qualitative research (Pope & Mays, 2006; Tracy, 2010), data were collected until saturation was reached, which was agreed upon by the three authors to be at the ninth interview.

4.4 Ethical Considerations

Human research ethics approval was gained on 28th May 2008 REC2059/5/11 and renewed on 22nd August 2012 REC2059/5/2014 from both hospital and university institutional review committees. This ensured ethics approval during recruitment of parents and interviewer, collection of data and until publication of the research.

4.5 Data Analysis

Thematic analysis (Pope & Mays, 2006) was chosen for this study and has been the favoured method used to investigate the experience and coping mechanisms of parents in the NICU (Franck, Cox, Allen & Winter, 2004; Franck, Cox, Allen, & Winter, 2005; Holditch-Davis & Miles, 2000; Jackson, Ternstedt, & Schollin, 2003).

NVIVO 9 was used to manage the transcribed interview data. The data was examined for themes following the thematic analysis methodology described by Pope & Mays (2006). This type of qualitative analysis develops a hierarchical thematic framework that is used to classify and index data according to key themes and concepts. The framework identifies a series of main themes subdivided by a succession of related subtopics. Once judged to be comprehensive each main theme is charted by

completing a chart, matrix or table. Each cell of the table or matrix contains relevant summaries from the data set. These charts are used to examine the data for patterns and connections and allow interpretation of the data using both inductive and deductive analysis. The first step in the analyses involved examination of the audit trails produced by the interviewer and the first author. Then, the first author compared themes between and within interviews, producing codes that were compared against the raw data by the second and third authors. Through discussion, consensus was reached to arrive upon the final themes. Themes were organized according to main themes and subthemes (see Figure 1).

4.6 Validity and reliability/rigour

An audit trail, (a continuous record of the progress of the research as well as investigator responses to interviews), was maintained by the first author and the interviewer throughout the research. Audit trails are one way of enhancing the rigour (Tobin & Begley, 2004) and trustworthiness (Krefting, 1991) of qualitative research (Tracy, 2010).

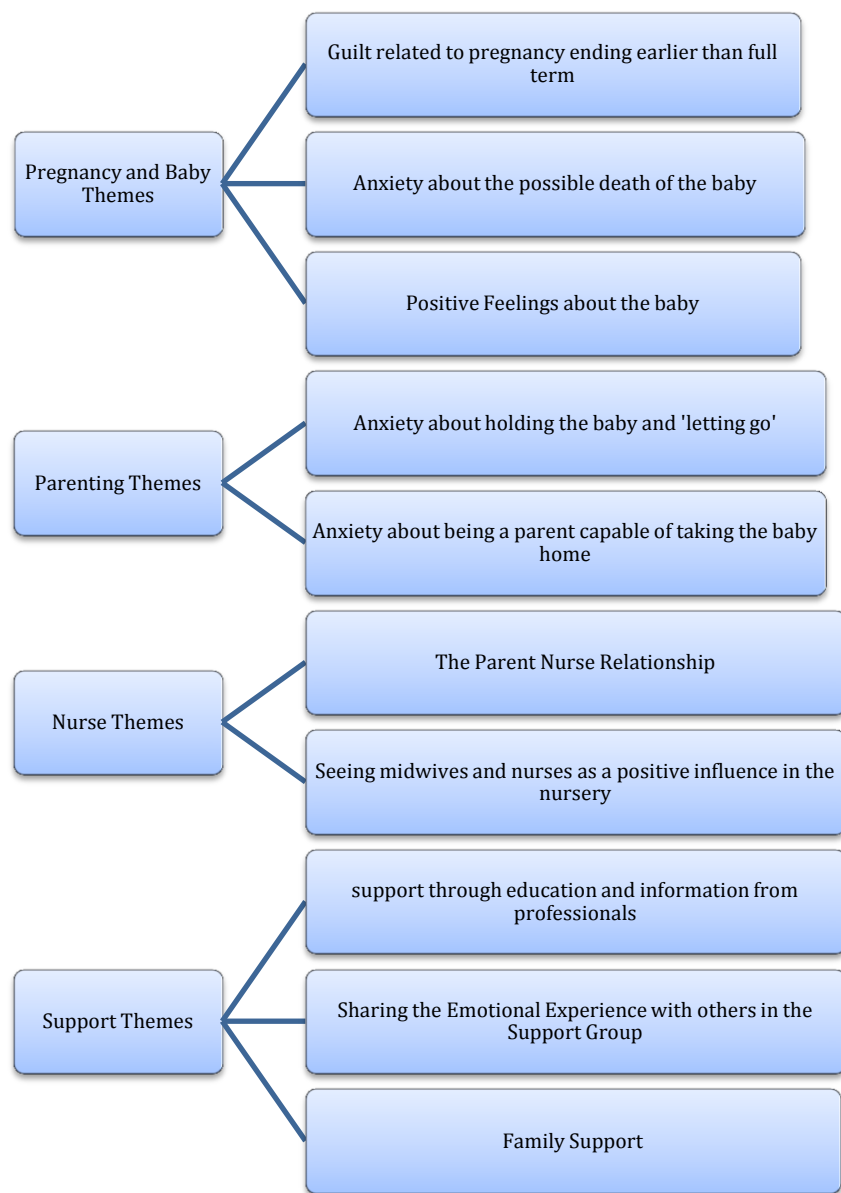
5 Results

5.1 Participants

The nine participants were all women; 20 to 40 years of age (mean=32.5). The average baby gestation at birth was 25 weeks (ranging from 24 weeks to 31 weeks and 5 days). Seven of the births were single, two were twins. Three participants had been aware prior to the birth that the baby would be born prematurely. Six participants lived in the metropolitan area, two lived 50 kilometres from the state capital city and one participant lived 300 kilometres from the capital. All participants

attended the support group with 8 attending more than one session. One contact with the NICU team social worker was provided to all parents in the NICU, and six of the participants requested further social work input. Two participants would have preferred more professional support and all participants felt well supported by family and friends.

Figure 1 Thematic Analysis of Interviews



5.2 Pregnancy and Baby themes

5.2.1. Guilt related to the pregnancy ending earlier than full term

Participants expressed their disappointment in not being able to maintain their pregnancy to full term and reflected on the role that their body or their actions may have had on the length of their pregnancy: *'I was sad that I couldn't keep her in, like that..was my fault'* (Participant 2). The theme of self-blame and guilt was echoed in other participants' narratives; *'If only I had been, I don't know, better at being pregnant, then maybe the story would be different for her (the baby)'* (Participant 6).

5.2.2 Anxiety about the possible death of the baby

Participants described anxiety about the health of their child and whether, indeed, their child would survive: *'They said 'you know, she's only got 60 to 70 per cent of surviving with minor problems. And then the 30 to 40 per cent, obviously, she'll die or survive with bad problems. So that scared me, and you just burst into tears, then you worry all the time'* (Participant 2). Participants were faced with the possibility that even though their child had survived delivery, the child might die as a patient in the nursery. They were asked to consider saying a final goodbye to their child whilst still recovering from the delivery: *'One of the doctors came, woke me up and told me to come back upstairs because they didn't think he was going to live. I think I froze, what do you do when someone says that'* (Participant 5). Some participants developed feelings of anxiety when they witnessed their baby being resuscitated while in the NICU: *'we nearly lost him. He turned blue, and they had to resuscitate him, and that was scary. That was scary'* (Participant 3).

The baby's critical illness also greatly affected some participants' ability to allow a relationship to form: *'I didn't want to feel anything in case he died'* (Participant 5).

5.2.3 Positive feelings about the baby

While the parents were in the nursery they spent much of the day with their baby, and described positive feelings about their baby: *'Seeing her, I light up, she's my precious baby'* (Participant 1). Holding and being involved in the cares of their baby was a time when parents were able to experience a special parent-child bond: *'Whenever we do have cuddles, she is content. When I am around, nothing seems to faze her'* (Participant 7).

5.3 Parenting Themes

5.3.1. Anxiety about holding the baby and then 'letting go'.

Parents in the early days of admission described fear when they were planning on holding their baby for the first time: *'It didn't feel like I was actually holding him; you couldn't do anything. I'm quite tense, I don't want to move the tube, and I don't want to move his head because it'll upset the tubes'* (Participant 5). The babies were small and had a variety of treatments and equipment that physically prevented participants from interacting with them in a comfortable way: *'I think it's just grief, or the sadness, you know, 'my god, look at my small babies'. Like, I don't know what I'm allowed to do with them'* (Participant 7).

The mothers were all admitted to the postnatal ward, which was one floor away from the NICU. They experienced their grief through seeing and hearing other mothers interact with their term babies: *'Even being on the post-natal ward, like, the other*

women are wheeling round their babies and I was wheeling round a breast pump, that was really hard. (Participant 3).

Going home without their baby was an emotional time for participants, with most being upset and tearful on their first night home without their baby. This was triggered in particular when objects or memories reminded them of the nursery admission: *'That was the worst I've cried I think, 'cause I went home, and then I saw her cot, and all her stuff was in there, and she wasn't there, but I got to be home'* (Participant 2).

5.3.2 Anxiety about being a parent capable of taking the baby home

After moving past the anxiety of the first few days or weeks of the NICU admission participants formed a growing concern that the baby would become ill again: *'He is better, but keeps having low oxygen levels. Is there going to be some brain damage, you know? What do we do then?'* (Participant 3). Participants had on-going anxiety about the possible complications of taking home a baby that may require interventions such as home oxygen: *'One of the doctors said, 'if he's not on oxygen, he won't die'. That was actually quite reassuring for me, 'cause I thought, you know, 'what if we go home and the canister runs out'* (Participant 5). Some participants struggled to think about taking home a baby that may require on-going medical care: *'I'm not sure how I'd cope if they said he needed oxygen at home, I don't think I could do that'* (Participant 8).

5.4 Nursing themes

5.4.1 The Parent-Nurse Relationship

Participants described feeling that at times it was not acceptable for them to make decisions about their child's care while in the nursery. Disagreements occurred with the NICU staff about when they could have physical contact with their babies: *'I wanted to hold him, the nurses say, "depending on how he's going." When I go back, they'll decide if I can, I just don't get why they don't see how important that is'* (Participant 9). Parents were also concerned that at times the baby felt more like a child of the hospital or nursing staffs and not their child: *'They tell me when I can come in, and when feeding times are, and stuff. No, he's my baby now. I want him back now'* (Participant 8). Participants in turn became more assertive in the way that they approached staff. This assisted them to feel more in control and less helpless during their experiences of being a nursery parent: *'Because I just say the way it is. If I don't agree with something (with the nursery staff), I let them know'* (Participant 3).

Parents identified that they were concerned about their baby moving into a different unit, in particular moving from an intensive care unit to a special care unit: *'If something goes wrong, maybe no one will take any notice'. 'Cause they're busy with a baby three doors down, and they don't really know what they're doing'* (Participant 6). *'I won't know who's looking after him, I hear I might not even know when he moves, that worries me'* (Participant 7).

5.4.2 Seeing midwives and nurses as a positive influence in the nursery.

Parents identified that the nursery provided a safe and caring environment for their baby and that despite complex relationships with staff, they felt supported by the availability of knowledgeable staff: *'Everyone knew a bit about her (the baby) and was able to answer questions'* (Participant 1). The participants described positive

experiences with the nurses and midwives who represented a large portion of staff in the neonatal nursery: *'[The nurses] Oh, brilliant. They're all wonderful. Thank you, to all of them'* (Participant 4). The style of staff communication was also identified as important in participants' developing confidence in the nursery: *'The way they spoke, answered questions and spoke about things, they were confident in the way they responded. It was nice to go back and have the same nurse the next day, or 3 or 4 times'* (Participant 6).

5.5 Support Group

In relation to whether the support offered met participants' needs, the sharing of information with professionals, meeting other parents and the feelings of emotional support and a shared experience were key aspects of the supportive experience.

5.5.1 Support through education and information from professionals

Being informed enabled participants to feel more positive about being a parent and more confident with interacting with their baby and the nursery staff: *'They've studied that kind of stuff, they've got the professional side of it – they can say “you're doing a good job”, “what you're doing is right”'* (Participant 2). Participants discussed that due to premature delivery they had not had the opportunity to prepare for parenthood. This left some looking for information about being a parent in the NICU and they were able to ask about this in the support group: *'I appreciated their professional advice. The stuff in the black and white. I hadn't even got up to the chapter about birth'* (Participant 4). Two participants identified that they would have preferred more professional support before their baby was an inpatient in the NICU: *'I like getting it (the support group information), but I would've liked to have got it*

before I went there, for instance' (Participant 6). 'It's been a very helpful group, but it would have been better to know about it when I was in antenatal ward [while waiting to have their premature baby]' (Participant 1).

5.5.2 Sharing the emotional experience with other parents in the support group

Being able to share the emotional experience with other parents was also identified as a key factor for participants attending the support group. The group gave participants the chance to identify with other parents who were feeling similar stress and anxiety: *'(Well) family can help you, but they don't know medical terms, if you say "yeah, you know, she's on C-PAP", what's that? What does that mean? But other parents know. So it helps' (Participant 2).*

The group also gave participants an opportunity to initiate friendships and maintain social contact with other NICU parents: *'It was great because even just in the corridors now, you can smile and say "hi" to those mums that were there.'* (Participant 4). Some participant mothers looked forward to, what they hoped to be, on going relationships: *'I think I'll call the mums [that are from the NICU group] when I am home, because who else will know what I'm talking about?'* (Participant 9).

5.5.3 Family support

Partners played a role in providing support, as every participant in this study had a partner they described the positive input that they had on their coping ability; *'My husband's been great. I thought he'd be a bit scared and reluctant, but he's in there*

changing his nappy as well, so that's good' (Participant 4). Family support was important for families, and those who lived far away felt supported by both telephone and face-to-face contact: 'It's nice to know that they care. 'They'll make a phone call just to see how she is or they come in to see her' (Participant 6).

When some women knew that their babies might be born early they chose to be close to the capital city so that family supports were close by: *'Let's get back to the capital, 'cause then if the babies are born, at least we're in the city. We've got family' (Participant 8). Family that didn't live in the capital city also played a role in visiting the parents to show their support: 'So quite a few have travelled a special trip, to come (here). Which is really nice. You know, we've had lots of phone calls, throughout the last eight weeks' (Participant 9).*

6 Discussion

6.1 Emotional Distress and the NICU

Past studies have all drawn results that have assisted in identifying elements of parental stress (Miles, Funk, & Carlson, 1993). However there has been little research considering parents' self-reported NICU experience and their need for appropriate and specific support. This study identified that a NICU mothers' distress is experienced through the complex relationships with nursing staff, their uncertainty about their ability to care for the baby and the need for professional support to manage the distress and increase their knowledge about the NICU.

Consistent with previous research, participants described anxiety about their baby's health throughout the NICU admission (Smith, Steelfisher, Salhi, & Shen, 2012; Jackson, Ternstedt, & Schollin, 2003). As we have reported elsewhere, although participants were concerned about their labour and delivery, their anxiety about the

health and interaction with their baby were strong themes (Turner, Chur-Hansen, & Winefield, 2013). Grief was experienced by participant mothers when leaving their baby to return home or related to the lost experiences of having a healthy baby (Turner, Chur-Hansen, & Winefield, 2013). Smith, Steelfisher, Salhi & Shen, (2012) similarly described the grief experienced when parents leave the NICU even for a short period of time.

6.2 Family and Staff Support for NICU Parents

Participants struggled with sharing the care of their baby with the NICU nurses and in building strong relationships with staff. Despite this participants also felt that there were positive relationships with the midwives and nursing staff on the NICU. Finding positives in a crisis such as a neonatal intensive care admission has been identified in other studies (Affleck, Tennen, & Rowe, 1991; Tran, Medhurst, & O'Connell, 2009). The strong positive relationships with nursing staff played a role in participants' ability to cope with their experience of the NICU. Family support has been a key component of the strategies used by parents when caring for a baby with high medical needs (e.g., Green, 2013). In addition to family, participants also sought out the support group for interpersonal support. Parents seek out other NICU parents for support and on-going friendship during a time of stress (Smith, Steelfisher, Salhi & Shen, 2012) and the support group provides the meeting place for these relationships to begin.

6.3 The NICU Parent Support group

Parents in this study found the support group to be an important part of emotional support in the NICU. This group was designed to meet the emotional, educational

and supportive care needs of the parents and allowed parents to share their experience with other parents. Intervention programs such as support groups have been shown to decrease symptoms of stress and trauma in NICU parents (Jotzo & Poets, 2005). Having a staff facilitator manage the group, including the provision of education and structure, was seen as a positive in this group. In this support group it allowed parents to focus on their own needs and story and allow the facilitator to provide appropriate and relevant information to the group as a whole (Martin & Smith, 1995). The provision of counselling, such as the supportive counselling approach in this group, may lessen parent stress levels (Chourasia, Surianarayanan, Bethou, & Bhat, 2013).

7 Limitations of this Research and Implications for Future Research

Thematic analysis uses saturation as its end point when no new data emerges. In this study all authors agreed that this was reached with 9 participants, although these participants had varying ages, gestational ages of the baby and other demographic elements. This group was made of interviews with the same interviewer, a semi-structured style and transcribed verbatim so that no interview content was lost. These factors contributed to the high quality of the data and information.

As shown by other researchers (e.g., Jackson, Ternstedt, & Schollin, 2003; Garten, Nazary, Metze, & Buhner, 2013), there is little known about the specific emotional and support needs of fathers in the NICU. Fathers may search for control when in the NICU (Arockiasamy, Holsti, & Albersheim, 2008) as indicated in this study mothers also seek control during their NICU experience. The results of this research reflect the maternal experience only and do not address the specific emotions or support needs of fathers. Further research into the paternal view of the NICU would also allow further

understanding of the impact that a NICU admission has on the relationship between the parents (Manning, 2012).

Further elements that would add to this research are the perspectives of the medical, nursing and other supportive staff and of those who chose not to attend the support group. Adding further survey-based tools such as the PSS NICU (Parental Stressor Scale NICU, Miles, Funk & Carlson, 1993) could also further examine stress in NICU parents.

8 Conclusion

Based on the findings of this study which examined the experience of NICU mothers, the educational and supportive content of the support group should be focussed on assisting parents to deal with caring for their baby, finding their parenting role, building communication and rapport with nursing staff and utilising the emotional supports available. Encouraging parents to express their positive feelings and participate in the baby's care also are likely to assist in the parent feeling supported and learning to parent (Skene, Franck, Curtis, & Gerrish, 2012).

Involving a professional or professionals in a support group can provide information, guidance and emotional support to the parents of NICU baby. The participants in the group should be carers/parents of babies in the NICU so that there is a common shared experience (Goutaudier, Lopez, Sejourne, Denis, & Chabrol, 2011).

Information provided to participants in the group should be delivered early on in the baby's admission to allow parents to have maximal exposure to education and staff should encourage parents to attend the support group. This may maximise the opportunities for the parent to seek professional support and guidance. Maintaining a structure to the parent support group allowed a wide range of information to be

prepared and then shared with parents. Group facilitation by professionals allowed parents in the group to form friendships and develop meaning from their shared experience under the guidance of staff.

The identified need for support at home from previous research (Cardinal & Chapman, 1993) indicates that this support group could have extended its services to provide support after discharge. Further enhancement and refinement of the support group by seeking parent input and researching variables that identify parents who would benefit from post discharge care (Tien, Peterson, & Shelley, 2002) may also further assist appropriate supportive follow up care (Vale, de Souza, & Carmon, 2005; Garel, Bahuaud, & Blondel, 2004).

Chapter 3 - The Emotional Experiences and Supports for Parents with Babies in a Neonatal Nursery

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I was responsible for the conception of the research upon which this paper is based. I produced the first draft of the manuscript and submitted the final manuscript. All of the data analysis and literature search were completed by me. As the primary author, I have been the party responsible for responding to reviewers and editors based on discussions with and consent from my supervisors ACH and HRW.

Dr Melanie S Turner date -

Professor Anna Chur-Hansen and Professor Helen Winefield (supervisors)

Professor Anna Chur-Hansen and Professor Helen Winefield were the supervisors of my doctoral candidature. As co-authors and supervisors their role was to guide and assist me by reading paper drafts and making suggestions. The interview

transcriptions were checked by ACH and HRW for accuracy and the initial stage of coding of one interview to ensure consistency and to improve rigour in my findings. We, Anna Chur-Hansen and Helen Winefield, hereby certify that this statement of contribution is accurate, and give our permission for this paper to be incorporated into the doctoral thesis of Melanie Turner for submission for the degree of Doctor of Philosophy from the University of Adelaide.

Anna Chur-Hansen.....date.....

Helen Winefield.....date.....

1 Abstract

The experience of the neonatal intensive care unit (NICU) for parents can be anxiety provoking, fearful and distressing. To help parents cope with these overwhelming feelings a number of interventions including parent support groups are typically offered. It is hoped that the provision of these groups and other forms of emotional support lessen the distressing experience for parents and lessen the anxiety of hospital discharge. This study focuses on the emotional reactions during the transition to home from the NICU for parents who participated in one such support group. Parents were interviewed 4 to 6 months post discharge of their baby from hospital. Themes from these interviews included anxiety and concern about the baby's readiness for discharge, concerns about the risks of further illness and rehospitalisation, and whether the parent felt prepared sufficiently to care for their baby at home. Recalling their time in the nursery was distressing for parents but despite this they identified that positive staff interactions helped them through the hardest times in the NICU. The support group was reported to be effective and helpful for parents. Parents often maintained social contact with other parents and recalled advice and supportive information from the group as needed. Participants recommended that the support group continue to assist other parents.

2 Introduction

Advances in care for sick neonates have greatly increased the survival rates for babies born preterm (Moore et al., 2012). Consequently, a larger number of families take home babies after discharge from a neonatal intensive care unit (NICU) as compared

to entering palliative care or a long-term hospital admission. The NICU environment, which consists of extensive medical and nursing intervention whilst a baby is a hospital inpatient, is often a time of great stress for the baby and the parents (Balakrishnan et al., 2011). As well as the general impact of the birth of a premature baby upon the family and family relationships, parents experience negative impacts upon their own mental health (Rogers, Kidokoro, Wallendorf, & Inder, 2013).

In 1991 Kratochvil, Robertson and Kyle interviewed parents with eight year old children who were premature at birth. Forty per cent of these parents felt that there was an on-going negative effect on the parent-child relationship due to the separation and experience of having a premature baby. Further studies that have examined the infant-parent relationship have shown that parents in the NICU often cope with stress by avoiding negative experiences, including distressing experiences with their baby. This can lead to a maladaptive relationship with their child (Greco et al., 2005), and parents are at risk of developing Acute Stress Disorder (Shaw et al., 2006). Up to 40% of women report significant depressive symptoms after preterm delivery (Davis, Edwards, Mohay, & Wollin, 2003).

Families must prepare for the discharge of their child back to their home and adjust their lifestyle to manage a premature infant. Prior to discharge premature babies need to meet a variety of physical requirements including stable oxygen saturation levels, maintenance of body temperature and reasonable weight gain and the ability to have one or a combination of breast or bottle and at for some, nasogastric feeds. Frequently these infants also have a range of medical needs after discharge that differs from term infants (Merrit, Pillers, & Prows, 2003).

Many parents must continue treatments that were initiated in the NICU including supplemental oxygen, gavage feeding and apnoea monitoring (Lopez, Anderson, & Feutchinger, 2012). There has been discrepancy in previous research (Sheikh, O'Brien, & Mc-Cluskey Fawcett, 1992) between parental recall of poor preparation for difficulties with their babies as compared to staff recall of well-delivered discharge planning discussions. These infants are also at risk of re-hospitalisation due to complications with their growth or recurrent illness, particularly respiratory illnesses (Ralsler, Mueller, Haberland, & Fink, 2012). The parental experience and emotions related to 'ex-premature' baby illness after discharge and hospital readmission have not been well researched.

The optimal environment for the discharged baby requires staff to ensure that parents feel supported and are coping with their stress (Howland, 2007). Supportive services for parents have been instituted in a number of NICUs in a range of ways: nurse counselling roles (Parker, 2011), a parent buddy program (Preyde & Ardal, 2003) and by general medical and nursing support (Tran, Medhurst & O'Connell, 2009).

Support groups of varying styles have also been initiated at a number of sites.

Affleck, Tennen, Rowe, Roscher, & Walker (1989), found that for mothers who needed the most support a support group had a positive effect, whereas for those who had low need for support, participation in the support group had negative effects.

Further research on NICU parent group supports is needed to understand who might benefit and how delivery can best be offered (Butt, McGrath, Samra, & Gupta, 2013).

Research has focussed primarily on the experience of parents while their babies are acutely ill in the neonatal intensive care unit (Seideman et al., 1997), where parents experience grief, anxiety (Smith, Steelfisher, Salhi, & Shen, 2012), guilt, anger, fear and a range of positive feelings (Affleck & Tennen, 1991).

The purpose of this research was to build on existing knowledge by interviewing parents whose babies had been discharged from the NICU at a major tertiary hospital in a capital city in Australia, in order to examine the emotional experience of parents and their retrospective view of their supports, in particular the NICU formal support group. The research questions for the study are: “What are parents’ reflections afterwards, on their experiences as a NICU parent?”, “How do they describe their relationship with the baby after discharge from the hospital?” and “How helpful was the pre-discharge support group?”

3 Methods

After approval was gained from hospital and university ethics committees, parents were initially invited to participate in this study while their baby was an inpatient in the nursery. This research represents the findings from the second study with this parent group. The first study was an analysis of a set of interviews performed while parents had babies who were inpatients in the NICU, between 2 weeks and 5 weeks after admission. All parents in these studies had participated in the NICU support group provided by the hospital. The support group sessions were part of a weekly program conducted by medical, nursing and allied health staff, where written and verbal information was provided in an open format for any parents, caretakers and grandparents of an infant in the hospital’s NICU. The support group did not continue to provide a service after discharge of the baby.

The focus of these second interviews was of parental experience and recall of the NICU and NICU support after discharge of the baby. All babies had been discharged

for a minimum of 12 weeks by the time of the interview. Five parents had attended the premature baby playgroup, available to all discharged babies from the NICU, which was offered by the physiotherapy and occupational therapy teams at the hospital. The interviewer had no role in either clinical care or provision of formal or informal support.

Participants were provided with a consent form and information sheet explaining the study. Interviews were semi structured and employed open-ended prompts.

Interviews took place over the telephone: face-to-face interviews were offered but all participants chose telephone interviews. The interviews ranged from 45 to 70 minutes and all were digitally recorded with the participant's permission. The prompts for each interview included asking for reflections on being a NICU parent, their relationship with their baby and the helpfulness of the parent support group.

The interviewer transcribed each interview verbatim. Participants were offered a copy of the transcription, with no participants asking for the written interview. The transcribed data were examined for themes following the methodology described by Pope and Mays (Pope & Mays, 2006). Data collection continued until saturation, meaning, until no new themes were identified. An audit trail was maintained throughout the research. The first step in the analyses involved examination of the audit trail. The first author then compared themes between and within interviews, producing codes. NVIVO 10 was used to assist in analysis of the data. The codes were compared against the raw data by the second and third authors. Through discussion, consensus about the final themes and subthemes was reached.

4 Results

Table 1 Interview themes.

Research Question	Themes
What are parents' reflections afterwards, on their experiences as a NICU parent?	Recalling time in the nursery is distressing
	Parents are anxious about taking their baby home
How do parents describe their relationship with the baby after discharge from the hospital?	Anxiety about possible rehospitalisation of baby
	Coping with on-going medical needs after discharge is difficult
	Home oxygen therapy
	Feeding
	Learning to parent their premature baby
	Regaining Control
What are the parents views of the pre-discharge support offered?	Thankful to see babies developing normally
	Good relationship with baby after leaving hospital
	Positive views
	Support group
	Nursing staff
	Support group enabled on-going relationship with peers
Negative views	
	A better balance of information and support in parent support group sessions was needed

4.1 Demographics of Participants

Approximately 50% of parents or primary caretakers of babies in the NICU attended at least one session of the NICU support group. Sixteen parents were approached to participate in the study with all three fathers declining and the 13 mothers consenting to participate. Nine parents who had agreed to an interview whilst their baby was in the NICU all consented to this second interview. The nine participants were all women, who ranged from 20 to 40 years of age (mean=32.5). The average baby gestation at birth was 25 weeks (ranging from 24 weeks to 31 weeks and 5 days). Seven of the births were single, two were twins. Three participants had been aware prior to the birth that the baby would be born prematurely. Six participants lived in

the metropolitan area, two lived 50 kilometres from the state capital city and one participant lived 300 kilometres from the capital. All participants attended the support group with 8 attending more than one session. All parents in the NICU received one visit from the social worker; six of the participants requested further social work input. All participants felt well supported by family and friends and two participants would have preferred more professional support.

4.2 What are your reflections on being a NICU parent?

In relation to the research question, “What are your reflections on being a NICU parent?” parents described distressing emotions that emerged when recalling their time in the nursery and emotions related to when their baby was discharged from the NICU. At discharge from the nursery parental anxiety about taking the baby home was also described.

4.2.1 Recalling time in the nursery is distressing

Three to six months after the baby was discharged from hospital participants described avoiding thoughts about the admission or having unpleasant memories. The intensity of these feelings varied but most participants recalled them when looking at photos or sentimental items from the time of the NICU admission.

“Because I’ve got this little box of keepsakes, you know. And I take them out every now and then and see how small they were. And I remember, how scary it was..”.

Some felt teary or distressed when recalling the events of the admission and chose not to speak about it in detail in the interview. *“You know, when I think back on that time, um, I get a bit emotional about it..... it reopens all those emotions, and stuff.”*

Recalling premature baby playgroup, participants described feeling overwhelmed:

“But they do a ‘being a preemie parent’ session and they come in and they ask all these questions, like, you know, what your experience was and stuff. Half the room cries...”

4.2.2 Anxiety about taking their baby home

As the end of each hospital admission participants were anxious about taking their baby home. These babies had been admitted to the intensive care unit for a range of 4 weeks to 16 weeks since birth. Parents wanted their baby to be well enough to be discharged but were unsure if they would be healthy enough to be away from hospital. Participants described anxiety about being able to cope with their baby without assistance as well as about managing any medical complications that may arise after discharge.

“And they taught us, you know, CPR and stuff like that, and all that stuff. And in my head it was like ‘well what if something goes wrong and I don’t know how to do the CPR?’”

Participants felt that they may not have been ready to take their baby home and wondered if they were prepared despite their baby’s long admissions.

“I was nervous and scared, and um, I think a little bit stressed as well, that the day finally came, and maybe that I was ill-prepared”.

Family or friends’ input about their concerns regarding the baby’s health heightened the participants’ distress at discharge. *“Like, one of my girlfriends was bombarding me the day before we actually picked her up,. My head was spinning. I got in the car and I said to my partner ‘I’m not going to cope. This is too much.’”*

4.3 How do parents describe their relationship with the baby after discharge from the hospital?

Participants described anxiety related to possible further illness and hospital admissions for their baby, protective behaviours to prevent their baby from becoming ill, and concern that they would be unable to manage the medical needs of their baby. This contrasted with participants' positive emotions including the regaining of control, building a positive mother-baby relationship away from the nursery and enjoying baby growth and development.

4.3.1 Anxiety about possible rehospitalisation of baby

Babies were discharged home from the neonatal nursery and not admitted to a longer stay hospital unit. Participants were concerned about their child being readmitted, at a later date, to a medical or surgical ward for complications related to prematurity. Many took their other children out of day-care, preschool, play groups and group activities to avoid potential viral infection transmission to the baby from other children. Increased vigilance with their home hygiene was also a part of trying to prevent their child becoming unwell.

“Cause a couple of the women that I know have preemie babies, have been back. Their kids have been back into hospital with bronchitis and stuff and I’m actually quite glad that we’ve taken the precautions we have, and that he ...he has hasn’t been back in yet, touch wood.”

Participants who had other children at home changed their way of handling their baby, where they went and whom they let hold their child.

“since our NICU graduate baby (was ill), we’ve been really conscious of keeping him away from other kids who are sick, and I took my other son out of childcare. If friends invite us over we ask if their kids are going to be sick, and if they are, we don’t go.”

Some parents physically covered their babies when around other people to avoid potential infection. *“And the first time I took her out, I held her very close to me and covered her with a cloth, so no one could breathe on her.”*

Participants became more vigilant about what they did to try and prevent exposure to any illnesses. *“When I hear someone cough (near my baby), you know. ..I don’t know, but you sort of like, turn and run, almost.”*

Participants voiced concern that contracting any kind of illness would mean another admission to hospital for an unknown length of time.

“And thinking ‘if she goes back into hospital, how long’s she going to be there for?’”

4.4 Coping with on-going medical needs after discharge is difficult

4.4.1 Home Oxygen therapy

Four of the 11 babies in this study went home on oxygen, for time lengths that ranged from four weeks to four months post discharge. Participants were given an introduction to using oxygen at home by nursery staff but felt unprepared for the change in mobility and lifestyle that it would mean for life at home.

“We’re limited in where we can take him in the house without moving the oxygen cylinder. We’re limited on what we can do, we sort of keep him away from any stuff where he’s likely to catch a cold.”

Participants identified that they found caring for their babies much easier and less stressful when they no longer required home oxygen.

“She was on the oxygen up ‘til about six weeks ago, so a good couple of months.. And it’s just so much easier now that she’s off the oxygen.”

Some of these babies also became ill when on oxygen and parents had a heightened level of concern about their illness requiring hospitalisation.

“Yeah, it was pretty scary, ‘because he was on oxygen, and quite sick. I caught it as well, but I didn’t really notice ‘because I was just concentrating on getting him through the week.”

4.4.2 Feeding

All of these premature babies were born before their suck reflex, for breast or bottle-feeding had developed and therefore a range of nasogastric and intravenous nutritional support methods were used. Some of the infants required gavage (nasogastric) feeding at home after discharge from the NICU. Participants struggled at times with managing the balance between nasogastric feeding and breast and bottle-feeding.

“I think the hardest thing really was trying to get her off the gavage feed. She was used to having her tummy filled for her, and not having to do any work for her milk.”

Learning how to care for a feeding tube and how to gradually teach the baby to suck milk from breast or bottle was a challenge for participants who had to develop their own feeding regimens.

“So she still had the feeding tube in. And we, we had to, sort of, um, slowly increase the sucking feeds to, er, so like, slowly remove the gavage, um. So .. We were juggling.”

4.5 Learning to parent their premature baby.

Seven of the nine participants were first time parents, and their experience of parenting had solely been in the NICU. Confusion was expressed at how to manage their baby and whether their premature baby should be managed like other term babies. *“Do we do things differently ‘because he’s a preemie, or do we just do the same as what I would think you do normally?’ I felt a bit confused. I thought, ‘what do I do?’”* Participants described being overwhelmed by the change from inpatient care 24 hours a day to being completely responsible for baby care at home. They highlighted the need to adjust to the change not only in roles but also the responsibility of being the main caretaker of their baby. *“Because she was...it’s just a really big adjustment, having her...having to care for her 24/7, and not have the nurses to guide me, I think.”*

4.5.1 Regaining control

Although participants described worry about taking their baby home, one positive was the ability to be in control of how they cared for their baby. Being able to hold their child, deciding when their child went to bed and what they were fed all contributed to their sense of control in being parents. *“And really you were just excited about getting some of that control back, and, and fully being the mum.”*

In this NICU there was a range of guidelines used by staff about how long a baby could be held by the parents. Once they were at home with their baby, participants described the feelings around being able to have physical contact with their baby when they felt it was right to give it, and not based on someone else's recommendations. *"I can actually pick him up when I want now. It was a bit hard in the hospital, especially earlier on. ...I didn't actually have my first cuddle until he was a week old."*

4.5.2 Thankful to see babies developing 'normally'

The anxiety about going home and having to manage parenting alone was also in contrast with the participants' description of their happy experiences with their baby. Watching their baby grow, smile, use their voice and become more social within the family atmosphere were positive elements of parenting. *'They're putting on weight, they're growing, and they're happy, content babies'.*

Participants described the contrast between their time in the nursery and the positive time watching their baby get closer to non-premature babies in size. Comparing baby sizes became more common as participants took their baby out of the nursery and into the community. *"Yeah, I think he's, has almost caught up with those children who are at his chronological age, like his adjusted age."*

4.5.3 Good relationship with baby after leaving hospital

Participants described the large gaps in time away from the baby during the hospital admission, often overnight, being a missed period of time bonding.

“I felt we hadn’t really bonded, ...because we weren’t spending 24 hours together, we weren’t the primary caregivers as such, um, and he wasn’t actually dependent upon us at all, it (NICU) probably did hinder the initial bond.”

Although participants had spent time away from baby while they were in the nursery they described a positive, enjoyable relationship with their baby after discharge in their home environment. *“I mean, he’s obviously more dependent upon me now, ...even though I think he knew who I was in hospital, he’s more aware of what’s going. So that makes our relationship a little bit stronger I think.”*

Participants post-discharge described a strong, connected relationship with their infants now that they were able to spend time with them at home. *“Um, we’re very, very connected. If I leave her anywhere, I just feel odd. Yeah, she’s like attached to me really.”*

4.6 Experiences of emotional support in the NICU

What Are Parents’ Views of the PredischARGE Parent Support Offered?

Positive reports of the support group were identified as well as one participant describing a poor balance of information and support content in some group sessions. Participants also identified that emotional support from staff and in particular other NICU parents was an important part of ‘surviving’ the NICU.

4.6.1 Positive view of support group

Participants had a positive view of the support group. They identified the NICU support group as an element that assisted them with their stay in the nursery. *“But*

I'm just really grateful (with) the amount of support that we had. Like having that Support Group, um, then a couple of midwives that were just incredible."

Participants continued to describe the group as a place where they felt understood and where they were able to feel 'not alone' in their nursery experience.

"Um, oh just seeing that I wasn't, I wasn't the only one." Forming connections with other parents in the nursery was identified as another important function of the support group. *"Whereas it seems, you know, if we can get a group together, then when you come together, you know you're there to talk and meet other people, um, and it's hopefully not quite so awkward (compared to the nursery)."*

4.6.2 Positive recollection of staff from the nursery

Participants identified positive input and support from staff.

"Most of the midwives were just fantastic. They were, they were just so supportive. I just, you know...they were, they were brilliant."

Feeling supported by the NICU staff and experiences of the nursery as a place to, ease into parenthood, were discussed.

"When you're a first time mum, and your head's spinning you're like 'oh my god', and even though she needed extra attention, it was ..It was a nice way to get into parenthood. 'Cause you sort of had the responsibility, but not 100%. So you could sort of, um, gradually increase your increase your knowledge and your confidence."

4.6.3 The support group enabled on-going social contact with other parents

In the nurseries participants explained it was difficult to make friendships or

connections with other parents due to the rules around noise levels and providing privacy to families. The support group gave parents a place to meet and then continue to foster their friendships.

“It’s kind of stressful watching your little baby. And then to be able to just go and chat with people who were in the same situation as me; and go in a different environment was good.”

Participants continued their newly formed friendships after leaving the group as well and benefitted from these. *“In the group someone else had the same fears and the same concerns, and the, you know, and the same stress, the same daily stress. Yeah, I do [see the benefits of those relationships]. ‘Cause you’ve still got...we’ve still got some of that stress with us.”* The preemie baby playgroup was a place where some parents reconnected after discharge from the hospital. *“the support is carrying on now that um, you know, for the ...having a kid who’s like, at the moment, nearly six months old, but only four months corrected, and I’m sort of, you know, starting to think about solids and, you know, should I be waiting longer and stuff, and that’s something that I’ll, you know, go to the Playgroup.”*

4.7 The balance of information and support in the group sessions

Participants expressed a number of gains from attending the support group, including friendship and emotional support. They also described using the information provided by the group as well, in particular when they were home post discharge.

“Oh definitely [found information and educational content useful]. The whole...that’s what I’m saying. The whole lot was just, was just brilliant.”

Some participants felt reassured by the content in the support group and this supported them in their journey through the NICU.

“But the things that they said, you know ‘just keep doing the things that you’re doing’, and letting me know that it was all...the right thing to do, helped.”

One participant outlined the variation in some group sessions, where there was a lack of information given in some sessions and more information given in others.

“I would’ve liked more of a balance. I would’ve preferred like half and half (information and emotional support). Because the stuff that, you know, we were told, that we were taught in that group, was, was quite in...you know, informative rather than just making me feel better.”

5 Discussion

This research investigated the reflections on being a NICU parent including the usefulness of the parent support group while their baby was a patient in the nursery. Participants described both distressing memories when recalling the nursery as well as more positive experiences, which may have been helpful for coping.

5.1 The Key Aspects of the NICU Experience for Parents

Participants described anxiety about taking their baby home from the NICU even when they were medically fit to be discharged. Anxiety has been found in 40% of mothers with infants in the NICU in previous research (Rogers, Lenze, & Luby, 2013). Parents have previously expressed that having a baby requiring medical care after discharge can be overwhelming (Lasby, Newton, & Von Platen, 2004) and discharge teaching has been found to be an important part of parent preparedness to

leave the NICU (Smith, Steelfisher, Salhi, & Shen, 2012). In particular, parents with babies requiring feeding support or home oxygen support were unsure of their ability to do these cares ‘properly’ once away from the 24 hour care of the nursery. Adding in clear discharge teaching for parents and the ability to contact professional emotional support may improve the parents’ confidence with their baby.

5.2 Parents’ anxiety and fear of rehospitalisation of their NICU graduate infant

Parents increased their protective behaviours to try and avoid their children becoming ill or experiencing an adverse event that would require readmission to hospital.

Babies in this study were protected from potential contagious illness by parents keeping their baby away from others, avoiding social outings and covering or hiding their baby. This increased protective behaviour has not been researched in the literature before and indicates that parents may alter their interactions with their ex-premature babies out of fear of illness and rehospitalisation. This has potential repercussions on the parents’ interactions and relationship with their baby and may lead to a more avoidant social life for the family. This is an important consideration as neonatal intensive care unit survivors have already been identified as being at high risk for poor social development (Yamada et al., 2011) and may have inhibited social development due to lack of social activity. Orenstrand, Winbladh, Nordstrom & Waldenstrom (2001), found that 40% of mothers of NICU discharged premature babies were still unsure of their baby’s ability to survive even once they had reached their expected term date. This is despite the death rate of babies after discharge to home from the NICU being very low. The EPICure study (Moore et al., 2012) found that only 1% of babies discharged from the NICU died prior to the age of three years.

The participants' concern about health of the infant may also be related to their fear of the high rate of neurological and developmental impairment, up to 45% if born at 23 weeks, of NICU survivors at 2 and 3 years of age (Moore et al., 2012). Being made aware that long-term developmental outcomes are rarely related to exposure to common viruses and infections as an infant after hospital discharge may lessen parental anxiety. Despite these concerns parents in this study were able to move past this stage of fear of baby illness and with a gradual building of confidence progressed in their parenting. Further research examining the way in which parents are able to do this may allow development of support programs to address this in discharge planning sessions.

5.3 Positive experiences of their baby

Participants described positive experiences with their baby and the growth of a stronger mother-baby bond post discharge. These positive moments with the baby and improving confidence in parenting skills assisted parents to cope with their transition to home. The change of role from being a 'part time' parent in the NICU to a full time parent at home allows parents to take control of their day to day activities and learn to parent with the support of family and friends.

5.4 Future Support Group implications

Given the value ascribed to support from other parents, it may be useful for support groups to recruit and train NICU 'graduate' parents as presenters or facilitators in the group. This may have improved parent attendance above the 50% of parents that attended our support group sessions; and also provided a non-clinical person for parents to approach. In previous research parent-to-parent support has been found to

be helpful for parents (Preyde & Ardal, 2003). However, there are also risks associated with this. Parents who volunteer as a ‘buddy’ or supporter must be properly screened and trained and this needs to occur on an on-going basis (Gooding, Cooper, Blaine, & Franck, 2011).

As identified by one participant in this study, each group needs to balance education and emotional support, so that parents are prepared for their discharge to home. Having experienced staff in the support group who can speak about home medical care such as feeding plans and home oxygen use would allow parents to better address these needs prior to discharge from hospital. Outpatient group support has been shown to be one of the most meaningful interventions after discharge (Broedsgaard & Wagner, 2005) for NICU parents.

5.5 Implications of this research for NICU staff

Nurses in particular were seen as a positive influence during the baby’s admission through to discharge. Nurse involvement is key to developing not only good parent and infant experience in the NICU but also in successfully transitioning from hospital to home (Lopez, Anderson, & Feutchinger, 2012; Smith, Steelfisher, Salhi, & Shen, 2012). Nurse relationships with parents also effect the mental health of the mother and hence their interactions and relationship with their baby. Research has indicated that as the mother’s perception of support from nurses decreases, her depressive symptoms increase (Davis, Edwards, Mohay, & Wollin, 2003). Encouraging nurse support of parents, maintaining nurse staffing that allows a baby to have the same group of nurses over their NICU stay and providing training and education for nurses

may improve nursing staffs' ability to maintain an emotionally supportive stance while caring for the baby in the NICU.

Health care workers' interactions with family, communication and professionalism are all identified by parents as critical to quality care in the neonatal nursery (Butt, McGrath, Samra, & Gupta, 2013). Better understanding of strengths and weaknesses in each family by these health care workers may enhance the discharge planning and support planning for parents of NICU babies (McHaffie, 1992). Improved emotional support leading up to and after discharge may assist parents with the transition to home and lessen their anxiety and distress. It is important when considering an on-going outpatient support system that any on-going support program would need to be flexible in its service delivery (Parker, 2011). In particular in this study group, managing the aspects of distance from the capital city would suggest that telephone link ups (Lichstein et al., 2013), videoconferencing or outreach clinics would be needed to provide the same level of support as for those in the CBD.

6 Limitations of this research

This study was limited by its lack of father perspective in the interviews. Further research that recruits fathers would delineate their emotional experience and allow modification of the support methods to be better tailored to their needs. Gaining the neonatal nurse and/or neonatal doctor perspective would also allow triangulation about self-identified and professionally identified areas of support and in turn, contribute to modifying parent support groups to maximize their helpfulness to these stressed parents.

7 Conclusion

Identifying the needs of parents at the time of and after NICU discharge allows the support team to develop a service that decreases parental anxiety, improves communication between staff and parent at discharge as well as addressing the fears and concerns about caring for the baby at home. In particular this research identified the heightened anxiety and fear about contagious illness. Addressing these concerns may be important to improving the discharge experience for parents. Both an inpatient and outpatient form of support should be available to parents with consideration given to a video conferencing service for those who are unable to attend the hospital or clinic.

Chapter 4 – The neonatal nurses’ view of their role in emotional support of parents and its complexities

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I was responsible for the conception of the research upon which this paper is based. I produced the first draft of the manuscript and submitted the final manuscript. All of the data analysis and literature search were completed by me. As the primary author, I have been the party responsible for responding to reviewers and editors based on discussions with and consent from my supervisors ACH and HRW.

Dr Melanie S Turner date -

Professor Anna Chur-Hansen and Professor Helen Winefield (supervisors)

Professor Anna Chur-Hansen and Professor Helen Winefield were the supervisors of my doctoral candidature. As co-authors and supervisors their role was to guide and assist me by reading paper drafts and making suggestions. The interview

transcriptions were checked by ACH and HRW for accuracy and the initial stage of coding of one interview to ensure consistency and to improve rigour in my findings. We, Anna Chur-Hansen and Helen Winefield, hereby certify that this statement of contribution is accurate, and give our permission for this paper to be incorporated into the doctoral thesis of Melanie Turner for submission for the degree of Doctor of Philosophy from the University of Adelaide.

Anna Chur-Hansen.....date.....

Helen Winefield.....date.....

1 Abstract

Background - The neonatal intensive care nurse has a large and complex clinical role but also a role of emotional supporter for parents in the Neonatal Intensive Care Unit (NICU). Identifying components of their role and recognising the elements within the nursery that obstruct or encourage this role can allow for modification of nurse education and peer support.

Objective - This study explores the nurses' views of their role both in the NICU and in the provision of interacting with, and emotionally supporting, families.

Design – Qualitative study based on semi structured interviews.

Method - Nine neonatal nurses from a single NICU were interviewed and the data analysed thematically using NVIVO10.

Results - Participants viewed their role as an enjoyable yet difficult one, requiring seniority, training and experience. They provided support to parents by communicating, listening, providing individualised support and by encouraging parental involvement with their baby. Constructive elements that contributed to the provision of support included a positive NICU environment and providing a parent support group. More obstructive elements were a lack of physical NICU space, little time available for nurse-to-parent conversation and language and cultural barriers between nurses and parents.

Conclusion - The role of the neonatal nurse in providing emotional support is complex and requires a high level of on-going support and education for staff, and minimisation of physical and staff-related obstructions.

Relevance to Clinical Practice – The modern NICU offers complex medical and nursing services and with this care comes higher needs from both babies and their parents. NICU nurses should be supported in their roles by having peer support

available in the NICU and education and training in emotional support and counselling skills. The nursing staff also require a comfortable and practical physical working space in which to assist parents to be with their baby.

Keywords - Neonatal Care; Nurse patient relationship; Nurse Role, Nursing Education, Parental Guidance, Parents' experience

1.1 'What does this paper contribute to the wider global clinical community?'

-This research identifies that the NICU nurse role has high emotional demands and that parent emotional support is a core part of their role. Due to the focus on family centred care, the need for providing emotional support is likely to grow.

- The factors that influence a nurse's ability to provide support include: staff support within the unit; education and training specifically in counselling skills and managing distress; maximising physical space around the baby so that parents can be supported while caring for their baby directly; provision of other professional support for parents including support groups for nurses to utilise for distressed parents.

- Recommendations are made with regard to instituting these practices to support the nurse role and thereby support parents.

2 Introduction

Neonatal nurseries in Australia provide medical and nursing care for babies born prematurely between 23 weeks and 36 weeks gestation. Eight per cent of Australian babies, or 20,700 babies, were born prematurely in 2008 (Australian Bureau of Statistics, 2008, 2). Neonatal nurses bring diverse training and experience to a very complex and demanding role (McDonald, Baas Rubarth & Miers, 2012). The

physical needs of infants in neonatal intensive care units (NICU) are high and therefore care for the NICU baby has centred around them and less so around the emotional support of the family (McGrath, J., 2001). NICU nurses are often overstretched in their role (Oates & Oates, 1996) and can lack the time to provide this support. Parents however have described the need and desire for health care professionals to offer a range of supports in a consistent manner (Franck & Axelin, 2013).

A number of reports discuss the nursing role in the forming of the relationship between parent and child in the NICU or SCBU (special care baby unit) (McGrath, J. 2001). Parents look to nurses for ways to understand their babies' cues and ways to settle their baby. They may copy nurse behaviours and therefore the nurse's understanding of infant communication is very important. Physical activities of holding, feeding and performance of cares are the three main physical contacts that a parent has with a baby. These skills need experienced nurses, to balance the need for physical contact with the baby to improve the maternal bond and lower maternal depression (Discenza, 2011), with that of tactile overstimulation, (Alta & Goulet, 2003) and baby distress. Kowalski, Leef, Mackley, Spear, & Paul (2006, pg 44) state that parents identified nurses as 'the person who spent the most time explaining the baby's condition, 'the best source of information' and the person who told them 'about important changes in their baby's condition'. Therefore a nurse's understanding of a baby's physical condition and the baby's level of tolerance of physical contact is crucial to the parents' behaviour. As well as providing assistance with physical care, nurses provide informational support, which has been shown to

relieve anxiety and postpartum depression in mothers of premature infants (Wu et al., 2007).

3 Background

Holditch-Davis and Miles (2000) and Hurst (2001) found that nurses can have a major role in reducing parental stress. Determining the sources of this stress can help NICU nurses apply specific interventions to target and reduce parental stress (Muller-Nix et al., 2004; Turan, Basbakkal, & Ozbek, 2008) and thus, the rate of maternal perinatal depression (Bicking & Moore, 2012). Jones, Woodhouse & Rowe (2007, pg. 209) describe effective communication and support as involving both the infant and the parents, with ‘shared management of their baby and appropriate support and reassurance by nurses’.

This broader focus of support and communication has been gradually introduced into neonatal intensive care units as they take on the family-centred care model, which moves the focus to care of babies in the context of their families (Bicking & Moore, 2012). Educational and supportive nursing programs and support groups for NICU parents in this environment decreases parental stress (Turan, Basbakkal, & Ozbek, 2008) and eases the transition from hospital to home (Willis, 2008).

Given the vital role that nurses have in the care and wellbeing of premature babies and their parents, the literature is surprisingly sparse about how the nurses themselves see the satisfactions and stressors of their work. A better understanding of such matters might ultimately lead to more effective recruitment, training and retention of this highly specialised workforce. The purpose of this research was to broaden existing knowledge about nursing staff perspectives on working in a NICU and

interacting with and supporting parents by interviewing nurses currently working in NICU. The research questions for the study are:

1. How do participants view their role in the neonatal intensive care unit (NICU)?
2. How do participants provide support for parents in the NICU?
3. What elements obstruct and assist the NICU staff in providing emotional support for parents?

4 Methods

After approval was gained from hospital and university ethics committees, nursing staff from the hospital neonatal intensive care nursery or special care baby nursery were approached by the researcher and invited to participate in this study. All nurses were currently employed as registered nurses at the hospital at the time of the study. The hospital in which the study was conducted is a large tertiary teaching hospital in an Australian State, servicing a population of 1.2 million people and at the time of the study had 2 NICU (neonatal intensive care unit) areas and 3 SCBU (special care baby unit) areas within the one larger NICU complex, caring for a total of up to 52 babies. The NICU was staffed with a 1:1 baby: nurse ratio and both NICU and SCBU practiced elements of developmental care as in Vergara(1992). The SCBU areas were staffed with a ratio of 1 nurse to 3 to 4 babies, dependent upon their illness acuity.

All nursing staff working in the NICU at the time of the study were eligible to participate. Of the 20 staff invited, 18 consented to be interviewed. Data collection continued until saturation occurred, meaning, until no new themes were identified (Pope & Mays, 2006). In this research this was reached with 9 participants. All were

women, with 8 nurses having worked across both NICU (neonatal intensive care unit) and SCBU (special care baby unit) and one nurse having experience only in the NICU. The nurses were between 32 and 58 years of age. All the nursing staff completed general nurse training and then furthered their education with midwifery training and 2 with neonatal certificate training, to work in the neonatal intensive care unit. One participant was new to an Australian NICU having worked in other NICU's overseas and 2 of the participants were involved in educational roles with the NICU staff. Participants were offered either a face-to-face or a telephone interview and all requested that the interview take place over the telephone. The interviewer was employed as a research assistant and had no role in either clinical care or provision of formal or informal support to nursing staff or patients of the hospital.

Interviews were semi structured and employed open-ended prompts. The core questions were "Can you tell me about your role in the neonatal intensive care unit (NICU)?", "How do you feel parents cope in the NICU?", "How do you provide support for parents in the NICU?" and "Do you feel that the parents' support group assists parents?"

Interviews ranged from 45 to 70 minutes and all were digitally recorded with the participant's permission. The interviewer transcribed each interview verbatim. Participants were offered a copy of the transcription, with no participants asking for the written interview. All of the transcribed data were examined for themes following the methodology described by Pope and Mays (2006). An audit trail was maintained throughout the research. An audit trail is composed of a number of elements, including the reflections of researchers; inception of and design of the study including

process notes addressing methodology and recruitment; and data analysis from raw data through to final analysis. This trail is used to follow and provide evidence for the study from design through to results (Wolf, 2003), and is a standard way to enhance rigour and trustworthiness to qualitative research methods (Tracy, 2010).

The first author compared themes between and within interviews, producing codes. NVIVO 10 was used to assist in analysis of the data. The codes were compared against the raw data by the second and third authors. Codes were then collapsed by the first author into broader themes, and checked by the second author. Through author discussion, consensus about the final themes and subthemes was reached.

5 Results

Participants viewed their role in the neonatal intensive care unit as enjoyable and rewarding but challenging, and requiring training, experience and seniority. Support for parents in the NICU was provided through individualised bedside support as well as encouragement and guidance for parents in caring for their baby. A positive environment in the NICU and formal support groups fostered the provision of support. However, a number of barriers were flagged that interfere with nursing support. These included physical space constraints, a lack of time, lack of parental engagement, language and cultural barriers, and a lack of education and training for nurses in how to provide support. Also discussed was the lack of feedback given to nurses around what took place in formal support group sessions.

5.1 Participants' view of their role in the NICU

5.1.1 Role is enjoyable and rewarding

All of the nurses interviewed described enjoying their jobs, despite a wide range of difficulties and challenges. Many compared the role now in NICU with other roles that they had held in hospitals with children and babies who did not need such complex and intensive care. *“(My job is) very enjoyable, otherwise I wouldn’t be here for 17 years.”* (Participant 2). Working with a variety of babies and moving between the two units was described as a positive experience. *“I enjoy working in both the nurseries, um, being that they’re totally different levels of care and you tend to interact with the parents and the babies in a very different way, in both areas.”* (Participant 4.) Enjoying the progress that babies make as they work their way through the more intense areas of the NICU to the parenting unit, before discharge home, was mentioned by a number of participants. *“It’s quite nice because it’s sort of, even though the babies start out unwell, they all recover and go home healthy babies with their mothers. So it’s quite rewarding.”* (Participant 7.) Other participants identified that teaching parents about their babies and how to care for them was a key part to job satisfaction.. *“I just really enjoy working with the babies and, working with their parents and, teaching them to interact with their babies and watching their babies develop and grow.”* (Participant 8).

5.1.2 Role is challenging

This nursery, as in many other hospital neonatal nurseries, provides medical and nursing care for a range of babies in both intensive care and special care nurseries. Babies can move across the nurseries depending on their physical needs. The lower the level of care needed the higher the ratio of babies to nurses. Therefore nurses can move from 1:1 care of a baby in a NICU to being responsible for 5 babies the next day in SCBU.

“If you see the baby once and you see it again next week, they probably don’t even remember who you are, let alone the fact that, you know, did you look after my baby before or did I just pass you in the corridor? Because there are so many babies in there.” (Participant 1)

The change of staff from shift to shift and nursery to nursery contributes to the loss in continuity of information given to parents.. *“They [the parents] don’t need all this different information that’s being told to them. It often happens, you know. We’re always giving them different information. Um yeah, so I’ve sort of found out lots of things what the parents’ needs were, you know and tried to be consistent.”*

(Participant 6)

5.1.3 Role requires training, experience and seniority

Nursing staff described a wide range of staffing issues that were problematic. These included the range of nursing staff skills with some neonatal nurses able to cope with the physical and emotional demands of caring for severely ill babies and some less so. Staff also discussed the introduction of new staff, junior staff or ‘agency’ staff on a nursing roster and the extra burden therefore placed on experienced nurses.

“Often the junior staff or staff from other areas aren’t familiar with the areas so the senior staff not only take on their load, but someone else’s as well.” (Participant 6)

Participants discussed the changes that they would make to increase the NICU nurse staffing if they were able. The nurseries are known for being a very busy place of work as are other areas of intensive care. The busy work load, large number of babies and at times rapid patient turnover were described as being unrelenting at times.

“Well it is [very busy in the nursery], but they try and staff it to the ratio to the baby. But it is busy. It’s constant. It’s always constant. It doesn’t stop. You need a lot of experience to really make it work.” (Participant 1)

Staff recruitment and concern that a loss of staff or a failure of recruitment would decrease their current time available for babies and parents was highlighted as challenging in terms of junior nursing staff. *“We have a lot of junior staff in our unit at the moment and not a lot of senior staff. They’ve either, either retired or left or, you know or moved up in different positions. That there’s not a lot of senior staff left, really, and the juniors can’t seem to cope.”* (Participant 6).

5.2 The Emotional Support Provided by the Nurses

5.2.1 Individualised Support for each parent

Participants identified that parents needed individual support needs due to the highly individual medical state of each NICU baby.

“In, in NICU, you know, the babies are either very tiny or very sick and they have a good day, they have a bad day, if they try and die tomorrow, they’re better the next day. You’re actually, almost moment by moment trying to support the parents.”

(Participant 4). Each parent was considered to have their own need for information to be given personally to them and that this communication is key to supporting the parent. *“So, communication is a huge thing; making them feel comfortable and welcome, and making them feel that their babies are ours as well is really important.”* (Participant 2).

Having personal nurse-to-parent conversations on a regular basis helped families develop trust in the nurse and the admission to the NICU.

“It’s, it’s, really good to be able to, talk to the families and help them through. The parents really benefit from that relationship.” (Participant 6)

Parents have a variety of ways to communicate and recognising this and using a range of strategies to engage them in conversation builds a good nurse-parent relationship.

“I use various strategies. It would depend on the parent. Some who are reserved, you’d have to respond in a quiet. Others with humour, I do it with humour.”

(Participant 5)

5.2.2 Encouraging parents to participate in caring for their baby

As the NICU babies mature and become stronger parents are able to handle them more and participate in more baby care. Participants used encouragement and reassurance to assist parents in taking on more physical roles with their baby.

“Some parents are really scared to touch their baby because they’re really tiny or they’re a lot of tubes and lines in there. We teach them how to take temperature, or change the nappy, or just put their hands on their back.” (Participant 3). Participants described encouraging parents to be involved with their baby, even when they are hesitant, to assist in the baby-parent relationship. *“Offer them cuddles with the babies, even if they’re scared, just try to convince them, as it’s very good to hold your baby.”*

(Participant 9)

5.3 The elements that assist and obstruct the NICU staff in providing emotional support for parents.

5.3.1 Positive NICU environment provides a supportive atmosphere

Some participants identified that they build a supportive environment in the NICU with other nursing, medical and allied health staff as a way to work with the parents while their baby is in NICU.

“I think we’ve, what we try and do is build a supportive atmosphere and I really think we need to be more supportive of parents and each other.” (Participant 4)

Helping parents to feel relaxed and welcome into the unit as a participant in their baby’s care was seen as a part of supporting the parent baby relationship.

“Well I just talk with other staff and get them to help me if possible and encourage the parents to be as; independent as they can with, their baby’s cares. And just try and accommodate them, reassure them that, we will find space and that, it’s not an inconvenience and we really want them to be able to be there with their babies.”

(Participant 8). Participants explained that they talk to each other when they need to seek a way to assist parents when they feel out of their depth with emotional management.. *“And she was under extreme stress, which she spoke to me about. Now, I must admit, I immediately spoke to the rest of the staff about it so I was supported too.”* (Participant 3)

5.3.2 Support groups for parents are helpful

In the hospital in which this study was conducted, a formal group was offered to parents and other interested family members. The group was run a child and adolescent psychiatrist and a neurodevelopmental physiotherapist. It was run weekly, for one and a quarter hours on the postnatal ward of the tertiary hospital involved in this research. The group focussed on providing a supportive atmosphere for parents of babies who were admitted to the NICU. Group discussions were held covering a variety of topics, including coping with the grief and distress at the baby’s illness,

learning to parent in the NICU, developmental stages of premature babies, neonatal care vocabulary and the terms used in the NICU. Participants identified a number of positives about the formal NICU parent support group. These included parents using the group as a way to discuss problems and parents using the advice and support from the group to decide if they needed more emotional assistance from a counsellor, psychologist, psychiatrist or other external agency.

“Sometimes if a parent doesn’t open up to me, I think there’s more to what’s happening like I think she needs some support, some mental health support or something, sometimes I’ll send them to that group and then they might come back and then they’ll say, ‘you know, I’d like to see someone.’” (Participant 6)

Staff identified that information given in the group and feeling informed about their baby’s progress are central parts of a parent feeling supported.

“Attending the group can, you know, help them be well informed and feel like they know what is going on with their baby, rather than those that feel maybe that they don’t have enough information or, um, yeah, feel a bit distant and left out.”

(Participant 8)

Obstructions to the nurses providing support for the parents

Problems within the nursery were named as one of the factors that influenced participants’ ability to provide support for parents.

5.3.3 Physical Space as a Limitation in nursery care.

The physical space available within this particular nursery was a problem identified by all participants. The NICU was described by its cramped space with a large amount of equipment, a lack of privacy for parents and overcrowding with babies.

“I had a baby that was very unwell and I had stands and I had trolleys and staff and everybody around, and so much so that the parents couldn’t actually get in.”

(Participant 5)

Attempts for parents to have frequent physical contact with the baby, to engage in caring for the baby, such as feeding or changing a nappy as the baby becomes healthier, was inhibited at times due to the lack of space beside each baby.

“All our staff are really encouraging of parents being involved with their baby’s care; but the spacing issue is really the main thing that’s probably discouraging to them, because it is very busy.” (Participant 8)

The chaos in a crowded and busy unit can be off-putting for some parents despite the nurses’ encouragement to participate in caring for their baby.

“[It] can be just a bedlam sometimes; the parents don’t know what is going on. I think the unit is far too small.” (Participant 6)

Participants identified that the lack of space impedes the parents’ and babies’ privacy.

“Certainly one thing is there’s limited privacy because the babies, you know, they’re in all 3 parts of the SCBU, depending who else is there. But there’s limited privacy for the parents and probably even for the baby.” (Participant 1)

5.3.4 Lack of time to provide enough support

Nurses spoke about staff recruitment and their concern that a loss of staff or a failure of recruitment will decrease their current time available for babies and parents.

“But, um, they’ve actually tried to, um, get more staff, and recruit more staff and they haven’t been successful. So, it’s a wish but not a reality, yeah, because, you know, if you did have more staff then people...you’re not trying to cover so many bases. You

would actually have the time to talk to parents and probably help them with their stress more.” (Participant 5)

5.3.5 Lack of parent engagement as an obstruction to providing support

Participants discussed parents’ need for support but also their limited ability to engage some parents in discussing this. This limited ability may be due to factors within the parent, the family, the infant or the nurse. Some participants were unsure how to identify the individual needs of parents and how to cater for those who do not obviously present as distressed.

“Because we don’t know what they really want. I mean, it’s easy to put your clothes on, put your make-up on, put the smile on the face, come in, you know bring your milk, see your baby, cuddle your baby, feed your baby, wash your baby and go out the door again. You know, do we really know? They might tell us that they’re ok, but are they really? We don’t know that.” (Participant 4)

Some participants expressed having difficulty identifying when parents are in need of support and felt that some families just ‘keep going’ no matter what the stressors that arise.

“But when do they struggle? I’m not sure. Possibly they just keep going while the baby’s in there, depending what their home requirements are. I mean, do you have another child? Do you have another sick kid? Do you live in the country? Do you have any money to pay for the constant requirement of parking fees?” (Participant 1)

5.3.6 Language and Cultural barriers effect the support that nursing staff can offer

Participants identified that language proficiency prevented building a supportive relationship with the parents, which is heavily based on verbal communication. *“And I guess language is a problem. Some people don’t speak English. Actually quite a number of people don’t speak English, or minimal and then well, what do I say?”*

(Participant 1)

The difference in culture between parent and staff was also described as a challenge. Participants viewed this as an obstruction particularly as child rearing is a key aspect to many culture and family structures.

“Obviously, if you’ve got a language problem you’ve probably got a cultural problem along with it, [with] different expectations to what happens in hospitals. It is likely that the refugees are not used to health care probably to the degree that we have.”

(Participant 5). Participants talked about some of their own emotional and cultural difficulties with conversing with patients in a supportive way.

“I think, personally, I’m not really good at it. .. And on the other hand, English is not my first language so sometimes I have problems expressing myself, so yeah.

Sometimes it’s a bit hard.” (Participant 3)

5.3.7 The lack of education and training about providing emotional support.

Participants identified that there were gaps in their training in skills to work with distressed parents. While all staff described a busy and intense atmosphere, if more training about emotional support were available, participants felt that they would wish to attend. In particular participants described the need for practical, hands on skills that could be used to support parents at the bedside.

“Some training where you, have examples with answers you can come up with if somebody asks you a very difficult question,.. Just have a few examples, what you

could answer, or how to respond on some...in certain situations would be helpful.”

(Participant 3)

Techniques and methods that encouraged parents to enter into conversation with the nurse were also seen as potentially useful for training.

“Some information and training on techniques on, on how to get people talking and, opening up to you so that you can start that process of sorting out what’s going wrong, would be useful.” (Participant 4)

Other participants identified the lack of NICU nurse training from the supportive and therapeutic staff already located in the hospital. Some participants had sought out training outside of the hospital to meet their educational needs.

“Some more advice from [our] counsellors of how do to deal with the parents would be good. I do go to a lot of things outside of work to just go through that sort of stuff, how to cope with the women.” (Participant 7). Due to high staff turnover some participants suggested that training in emotional support be given at the beginning of a new staff member’s placement. *“I think it’d probably benefit from having training on emotional support, at the beginning of each rotation or just even education about the support group actually maybe going in, sitting in on one, so then you can see what, is going on.”* (Participant 8)

5.3.8 *Lack of feedback for nurses about support group discussions* Nursing staff were aware of the parent support group but felt that feedback about the group was lacking. *“It also might be beneficial if we talked to people that run support groups so they can see what the main issues are with, and stressors are for, parents that have babies in the nursery.”* (Participant 8). This feedback, it was argued, could be used by participants to change/modify their supportive practices in the nursery.

“The only thing is I’d like to sometimes get feedback and, you know, because..., not to, um, break confidentiality, but to know where we’re headed with it, you know, with these people that are struggling.” (Participant 5)

6 Discussion

This study was designed to broaden knowledge about the nursing staff role in the NICU and to gain the neonatal nurse perspective on the emotionally supportive care of NICU parents. Participants in this study found their role in the NICU to be enjoyable and rewarding, yet also a challenge and one that requires a great deal of experience. Nurses navigate the difficult aspects of their role, including challenges with resources and staffing and a lack of support-focussed education and training. Participant accounts are clear that both lack of senior staff and understaffing in general, added to the burden of a busy and emotionally intense environment, one in which neonates have severe and life threatening illnesses and parents grieve. From this study it is apparent that training in how to deal with parents and support them through a difficult time is lacking. What participants in this study did not discuss, but which these results make evident, is the need to consider the stress and emotional state of nursing staff.

Nurse stress and ‘burnout’ contributes to a lack of morale in the nursing team and lack of trust in the nurse on behalf of the patient (Braithwaite, 2008). Stress reduction methods that have been previously effective include supporting nurses through on-going professional education (Malach-Pines, 2006) and encouraging good relationships with colleagues (Buerhaus et al., 2007). These systems of support may also assist with retaining junior NICU nursing staff, who often leave due to the high

level of stress (Braithwaite, 2008). Instituting these supports may also lessen their stress and improve skills in junior staff allowing a better distribution of the complex emotional care of parents. Nurses' ability to spend time with the parents, as reflected in this research, is not just based upon their time availability but also the larger organisation of the nursery, rosters, staff training and experience and the nurse's personal ability to emotionally relate to parents. A better staffed unit would allow nurses more time to approach parents and build more rapport, in particular with those parents who need the most support (Wigert, Blom Dellenmark, & Bry, 2013) or who do not engage readily with staff. Providing this emotional support to parents is a challenge for many NICU nurses (Pannacciulli, 2012) but in particular the stress increases when there is a language or cultural difference between nurse and parent.

There are a wide variety of cultural backgrounds and languages in Australia. In the 2011 Australian Census 31.1% of residents in the state where this research took place have both parents born overseas and 16.3% of the households speak 2 or more languages. In addition 76% of recent migrants are from countries where English is not the main language (Australian Bureau of Statistics 1). Although interpreters are funded by the state health system for appointments and short consultations, they are not available for every day of the babies care. This places both staff and parents in a difficult situation when they see each other day to day and yet are unable to easily converse. Using 'limited conversation' was a technique identified in one study (McCarthy, Cassidy, Graham, & Tuohy, 2013). This is when nurses used shorter phrases, less detail and gestures when speaking to parents. At other times family members of the parent may be used as informal interpreters but their own involvement in the family may compromise their transmission of all medical and

nursing information to the parent (McCarthy, Cassidy, Graham, & Tuohy, 2013). Details about the baby's health and progress can be lost with these types of communication, and therefore having more readily available interpreters within the nurseries would allow parents quicker access to nursing and medical information. This would be complex to administer due to the variety of languages but coordination with interpreters visiting the hospital site that day may allow those interpreters to attend the nursery after their booked appointment.

For those nurses who feel less able to directly emotionally support parents, programs such as the COPE program, an educational-behavioural program that provides written, recorded and pictorial parent support (Melnik et al., 2001; 2006) may provide a structure for nurses to use. The provision of a booklet about their baby or recorded information may also address some issue with parents being able to recall information given to them (Koh, Budge, Butow, Renison, & Woodgate, 2005). These could better support nurses who are time poor but who need to communicate complex information. Provision of the support group in this study was found to be helpful in supporting nurses in providing emotional care for the NICU parents. Nurses described it as a useful resource for parents to ask further questions that the nurse may not have time or the specific knowledge to answer, and to also lessen the stress in parents so that they are better able to participate with the nurse to care for their baby. A similar group support structure may help other nurseries assist with parental distress.

The physical structure of the nursery can greatly impact on the function of the nursery and the emotions of the staff and parents who utilise it (Shahheidari & Homer, 2012). Unfortunately there has been little research based on the effect of nursery physical

environments and patient placement and its relationship to nurse and parent stress. Sound levels in a busy NICU are often above the recommended levels (Krueger, Wall, Parker, & Nealis, 2005) and this extraneous noise may add to the busy and chaotic environment of the nursery. The most recent recommended standards for NICU design (Report of the sixth census conference on new-born ICU design 2006, White, Smith, & Shepley pg S8.) states that the design of NICU “should contribute to positive first impressions for families and foster the concept that families are important members of their infant’s health-care team, not visitors. Facilitating contact with staff will also enhance security for infants in the NICU.” This is in contrast to the nursery in this study, which participants described as unwelcoming and lacking greatly in parent friendly space. The participants also described the lack of privacy in the NICU. The recommended standards for NICU as above outline that “The need for privacy for infants and families should be addressed not only in the design of each bed space, but also in the overall unit design—for example, by minimizing traffic flow past each bed.”(White, Smith & Shepley, 2013, pg S7). The findings from this study support these recommendations. Early neonatal discharge with community follow up has been used in this unit, to try and improve the physical space and privacy recommended for parents. However this intervention can only be used when the baby reaches 34 weeks gestation. Therefore the many weeks prior to this point are spent in the NICU with the challenges of space, privacy and support.

The support group was found to be a helpful addition to the emotional support provided by the nurses. Discenza (2010) also reported that formal support groups serve a valuable function for parents. The group in this study provided a source of information and support to parents in a private space away from the noise and

business of the nurseries. However the lack of feedback from those running the group prevented staff from using new information and suggestions from parents to modify their support techniques. Thus, it is important that such groups have clear lines of communication with nursing staff.

To our knowledge this is the first study to qualitatively examine nurses view of emotional support for parents in the NICU. It has a number of strengths. The qualitative methods used followed the guidelines for excellence in qualitative research as outlined by Tracy (2010). These include a worthy topic, and steps to ensure rigour and trustworthiness. An audit trail was maintained throughout the research process. All researchers discussed results and checked the analyses against the raw data. Thematic analyses were inductive and deductive. Data were collected to saturation. Participants were invited to validate their transcripts, albeit none chose to do so. The interviews were conducted by a trained interviewer who was not involved in any nursing or medical role, therefore reducing bias in data collection. Thematic analysis, based on Pope and Mays' (2006) description, is a well-researched method, which allowed grouping of themes across the interviews. However the study does have several limitations. The aim of qualitative research is not to generalise results: however, results should be applicable to other settings. Further research is needed to demonstrate the applicability of these findings to other NICU. These data are the perceptions of the nursing staff. To add to knowledge it would be informative to interview parents and other family members regarding their experiences in the NICU, to triangulate parental views with those of nursing staff. The views of other health professionals in the NICU may also be valuable.

7 Conclusion and Practice Implications

In conclusion, the complex nursing role in the NICU is made more challenging by its environment. Changing and modifying aspects of this environment may improve the experience of NICU for nurse and parents and therefore also for the babies as patients. The changes include offering education and training to staff around emotional support for parents, changing the physical layout to provide a quieter, private space for staff and parents, providing more interpreters for parents who do not speak English and using a support group as a resource for staff who want to refer parents for further care. These need to be coupled with on-going feedback to nursing staff about the parent needs for support and any current NICU concerns from the parent population.

Chapter 5 - The Assessment of Parental Stress and Support in the NICU using the PSS NICU.

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I was responsible for the conception of the research upon which this paper is based. I produced the first draft of the manuscript and submitted the final manuscript. All of the data analysis and literature search were completed by me. As the primary author, I have been the party responsible for responding to reviewers and editors based on discussions with and consent from my supervisors ACH and HRW.

Dr Melanie S Turner date -

Professor Anna Chur-Hansen and Professor Helen Winefield (supervisors)

Professor Anna Chur-Hansen and Professor Helen Winefield were the supervisors of my doctoral candidature. As co-authors and supervisors their role was to guide and assist me in reading paper drafts and making suggestions. The statistical calculations

were completed by Dr Melinda Stanners and these results were also reviewed by all four authors.

We, Anna Chur-Hansen, Helen Winefield and Melinda Stanners, hereby certify that this statement of contribution is accurate, and give our permission for this paper to be incorporated into the doctoral thesis of Melanie Turner for submission for the degree of Doctor of Philosophy from the University of Adelaide.

Anna Chur-Hansen.....date.....

Helen Winefield.....date.....

Melinda Stanners.....date.....

1 Abstract

This study aims to identify the most stressful elements for parents in the neonatal intensive care unit (NICU). Parents of babies in an Australian NICU (N =73) completed both the PSS (Parent Stress Scale) NICU (Miles 1993) and a survey of parent and baby demographic and support experience variables (Parent Survey). Older parental age, Very premature birth and twin birth were significantly associated with a higher PSS NICU scores. Having a high score in the Relationship and Parental Role scale was strongly associated with attendance at the Parent Support group. These parent stress scores and support approaches are discussed.

2 Introduction

There were 301,617 births registered in Australia in 2011 (Australian Bureau of Statistics 3, 2012). Of these births approximately 8% of babies were delivered pre-term, referred to as a premature birth (Australian Bureau of Statistics 3, 2012). Neonatal intensive care units (NICU) provide care to these babies born prematurely as well as babies who are ill or who require surgery very soon after delivery. The experience of being a parent of a child in the NICU is stressful (Singer et al., 1999; Affleck, Tennen, & Rowe, 1991; Treyvaud, Lee, Doyle, & Anderson, 2014; Wigert, Johansson, Berg, & Hellstrom, 2006) and the effects of the NICU experience may continue beyond the acute admission and influence subsequent family functioning and parent mental health (Pinelli et al., 2008).

For better outcomes in parent-baby relationships the key elements are finding and instituting ways to decrease parental stress and improve parental well being in the NICU (Korja, Latva, & Lehtonen, 2012; Woodward et al., 2014). Lam, Spence, & Halliday, (2007) found that psychologically informed support is indicated in NICU

environments. To provide this support a range of programs has been trialled, and includes Buddy programs (Preyde & Ardal, 2003), recorded information via CD or booklet (Melnik et al., 2004) and support groups run by professional hospital staff (Kaaresen, Ronning, Ulvund, & Dahl, 2006). Matching the content and style of support offered to the stress profile of NICU parents has not been examined. An understanding of the components of parental stress is necessary in order to offer effective supportive interventions to parents.

2.1 The provision of support in the NICU

In the unit described in this paper, which principally cares for premature infants, there are three methods with which all parents are offered emotional and psychological support. The first is support from the medical, nursing and allied health staff responsible for the direct and day-to-day care of the baby. The second is support provided by the mental health trained staff including the team social worker and the perinatal mental health team. The third form of parent support was a weekly open parent support group, provided by the first author and a co-facilitator.

2.2 Parent Support Groups in the NICU

Group support for NICU parents has been initiated in a number of hospitals throughout the world (Kaaresen, Ronning, Ulvund, & Dahl, 2006; Melnyk et al., 2006). The various methods of NICU support groups include structured closed groups, open groups, groups run by volunteers and groups run by parents (Bracht, Ardal, Bot, & Cheng, 1998). Provision of a one 45 minute support session for parents has previously shown improvement in PSS subscale stress scores (Chourasia, Surianarayanan, Bethou, & Bhat, 2013).

The parent support group in this study was provided every week for one hour and fifteen minutes and was available to parents who had a baby or babies in the NICU. The content was tailored to those attending the session by determining the age and medical state of their baby at the beginning of the session. The topics addressed were: the stress of the NICU on you, your baby and your partner; being with your baby and feeding your baby; learning to touch/contain or hold baby; learning about baby cues; use of voice, reading and narrative with your baby; the move from NICU to special care nursery; the anxiety of the long admission and anxiety about going home; going home, baby carriers, baby slings, external support groups; common premature baby development, corrected age, play and interaction with your baby, and explaining prematurity to everyone else. These sessions were provided verbally and written information was given to support what was presented.

2.3 Identifying Parental Stress

To assess parental distress, the PSS NICU was developed from the Parental Stressor Scale: Paediatric ICU (PSS: PICU) by Carter and Miles, (1989) and Miles, (1982). It was further refined by Miles, Funk and Carlson in 1993 to measure the parental perception of stressors due to the physical, psychosocial and emotional environment of the neonatal intensive care unit. In this study, a modified version of the PSS: NICU (Miles, 2002), from which the subscale of Communication with Staff was excluded after revision (Miles, 2002; Reid & Bramwell, 2003), has been used. This scale has had its validity and internal consistency confirmed in the USA (Miles, 1995; Shields-Poe & Pinelli, 1997; Seideman et al., 1997) and the UK (Reid & Bramwell, 2003).

In previous research (Zelkowitz & Papageorgiou, 2005) a small range of factors have been found to be associated with anxiety in postpartum women, including perinatal complications, poor marital relationship, a baby with a small birth weight, younger gestational age and few social supports. Other research has shown that stress was not associated with education, marital status, infants' birth weight, gestational age, congenital anomalies or if the parents expected the baby to be in the NICU (Bouet, Claudio, Ramirez, & Garcia-Fragoso, 2012). These conflicting findings have made it difficult to determine the target population for parent support and therefore those parents whom we should encourage to receive emotional support to improve their level of distress.

This research aimed to (a) identify the most stressful elements of the NICU for parents and (b) examine relationships between parent and baby variables and the particular sources of stress as per the subscales in the PSS NICU,..

3 Methods

3.1 Participants

A prospective study was undertaken in a tertiary level NICU in a large Australian Children's Hospital over a 12-month period. Participants were parents of a baby, or babies, admitted over this time to the NICU. This NICU primarily cared for premature infants (23 to 36 weeks of gestation completed) with over 95% of admissions being for these infants. Participants, including those who attended and those who did not attend the parent support group, completed a self-administered PSS NICU questionnaire (N = 73). The PSS NICU questionnaire was only provided in English.

3.2 Measures

3.2.1 Measuring Parent Stress

The PSS NICU (Miles 2002) was used in this study. There are 34 questions in total in the PSS NICU and parents are asked to mark on a Likert scale to rate a range of experiences from 1 (not at all stressful) to 5 (extremely stressful; the experience upset you and caused a lot of anxiety or tension). The questions are grouped in three categories. The first addresses the sights and sounds commonly experienced in the NICU (Sights and Sounds subscale) (6 items); the second considers how the baby looks and behaves as well as the treatments that the baby has had (Look and Behaviour Subscale) (17 items). The third group of questions address how the parent feels about their relationship with the baby and their parental role (Relationship and Parental Role) (11 items) (Table 1). A score was derived for each subscale, for each parent, by adding all of the ratings for each question within each subscale.

According to Miles (1993) the PSS NICU can be scored in two ways.

Metric 1: Stress Occurrence Level, is the level of stress experienced in a particular situation. Those who report the experience receive a score and those who do not are coded as missing. The total denominator is the number of parents who experienced the particular stress.

Metric 2: Overall stress level is the stress from the total NICU environment. Parents who do not report a score on an item are given a score of 1. The total denominator is the number of items on the scale. Metric 2, as outlined by Miles (1993) and Mannix (2012) best describes levels of parental stress due to the total NICU environment.

Demographic and emotional support information – Parent Survey

The parent survey included questions about parental age (years), educational status (highest level achieved), presence of a partner (yes/no), whether the parent was aware

that they were going to have a premature infant (yes/no), rurality (distance home to hospital), attendance at the NICU parent support group (yes/no), how often they met with the NICU social worker, and whether or not they would have preferred more professional emotional/psychological support than they were currently receiving. This Parent Survey was attached to the front of the PSS-NICU.

3.3 Procedure

Ethics approval was obtained from the local Ethics committee at the hospital concerned as well as from the institutional Human Research Ethics Committee. The PSS NICU with the attached demographic and emotional support survey (Parent Survey) was available to all parents who had a baby in the neonatal intensive care unit, which comprised two intensive care units, and two special care units. All parents for these units shared the one waiting room. Signs advertising the research were placed in the parent waiting room, the intensive care and special care nurseries as well as next to the survey box, inviting all parents of babies in the NICU to complete the survey. Surveys, information sheets regarding both the research and confidentiality and sealable envelopes were available in the waiting room. Next to this was a locked survey box, to protect parents' privacy and confidentiality. Further surveys and locked collection boxes were located near the nursing stations in each unit. These boxes were emptied weekly during the research period.

3.4 Analysis

As this study was assessing parental experience of stress and support, Metric 2 was used. Miles et al. (1993) used principal components analysis to examine this survey

and found that these 3 subscales accounted for 57% of the variance in their original PSS NICU survey.

To explore associations between parent survey variables and the different domains of stress explored in the PSS NICU, scores were generated for the Sights and Sounds, Look and Behaviour and Relationship and Parental Role subscales. To identify the most stressful elements of the NICU for parents, scores were generated for each subscale by simply adding the ratings together, giving NA a score of zero because where not applicable the item is not causing the parent stress. Cronbach's alpha was calculated to evaluate internal consistency of the subscale scores.

The wording and mean response for each item of the PSS NICU survey are shown in Table 1. Some surveys were incomplete with the n varying depending upon blank responses. These scores were recorded as 0, as either "not applicable" or "not important" to the parent. Listwise deletion was used in the regression analysis as a method for managing the missing data. Therefore the recording its entirety was excluded if any single response to the PSS NICU was missing. Due to the large number of dichotomous variables, the relationships between individual parent survey variables and PSS NICU subscale scores were explored using simple linear regression. Linear regression was conducted in turn for each PSS NICU subscale score to explore the independent association of each variable on the parent survey (Table 3).

The statistically significant parent survey variables associated with each subscale score were then included in a stepwise multiple regression to predict each subscale

score. Logistic regression was used to calculate odds ratios of parent survey variables and group attendance as seen in Table 4.

4 Results

4.1 Parent characteristics

Seventy-three parents (mean age 30.8 years, range 19-44) of eight sets of twins and 65 singleton babies provided data, with 61 mothers and 12 fathers. The majority of participants (89%, n=65) had a partner and 40 (54.8%) had no other children. Twenty had tertiary educational achievements and only one participant had no secondary schooling. One participant's home was overseas and 13 lived in rural areas 120-800 km from the hospital. Forty-two parents (57.5%) had not known beforehand that the baby would be delivered prematurely. Thirty-three parents had other children in their family as well as their baby in the NICU. The majority of parents (53%) attended the NICU parent support group, 42% of parents had more than one session with the NICU social worker and 42% of parents would have preferred more professional support.

4.2 Parent stress experiences

Table 1 shows the items of the PSS NICU and the average ratings of stressfulness, with subscale and overall totals. Of the 3 subscales of the PSS NICU the lowest scores for distress were those in the Sights and Sounds in the NICU. Average responses for questions in this scale ranged from 1.71 to 2.96, reflecting moderate stressfulness, except for one outlier regarding stress related to the presence of a ventilator (mean = 3.39).

Cronbach's alpha was performed to assess internal consistency (Bland & Altman, 1997), across the 3 subscales of Sights and Sounds (alpha 0.76), Look and Behaviour of baby (alpha 0.81) and the Relationship and Parental role in the PSS NICU (alpha 0.79).

In the scale examining Look and Behaviour, parents were most stressed about their baby being in pain and their baby being sad, as well as two physical characteristics: bruises and cuts on the baby as well as the baby changing colour. The greatest parental distress was reported for items within the Relationship and Parental Role subscale of the PSS NICU, with parents identifying that being separated from their baby, not feeding their baby and not taking care of their baby caused the highest levels of stress.

Means and standard deviations were also calculated for subscale totals: Sights and Sounds (Mean = 15.68, Std Dev = 5.40), Look and Behaviour (Mean = 44.08, Std Dev = 13.87), and Relationship and Parental Role (Mean = 32.57, Std Dev = 11.29), and subscale scores were highly correlated. Pearson's r identified a very strong correlation between Sights and Sounds and Look and Behaviour scores, $r=0.82$, $p<0.001$. Strong correlations were found between Sights and Sounds and Relationship and Parental Role scores, $r=0.65$, $p<0.001$, and Look and Behaviour and Relationship and Parental Role scores, $r=0.59$, $p<0.001$

Table 1. PSS NICU results

Item on the PSS NICU	Avg score	range	N
Sights and sounds in the NICU total subscale score	2.38		
The presence of monitors and equipment	1.71	1 – 5	72

The constant noise of equipment	1.87	1 – 5	72
The sudden noise of monitor alarms	2.96	1 – 5	71
The other sick babies in the room	2.04	1 – 5	70
The large number of people working in the unit	2.30	1 – 5	69
Having a ventilator breathe for my baby	3.39	2 – 5	48
Look and Behaviour total subscale score	2.85		
Tubes and equipment on or near my baby	2.87	2 – 4	69
Bruises and cuts on my baby	3.03	2 – 5	60
Unusual colour of my baby	2.83	1 – 5	65
Unusual breathing of my baby	2.89	1 – 5	69
The small size of my baby	2.61	1 – 4	69
The wrinkled appearance of my baby	2.59	1 – 5	65
Seeing needles and tubes put in my baby	2.82	2 – 4	68
IV line in my baby	2.77	1 – 5	62
When baby seemed to be in pain	3.17	2 – 5	67
When baby looked sad	3.11	2 – 5	64
The limp and weak appearance of my baby	2.89	1 – 4	64
Jerky or restless movements of baby	2.78	1 – 5	64
My baby not being able to cry like other babies	2.93	1 – 5	63
My baby crying for long periods	2.76	1 – 4	63
When my baby looked afraid	2.93	1 – 5	61
Seeing my baby suddenly change colour	2.95	1 – 5	61
Seeing my baby stop breathing	2.53	1 – 5	55
Parental Role Alterations total subscale score	3.47		
Being separated from my baby	4.32	3 – 5	68
Not feeding my baby myself	3.43	2 – 5	64
Not being able to care for my baby myself	3.43	2 – 5	67
Not being able to hold my baby when I want	3.91	2 – 5	66
Feeling helpless and unable to protect my baby from pain and painful procedures	3.17	1 – 5	64
Feeling helpless about how to help my baby during this time	4.24	2 – 5	62
Not having time to be alone with my baby	3.31	1 – 5	63
Sometimes forgetting what my baby looks like	3.03	1 – 5	58
Not being able to share my baby with other family members	3	1 – 5	69
Being afraid of touching or holding my baby	3.13	1 – 5	62
Feeling staff are closer to my baby than I am	3.17	1 – 5	66
Overall stressfulness	2.96		

4.2.1 Relationships between parent and baby variables and sources of stress as per the subscales of the PSS NICU.

Shapiro-Wilk normality testing showed that continuous and ordinal variables in this study were all normally distributed. Very few variables were independently associated with subscale scores.

Sights and Sounds Subscale

Linear regression found that parental age, infant gestational age at birth and having a twin birth were all significantly associated with having a higher Sight and Sound score. Multiple regression found that older parental age was the variable most strongly associated with Sights and Sounds Score ($\beta=0.27$, $p<0.05$), followed by shorter gestation ($\beta=-0.27$, $p<0.05$), and having a twin birth ($\beta=0.23$, $p<0.05$), but knowledge of prematurity ceased to be significant ($\beta=0.11$, $p=0.32$). The model accounted for 23.6% of variance in the score, $R^2=0.23$, $F(4,64)=4.94$, $p<0.01$.

Look and Behaviour Subscale

Infant gestational age at birth, having a twin birth, knowledge of the premature birth and having more than one social work contact were significantly associated with the Look and Behaviour score. Multiple regression found that when gestation ($\beta=-0.36$, $p<0.001$) and twin birth ($\beta=0.24$, $p<0.05$) remained significant, knowledge of prematurity ($\beta=0.11$, $p=0.30$) and having more than one social worker ($\beta=0.12$, $p=0.30$) were no longer significant. The model accounted for 29.2% of the variance in score, $R^2=0.29$, $F(4,64)=6.61$, $p<0.001$.

Relationship and Parental Role Subscale

Gestation and attending one parent support group were significantly associated with the Relationships and Parental Role score. Multiple regression found that when one group attendance was considered, gestation ceased to be significantly associated ($\beta=-0.20$, $p=0.09$), but support group attendance was significantly associated with

Relationship and Parental Role Score ($\beta=0.27$, $p<0.05$). The model accounted for 14.0% of the variance in score, $R^2=0.14$, $F(2,69)=9.03$, $p<0.01$).

Table 2. Correlation between parent and baby variables and PSS NICU subscale scores

Parent/Baby variable	SSS score	LBS score	RPR score
Age of parent	0.288*	0.111	0.148
Gestation at birth	-0.346**	-0.424**	-0.266**
Education level of parent completing the survey	0.145	0.090	0.064

SSS – sights and Sounds Score LBS – Look and Behaviour score
RPR – relationship and parental role score

** Correlation is significant at the 0.01 level

* Correlation is significant at the 0.05 level

Parents who were of older age had higher Sights and Sounds scores and shorter gestation was correlated with all the PSS NICU subscale scores. The educational level of the parent did not contribute to their stress level as measured by the PSS NICU.

4.3 Comparison of participants attending the group and associated parent survey variables and PSS NICU subscales.

Analysis of factors related to attendance at the support group is reported in Table 3 below. Gender almost reached significance, and gestation and multiple social work contacts were significant. In addition the LB score almost reached significance (as in per point odds of attending group) and RPR score was significant (where each RPR score point increased the odds that they would attend the group by 9%).

Table 3. Individual regression coefficients for section scores:

	Sights and Sounds Coefficient (Std Error), R2	Look and Behaviour Coefficient (Std Error), R2	Relationship/Role Coefficient (Std Error), R2
Parent Gender	-1.92 (1.84), 0.02	-0.89 (4.41), 0.00	5.92 (3.45), 0.04
Partner	-0.70 (2.29), 0.00	-6.62 (5.56), 0.02	-3.99 (4.50), 0.01
Parent Age	0.24 (0.10), 0.08*	0.24 (0.24), 0.01	0.23 (0.20), 0.02
Education	2.03 (1.53), 0.03	3.79 (3.61), 0.02	2.28 (2.99), 0.01
Gestation	-0.65 (0.22), 0.11**	-1.88 (0.53), 0.00***	-0.93 (0.44), 0.06*
Number	0.81 (0.84), 0.01	2.61 (2.06), 0.02	2.11 (1.64), 0.02
Single/Twin	4.59 (2.05), 0.07*	12.77 (5.01), 0.08*	4.88 (4.13), 0.02
Metro residence	-0.40 (1.64), 0.00	-0.48 (4.05), 0.00	-2.27 (3.21), 0.01
Distance travelled	0.90 (0.56), 0.16	0.43 (1.53), 0.01	-0.15 (1.41), 0.00
Knowledge of prematurity	2.14 (1.13), 0.05	5.56 (2.78), 0.05*	3.53 (2.24), 0.03
Attend group	2.25 (1.19), 0.03	6.96 (3.57), 0.05	8.27 (2.75), 0.11**
More than one group	-0.23 (0.85), 0.00	0.82 (2.08), 0.00	1.49 (1.65), 0.01
More than one social work contact	2.34 (1.36), 0.04	9.00 (3.26), 0.10**	4.91 (2.67), 0.05
Req More support	1.91 (1.48), 0.03	4.15 (3.78), 0.02	4.90 (2.96), 0.04

- p<0.05, **p<0.01, ***p<0.001

SSScore: Mean = 15.55, Std Dev = 5.62 LBScore: Mean = 42.75, Std Dev = 13.87
RPRScore: Mean = 31.53, Std Dev = 11.05

Table 4. Prediction of group attendance by individual logistic regression models

Parent Survey Variable	Odds Ratio (95%CI)	P
Parent Gender	3.35(0.93-12.06)#	0.06
Participant has a partner	0.39(0.043-3.42)	0.39
Parent Age	0.99(0.911-1.07)	0.79
Education of parent completing survey	0.68(0.22-2.14)	0.51
Gestation	0.81 (0.67-0.99)*	0.04
Number of children in family	0.96(0.50-1.83)	0.89
Single/Twin infant	0.33(0.07-1.46)	0.14
Knowledge of Prematurity prior to delivery	1.18(0.47-2.98)	1.00
Attendance at more than one group	0.69(0.38-1.29)	0.25
More than one Social Worker contact	6(1.55-23.15)**	0.01
Parent requested more support	1.65(0.47-5.82)	0.43
PSS NICU Subscales		
SSScore	1.08 (0.98-1.20)	0.13
LBScore	1.04(1.00-1.08)#	0.06
RPRScore	1.08(1.02-1.14)**	0.01

** p < 0.01 * p < 0.05 # p < 0.10

Parents who attended the group were more likely to have a baby of younger gestation, to have requested to see the NICU social worker more than once and to have a high RPR score. There was no significant association between having attended a parent support group and wanting more professional emotional support. Those who attended the group compared to those who did not; did not differ in SSS score, were closer to differing in LBS score but not significantly. Using a t-test, people who attended the group differed markedly in their RPR score; mean 33.8 vs. mean of 25.5, $t = 3.01, p = 0.004$. People who attended the group did not differ markedly with their LBS score

(mean 44.6 vs 37.7, $t = 1.95$, $p = 0.055$) and did not differ markedly with their SSS score (16.1 vs 13.90, $t = 1.51$, $p = 0.14$).

5 Discussion

The use of the parent survey with demographic and support data as well as the PSS NICU were able to identify which areas of the NICU experience are most stressful as well as the parent and baby factors that contribute to high parent stress levels. This study demonstrated that the PSS NICU in the Australian context maintains internal consistency equivalent to that found in the UK, USA and Italy (Miles et al., 1993; Montiroso, Provenzi, Calciolari, & Borgatti, NEO-AQUA Study Group. 2012; Reid & Bramwell, 2003) and is an appropriate tool to assess parental stress. Therefore as 42% of parents identified that they needed more professional support, these results can be used to inform modifications to the support provided to parents. The highest level of stress identified in the PSS NICU was for items in the RPR subscale, representing the challenges faced by parents in their role as a parent and their relationship with the baby. The factors that have been shown to be statistically significant in influencing parent stress levels are; older parent age, having a very early premature baby, and twin birth. Parents are more likely to attend a support group if their PSS NICU RPR score is high, have a very early premature baby, and have asked for more than one social work contact.

5.1 Nursery Factors contributing to stress.

Parents of babies of very early gestation and twins had the highest scores in the Sight and Sound subscale. This subscale reflects the parent's ratings of stress due to the sights and sounds of the physical nursery space. This greater level of stress with

these parents may be modified by using NIDCAP principles (Als, 1999; Als et al., 2004). These principles address noise, lighting and activity in the nursery and recommend changes to the physical environment (as well as other recommendations), which allow a more appropriate developmental space for the infant. Minimising noise in the NICU to below 50dB during the day and 35dB at night is recommended by the American Academy of Pediatrics (Lasky & Williams, 2009). Previous studies have shown nurseries to be consistently above these thresholds (Darcy, Hancock, & Ware, 2008). Instituting ways to decrease noise such as ‘quiet zones’ in the nursery, moving patient areas away from sinks and doors and installing noise absorbing furniture and sound proofing, can all decrease the noise experienced by parents and babies in the nursery.

Using DVD’s for parents to be oriented to a hospital unit has been used in a pediatric burns intensive care unit (Lehna et al., 2011). Using a DVD for the NICU may assist parents in being exposed to the sight and sounds of the unit before physically being in the unit. This too may lessen their stress associated with the sights and sounds of the NICU.

Older parents also scored highly in the Sight and Sound subscale. The reason for older parents finding these factors more distressing is unclear. Being an older mother increases the risk of preterm birth, stillbirth and NICU admission overall (Lisonkova et al., 2010). Although these factors are associated with higher parental stress it may also give multiple points of contact with perinatal professionals to review these parents. Therefore if these mothers are identified and are able to be engaged in education about the physical environment of the NICU it may lessen their sights and sounds PSS NICU score.

5.2 Parent and Baby Factors contributing to stress

The Look and Behaviour subscale is primarily focussed on the appearance and behaviour of the baby. Early gestation and twin birth were causes of high scores in this subscale. Very early gestation babies have a very different physical appearance i.e. translucent skin, very large heads, and are usually ventilated and therefore require more sedation, which decreases their physical responses (Cooke & Griffin, 2009). Negative parental perceptions are associated with early gestational age of the infant (Tooten et al., 2013) and contribute to poor parent and infant interactions and poor maternal mental health (Howe, Sheu, Wang, & Hsu, 2014). Parents stress could be lessened by providing education about the normal appearance of premature babies and their common physical behaviours.

Preparing for the altered physical appearance of a premature baby was addressed in the parent support group in this research by using doll replicas of premature babies. Each doll represented a week of gestation from 23 weeks to 36 weeks and was made to the correct size and average weight for each gestational stage. Information about baby cues related to premature baby development was provided in written and verbal forms to the parents. Encouraging skin to skin or kangaroo care with baby and parent in the NICU assists with parent confidence but needs to be instituted with emotional/social support to ensure their ability to manage their baby's fragility (Tessier et al., 1998; Riikka, Maunu, & Kirjavainen, 2008).

The Relationship and Parent Role PSS NICU scale measures the stress parent's experiences due to their challenges, both physically and emotionally, being able to be a parent to their baby. Expanding ways in which parents can observe their babies,

such as teleneonatology, is developing to assist this element of stress. With more recent technology, parents are able to communicate with their baby and nursing and medical staff in real time (Minton, Allan, & Valdes, 2014). Improving discharge planning and involving parents from admission also improves parent confidence for the process of going home (Jeffries, 2014). Discussing discharge plans and the developmental phases of the premature baby, such as in the support group in this research, may assist in this plan for discharge and the role of being a parent. This may explain the relationship between a high RPR score and group attendance.

Parents of twins were shown in this research to have higher PSS NICU stress scores in all 3 subscales. Parenting twins has already been shown to be a more stressful experience than parenting a single baby (Beer et al., 2013), with twins in particular having more medical complications (Glazebrook, Sheard, Cox, Oates, & Ndukwe, 2004). Mothers of twins compared to singleton babies also have been shown to have fewer initiative and responsive behaviours (Ostfeld, Smith, Hiatt, & Hegyi, 2000) to their babies, which adversely effects cognitive development. Early supportive interventions, which improve parent and baby interaction, could improve these parent interactions and thereby lessen parental stress.

Almost half (42%) of parents would have preferred more support than they received, and parents who attended the group were more likely to have seen the team social worker more than once. The limitations of nursery support were a challenge for these parents, and this lack of identification of these parents and their extra need for support contributed to their higher level of distress. Maintaining a theme of support that also incorporates emotion focussed coping (Seideman et al., 1997), and consideration of a

more structured approach such as in Shaw et al. (2013) which include cognitive therapy based support, may also assist these parents.

5.3 Implications for Further Research and NICU Parent Support

Other factors that may influence parental stress, including family income, housing stability, physical wellbeing of the mother and other factors were not considered in this study. Further research including these factors as well as a larger sample would allow more comprehensive prediction of the PSS NICU scores by and demographic variables.

Although surveys were available in areas of high parent traffic to allow the maximum number to be completed, some parents may not have had the opportunity to attend a group before they completed the survey. Further research which includes a larger group of parents who all had the opportunity to attend the support group may help identify how choosing to attend/not attend the support group is related to wanting more support.

To apply the results from this study: support systems in a NICU should offer 1:1 or increased emotional support for parents who have a very early premature baby as this is the only factor that causes increased scores in all 3 PSS NICU subscales.

Identifying these parents early, which could occur at the point of delivery, and providing support at the beginning of the NICU admission may lower parental stress. In light of these results changes to group support for parents in the NICU should be considered. A NICU parent support group should ensure that its content and facilitators cater for older parents and parents of twins as these parents may

experience higher levels of stress. Systems within the NICU are needed to allow staff to assist early referral to a NICU support group and other psychological supports.

5.4 Limitations of this study

The limitations in this study need to be considered in its interpretation. These include the missing data in some surveys, the small n and also the lack of follow up of parents to compare stress levels at differing stages of their infant's admission. Sampling of a broader group of parents would further inform this study, potentially capturing a larger number of parents who could not, or chose not to, attend the support group. Collecting data related to the length of hospital stay would be able to better determine how the stress in parents changes over their babies' admission time and therefore better guide interpretation of stress scores. This would better delineate the population of parents that should be targeted for supportive interventions. The provision of the support group as a service for parents may have influenced the group who completed the surveys. The availability of this type of supportive intervention and the staff facilitators may have changed the staff dynamics within the nursery; this may in turn have provided a different NICU environment in comparison with other nurseries. Therefore the results need to be interpreted with these factors in mind and further research to address these issues would improve the research base..

6 Conclusion

This study was able to identify a range of factors that influence parent stress when their baby is in the NICU. The PSS NICU, which was confirmed in this study as an internally reliable of parental stress in the NICU, indicated that parents experience the most stress related to their role as a parent. Parent variables that are linked to high

PSS NICU stress scores are a twin delivery, a very early premature baby and parents of an older age group. Aspects of the parental support already provided in this nursery are appropriate but aspects such as managing the NICU environment and making it welcoming for parents, assisting parents to manage the appearance of their very premature babies, including holding their babies and providing emotionally supportive parental care throughout the admission are needed for a better stress outcome for parents (Ichijima, Kirk & Hornblow, 2011). Providing a professional group facilitator (Cherniss & Cherniss, 1987) and focussing support on elements of the parental role and relationship with the baby would also address the element of the admission that causes the greatest stress.

Predictors of attending the support group need further research with a larger sample. In addition the use of a clearer scale for parents reporting their experience of the support group may further delineate the specific gains that parents make through attending. Turner, Chur-Hansen & Winefield (2013) have described the beneficial aspects of attending a support group, including the on-going benefits post discharge. Addressing the stress associated with multiple preterm births (Bryan, 2003) is also another avenue for research and could be completed by widening the demographic questions

Nursing support was not considered separately in this research, although this experience is intertwined in the day-to-day NICU experience for parents (Turner, Chur-Hansen, & Winefield, 2014). Collection of the NPST (nurse parent support tool, Miles et al., 1999) alongside the PSS NICU would allow an examination of nursing support.

Chapter 6 - Conclusion

1 Summary of the Findings

This thesis explored the emotional experience of the NICU for parents, the view of the nurse's role in NICU and the parental stress and support factors associated with a NICU admission for their baby. Mothers were interviewed at two separate points in time, one during their baby's NICU admission and one when they were at home some weeks after discharge. Nurses were interviewed and their responses analysed to consider the view of the nursing professional in the nursery. Parents' responses to a demographic and parent support survey (Parent Survey) as well as the PSS-NICU (Parental Stress Survey – Neonatal Intensive Care Unit; Miles, Funk, & Carlson 1993) were analysed statistically to provide triangulation with interview data, of the parent NICU experience in relation to emotions and support. In particular this was considered in relation to the provision of professional group support and the appropriateness of the emotional supports offered to parents.

Paper 1 Mothers' Experiences of the NICU and a NICU Support Group Program

Paper one focussed on parents during their babies' inpatient stay in the NICU. The NICU admission presents multiple challenges and a range of stresses related to their role as a parent as well as concerns about their baby's survival and growth. Various supportive interventions have been trialled with this population. The focus of this support and how it should be delivered, however, lacks research as an evidence base for practice. Parents' experiences of the NICU and a professionally facilitated NICU support group at a South Australian Hospital were examined with nine parents

interviewed while their babies were NICU inpatients. Interviews were recorded, transcribed and analysed thematically.

This paper contributed to existing knowledge by revealing that parents face challenges in getting to know their baby, forming their parenting role while in the NICU, and a reliance upon, but resentment toward, nursing staff. Positive feelings about their baby's strengths were also apparent. The parent support group was an important part of managing the experience of the NICU and was reported to meet the emotional support needs of these NICU parents.

Paper 2 - Parent Accounts of Neonatal Intensive Care (NICU) and NICU supports, after hospital discharge.

This paper considered the experience and needs of parents after the discharge of their baby home from the NICU. Identifying the needs of parents at the time of and after NICU discharge allows the support team to develop a service that decreases parental anxiety, improves communication between staff and parent at discharge as well as addressing the fears and concerns about caring for the baby at home. In particular this research identified the heightened anxiety and fear about contagious illness and its risk to the baby. This paper contributed to the literature by identifying the challenging portions of the discharge experience for parents and how these concerns influence the parent and baby relationship. It was found that support, in the form of a professionally facilitated support group after discharge, should be available to parents. Consideration should also be given to an alternate version of a support service for those who are unable to attend the hospital or clinic.

Paper 3 - The Neonatal Nurses View of their Role in the Emotional Support of Parents and its Complexities.

This paper considered the view of the neonatal intensive care nurse in the NICU in regard to parent stress, the emotional support provided to parents by staff and the needs of staff to provide enough support for parents. Elements of the nursing role that impede their ability to provide support were identified and these findings added to the literature important aspects of the barriers to parent support. The complex nursing role in the NICU is made more challenging by the NICU environment. Changing and modifying aspects of this environment may improve the experience of the NICU for nurses and parents and therefore also for the babies as patients. The changes include offering education and training to staff around emotional support for parents; changing the physical layout to provide a quieter, private space for staff and parents; providing more interpreters for parents who do not speak English and using a support group as a resource for staff who want to refer parents for further care. These need to be coupled with on-going feedback to nursing staff about the parent needs for support and any current NICU concerns from the parent population.

Paper 4 – The Assessment of Parental Stress and Support in the NICU using the PSS NICU

This fourth paper contributed to the literature by examining parents stress using a quantitative analysis of the PSS NICU (Parental Stressor Scale – Neonatal Intensive Care Unit) and demographic and support experience survey results. This is the first research project to examine the relationships of PSS NICU results and attendance at support groups as well as examining the demographics associated with the highest amount of stress in NICU parents.

Parents who are older parents, parents of twins or a baby of very early gestation are all at higher risk of stress than other NICU parents. Over 40% of NICU parents requested more professional support than they were receiving and most felt well supported by families. Emotional support for NICU parents can be modified, or improved upon by staff using these results. Addressing this by identifying and referring parents early who fit the high risk of stress criteria, providing a referral pathway for further mental health care for those who appear distressed are discussed in this paper.

2. Contribution to the understanding of the theoretical aspect of this thesis.

2.1 Attachment Theory

The early years between a parent and infant are recognised as being the most crucial of a person's life and this has been researched and documented by a range of child researchers including those discussed earlier in this thesis, including Bowlby, Ainsworth and Winnicott. However this research also has links to new research, which considers the attachment relationship with respect to the neurobiology of attachment. Research that considers the relationship between attachment, emotional regulation and the foetal and infant brain and epigenetics has gained momentum since the research for this thesis began in 2008. What has been recognised in this new field is the requirement for ongoing, positive and reciprocal interaction between mother and baby to form a relationship as the essential task of the first year of life (Schoore, 2005). The more recent research into brain development in infants, and the way that that is related to attachment examines the component of genetics and relationship experience and their influence on each other.

An understanding of epigenetics has changed the way that we think of interaction of our genes and the environment (Feinberg, 2008). Allan Schore (2005, p 204) describes this ‘Although the role of early expressed genetic factors is an essential focus of current study, it has become clear that genes do not specify behavior absolutely; prenatal and postnatal environmental factors play critical roles in these developmental origins (of the brain in infants). The social environment, particularly the one created together by the mother and infant, directly affects gene-environment interactions and, thereby, has long-enduring effects.’”

Therefore this parent population, which has been shown in this thesis to have a higher rate of parental trauma, distress and resulting higher divorce rates in parents are also at risk of children with poorer attachment relationships. This may be due to their poor initial relationship and attachment experience while surrounded by the stressful environment of the NICU. The brain ‘growth spurt’ which it is now believed is the period of peak attachment relationship formation, begins in the third trimester of pregnancy (Schore, 2000). In this research population this time begins while both baby and parent are in a stressful environment. These early life experiences influence the physiological and mental health of an individual through epigenetic modification of DNA (Kantake, Yoshitake, Ishikawa, Araki, & Shimizu, 2014), as shown in Murgatroyd and Spengler (2011).

Early life stress, including premature birth, has been found to be a major risk factor for developing behavioural dysfunctions and mental disorders. Prenatal increased cortisol, released in stressful states, has been shown to cause impaired cognitive development in the infant and that its impact can be modified by a good quality attachment relationship (Bergam, Sarkar, Glover, & O’Connor, 2010). This is related

to the possible ‘scars’ in the areas of the brain which manage emotional control, learning and memory (Bock, Rether, Groger, Xie, & Braun, 2014). Therefore when examining attachment theory in this premature population we need to consider these new developments and the physical change to the baby brain and genes due to their interaction, or lack of, with their mother. It encourages us to consider whether the higher rates of disorganised attachment in NICU babies (Wolke, Eryigit-Madzwamuse, & Gutbord, 2014) are related to the poor relational environment in the NICU in which to form a parental relationship.

Although this thesis was unable to consider genetic testing or other biological assessments, with these new findings it may be appropriate for further research with NICU parental stress to look at epigenetics and its effect on attachment. The recommendation made by Bergam, Sarkar, Vivette and O’Connor (2010, pg 1032), that ‘early postnatal interventions may confer benefit to the child on both behavior and biology, and that some prenatal effects may be modifiable by infant-parent attachment in the postnatal period,’ could be met by provision of support to the NICU parents as provided in this research.

2.2 Grief and Loss Theory

Grief and loss are clearly expressed by mothers in the thesis. However this research has been able to outline the areas where these mothers have felt their loss the most. Mothers described grief at the loss of a normal delivery and of the faith in their body to maintain the pregnancy. This was experienced early on in the NICU admission. Parents struggle to manage the loss of the ‘normal baby experience’ and when at home they also have a sense of needing to hide their baby for fear of illness from

others. Research shows that parents may have an increased risk of insecure attachment due to this grief (Shah, Clements, & Poehlman, 2011). Mothers recollections of a distressing birth experience can have long lasting effects on the behavioural and emotional symptoms of their child until primary school age (Latva, Korja, Salmelin, Lehtonen, & Tamminen, 2008). Based on this research, and the data that supports that many premature deliveries are traumatic, this NICU parent population will experience parental grief and loss as well as their children having a range of emotional distress. Therefore there should be recognition in this population of the ongoing effects of grief in the parents. Treating their emotional distress with psychological support such as a support group can not only mitigate their own emotional state but the future emotional state of their children.

2.3 The Theory of Group Support for NICU Parents.

People's frequent response to crisis, to reach out for help with those of either like mind or from a similar situation, was shown to occur in this circumstance of having a baby in the NICU. Finding other parents with whom to continue contact, as in Ardal, Sulman and Fuller-Thomson (2011), also occurred in this study. Parents delineated the aspects of sharing their experience with others who 'understand them', and these parents were often from the support group. The group therefore acted as an agent of introduction for these parents, who otherwise had a lack of social contact within the physical confines of the NICU.

2.4 The Theory of Social support

The mothers interviewed described that social support was a key reason for attending the support group. The group provided a range of social supports as identified and

described by House (1981). However this research was unable to show if those who had better social supports were negatively affected by participating with those who had fewer social supports. These social interactions can be observed and managed in a group setting with facilitators but this does not continue once the group finishes. Consideration needs to be taken that those who are more emotionally vulnerable may become anxious or concerned about providing enough support for other group members. As the impact of support has been shown to be greatest for those who have little social support initially (Cohen, Schulz & Yasko, 2000) further research should provide a range of support groups, where participants are identified to have similar support needs. This would allow a better understanding of the role of social support within the group.

3 Significance of the findings

Caring for an ill child is known to be stressful, but this research extends and adds to this by looking at where parental emotional support in the NICU is lacking and where it needs to be provided. There is little evidence-based research addressing the provision of appropriate support to NICU parents, as described throughout this thesis. Thus this thesis contributes to the knowledge and literature of the NICU experience and support. These results can be combined with other research related to maternal mental health (Hynan, Mounts, & Vanderbilt, 2013), parent emotional support and early parent and baby attachment (Bowlby, 1989) to enrich the support available to parents to improve the parenting experience in the NICU.

This is the first research to examine parents' view of their NICU experience and to relate that to their support needs. Although other research has considered the

emotions that parents feel and the symptoms that they may display none has been able to link this to how support for these parents can be offered effectively. This thesis identifies that parents sought out friendships, support from those 'in the same situation' as they were, as well as consistent, sound professional support and information. Parents' identification that the support group was a key structure that allowed them to 'survive' the NICU experience was key in showing the importance of emotional support in the NICU. The areas that need to be addressed to meet parents' support needs were identified as well as how to address the nursing role to maximise the emotional support they can provide.

The identification of parent stress after discharge is also highlighted in this thesis. Parents described their on-going fear of their baby becoming ill and requiring readmission and as a consequence they avoided contact with others and some covered their babies. These parents were modifying their lives to manage their premature baby, and many had no professional support. This study showed that the time post discharge from the NICU is lacking in structured support, despite the high degree of parental distress. Parents sourced their own NICU supportive connections, with other post NICU parents, to manage this phase after discharge.

Parents try and bond with their babies in the NICU and the struggle that parents face is in managing the array of complex emotions while still maintaining their relationship with their baby. They look to the NICU staff to provide education, support and communication to enable them to manage the NICU admission. However these nurses themselves face a range of obstacles and this interferes with their ability to provide support for parents. NICU nurses work in a high stress and understaffed

environment (Oates & Oates, 1995), which leads to feelings of being professionally unsupported and unappreciated, as shown in Paper 3. Beyond this, nursing staff also reported in this research that they work in an environment that is cramped and crowded, preventing them from providing close physical and emotional support for all parents. Nurses indicated that they coped by forming a positive environment, without which it was hard to take on the role of emotional supporter.

Beyond the parent-nurse experience, nurses described a lack of education and training about the emotional care of patients. Nursing staff described the difficult dual role of decreasing the stresses in their staff team as well as managing the stress of the crowded NICU physical space. This led to their own education and professional training being set aside.

It is also important to recognise that despite the range of negative experiences and stress in the NICU for staff, that parents highlighted strong positive experiences with staff. At times these experiences and interactions enabled them to continue the NICU journey when they felt that they couldn't cope. It was these staff that parents relied upon and looked for in the nursery for 'unofficial' emotional support.

Potentially changing the NICU environment to be quieter, more private and a place where it is encouraged and possible for parents to have physical contact with their babies, could lower PSS - NICU scores in many NICU parents. Also targeting support to parents identified by the PSS-NICU as experiencing higher stress; older parents, parents of premature babies and parents of very premature babies, could prevent the post discharge distress experienced by these parents.

When the results from this study are triangulated, it is seen that the key message is that it is the complex and longitudinal NICU journey for parents and staff that needs to be considered, and not short-term support. Professional emotional support, such as the support group, is needed for parents during and after discharge. This support should be targeted at the high risk parents as identified in this thesis, but is also helpful for all NICU parents who attend the support group in the NICU. Nursing staff need support in terms of training and education and the provision of clinical supervision.

4 Implications of the findings

These findings can be translated into a modification of clinical services to better support staff and parents within the nursery.

Those parents interviewed and those who completed the PSS NICU survey in this research described a stressful and emotionally distressing experience in the NICU. The support received from NICU professionals, the NICU support group and family were important aspects to helping NICU parents survive their experience. The findings suggest that elements of this support need to be modified to suit the parent and baby demographic of each NICU. The support also needs to consider the needs of fathers and those who speak languages alternative to the primary language of the NICU. The importance of programs and initiatives that address the nurses' need for on-going education, to address the important element of parent emotional support, has been recognised in this research. This lack of training contributes to sporadic emotional care for parents at the end of their baby's life (Wright, Prasun, & Hilgenberg, 2011).

The provision and structure of support needs to be seen as a more core component of the NICU services. To reduce parental stress there needs to be an evidence base for the development of a support group and training of a group of professionals who are able to cofacilitate the group. In this study parents at high risk of stress were identified during the NICU admission of their baby, which allows for the active recruitment of parents for the group. Assessing parental stress throughout the NICU admissions allows a dynamic approach to care of parents, to match the changing and stressful NICU environment. Nursing participants highlighted that an improvement to professional education needs to be a valued part of nursing training. This training needs to be supported by the NICU and offered as an on-going training program, and as outlined by this research, a requirement for all nurses who are new to the NICU environment. Implementing education and training that is evidence based requires specific nurse dedicated training times, supervision and evaluation of its effectiveness (Melnyk et al., 2010).

Addressing the areas of stress with a psychosocial intervention such as the parent support group, may not only decrease maternal stress but also shorten the length of stay of an infant, therefore increasing the time that the baby has at home as an infant (Nearing, Salas, Granado-Villar, Chandle, & Soliz, 2012). While the parent support group was helpful during the baby inpatient stay, a post discharge group should be considered, but with a modified approach covering the themes found to be most important at that stage of the NICU experience. This needs to focus, in particular, on parent anxiety about future baby illness and the changes to their behaviour to prevent illness in their baby.

5 Contribution of the Findings

This thesis contributes to the NICU parent support literature by highlighting parents' emotional journey and parent and nurse views of the support that they need and the support they receive. Having this knowledge of the stressful components of the NICU for parents allows changes to a range of interventions offered to parents.

Recommendations for nurse training and professional development and modifications to parent support programs and providing parameters to delineate those parents at higher risk of stress can also be drawn from this research. Nursing staff identify that they need more senior staff support, formal training in providing emotional care to parents as well as a suitable physical space and staff structure to enable free and easy communication with parents at the bedside.

Recognising and naming the themes of stress that parents experience during and after their NICU experience is also an important component to this research. In this research the parents who are most likely to experience the highest levels of stress in the NICU were older parents, parents of twins and those with very early premature babies. NICU parents described challenges in managing the parental role in the NICU, forming a good relationship with staff and accessing enough emotional support. In turn the nursing staff identified that they are at times overwhelmed by the support needed by parents and their large workload. Nurses identified that there were gaps in further education and training as well as provision for supervision and training of new staff without negative effects on patient care. The parent support group was a useful support program and identified as such by parents and nurses in this research.

By taking the results and using them to modify support it is possible to identify parents more at risk, provide a group that uses education and support as a combined structure and encourages parent-to-parent interaction. This support group environment was seen as less threatening and frightening by parents and allowed them to build their own support structure from those who were experiencing a similar situation with their own baby in the NICU. Provision of feedback to nurses about the group and concerns within the group should be introduced to allow the valuable learning from the Parent Support Group to be shared and used to modify aspects of the nursery experience. Parents continue to feel overwhelmed, avoid mixing with others and describe an initial feeling of detachment after their baby is discharged from the NICU. These lingering issues after discharge are important to address when, in particular, we consider the need for a strong attachment relationship for mother and infant (Jeffries, 2014). Identifying the need for mothers to continue to have a supportive, understanding network of peers was identified as being crucial to their relationship with their baby in this and other research (Smith, Steelfisher, Salhi, & Shen, 2012; Lindsay et al., 1993).

5.1 Contribution to the structure of parent support groups.

This is the first parent group to trial a structured delivery of support and information and to then research parents' views on the support. This research has outlined that a group needs to have both emotional care and the sharing of stories as well as professional support and education to be useful to parents. Continuing to examine that a group does not sway too much to one form of content is necessary to maintain the balance of information and emotional care. The participants in the group should be carers/parents of baby's in the NICU so that there is a common shared experience.

Information provided to participants in the group should be delivered early on in the baby's admission. Staff should encourage parents to attend the group to maximise the opportunities for the parent to seek professional support and guidance as well as to develop supportive relationships with other parents. Staff should be aware that family support and family involvement in the baby's care and medical state is usually helpful but can be overwhelming and unhelpful to parents at times. Information within the group should be available in both a written and verbal form so that partners, often fathers, who do not attend are able to read the information away from the group. Providing some core information in multiple languages would also assist parents who do not speak the first language of the NICU. Each group should determine if interpreters are appropriate for their population and should be considered for parents who wish to attend the parent support group but who do not speak the first language of the country of admission.

Fathers' groups, or encouragement of fathers to attend the support group, should be made as their emotional needs are less known but appear to be similar to the mothers' needs when a baby is in intensive care (Nagorski Johnson, 2008).

Providing channels for referral for more specialised social work and mental health follow up while the parents are in the NICU and after discharge is key to continuing the support once the group session time has finished. Post discharge support groups may be beneficial for some parents who require more information or supervised experience with their babies (Burnham, Feeley, & Sherrard, 2013). Further qualitative research determining themes raised by parents with support after discharge, would allow any gaps in a professional discharge support group to be addressed.

5.2 Contribution to Nursing training

Recognising that there is a need for nursing staff to cope with the parents' needs for support highlights an area lacking in nursing training. Nursing education, provided either in the undergraduate nursing course or when nurses complete postgraduate training in neonatal intensive care, could address this. Elements of education and training such as reflective practice (Lawrence, 2011), the use of supervision (Taylor, 2013) and mentorship for junior nurses working in the NICU could be implemented to better support staff in this complex role of emotional support. Identifying new graduates who work in the NICU and assisting them with these skills will build better skilled junior staff (Maxwell, 2011) and is core to preventing senior staff from feeling overwhelmed.

6 Methodological strengths and limitations

The design of this study using mixed methods was to allow a broad view of both interview and survey based data for triangulation. The qualitative process, interviewing parents at two times of their NICU experience, and the nurse interviews, provided rich data from which to draw conclusions. The rigour and quality of the elements of this research and the combined interview and survey data contributed to the trustworthiness and rigour of the research findings.

6.1 Methodological Strengths

The application of mixed methods in this thesis allowed both qualitative and quantitative data to be used to better understand the participant NICU experience from both nurse and parent perspectives.

Using both research styles prevented the parent interview data being discredited by the lack of a larger scale study. Two separate groups of participants were recruited for the parent research one group for the parent interviews and another for the PSS NICU survey. The quantitative data showed a high rate of stress, confirming and supporting the theory that the NICU is distressing and that parents seek support. The qualitative data also supported the quantitative data by giving it a context in which to understand the PSS NICU ratings. By combining both qualitative and quantitative research it was possible to both use a survey and face-to-face and telephone interviews to ensure that the breadth and depth of the effect of the NICU was addressed. Including the views of staff and parents, this research is unique in that it can triangulate the data and synthesise an overall NICU stress experience and the view of supportive interventions.

6.1.1 Qualitative research evaluation

This research focussed on addressing the eight areas of quality discussed by Tracy (2010). These are 1) having a worthy topic, 2) rich rigor, 3) sincerity, 4) credibility, 5) resonance, 6) significant contribution, 7) ethics and 8) meaningful coherence.

1. Topic – this topic was chosen by recognising gaps in the research, which needed to be addressed to provide evidence based clinical care for patients and education for staff. This theme of defining parent support needs was followed through each element of this research project and recommendations were given for professional practice.

2. Rigor – “is the means by which we demonstrate integrity and competence” Aroni et al., 1999. This was achieved in this study by ensuring that interviewers and the author of this thesis maintained an audit trail. The

process of sampling of participants was clearly outlined for each study and each participant group was relevant to the research questions posed. The rigor was further supported by the thesis supervisors checking themes against raw data, provision of quotes from participants from the data and triangulation.

3. Sincerity and solid theory – One of the central theories describing the importance of the relationship between parent and child is attachment theory (Bowlby, 1969). This theory describes the primary carer relationship that is built between child and parent, the importance of this relationship and changes to this and their effects have long-term consequences. This research was guided by this description of the first relationship and the parental stress related to the lack of contact with their baby. Grief has been described as the emotional core of the experience of delivering prematurely (Davis & Stein, 2004, p 21; Romesberg, 2004). Assessing the parents' view of support provided was informed by the need for parents with grief to seek help and support from others.

4. Credibility was addressed by using well-researched methods including participant interviews and presenting this research to other researchers and those who work in the NICU at conferences and training presentations for feedback. Reflections upon these interactions were made through maintaining an audit trail and supervision. Using combined interview and quantitative research methods in the same population also improved the credibility.

5. Resonance – was addressed in this research by remaining open and receptive to participants interview results and using a method of both deductive and inductive analysis.

6. Significant contribution – by addressing a topic that had little clinical research and little evidence based literature upon which to build a parent support group; this research contributed to an area lacking research.
7. Ethics - This research was granted ethical approval by both Child, Youth and Womens Health Network Human research ethics committee and the University of Adelaide ethics committee. Confidentiality, anonymity and safety of the participant were addressed in the structure of the research protocols, information sheets and consent forms. Participants were also offered mental health care if this was required after the interviews or survey completion.
8. Meaningful coherence – the bringing together of this information from the four studies into this thesis and through the structure of the research papers allows the participants’ voice to be heard and for meaning to be given to their experience.

5.1.2 Quantitative Research Evaluation

The PSS NICU (Parental Stress Scale – Neonatal Intensive Care Unit; Miles, Funk & Carlson, 1993) was the quantitative instrument used in this research. The PSS NICU is an instrument developed to measure stress of parents who have inpatient babies in the neonatal intensive care unit. This instrument was developed after a review of stress theory, literature reviews and consultation with experts and interviews with parents (Miles, Funk & Carlson, 1993). Construct validity was supported by this thorough background investigation and information collection and factor analysis. High internal consistency and split half reliability was also found for the PSS NICU

scale in the United Kingdom (Franck, Cox, Allen, & Winter, 2005) and in Italy (Montirosso, Provenzi, Calciolari, & Borgatti, NEO-AQUA Study Group. 2012). This study confirmed that the PSS NICU is able to be used in Australia with high internal consistency and applicability to the parent NICU population.

6.2 Methodological Limitations

As with other research, only participants who consented were interviewed, therefore those who did not consent were unable to have their views presented. Their views may have been greatly different, or they may have been so distressed that they did not want to speak about their experience.

Although nursing perspectives were gathered in the nurse interviews, other medical and allied health perspectives were not assessed. Allied health professionals such as speech therapists, occupational therapists and nurse practitioners are often heavily involved in the care of babies in the NICU. Often these specialties also have a larger amount of hands-on therapies with the NICU babies and direct teaching of their parents. Input from this population may have added to the suggestions for group support, or revealed other aspects of parent stress that, as yet, are unknown.

Quantitative assessments of nurse experience to further broaden the understanding of their stress and view of role were not completed and would have complemented the nurse interview themes.

Fathers and other family members were also not interviewed in this research, this could have added to the parent experience of the NICU.

The sampling in this research was limited by not knowing if the data represented the NICU parents at this NICU unit, or if they represent other NICU parents elsewhere in

Australia. At the time of this research these data were not available, with most data being collected about the baby and its health and some about the mother and her health, but little to do with in depth demographic information or information about parental mental health. Without these data it is difficult to truly extrapolate these results. This service was located in a large public hospital with a range of highly experienced staff. Other services with a smaller NICU unit and who provide care for infants who are of better health and later gestational age at birth may therefore not find that this model of supportive care is appropriate for their population. A trial of this group and a research project within a location with these infants would be appropriate to ascertain its suitability.

7 Practical Limitations in this Research Population

The intense nature of the neonatal intensive care units and the very large multidisciplinary teams can overwhelm a parent and contribute to a low recruitment rate of research participants. Recruiting and following up parents prior to discharge and performing on-site interviews allowed the information from parents and nurses to be recent and applicable at the time of interview. Having a flexible timetable for parents also ensured that the participants took up the opportunity without taking away time that was needed for other medical or nursing interventions.

Many babies move from the intensive care unit in a large hospital to smaller, more regional hospitals, and therefore follow up of research participants can be challenging.

8 Suggestions for Further Research

The findings from the research in this thesis provide an understanding of the emotional distress of parents with babies in the NICU, the view of NICU nurses about their own role in supporting parents and their capabilities in this role and the areas that parents find the most distressing during their baby's NICU stay. These findings expand and provide detail to parents support groups for inpatient and outpatient NICU families, interventions that may be helpful within the nursery and methods in which to expand nursing support and training for emotional care of parents.

Further research to look at parents' stress before and after attending a support group session could give further input to designing and refining the delivery of a group. Using pre and post support group attendance PSS NICU scores could further delineate the role of specific support, including areas to be addressed in each support session. Developing and trialling a manual for the support group could also be an avenue of further to research, to improve the clinical care of parents but to also allow other researchers to use the same delivery method as undertaken in this research. Further data related to the baby's physical state and length of stay may have further strengthened this research, but at the time that this study was undertaken it was unavailable to this researcher. However including this data would allow consideration of the effect of attending the group on baby length of stay, which could make a great difference to the uptake of a formal parent NICU support model in a neonatal nursery.

To better understand the support needs of parents further research that examines this in more depth is needed. A further understanding of the parents' view of the staff role in support is needed in the NICU setting. In particular identifying specific helpful and non-helpful behaviours of staff would allow the NICU to modify their approach to

parent support. In line with this, Identifying the most and least helpful elements of the support group would also allow modifications to be made to the group and maximise its benefits for parents. Examining the components of the group, providing a manual and replicating it at other sites would also provide further data for a broader view of parent emotional care.

Integrating the use of assessments such as the Newborn Behavioural Observation System (Nugent, 2007) with parents of NICU babies, or an attachment behaviour model such as the alarm distress baby scale (Guedeney 2001) would strengthen the research with an observation of interaction between parent and baby. This could then be triangulated with the results presented for this thesis.

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APPENDICES

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MEDIA

Friday 4 April 2014

Neonatal nurses need more training to support parents

New research from the University of Adelaide shows that nurses working in neonatal intensive care feel poorly equipped to provide the intense emotional support needed by parents, and they require more training and improved facilities to carry out their work effectively.

These are some of the findings in a paper published in the [Journal of Clinical Nursing](#), the first paper of its kind to explore the nurses' own views of their role in neonatal care and the emotional support they provide.

"Nurses working in neonatal intensive care have high emotional demands placed upon them, in addition to providing a high level of care to premature babies," says lead author Dr Melanie Turner, who conducted this research as part of her PhD in the University of Adelaide's School of Psychology.

"Parent support has become a core part of the nurses' role, but many of them have not been trained for the level of mental health care or emotional support required. They feel they need additional training to be able to assist families in a meaningful and consistent way.

"Also, while some staff are very experienced in the role, neonatal units often have junior staff working on placement, because they're still learning the specialisation of neonatal intensive care nursing. These junior staff can find it difficult to support families who are experiencing an extremely emotional time in their lives," Dr Turner says.

Figures show that 20,700 or 8% of all Australian babies were born prematurely in 2008. Dr Turner says many hospitals simply don't have the physical space to cope with such large numbers of premature babies.

"An issue that is common among the neonatal nurses is the lack of physical space to work in. Many of the newer hospitals are better equipped, but it's the bigger, inner-city hospitals that handle the most extreme cases, and these are often constrained for space," Dr Turner says.

Other issues identified by nurses include: movements of staff from shift to shift leading to inconsistent communication with parents; language and cultural barriers; busy workloads and rapid patient turnover.

"These issues are very real concerns for nurses and the level of care they're able to provide," Dr Turner says.

"Neonatal nurses view their jobs as rewarding but difficult. We hope the recommendations made in this paper will help lead to improved support for nurses, and ultimately for the families who have special care needs at this time."

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NOTE:

This appendix is included on pages 211 of the print copy of the thesis held in the University of Adelaide Library.

The Advertiser, Saturday edition, 5th April 2014, page 34.

NOTE:

This appendix is included on pages 212 of the print copy of the thesis held in the University of Adelaide Library.

Neonatal nurses struggle to support parents

Neonatal nurses struggle to support parents

By Karen Keast | Date of Posting: 08-04-2014

New research shows neonatal nurses are struggling to provide emotional support to parents in the neonatal intensive care unit (NICU).

[University of Adelaide](#) research reveals a lack of physical space in the unit, little time for nurse-to-parent conversations, and language and cultural barriers are hindering nurses in the level of care they can provide to parents.

The research is the first to investigate neonatal nurses' views of their work and the emotional support they provide.

Figures show eight per cent of Australian babies, or 20,700 babies, were born



prematurely in 2008 while earlier studies reveal nurses' informational support can relieve anxiety and postpartum depression in mothers of premature infants. Researchers recommend offering education and training to staff in the provision of emotional support for parents, and changing the physical layout of NICUs to provide a quieter, more private space for staff and

parents.

They also suggest providing more interpreters for non-English speaking parents while staff should also have access to resources, such as support groups for parents to use.

The study, [published in the Journal of Clinical Nursing](#), interviewed nine neonatal nurses, aged between 32-58, working at a large tertiary teaching hospital in Australia.

Lead author Dr Melanie Turner, who conducted the research as part of her School of Psychology PhD, said nurses working in neonatal intensive care cope with high emotional demands while providing a high level of care to premature babies.

“Parent support has become a core part of the nurses' role but many of them have not been trained for the level of mental health care or emotional support required,” she said.

“They feel they need additional training to be able to assist families in a meaningful and consistent way.

“Also, while some staff are very experienced in the role, neonatal units often have

junior staff working on placement, because they're still learning the specialisation of neonatal intensive care nursing.

“These junior staff can find it difficult to support families who are experiencing an extremely emotional time in their lives.”

The research states while participants in the study found their role enjoyable and rewarding, it was also extremely challenging.

“Participant accounts are clear that both lack of senior staff and understaffing in general added to the burden of a busy and emotionally intense environment, one in which neonates have severe and life-threatening illnesses and parents grieve,” it states.

“From this study, it is apparent that training in how to deal with parents and support them through a difficult time is lacking.

“What participants in this study did not discuss, but which these results make evident, is the need to consider the stress and emotional state of nursing staff.”

Dr Turner said nurses also identified issues such as shift changes leading to inconsistent communication with parents, busy workloads and rapid patient turnover.

“These issues are very real concerns for nurses and the level of care they're able to provide,” she said.

Premature Babies & Beyond

https://www.facebook.com/PrematureBabiesandBeyond/posts/452176018262636?stream_ref=0

April 11 ·

Lead author Dr Melanie Turner, who conducted the research as part of her School of Psychology PhD, said nurses working in neonatal intensive care cope with high emotional demands while providing a high level of care to premature babies.

“Parent support has become a core part of the nurses’ role but many of them have not been trained for the level of mental health care or emotional support required,” she said.

<http://www.ncah.com.au/news-events/neonatal-nurses-struggle-to-support-parents/2056/>



Neonatal nurses struggle to support parents

New research shows neonatal nurses are struggling to provide emotional support to parents in the neonatal intensive care unit (NICU). University of Adelaide research reveals a lack of physical space i.

[NCAH.COM.AU](http://www.ncah.com.au)



ACNN SA Branch
AGM Dinner Meeting
June 5th 2014
“Tiffins On the Park”

1730 hrs Pre-dinner drinks
1800 hrs AGM and election of office bearers
1900 hrs 1st Course
1930 hrs Presentation



Speaker: Dr Melanie Turner
(Adelaide University)

Topic: The Neonatal Nurses' view of their
role in Emotional Support and its
Complexities

Cost Members \$55.00 per person
Non Members \$60.00

For further information and bookings please

Contact Nettie Birtles or Mary Wooden @ FMC
Diana Johansson @ WCH
Leanne Mills or Trish Viegever @ LMH

Or payment via post PO Box 1710, Adelaide 5001

Dietary requirements will be catered for if requested
Numbers and payments required by COB 30/5/14

NOTE:

This appendix is included on pages 217-218 of the print copy of the thesis held in the University of Adelaide Library.

AWARDS

The Connell Werry Prize

Terms of Reference



Description:

The Connell Werry Prize is an annual prize awarded to an Advanced Trainee in Child and Adolescent Psychiatry for the most outstanding paper or poster presented at the annual meeting of the Faculty of Child and Adolescent Psychiatry. The Prize honours Dr John Werry and Dr Helen Connell, who were pioneers in the field of Child and Adolescent Psychiatry in New Zealand and Australia.

Eligibility criteria:

The prize is made to an Advanced Trainee in Child and Adolescent Psychiatry who presents the most outstanding paper or poster at the Faculty of Child and Adolescent Psychiatry's Annual Scientific Meeting.

Form of award:

The prize consists of a certificate together with \$1000 to be spent attending a Faculty of Child and Adolescent Psychiatry Annual Scientific Meeting or an international conference in the field of child and adolescent psychiatry.

Frequency:

The Connell Werry Prize is presented annually.

Application Process:

Advanced Trainees who meet the criteria and whose abstracts are accepted for presentation at the Faculty of Child and Adolescent Psychiatry's Annual Meeting will be automatically considered.

The Prize may be given to one person, or if there are no suitable applicants, the Prize will not be awarded in that year.

Application deadline:

It is the applicant's responsibility to ensure that their abstracts for the Faculty of Child and Adolescent Psychiatry Conference are submitted before the due date. All abstracts accepted for presentation will automatically become eligible.

Selection Process:

Abstracts will be judged by the following selection criteria:

- Overall contribution to child and adolescent psychiatry
- Demonstrated developmental focus
- Original contribution to Child and Adolescent Psychiatry
- Potential for ongoing work in Child and Adolescent Psychiatry

If a Prize is awarded, it should be formally presented during the College Ceremony at the RANZCP's next College Congress. If the Prize winner is unable to attend the College Congress, the Prize will be announced in absentia. The Prize does not include support for an airfare for the winner to attend the Congress. If possible, the Prize winner will also be announced at the FCAP Conference Dinner.

Award Selection Composition:

The judging panel of the Prize will comprise of the Conference Convenor and at least one member of the Faculty of Child and Adolescent Psychiatry Executive Committee.

Contact information:

Please contact Membership Services on 03 9601 4962 or email awards@ranzcp.org.

Previous recipients:

2001 Dr Kathy McGuckin (NSW)

The Development of a best evidence medical education module for psychiatry trainees in child and adolescent psychiatry

2002 Dr Andrew Cox (NZ)

Adolescent autonomy and consent to treatment

&

Dr Michelle Fryer (QLD)

Seclusion use in child and adolescent psychiatry: a retrospective study

2003 Dr Karen Gaunson (VIC)

Pilot magnetic resonance imaging study of the orbitofrontal cortex in young people with an emerging borderline personality disorder

2005 Dr Beate Harrison (VIC)

Attention Deficit Hyperactivity Disorder and Anxiety Disorders in Primary School-Age Children: Association with Neurodevelopmental Deficits

2008 Dr Melanie Turner (SA)

One Finger to Bond With - The Establishment of A Therapeutic Support Group For Parents Of Babies In Neonatal Intensive Care

2009 Dr Yolisha Singh (NZ)

Innovative Developments and Research in the Youth Forensic Field in Auckland, New Zealand

Approved: September 2008 (RANZCP Manager, Membership Services)

For review: July 2010

Connell Werry Prize Certificate



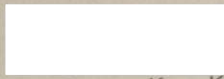
The Royal
Australian &
New Zealand
College of
Psychiatrists

Connell Werry Prize 2008

Awarded to
Dr Melanie Turner

The Connell Werry Prize is awarded to an Advanced Trainee in child and adolescent psychiatry for the most outstanding paper or poster presented at the annual meeting of the Faculty of Child and Adolescent Psychiatry.

The Prize honours Dr John Werry and Dr Helen Connell, who were pioneers in the field of child and adolescent psychiatry in New Zealand and Australia.


Professor Ken Kirkby
President
25 May 2009

12 May 2010

Dr Melanie Turner
By email to: melanie.turner@bigpond.com

Dear Dr Turner,

Re: 2010 Pfizer Congress Presentation Award

It is my great pleasure to advise that you have been awarded the 2010 Pfizer Congress Presentation Award, for your presentation at the 2010 RANZCP Congress entitled "A qualitative research project into the experience of being a neonatal intensive care patient".

Congratulations on this achievement. The field of eligible presenters was strong, and the judges were very impressed with your work and hope that the award will encourage you to continue further with your research career.

The Pfizer Congress Presentation Award was established in 1996, to recognise and encourage young researchers to participate in the RANZCP's Annual Congress. It is given to the RANZCP trainee or recent Fellow who has given the best oral presentation at the RANZCP Congress in the category of new research.

The Award comprises support to the value of \$10,000 to attend a major international psychiatry meeting in the following 12 months.

I will be in touch again with you in due course regarding the provision of the award.

Kind regards,



Jon Cullum
RANZCP Manager, Membership Services

Pfizer Congress Presentation Award 2010

doi: 10.3109/10398562.2010.497630

Australian Psychiatry August 2010 vol. 18 no. 4 368-380

GRANT APPLICATION



THE ROYAL
 AUSTRALIAN AND NEW ZEALAND
 COLLEGE OF PSYCHIATRISTS

BOARD OF RESEARCH
YOUNG INVESTIGATOR GRANT
2008 APPLICATION FORM

Name (applicant)	Dr Melanie Suzanne Turner	
Project title	A pilot study of a structured parent support group with parents of premature babies	
Position	Psychiatry Registrar – Advanced Training in Child and Adolescent Psychiatry – Chief Investigator in this study	
Address	PO Box 203, HIGHBURY, SA 5089	
Telephone	0408152810	
Email	melanie.turner@bigpond.com	
Supervisor (name & contact number)	Dr Phill Brock, Consultant Psychiatrist – Director of Boylan Ward Inpatient Services, Womens and Childrens Hospital Adelaide Ph – 08 8161 7000 Assoc Prof Anna Chur Hansen – University of Adelaide Faculty of Psychiatry Ph – 8222 5141	
Amount Requested	\$AUS 3900	
Signatures	Applicant	
	Supervisor	
Date	2008	

<p>PROJECT SYNOPSIS (max 300 words)</p>	<p>I am a psychiatry registrar in my last eighteen months of subspecialty training in Child and Adolescent Psychiatry. For the last nine months I have been working in the perinatal and infant mental health (PIMH) team at the Womens and Childrens Hospital. As part of this role I see women antenatally and up to one year postnatally who present with difficulties with depression, anxiety, self harm and a range of other issues. I have frequently been asked to provide therapy to mothers of recently discharged babes from NICU (neonatal intensive care unit) or SCBU (special care baby unit). This is often due to the mother having difficulty bonding with her child and feelings of detachment in the relationship. Although I was able to offer one on one therapy for a small number of women I wanted to offer help to the majority of parents. Hence the new NICU/SCBU parenting group was developed.</p> <p>The purpose of this study is to examine if offering a group intervention for parents of NICU SCBU infants, based on infant therapy and developmental therapy techniques, can improve the relationship between a child and its parent and shorten the infants length of stay in NICU or SCBU.</p> <p>Studies done on a variety of interventions when infants are in the nursery have shown that the outcomes from supportive therapy for NICU/SCBU parents can be</p> <ul style="list-style-type: none"> - Shorter length of stay for the neonate - Increased parental confidence with the infants care - Decreased parental anxiety - Improved relationship between parent and infant <p>There are very few detailed journal articles about groups that are offered in a face to face arrangement. This group provides the chance to look at the benefits from group therapy for this cohort.</p>
<p>AIMS AND HYPOTHESES:</p>	<p>The aim of this study is to determine if running a support group to this cohort provides a benefit to either parent or child or both. Based on the small group of studies completed overseas there is an overall benefit to parents, particularly in their stress levels and levels of depression. They also report better relationships with their children.</p> <p>There have been no studies of face to face groups in Australia and therefore this pilot study will allow a closer examination of this type of group in the Australian medical and cultural setting.</p>
<p>BACKGROUND AND LITERATURE REVIEW (selected):</p>	<p>The centre for neonatal intensive care in South Australia is the Womens and Childrens Hospital. Servicing this centre is the Perinatal and Infant Mental Health Service (PIMHS) , for whom I work. Over the last twelve months there has been an increasing number of referrals to our mental health service from clinicians who are caring for infants who were born prematurely. These referrals</p>

were made due to a number of issues but in general all had been overlooked at an early stage of the baby's life. We appeared to be missing the most vulnerable time, when there is maternal traumatic experience and premature birth (Muller-Nix, Forcada-Guex, Pierrehumbert, Jaunin, Borghini & Ansermet, 2004)

As a result of an increasing identification of children who had feeding and bonding issues after their NICU or SCBU stay I considered initiating an early intervention program. Researchers such as Eidelman and Feldman (2006) have already found that premature infants are at higher risk for difficulties with mother-infant interactions as well as other cognitive delays. The most researched program for a support program for NICU SCBU parents is the COPE program from the USA. COPE (Creating Opportunities for Parent Empowerment) was developed by Bernadette Melnyk, a Professor of Nursing in Arizona. Her investigations into NICU parents showed (Neonatal Advanced Practice Nursing Forum)

- Low birth weight (lbw) infants experience varied adverse physical/mental/behavioural outcomes persisting beyond school age
- Parents of preterm infants experience high stress levels and are usually inadequately prepared for their experiences
- Increased rates of parental depression and anxiety are evident in NICU families
- NICU parents have increased rates of dysfunctional parenting

Melnyk's work was reviewed by Browne and Talmi who noted that parental behaviour is the most significant environmental modification that can be provided for high-risk infants.

COPE exposed infants and families have lower parental stress, increased confidence in parenting skills, more developmentally sensitive interactions with their babies and less depressive and anxiety symptoms (Melnyk et al., 2001)

The study by Melnyk showed that babies weighing under 1500grams went home an average of eight days sooner if their parents completed the COPE program. (Melnyk 2006)

At present there are no programs or inpatient support groups aimed at parents of NICU /SCBU babies in any hospital in South Australia. Due to the increasing number of referrals of parents and babies after discharge from NICU SCBU for mother infant therapy with our PIMH team, I felt that there was a need for a group such as COPE. COPE is provided by tapes and booklets given to parents but as I was unable to access these I felt that a face to face session aiming to cover the same topics was appropriate.

COPE covers

- The appearance and behavioural characteristics of premature infants and how parents can participate in their infants care, meet their infants needs, make interactions with their infant a more positive experience and aid in their infants development.
- Activities that assist parents in implementing the experimental information, such as recognising their infants alert states and stress cues, and identifying special characteristics of their infants.

Lindsay et al., outlined the use of parent of parent support at Butterworth Hospital in Michigan USA. The provision of this group improved maternal mood states, maternal-infant relationships and improve the home environment.

In Norway there was a study completed by Kaaresen et al., which looked at the result of eight sessions by specially trained nurses with NICU parents. This showed that this intervention reduced parenting stress levels to one comparable with their peers without NICU babes. The follow up study (Kaaresen et al., 2008) also showed decreased stress levels in parents 2years after completing the sessions. A Swiss study (Forcada-Guex et al.) and Singer et al.,’s research outlined that the main clinical goal should be to support a healthy parent-infant relationship in the NICU and in the first few months of life.

At present there are very few other studies examining the effect of a group on the parent or NICU infant. Therefore my group will be initially examined by using a pilot study.

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7. Melnyk BM, Feinstein NF, Alpert-gillis L Reducing Premature Infants length of stay and improving parents mental health outcomes with the Creating Opportunities for Parent Empowerment (COPE) neonatal intensive care unit program: a randomised controlled trial

	<p>Paediatrics 2006; 118: 1414 - 1427</p> <p>8. Melnyk BM, Alpert-Gillis L, Fischbeck Feinstein LF et al., <u>Improving cognitive development of low-birth-weight premature infants with the COPE program ; a pilot study of the benefit of early NICU intervention with mothers.</u> Res Nurs Health 2001; 24 373-389</p> <p>9. Muller-Nix C, Forcada-Guex M, Pierrehumbert B et al., <u>Prematurity, maternal stress and mother child interactions</u> Early Human development 2004 Sep;79(2):145-58</p> <p>10. Singer LT, Salvator A, Guo S, Collin M, Lillen L, Baley, J. <u>Maternal Psychological distress and parenting stress after the birth of a very low birth weight infant</u> Journal of the American Medical Association 1999 March 3;281(9):799-812</p>
<p>METHODOLOGY:</p>	<p>Selection Criteria The parents attending the sessions must have a child or children admitted to NICU or SCBU or discharged from either unit at the WCH within the last three months. The parent must attend at least one full session of the three sessions available.</p> <p>Exclusion Criteria Those who have a child in a NICU or SBCU outside of the WCH</p> <p>1. Plan and Study Design</p> <p><u>Qualitative interview and length of stay - Part 1</u> Each parent will be offered, at the end of a group session, the opportunity to participate in the study. Participants will be given a consent form and information sheet which will explain the two parts to the study</p> <ol style="list-style-type: none"> 1. The qualitative interview <ol style="list-style-type: none"> a. This interview will be done between two and four weeks after they have attended a full group session. The interview will have three set questions <ol style="list-style-type: none"> i. What was it like being a NICU/SCBU parent? ii. How would you describe your relationship with your baby? iii. Did the group sessions address issues relevant to you? <p>This interview will take place either at the WCH or over the telephone. This interview will be transcribed at the time of interview.</p> <p>Qualitative interviewing speaks to how the participants feel about what is happening and its meaning in their lives. The insights recorded from the interviews can be very helpful to those who may want to replicate this model elsewhere. At present there are no quantitative interviews</p>

	<p>available that would allow appropriate evaluation of this group. The qualitative information will be used to</p> <ol style="list-style-type: none"> 1. Determine the parental thoughts about the group 2. Reform the structure of the group to better meet the needs of the patients 3. Further refine the group to allow training for other centres who may want to start a NICU/SCBU group <p>I will examine the qualitative data with qualitative content analysis, looking at themes in the interviews and coding those themes. A coding agenda will be derived once I have transcript of each interview and am able to look at the common themes.</p> <p><u>Quantitative Analysis - Part 2</u></p> <p>The Parental Stress Scale :Neonatal Intensive Care Unit (Margaret S Miles, 2002) is a scale specifically designed for assessment of stress in parents of babes in NICU or SCBU. It has been used in the US and UK and has been found to be suitable for both countries. This is a 34 question tool that can be completed at interview or filled out by the parent alone. This tool will be offered to all parents who are in the NICU/SCBU units of the Womens and Childrens Hospital in Adelaide over four months in 2009 (the exact dates are yet to be confirmed). Parents will indicate whether they have attended a support group session or not.</p> <p>This scale will be scored using Metric 2 – the overall stress level of a parent of NICU infants. The three a priori scales are – infant appearance, parental role alteration and sights and sounds.</p> <p>Scale scores are calculated by averaging these stress responses for the items on each scale and for the total scale. The average for each scale will be determined and then compared amongst the two groups of parents.</p> <p>These results will show the level of stress of parents in the NICU/SCBU and also whether there is a decrease in these scores when the parent attends the support group. These scores can also be interpreted with Metric 1 – which will allow an analysis of the level of stress occurring with particular interventions such as blood taking.</p> <p><u>Qualitative Arm - Part 3</u></p> <p>15 to 25 nurses will be interviewed with the following questions</p> <ol style="list-style-type: none"> 1. How do you feel most parents cope with having an infant in NICU/SCBU? 2. Do you feel able to manage their distress? 3. Has the parent support group been helpful for parents? <p>This will be analysed with thematic coding, similar to Part 1 of the study.</p>
<p>DATA ANALYSIS:</p>	<p>I will examine the qualitative data with qualitative content analysis, looking at themes in the interviews and coding those themes. A coding agenda will be derived once I have transcript of each interview and am able to look at the common themes.</p>

	<p>The COPE program in the US, which provides support for parents of NICU infants, shortens the length of stay of infants between 4 to 8 days compared to those who do not complete the program. The length of stay of the participants infants will be compared to the 2007 mean length of stay for infants in the WCH nurseries.</p>
<p>ETHICAL CONSIDERATIONS</p>	<p>The main consideration is the collection of interview data and the keeping of it. This will be achieved by having the data kept on site in the Perinatal and Infant Mental Health (PIMH) Office at the Womens and Childrens Hospital with all data assigned a number; the child with a suffix 'a'. The data will initially be kept on paper in the PIMH office in a locked filing cabinet. It will be transferred ,with the assigned numbers and no names used, to electronic form which will be stored on a flash drive with a password lock. This information will be used by me to complete my research.</p>

BUDGET:

(including rationale for costs and all inclusions)

A key part of this group are - Premature baby dolls required to help parents desensitize to lifting, holding and wrapping very low birthweight infants, each is the right size and weight for a variety of ages of infants from 26 weeks to 35 weeks.

\$100 per doll, 10 dolls = \$1000

To encourage participation in the group and to promote self care- I also provide lunch for the parents that attend and this helps to encourage self care while in the hospital with their infants (the hospital doesn't consider the parents patients and food is not provided), I have funding for six months only and would like to continue to offer this until the end of my research.

\$50 per week x 52 weeks = \$2600

I am collecting and analysing the data myself and need assistance to obtain qualitative analysis texts and software to examine the data.

\$300 for books

The total for the research budget as outline above is \$3900



THE ROYAL
AUSTRALIAN AND NEW ZEALAND
COLLEGE OF PSYCHIATRISTS

24 September 2008

Dr Melanie S Turner
PO Box 203
Highbury SA 5089

Dear Dr Turner,

RE: Young Investigator Grant application May 2008

Thank you for re-submitting your methodology for your pilot study of a structured parent support group for parents of premature babies. I am pleased to confirm that the Board is satisfied with your revised methodology and is now happy to award you a grant of \$3900.00. I will arrange for payment to be sent to you shortly.

I wish you all the best with the project and your future endeavours.

Kind regards

Associate Professor Mal Hopwood
Chair, Board of Research

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PRESENTATIONS

Presentation April 2010, RANZCP Congress

Auckland, New Zealand/

**The neonatal nursery
experience of South Australian
Parents**

Research into support for parents of babies
in neonatal intensive care and special care
baby unit.

Dr Melanie Turner
Consultant in Child and Adolescent Psychiatry
Child Youth and Womens Health Service, SA
PhD candidate - University of Adelaide



The South Australian NICU

- 5000 babies a year are admitted to intensive care units throughout Australia.
- Most babies stay in the NICU or SCBU until they reach their due date, which for many is between 8 and 12 weeks.
- Over 40% of premature deliveries are associated with a traumatic birth for both mother and baby.
- The Women's and Children's Hospital (WCH) in Adelaide, South Australia is the main tertiary referral centre for all neonatal, paediatric and obstetric patients in South Australia and cares for 400 babies a year.



An overview of the NICU/SCBU support group

- Initially - After meetings and proposals to the nursery and becoming more aware of the role of the nursery staff we submitted a proposal.
- This is an open group, all parents/grandparents/older siblings of babies in NICU/SCBU are welcome to attend any Thursday session and as many as they would like to attend.
- It is run every week for 1 hr 15 mins at the WCH in the postnatal ward, located one floor above the nurseries.
- Run by myself and the neurodevelopmental physiotherapist, Therese Misso.



The goals of the group

The primary goal is to provide a place of support for parents in a highly anxious state.

To improve the physical relationship between parent and baby

Reading the baby's cues and responding to them in a developmentally appropriate way. Therefore enhancing the parents ability to see these babes cues as language and communication.

Helping parents remember self care, including time away from the nursery and time on their other relationships.

We also talk to parents about using voice and story to help bond with your baby.



Research

I have ethics permission to do three years of research about this group and the NICU experience. This is the basis of my PhD

- Main research question to be covered in this study is “Do parents of babies in intensive care find supportive interventions meet the parents’ needs?”.
- Qualitative (interview) and Quantitative (PSS-NICU) methods will be used to assess parents’ experience of their children having an admission to the neonatal intensive care units at the Womens and Childrens Hospital (WCH) and the effect of a new support group intervention on this experience.



Dr Melanie Turner - Neonatal Intensive Care Unit (NICU) Support Group

Other Groups

- There have been no other studies using analysis of qualitative interviews of parents support experience. There are few other studies of groups.
- Roman et al outlined the use of parent to parent support at Butterworth Hospital in Michigan USA. - group improved maternal mood states, maternal-infant relationships and improved the home environment.
- Kaaresen study showed that group intervention reduced parenting stress levels to one comparable with their peers without NICU babes.

Dr Melanie Turner - Neonatal Intensive
Care Unit (NICU) Support Group



The 1st Arm – Qualitative Interviews

- Jan-Feb 2009: 10 parents
- Semi-structured and had 3 core questions
 - What was it like being a NICU/SCBU parent?
 - What is your relationship like with your baby?
 - Was the support group relevant to you?
- Use of framework analysis –
Review each interview 3 to 4 times and gradually develop a list of common points across the transcripts.
Continue to review the transcripts and narrow down the themes, further refining them using NVivo 8.

Dr Melanie Turner - Neonatal Intensive
Care Unit (NICU) Support Group



Results of the Survey

- Average parental age – 32.5yrs
- Gender – all female
- Average - Baby gestation – 25 weeks
- 70% lived in metro adelaide, 20% within 100km and 10% over 300km away
- 90% attended more than one support group session
- 100% felt supported by their family
- 20% wanted more professional help



Results of the 1st Study

- For 80% of those in the study this was their first child, for 20% it was their second
- 30% saw the social worker once (as do all parents)
- 70% saw the social worker more than once
- 30% were aware of their babies upcoming admission to the NICU when they were pregnant. 70% were unaware



Qualitative Analysis – What is it like to be a parent to a baby in NICU/SCBU?

A. Anxiety

- About the chance of baby dying
- About the upcoming discharge of the baby
- About the baby becoming ill
- About the move from NICU to SCBU

B. Grief

Over the lost normal experience

Over not having the normal baby homecoming

C. Happy feelings

both about the baby and the baby's gradual development

Dr Melanie Turner - Neonatal Intensive
Care Unit (NICU) Support Group



Qualitative Analysis – Themes related to question 1. What is it like being a NICU/SCBU Parent?

D. Control

Frustration at loss of control over parenting

'Seeking permission for everything I do with him, I can't wait for that to be over'

Not being able to take the baby home

'going home without my baby, well you're not really a mum without a baby are you?'

Loss of control during delivery

Dr Melanie Turner - Neonatal Intensive
Care Unit (NICU) Support Group



Qualitative Analysis – Themes related to question 2. What is your relationship like with your baby?

E. Fear and Frail appearance -
‘He was so little, and he was covered in tubes’



F. Positive relationship

Dr Melanie Turner - Neonatal Intensive Care Unit (NICU) Support Group



Qualitative Analysis – Themes related to question 3. Was the Support Group relevant to you?

G. Acceptance - Feeling that they can share their story with others and make friends was a core element for most mothers

- ‘the smiles and waves from other mothers made all the difference’
- ‘knowing that I wasn’t alone through all of this’

H. Information - Learning about their baby’s development

- ‘I didn’t know how to really look at him until someone told me how’

Dr Melanie Turner - Neonatal Intensive
Care Unit (NICU) Support Group



The Second Arm of the Study

- These same parents have been interviewed 5 months post discharge with the same questions used in the first interview
- - All parents who consented to the first interview also consented to a second interview
- All parents were located and interviewed by the same interviewer who completed the first interviews
- All of these interviews were over the telephone and were digitally recorded. They were transcribed within two days of the interview and an audit trail was kept during the data collection



Framework Analysis of second arm surveys

What is it like now being a parent to a premature baby?

- **Fear of returning to the hospital**

When we got to the hospital, it was just like...I said to the nurses and the doctors, I said, 'I feel like I've just got him home now, and he's already back in hospital.' And I just, I couldn't believe it. I just thought, 'my god, how did this happen?'
- **Fear of their child being ill again and requiring readmission**
- A feeling that they were unable to really be 'attached' to their babies during their stay in the neonatal nurseries but were able to bond when they got home



Themes from July interviews

- **Watching for growth and development in their baby**

you really are ticking off every milestone as you go, aren't you?

3: Oh yeah. We through a massive party for his...when he turned six months.

How do parents describe their relationship with their baby 5 months on?

A positive relationship

- So I think we're sort of at the stage now where, you know, I feel like she's...when she sees me when I get her up out of bed, she smiles at me like 'oh yes, I know who you are', and that sort of thing. I think we're, we're there, pretty much.



Was the support group helpful?

- Grateful for the support
- Feel that the key was a supportive space with parents in the same situation
- Continue to use the information given
- Can recall a lot of what occurred in the groups
- Two mums are setting up a support group outside of the hospital.

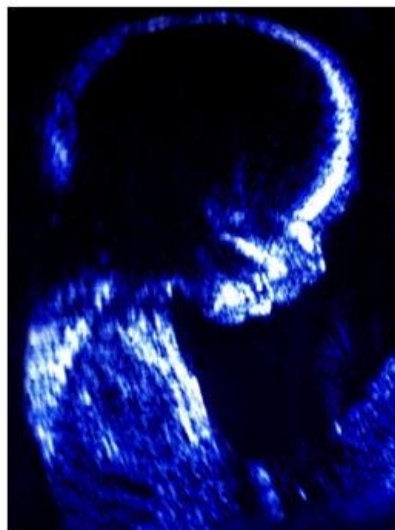
- My final set of interviews and PSS-NICU surveys are being analysed by me at present and hopefully will be completed by the end of 2010.



The dream of the perfect baby



An Abnormal finding



An emergency C-Section



A very ill baby



That I can barely touch..



Who can't even see me..



Who has other 'mothers' care for her every day, and I have to leave her behind every night



Who might die...



I'm sick of waiting...



I really want this



**But for the next few months I
have to cope with and bond with
my fragile baby...**



**So I have to readjust my goals –
my 1st bath – is when I'm 3 weeks
old**



My 1st nappy change into a micro-premmie nappy.



My 1st cuddle – waits until I'm 3 weeks old...til then I have to make do with touch..



Until eventually we can have real physical communication together



Thankyou's

- My supervisors for my PhD Dr Phill Brock and Prof Anna Chur Hansen
- The Nurseries at the WCH and all of the parents and babies who have taken part in the study.
- Therese Misso, the neurodevelopmental physiotherapist who runs the group with me and who keeps me going.
- CAMHS who pay for me to run the group and allowed me to start this new service.
- Fiona Mcdonald and Jessica Mignone, my summer research students who showed great aptitude working with nursery staff and distressed parents.



May 2014 RANZCP Congress

Perth, Western Australia



CRICOS PROVIDER 00123M

**The Emotional Experience of Parents and
Nurses in a South Australian Neonatal
Intensive Care unit (NICU)**

Dr Melanie Turner, Prof Anna Chur Hansen, Prof Helen Winefield

adelaide.edu.au

seek LIGHT

This Research

- Based in South Australian NICU
- Research Questions
 - What is the NICU experience like for parents during and after their babies admission?
 - How do NICU nursing staff see their role in the NICU and their role in emotionally supporting parents?
 - Which factors in the baby, the parent or the support offered influence parental stress levels?
- Was completed over 2 and a half years 2008 to 2010 with mixed methods research. Publications in 2013 and 2014.

The Australian NICU

- In Australia there are approximately 23 neonatal intensive care units and approximately 68 special care neonatal nursery units (Abdel-latif et al 2013).
- Most babies stay in the NICU or SCBU until they reach their due date, which for many is between 8 and 12 weeks.
- Over 40% of premature deliveries are associated with a traumatic birth for both mother and baby.

The NICU environment

- The environment of the neonatal intensive care unit is not the environment that most parents imagined for their first encounters with their baby.
- For a number of parents this is a loss of innocence as parents question their beliefs in safety, medical care and the roles of power (Davis and Stein, 2004) amongst parents and staff.
- The noise, chaos and large numbers of staff in a unit often cause parents to feel a lack of both control and input into their baby's admission (Zelkowitz, 2008; Singer, 1999).

Circa 1987 NICU - Ottawa



NICU circa 2012 - Miami



University of Adelaide

6

Parent Mental Health and the NICU

- Mothers of babies in the NICU experience increased rates of depression, anxiety and dysfunctional parenting as compared to families of babies not requiring NICU
- Both mothers and fathers have increased rates of PTSD and ASD during their baby's stay in the NICU
- Fathers have elevated levels of stress and anxiety (Miles, et al 1992) and are at risk of depression (Mackley et al 2010).
- Overall a very vulnerable population

University of Adelaide

7

Support in the NICU

- The provision of support is often a recommendation in research into assisting parents in the NICU, but how this is provided, what kind of support is offered and who provides it are frequently omitted (Kara et al 2013) with a varying level of evidence available to support these decisions (Brett et al 2011).
- In this study a support group, run by a child and adolescent psychiatrist was offered to all parents and primary carers, a weekly open group. Parents in this study were asked about their view of their NICU experience including professional support offered.

Parents and babies and the NICU

- For better outcomes in parent-baby relationships, finding and instituting ways to decrease stress is key (Korja et al 2012).
- Lam (2007) found that psychologically informed support is indicated in NICU environments.
- Support groups and individual support have been shown to be helpful in assisting parents during the time that they are in the NICU (Eriksson 2002).
- Buddy programs (Preyde 2003), recorded information via CD or booklet (Melnyk 2004) and support groups run by professional hospital staff (Kaarsen 2006) all trialled.
- An understanding of the components of parental stress is necessary in order to offer effective interventions to parents.

A very early premature baby in NICU



The NICU study

The 4 arms to this study

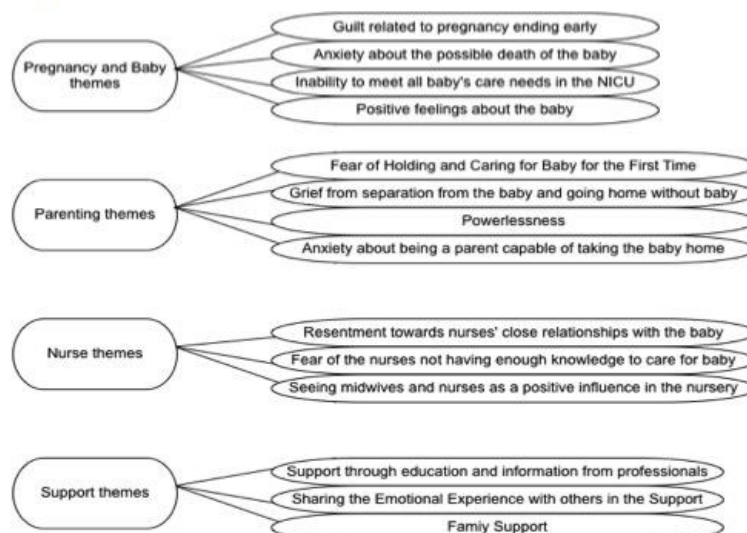
1. interview of parents during the babies inpatient stay
2. interview of parents 2 to 4 months after their baby was discharged from the NICU
3. interview of nursing staff who worked in the neonatal intensive care unit
4. administration of the PSS NICU (parent stress scale – neonatal intensive care unit) to 73 parents during their baby's admission to the NICU over a 14 month period.

Results of the 1st Study

- All 9 participants were mothers, all had completed high school with 4 having completed a university degree.
- All had a partner
- For 80% (of those in the parent interview arms of the study) this was their first child, for 20% it was their second
- 30% saw the social worker once (as do all parents)
- 70% saw the social worker more than once
- 30% were aware of their babies upcoming admission to the NICU when they were pregnant. 70% were unaware



Table 1 – Parent experiences when in nursery



- Parent interviews 2 to 4 months post discharge
- Framework analysis

TABLE 2. Interview post baby discharge Research Themes

<p>Research Question What are parents reflections afterwards, on their experiences as a NICU parent</p>	<p>Recalling time in the nursery is distressing Parents are anxious about taking their baby home</p>
<p>Research Question How do parents describe their relationship with the baby after discharge from the hospital?</p>	<p>Anxiety about possible rehospitalization of baby Coping with ongoing medical needs after discharge is difficult Home oxygen therapy Feeding Learning to parent their premature baby Regaining control Thankful to see babies developing normally Good relationship with baby after leaving hospital</p>
<p>Research Question What are the parents' views of the pre-discharge support offered?</p>	<p>Positive views Support group Nursing staff Support group enabled ongoing relationship with peers Negative views A better balance of information and support in parent support group sessions was needed</p>

Nurse Interviews

- All female staff
- All working in the NICU unit for at least 12 months
- All registered midwives with specialist NICU training
- Framework analysis

Table 3 - NICU Nursing staff research

Participants view of their role in the NICU

- Role is enjoyable and rewarding
- Role is challenging
- Role requires training, experience and seniority

The Emotional support provided by nurses

- Individualised support for each parent
- Encouraging parents to participate in caring for their baby

The elements that assist and obstruct the NICU staff in providing emotional support for parents.

- Positive NICU environment provides a supportive atmosphere
- *Support groups for parents are helpful*
- *Obstructions to the nurses providing support for the parents*
 - Physical Space as a Limitation in nursery care
 - Lack of time to provide enough support
 - Lack of parent engagement as an obstruction to providing support
 - *Language and Cultural barriers effect the support that nursing staff can offer*
 - *The lack of education and training about providing emotional support.*
 - *Lack of feedback for nurses about support group discussions*

Quantitative research component

- This arm of the research was to
 - (1) to report levels and sources of stress for NICU parents using a standardised scale;
 - (2) to explore the demographic data of parents who attend the NICU and NICU support group;
 - (3) to draw conclusions about support needs of NICU parents.

PSS NICU (Parental Stressor Scale NICU)

- Is a stress scale where parents mark from 0 (no stress) to 5 (very stressful) on a Likert scale
- The questions are grouped in three categories.
 - The first addresses the sights and sounds commonly experienced in the NICU (6 items);
 - the second considers how the baby looks and behaves as well as the treatments that the baby has had (17 items).
 - The third group of questions address how the parent feels about their relationship with the baby and their parental role (11 items)
- 55 women and 18 men completed the PSS NICU representing 82 babies.

PSS NICU results

- The highest PSS NICU scores were concerned with separation from and little contact with baby.
- Parental age, infant gestational age at birth and having a twin birth were all significantly associated with having a higher PSS NICU Sight and Sound score.
- Support group attendance was significantly associated with the PSS NICU relationship and parental role subscale.
- 42% of parents identified that they needed more professional support, these results can be used to inform modifications to the support provided to parents.

Parental Stress Scale NICU

- Parents with twins, very early gestational babies and parents of an older age group have statistically significant higher overall stress levels in the NICU.

PSS NICU results overall

- When we consider that journey we can pull together the results to rebuild parent support in the NICU
- The PSS NICU outlined that the focus on parent role and relationship should be addressed in any NICU support.

Maximising Parent support in the NICU

- The parent interviews indicated that parents are anxious, overwhelmed and fearful. They derive support from Family and in particular staff of the NICU.
- Themes of grief and loss over their lack of normal birth experience occur early on
- Later in the NICU admission parents struggle with sharing the care of the baby with others and their role as a parent is blurred with the role of the nurse.
- When preparing to go home with the baby parents are excited but feel unprepared and unsure if they will manage emotionally and physically

How to modify support to meet parent needs

- Provide a balance of information and emotional support in a support group
- Providing a professional facilitator allows parents to focus on their own experience and not on maintaining the group.
- Parents benefit from friendships and shared stories with other parents and these friendships often continue outside of the NICU
- Nursing staff are under a wide range of pressures and need further training in emotional care of parents.
- Providing enough senior, experienced staff is imperative as it allows nurses to concentrate of the wellbeing of both parents and babies.
- Physical barriers to parent involvement are a frustration for nurses, yet they are often unable to be changed

Published work

- Turner, M S. (2010) P01-259 - Supporting the neonatal intensive care parent - research into parental supports and perceptions of the intensive care experience in Australia, *European Psychiatry*, Volume 25, Supplement 1, 2010, Pages 470; 18th European Congress of Psychiatry. February 27, March 2, 2010 – Munich Germany, Child and adolescent psychiatry
- Turner, M., Chur Hansen, A., Winefield, H. (2013) Parent Accounts of Neonatal Intensive Care (NICU) and NICU supports, after hospital discharge. *Advances In Neonatal Care*, (13) 6, pg 438-446
- Turner, M., Chur Hansen, A., Winefield, H. (2014) The neonatal nurses' view of their role in emotional support of parents and its complexities. *Journal of Clinical Nursing*, in press. doi: 10.1111/jocn.12558

AACN Presentation June 5th 2014



CRCOS PROVIDER 001294

Dr Melanie Turner, B.App.Sci, MBBS, FRANZCP, Cert Child and Adol Psych

The complex role of the NICU nurse in supporting parents.

adelaide.edu.au

seek LIGHT

Who am I?

- Thankyou for my introduction
- I am a psychiatrist, who comes from a long line of nurses.
- My grandmothers, my aunts, my cousins, my mother in law, my grandmother in law are / or were all nurses.
- I think I devastated them when I got into medicine and I am still apologising.
- I work as a child and adolescent psychiatrist, with a special interest in parent/infant/baby relationships.

The nursery of the 2010's

- Times have changed, expectations have changed, people have changed and so has the nursery



The nursery as it used to be

- This is the nursery that my older relatives nursed in



Why is the NICU a tricky place to be?

- 1. Parental emotions
- 2. Parental expectations
- 3. Complex relationships (tricky with staff, parents, family of parents and babies etc etc etc). There is nothing like a stressful event to bring out a lot of emotion and a lot of relatives.
- 4. Acutely ill babies, and in general people have a strong feelings about ill children/babies, which bring out a lot of extreme views and emotional responses
- 5. The standard of care expected sometimes being above what can practically offered in the limitations of the system that we have, but perhaps that is not acknowledged by others in the system..

Parental expectations

- New parents often have unrealistic expectations of delivery, the postnatal experience, feeding and parenting in general.
- Many parents of premature babies, and other NICU admitted infants, describe distress and a loss of (what they perceived as everyone else having) a 'normal delivery'
- Research shows that negatively altered expectations of parenting are often generated by mental illness or distress in the mother or illness in the baby post nately (Flkyt et al 2014), therefore most NICU mothers.
- Fathers are less susceptible to being disappointed by the infants illness but more susceptible if there have been significant delivery problems

The NICU environment and its effect on parents

- The environment of the neonatal intensive care unit is not the environment that most parents imagined for their first encounters with their baby. Even those who have some awareness that they will have a baby admitted to the NICU show signs of distress, but less than those who did not know at all.
- For a number of parents there is a loss of innocence and the 'finding your way' beginning as a parent. These parents question their beliefs in safety, medical care and the roles of power (Davis and Stein, 2004) amongst parents and staff.
- The noise, chaos and large numbers of staff in a unit often contribute to the parents feelings of a lack of both control and input into their baby's admission (Zelkowitz, 2008; Singer, 1999).

How does this strong first relationship happen?

- The appearance of a baby (small, fragile, warm etc) are all attractors, developed in evolution, for people to care for the baby.
- We are 'hard wired' (in general) to look to care and protect a baby and to build this early attachment relationship. It is through this relationship that the baby learns trust, how to communicate and how to navigate its world.
- Attachment theory (Bowlby) tells us that the first relationship that we have with a primary caregiver is the root of all our future relationships and is at the centre of developing social and emotional communication skills.
- When a baby is born ill, small, early etc, this interrupts the enacting of the 'hard wiring' and effects the parents and baby's relationships with each other. Often delaying the attachment relationship.

Parent Mental Health and the NICU

- Mothers of babies in the NICU experience increased rates of depression, anxiety and dysfunctional parenting as compared to families of babies not requiring NICU
- Both mothers and fathers have increased rates of PTSD and ASD (acute stress disorder) during their baby's stay in the NICU
- Fathers have elevated levels of stress and anxiety (Miles, et al 1992) and are at risk of depression (Mackley et al 2010).
- The parents are at a higher risk of divorce
- Overall a very vulnerable population

Parental stress and mental illness in the NICU

- 28% of parents in the NICU have been shown to have symptoms of acute stress disorder (Shaw, Psychosomatics)
- This is why looking after some of these parents is such a challenge, as they have the signs of an acute mental illness. So your ordinary interactions, ordinary reminders, phone calls etc, can be misread/forgotten by this population
- What is Acute stress disorder and what does it look like? Description is on the next slide

How to we identify the parents to approach with extra support?

- So far no particular demographic identifiers are available for this population of parents who need more support for ASD than the 'average' NICU parent
- Universal screening for symptoms is needed, but the stress scales to use are still being decided upon.

DSM-IV-TR diagnostic criteria for ASD

- A1. Exposure to catastrophic stressor
- A2. Intense emotional reaction to stressor
- B. During or after experiencing the distressing event, the individual has three (or more) of the following dissociative symptoms
 - (1) Sense of numbing, detachment, or absence of emotional responsiveness
 - (2) Reduction in awareness of surroundings (e.g., "being in a daze")
 - (3) Derealization
 - (4) Depersonalization
 - (5) Dissociative amnesia
- C. The traumatic event is persistently re experienced in at least one of the following ways: recurrent images, thoughts, dreams, illusions, flashback episodes, or a sense of reliving the experience; or distress on exposure to reminders of the traumatic event
- D. Marked avoidance of stimuli that arouse recollections of the trauma (e.g., thoughts, feelings, conversations, activities, places, people)
- E. Marked symptoms of anxiety or increased arousal (e.g., difficulty sleeping, irritability, poor concentration, hypervigilance, exaggerated startle response, motor restlessness)
- F. The disturbance causes significant distress or impairment
- G. The disturbance lasts for a minimum of 2 days and a maximum of 4 weeks and occurs within 4 weeks of the traumatic event

Being a nurse

- I have never been a nurse
- So I decided that I needed to understand their role better, to understand the NICU so that I could work out how to help the early relationships with the baby; and this formed the central theme of my PhD.
- Nurses from a NICU were interviewed for my research paper in the Journal of Clinical Nursing.
- I am sure that many of you share their sentiments.

- But first, what did the people before me, find about working in the NICU

Nursing in the NICU

- Arch Dis Child Fetal Neonatal Ed. Mar 1995; 72(2): F107–F110.
- **Stress and mental health in neonatal intensive care units.**
- This research was in Sydney, and looked at stress in the NICU in doctors and nurses.
- 71% of neonatologists and 50% of nurses felt that conflict between their job demands and the needs of their personal lives were a problem.
- 58% of nurses felt that the nursing administration did not support them in their role
- 45% of nurses felt that conflict between neonatologists and nurses was a problem
- The highest ranked problem was understaffing and overwork.
- The next highest problem was a lack of communication from senior staff to nurses
- Both doctor and nurse participants had higher stress scores than the 'average' population

Nursing stress (Astbury 1982)

- Paediatric consultants and NICU nurses both commented on the stress associated with
- (1) trying to support the parents of and care for a child with an alternating prognosis,
- (2) the ethical problems related to the appropriate length or intensity of treatment,
- (3) avoidable trauma to the infant, and
- (4) administrative problems.
- 70% of the total sample rating them as highly stressful, were the problems of understaffing/ overwork and the sudden death/relapse of an infant. Close in importance to these were nurse/ doctor conflict, priorities of care
- Archives of Disease in Childhood, 1982, 57, 108-111 Determinants of stress for staff in a neonatal intensive care unit

The effects of shift work and not enough staff..



"I was going to ask how working with a severely limited staff was, but I think I can already guess."

Parent support

- So if the parents are distressed, forgetful and overwhelmed then instituting formal support for them may improve their mental health and therefore their ability to participate in the nursery and the cares of their baby.
- So part of my PhD examined the parent experience so that this support could address their needs and hopefully also support the nursing staff.

Parents and babies and the NICU

- For better outcomes in parent-baby relationships, finding and instituting ways to decrease stress is key (Korja et al 2012).
- Lam (2007) found that psychologically informed support is indicated in NICU environments.
- Support groups and individual support have been shown to be helpful in assisting parents during the time that they are in the NICU (Eriksson 2002).
- Buddy programs (Preyde 2003), recorded information via CD or booklet (Melnik 2004) and support groups run by professional hospital staff (Kaarsen 2006) all trialled.
- An understanding of the components of parental stress is necessary in order to offer effective interventions to parents.

Support in the NICU

- The provision of parent support is often a recommendation in research into assisting parents in the NICU, but
 - how this is provided,
 - what kind of support is offered and
 - who provides it are frequently omitted (Kara et al 2013)
 - with a varying level of evidence available to support these decisions (Brett et al 2011).

So what does it all mean??

- Nurses are under a lot of pressure to support parents.
- Nurses are under pressure to look after babies
- Parents are under pressure due to the anxiety about having a sick/prem baby
- Research shows we should do ‘something’, to help parents..
- Research shows that nurses are overworked and need to help parents and we should do ‘something’ to change that....
- Those 2 things frustrated me so I thought I’d try and work out what to do

My NICU PhD study

The 4 arms to this study

1. interview of parents during the babies inpatient stay
2. interview of parents 2 to 4 months after their baby was discharged from the NICU
3. interview of nursing staff who worked in the neonatal intensive care unit
4. administration of the PSS NICU (parent stress scale – neonatal intensive care unit) to 73 parents during their baby's admission to the NICU over a 14 month period.

Results of the Parent Survey

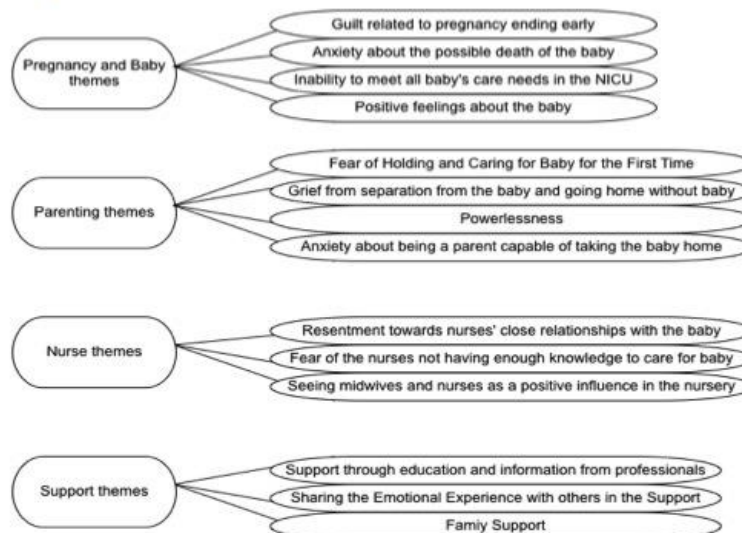
- Average parental age – 32.5yrs
- Gender – all female
- Average - Baby gestation – 25 weeks
- 70% lived in metro Adelaide, 20% within 100km and 10% over 300km away
- 90% attended more than one support group session
- 100% felt supported by their family
- 20% wanted more professional help

Results of the 1st Study

- All 9 participants were mothers, all had completed high school with 4 having completed a university degree.
- All had a partner
- For 80% (of those in the parent interview arms of the study) this was their first child, for 20% it was their second
- 30% saw the social worker once (as do all parents)
- 70% saw the social worker more than once
- 30% were aware of their babies upcoming admission to the NICU when they were pregnant. 70% were unaware



Table 1 – Parent experiences when in nursery



Parents view of the nursery staff

- Parents identified that they were concerned about their baby moving into a different unit, in particular moving from an intensive care unit to a special care unit.
- *'If something goes wrong, maybe no one will take any notice'. 'Cause they're busy with a baby three doors down, and they don't really know what they're doing. (Participant 6)*
- The style of staff communication was also identified as important in participants' developing confidence in the nursery.
- *"The way they spoke, answered questions and spoke about things, they were confident in the way they responded. It was nice to go back and have the same nurse the next day, or 3 or 4 times."*

Dr Melanie Turner - Neonatal Intensive
Care Unit (NICU) Support Group

The Second Arm of the Study

- These same parents have been interviewed 5 months post discharge with the same questions used in the first interview
- - All parents who consented to the first interview also consented to a second interview
- All parents were located and interviewed by the same interviewer who completed the first interviews
- All of these interviews were over the telephone and were digitally recorded. They were transcribed within two days of the interview and an audit trail was kept during the data collection

TABLE 2. Interview post baby discharge Research Themes

<p>Research Question What are parents reflections afterwards, on their experiences as a NICU parent</p>	<p>Recalling time in the nursery is distressing Parents are anxious about taking their baby home</p>
<p>Research Question How do parents describe their relationship with the baby after discharge from the hospital?</p>	<p>Anxiety about possible rehospitalization of baby Coping with ongoing medical needs after discharge is difficult Home oxygen therapy Feeding Learning to parent their premature baby Regaining control Thankful to see babies developing normally Good relationship with baby after leaving hospital</p>
<p>Research Question What are the parents' views of the pre-discharge support offered?</p>	<p>Positive views Support group Nursing staff Support group enabled ongoing relationship with peers Negative views A better balance of information and support in parent support group sessions was needed</p>

Framework Analysis of second arm surveys

What is it like now being a parent to a premature baby?

- Fear of returning to the hospital**
When we got to the hospital, it was just like...I said to the nurses and the doctors, I said, 'I feel like I've just got him home now, and he's already back in hospital.' And I just, I couldn't believe it. I just thought, 'my god, how did this happen?'
- Fear of their child being ill again and requiring readmission**
- A feeling that they were unable to really be 'attached' to their babies during their stay in the neonatal nurseries but were able to bond when they got home

When they went home what did they think of the nursing staff?

- **Positive Recollection of Staff From the Nursery**

Participants identified positive input and support from staff.

“Most of the midwives were just fantastic. They were, they were just so supportive. I just, you know ... they were, they were brilliant.

- **Feeling supported by the NICU staff and experiences of the nursery as a place to ease into parenthood were discussed.**

“When you’re a first time mum, and your head’s spinning you’re like “oh my god,” and even though she needed extra attention, it was ... it was a nice way to get into parenthood. ‘Cause you sort of had the responsibility, but not 100%. So you could sort of, um, gradually increase your knowledge and your confidence.”

Nurse Interviews

- All female staff
- All working in the NICU unit for at least 12 months
- All registered midwives with specialist NICU training
- Framework analysis

What do nurses say about staffing

- Overwork - “Well it is [very busy in the nursery], but they try and staff it to the ratio to the baby. But it is busy. It’s constant. It’s always constant. It doesn’t stop. You need a lot of experience to really make it work.”
- The change of staff from shift to shift and nursery to nursery contributes to the loss in continuity of information given to parents.
- “We’re always giving them different information. Um yeah, so I’ve sort of found out lots of things what the parents’ needs were, you know and tried to be consistent.”

What staffing issues are a problem?

- Nursing staff described a wide range of staffing issues that were problematic. These included the range of nursing staff skills with some neonatal nurses able to cope with the physical and emotional demands of caring for severely ill babies and some less so.
- Staff also discussed the introduction of new staff, junior staff or ‘agency’ staff on a nursing roster and the extra burden therefore placed on experienced nurses.

What do nurses say about supporting parents each day?

- Each parent was considered to have their own need for information to be given personally to them and that this communication is key to supporting the parent
- “In, in NICU, you know, the babies are either very tiny or very sick and they have a good day, they have a bad day, if they try and die tomorrow, they’re better the next day. You’re actually, almost moment by moment trying to support the parents.”

The physical space of the nursery

The physical space available within this particular nursery was a problem identified by all participants. The NICU was described by its cramped space with a large amount of equipment, a lack of privacy for parents and overcrowding with babies:

“I had a baby that was very unwell and I had stands and I had trolleys and staff and everybody around, and so much so that the parents couldn’t actually get in.”

The chaos in a crowded and busy unit can be off-putting for some parents despite the nurses’ encouragement to participate in caring for their baby:

“ [It] can be just a bedlam sometimes; the parents don’t know what is going on. I think the unit is far too small.”

Cultural Challenges

- Just in my last week I saw families with 3 different first languages, of which I spoke none. Multiculturalism is a great thing, but a challenge in health care.
- The difference in culture between parent and staff was also described as a challenge. Participants viewed this as an obstruction particularly as child rearing is a key aspect to many culture and family structures:

“Obviously, if you’ve got a language problem you’ve probably got a cultural problem along with it, [with] different expectations to what happens in hospitals. It is likely that the refugees are not used to health care probably to the degree that we have.”

Summary- NICU Nursing staff interviews

Participants view of their role in the NICU

- Role is enjoyable and rewarding
- Role is challenging
- Role requires training, experience and seniority

The Emotional support provided by nurses

- Individualised support for each parent
- Encouraging parents to participate in caring for their baby

The elements that assist and obstruct the NICU staff in providing emotional support for parents.

- Positive NICU environment provides a supportive atmosphere
- *Support groups for parents are helpful*
- *Obstructions to the nurses providing support for the parents*
 - Physical Space as a Limitation in nursery care
 - Lack of time to provide enough support
 - Lack of parent engagement as an obstruction to providing support
 - *Language and Cultural barriers effect the support that nursing staff can offer*
 - *The lack of education and training about providing emotional support.*
 - *Lack of feedback for nurses about support group discussions*

Quantitative research component

- This arm of the research was to
 - (1) to report levels and sources of stress for NICU parents using a standardised scale;
 - (2) to explore the demographic data of parents who attend the NICU and NICU support group;
 - (3) to draw conclusions about support needs of NICU parents.

This could be a scale to help early identification of parents most at risk of stress disorders; therefore early referral and increased support early on in the babies NICU admission.

PSS NICU (Parental Stressor Scale NICU)

- Is a stress scale where parents mark from 0 (no stress) to 5 (very stressful) on a Likert scale
- The questions are grouped in three categories.
 - The first addresses the sights and sounds commonly experienced in the NICU (6 items);
 - the second considers how the baby looks and behaves as well as the treatments that the baby has had (17 items).
 - The third group of questions address how the parent feels about their relationship with the baby and their parental role (11 items)
- 55 women and 18 men completed the PSS NICU representing 82 babies.

PSS NICU results

- The highest PSS NICU scores were concerned with separation from and little contact with baby.
- Parental age, infant gestational age at birth and having a twin birth were all significantly associated with having a higher PSS NICU Sight and Sound score.
- Support group attendance was significantly associated with the PSS NICU relationship and parental role subscale.
- 42% of parents identified that they needed more professional support, these results can be used to inform modifications to the support provided to parents.

Parental Stress Scale NICU

- Parents with twins, very early gestational babies and parents of an older age group have statistically significant higher overall stress levels in the NICU.

PSS NICU and parent mental illness

- PSS total stress score was significantly correlated with
- anxiety ($r = 0.61$),
- depression ($r = 0.36$), and
- sleep disturbance ($r = 0.60$).

- Therefore a high PSS NICU score is a useful way to identify parents who are experiencing the above and therefore at risk of long term mental illness.
- Parents' Responses to Stress in the Neonatal Intensive Care Unit (Critical Care Nurse)
- [Morgan Busse, RN, BSN, Kayleigh Stromgren, RN, BSN, Lauren Thorngate, RN, CCRN, PhD and Karen A. Thomas, RN, PhD](#)

So...helping parents emotionally

- Parents benefitted from the support group.
- Parents are overwhelmed early on but are able to see positives with support around them
- They are all afraid that their baby will/could die
- They all struggle to feel like a parent in the NICU
- When they go home they enjoy the autonomy but are afraid of it
- Their greatest fear after going home is that their baby will need to go back to hospital
- A support group needs to focus on education and support with a finely divided line between the two and modifying as it goes
- A focus on supporting friendship when parents come to group as sharing the experience was a key to parents 'getting through the crisis'

Nurses

- Feel overworked when the unit is understaffed and/or cramped
- Feel that they are unable to help some parents and can be stuck with what to do
- Know that some parents are much harder to help than others and that getting these parents to change is a challenge
- That the physical space in a nursery is crucial and should be better planned
- That senior staff are needed all the time as the work place can become stressful very quickly
- Some nurses naturally cope better with the emotional side of nursing and they see it as a great advantage as finding training specifically for the emotional role in the NICU is hard to find



Nurse training at university

- I have a role in training medical students but not nursing students (other than those on placement where I work, where they are able to sit in with me with assessments etc)
- I think that what I teach is just as applicable for nurses to be.
- I wonder how the approach to early childhood development is taught, because I'd be happy to teach!
- Covering the elements of perinatal mental health, attachment theory and the approach to the distressed parent/patient; may be helpful, in particular for nursing students about to take their first rotation/placement in a baby focussed workplace (ie O and G, nursery, antenatal clinic, toddler ward, community visiting etc)

Conflicts with administrative/paperwork

- This was identified by nurses in other research
- I am yet to conquer this in my own field of work.
- It is a constant frustration of the modern day health practitioner that we have so much paperwork which takes us away from parents.
- Most of us do not like having to prove what we do so many times (notes, letters, statistical systems, summaries etc) which we feel duplicate a lot of work.
- My reflection is that it is due to non clinicians demanding the increased paperwork, perhaps who do not understand what we do.
- Certainly in all aspects of health care this element is stressful, unfulfilling and contributes to peoples dissatisfaction with their workplace.
- Anyone with a solution let me know!

How to know you've done enough paperwork...



Nursing assistance

- To enable communication about the parent to the nurse on a regular basis if parent is seeing a hospital based therapist (issues at different hospitals about the notes belonging to the baby..and the parent seeking the support)
- For parents to have ready access to a support group that covers emotional and educational topics, facilitated by a professional with feedback going back to the nursing staff.
- For information about parent concerns and views to travel back from that support group to the nursery to help facilitate change.

So how to change all of this??

- What I think is missing
 - The availability of training specific to the NICU, including perinatal mental health, attachment theory and acute stress reactions so that staff feel more knowledgeable when working with very stressed parents.
 - Clinical supervision (which in psychiatry is where every CAMHS staff member has either 1:1 or small group ‘mentorship’ where difficult cases or staffing issues are addressed). This is a requirement in CAMHS and must occur at least once a month for 1-2 hours. For our training registrars it is 2 hours a week. It is a confidential “space”.
 - A better assessment scale/tool that can identify those parents at highest risk (such as the Edinburgh depression scale for antenatal care) so that they can be referred very early on
 - Better staff, more space, less paperwork, nice doctors.....

The End...

- **Thankyou**
- **To the parents and staff who helped with my research and my PhD supervisors.**

POSTERS PRESENTED RELATED TO THIS
THESIS

Examining the experience of parents and staff in a neonatal intensive care nursery



Dr Melanie Turner, Prof Anna Chur-Hansen, Prof Helen Winefield
University of Adelaide, School of Medicine, Discipline of Psychiatry



Introduction

In Australia approximately 5000 babies are admitted to neonatal intensive care nurseries each year. Each nursery caters for babies and their families with different degrees of emotional support. Some offer psychiatric, psychological and social worker support. Other neonatal nurseries throughout the world offer 'buddy system' emotional support(1) or support in a group setting(2). This poster reports on data collected regarding a support group started at a tertiary level hospital in South Australia in 2008. The study considers emotional experiences of the parents of some of these babies from this hospital at admission and post discharge; and their view of emotional support offered.

Method

Nine mothers were interviewed at the beginning of the admission of their baby to the neonatal intensive care unit in January 2009 and again 4 months post discharge from hospital. A semi structured interview was used. The interviews were performed by a research assistant as the author was providing psychiatric support for parents in this nursery. Framework Analysis (3) was used to evaluate interview data. The Parental Stress Survey – Neonatal Intensive Care Unit (PSS-NICU) survey (4) was also administered to 73 parents of babies in the NICU over a 12 month period August 2009 to August 2010. The PSS NICU scores were collated for each category and averages for each category were recorded.

Results and Discussion

In the first set of parent interviews a range of themes and subthemes emerged. Emotions were a central theme, with parents describing anger, grief and anxiety about having a fragile, newborn baby in intensive care but also trying to look for positives in the admission. Attending the support group was identified as a key element in coping with their stress.



Post discharge parents interviews were still focussed on the emotions involved with their baby. Many still felt anxious about their baby possibly needing a further admission if unwell, in general preferring to not recall aspects of the neonatal nursery admission. Parents listed professional support as an important aspect of 'getting through' the experience of the nursery, as well as emotional support from family.



I've got this little box of keepsakes, you know, .. I take them out every now and then and see how small they were. And I remember, you know, how scary it was..'



"I mean I was happy that she was alive of course; that she was breathing and everything. And then I was sad that I couldn't keep her in, like that somehow was my fault."

In the PSS – NICU survey results parents listed being separated from their baby; being unable to feed their baby and being unable to care for their baby as the three most stressful things about being a parent in the NICU. Parents were least stressed by the small size and wrinkled appearance of their baby.

Mothers who were interviewed outlined strong emotions associated with their child's admission. Their feelings of anger were about the situation itself and the interactions with others. Having a baby who is in hospital removes a parent's ability to make independent decisions for their child and renders them powerless as often moving or feeding the NICU baby is a decision made with input from medical and nursing staff. These ongoing encounters with staff can cause friction and hostility in the staff-parent relationship. Parents also carry a constant burden of anxiety about their baby's fragility and vulnerability associated with their premature state. Despite these ongoing stressors, parents also had positive feelings about their baby and looked for positives in the environment and staff around them. Parents looked to three areas for support; family, the support group with a focus of education and information and each other.



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In the second interviews parents preferred to not reflect on their time in the nursery. At times these memories were overwhelming and parents preferred to focus on the positive development that their babies were making. Many kept in contact with other parents from the support group and sought these parents out for emotional support at times. Anxiety about their baby's health continued with concerns about taking their baby home post neonatal intensive care unit stay and worries that their baby may get ill and require readmission.

Conclusion

In general parents were anxious and overwhelmed by their child's admission to the neonatal intensive care nursery. After discharge this distress was less but continued, in particular when reflecting on their child's admission. Emotional support from professionals and friends and family are recognised as important coping factors for these parents.

Acknowledgments

The information on this poster forms part of a PhD dissertation. The supervisors for his research are Professor Anna Chur-Hansen and Professor Helen Winefield both of whom I am very grateful for their support and encouragement. I would also like to thank the Child, Youth and Womens Health Network, my employer, who funded my attendance at this conference and the production of this poster. I am also indebted to all the research participants who completed interviews and surveys.

All photographs purchased by the author from www.dreamstime.com

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Dr Melanie Turner and Prof Anna Chur-Hansen University of Adelaide, School of Medicine, Discipline of Psychiatry
 Prof Helen Winefield, University of Adelaide, School of Psychology



Introduction

Data were collected regarding a support group started at a tertiary hospital in South Australia for parents of babies born preterm. The study considered emotional experiences of the parents of some of these babies at admission and post discharge and their view of emotional support offered, including from a formal support group. The views of neonatal intensive care unit (NICU) nursing staff related to parent stress and the services provided to support them were also examined.

Method



Nine mothers were interviewed at the beginning of the admission of their baby to the NICU on admission and again 4 months post discharge from hospital. Nine nursing staff from the same neonatal nursery were also interviewed. Semi structured interviews were performed by a research assistant as the first author was providing psychiatric support for parents in this nursery. Data were analysed thematically.

Results

Parents while baby still in NICU

Research Question	Themes
What emotions do parents experience during their baby's NICU admission	Anger Fear Guilt Grief Anxiety Positive Feelings
What were the parents' views of emotional support while the baby was in the nursery	Support through education and information from professionals was essential Sharing the emotional experience with other parents in the support group was a large part of parent support Family support was important

Parents post NICU discharge

Research Question	Themes
What are parents' reflections afterwards, on their experiences as a NICU parent?	Recalling time in the nursery is distressing Parents are anxious about taking their baby home
How do parents describe their relationship with the baby after discharge from the hospital?	Anxiety about possible rehospitalisation of baby Coping with on-going medical needs after discharge is difficult Gradually learning to parent their premature baby and regaining control Good relationship with baby after leaving hospital
What are the parents' views of the pre-discharge support offered?	Positive views of the support group and nursing staff but a better balance of information and support in parent support group sessions was needed

NICU nurse interviews

Research Question	Themes
How do nurses view their role in the neonatal intensive care unit (NICU)?	Role is enjoyable and rewarding Role is challenging Role requires training, experience and seniority
How do nurses provide support for parents in the NICU?	Individualised support is given to each parent Encouraging parents to participate in caring for their baby
What elements obstruct and assist the NICU staff in providing emotional support parents?	Positive NICU environment provides a supportive atmosphere Support groups for parents are helpful Physical space is a limitation Lack of time to provide enough support Language and cultural barriers Lack of education and training about providing emotional support Lack of feedback for nurses about support group discussion

Discussion

Mothers outlined strong emotions associated with their baby's admission. Having a baby who is in hospital removes a parent's ability to make independent decisions for their child and renders them powerless as often moving or feeding the NICU baby is a decision directed by medical and nursing staff. These ongoing encounters with staff can cause friction and hostility in the staff-parent relationship.

During the NICU and post discharge parents carry a constant burden of anxiety about their baby's fragility and vulnerability associated with their premature state. Despite these ongoing stressors, parents also had positive feelings about their baby and looked for positives in the environment and staff around them. Parents looked to three areas for support; family, the support group with a focus of education and information and each other.

After discharge many kept in contact with other parents from the support group and sought these parents out for emotional support.

Conclusion

Addressing the needs of parents, including building in professional support into the nursery structure, and providing a support group as well as ongoing information and support after discharge may assist parents in their recovery from the NICU experience. Addressing nursing education in emotional care of parents as well as providing a supportive working environment will likely maximise the support available to parents.



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Acknowledgments

The information on this poster forms part of a PhD dissertation. The supervisors for his research are Professor Anna Chur-Hansen and Professor Helen Winefield both of whom I am very grateful for their support and encouragement. I am also indebted to all the research participants who completed interviews and surveys.

ABSTRACTS FOR CONFERENCE AND
CONGRESS PRESENTATIONS RELATED TO
THIS THESIS

Turner, M. (2008) One finger to bond with - the assessment of therapeutic support group for parents of babies in neonatal intensive care.

Presented at: Australian Association of Infant Mental Health (AAIMH) Conference, 9th November, Adelaide, Australia

NOTE:

This publication is included on pages 294-295 in the print copy of the thesis held in the University of Adelaide Library.

Turner, M., Chur-Hansen, A. & Brock, P. (2009) One finger to bond with - the assessment of therapeutic support group for parents of babies in neonatal intensive care.
Presented at: Royal Australian and New Zealand College of Psychiatry (RANZCP) Conference, 24-28 May, Adelaide, Australia

NOTE:

This publication is included on page 296 in the print copy of the thesis held in the University of Adelaide Library.

Turner, M. & Chur-Hansen, A. (2009) Further down the road - One finger to bond with, the neonatal nursery support group 1 year on.

Presented at: Royal Australian and New Zealand College of Psychiatry (RANZCP) Conference, 7 September, Queenstown, New Zealand

NOTE:

This publication is included on page 297 in the print copy of the thesis held in the University of Adelaide Library.



19th World Congress of the International Association
for Child and Adolescent Psychiatry and Allied Professions
The 6th Congress of the Asian Society of Child
and Adolescent Psychiatry and Allied Professions



June 2-6, 2010 Beijing, China

April 6, 2010

Invitation Letter

Dear Dr. Melanie Turner,

It is with great pleasure that we invite you to join the 19th World Congress of the International Association for Child and Adolescent Psychiatry and Allied Professions and the 6th Congress of the Asian Society of Child and Adolescent Psychiatry and Allied Professions which will be held from 2nd to 6th June, 2010 in Beijing, China.

This Congress is the first joint congress hosted by IACAPAP and ASCAPAP in an Asian country. We have invited many world class experts to speak at the congress and have planned a rich program with unique oriental characteristics. We are expecting over around 2500 participants from all over the world to attend this important event.

We sincerely hope that you could attend the Congress. Your submission "SUPPORTING THE NEONATAL INTENSIVE CARE PARENT - RESEARCH INTO PARENTAL SUPPORTS AND PERCEPTIONS OF THE INTENSIVE CARE EXPERIENCE IN AUSTRALIA" has been accepted as oral presentation on June 3, 2010, 16:00-17:30. We believe your attending is very important to improve the development of child and adolescent psychiatry and allied professions in the world and will make the Congress more successful.

Beijing, one of significant historical cities in human civilizations, is rich in history and culture. It is also a city embracing changes and exhibits a dynamic combination of the past with modern prosperity. It will leave you a rewarding and unforgettable experience.

Looking forward to seeing you in Beijing, China!

Per-Anders Rydelius	Daniel Fung	Yi Zheng
President of the Congress	Co-Chair of the Congress	Chair of the Congress
President, IACAPAP	President, ASCAPAP	President, CSCAP

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Turner, M. & Chur-Hansen, A. (2010) Infants and the experience of their parents in the neonatal intensive care unit.

Presented at: International Association for Child and Adolescent Psychiatry and Allied Professions (IACAPAP) Conference, 3 June, Beijing, China

NOTE:

This publication is included on pages 299-300 in the print copy of the thesis held in the University of Adelaide Library.

Turner, M. & Chur-Hansen, A. (2010) Supporting the neonatal intensive care parent - research into parental supports and perceptions of the intensive care experience in Australia.

Presented at: 18th European Congress of Psychiatry, 27 February - 2 March, Munich, Germany

NOTE:

This publication is included on pages 301-302 in the print copy of the thesis held in the University of Adelaide Library.

Turner, M., Chur-Hansen, A. & Winefield, H. (2012) Examining the experience of parents and staff in the neonatal nursery.

Presented at: International Association for Child and Adolescent Psychiatry and Allied Professions (IACAPAP) World Congress, 22 July, Paris, France

NOTE:

This publication is included on page 303 in the print copy of the thesis held in the University of Adelaide Library.

Turner, M., Chur-Hansen, A. & Winefield, H. (2014) The emotional experience of parents and nurses in a South Australian neonatal intensive care unit (NICU).

Presented at: Royal Australian and New Zealand College of Psychiatry (RANZCP) Conference, 13 May, Perth, Australia

NOTE:

This publication is included on page 304 in the print copy of the thesis held in the University of Adelaide Library.

Abstract Acceptance letter – Australian Childhood Trauma Conference, August 2014

Childhood Trauma Conference Organisers <childtraumaconf@icms.com.au>
To: Melanie Turner
Childhood Trauma Conference 2014: Abstract Submission Accepted

25 May 2014 3:46 PM

Abstract title: The Emotional and Traumatic Experience of Parents and Nurses in a South Australian Neonatal Intensive Care unit (NICU)
Presenter: Melanie Turner
Presentation type: Oral Presentation
Presentation duration: 15 minutes

Dear Melanie

On behalf of the Organising Committee, we thank you for submitting an abstract to our conference entitled *Childhood Trauma: Understanding the Basis for Change and Recovery* at the Melbourne Convention Centre on 4 – 8 August 2014.

The Organising Committee is pleased to accept your abstract. Details regarding your presentation type can be found above. Further details including presentation date and time will be available shortly.

If you have not been allocated the presentation type or time allocation you requested, please understand that we received an overwhelming number of abstracts. As such, we have tried to ensure that as many people as possible have been able to present their valuable work in this area.

Please note that it is mandatory for all presenters to register for the Conference. All presenting authors must be registered by **Monday, 30 June 2014**. Any presentation without a nominated presenter registration may be withdrawn from the Conference program. If you have not already registered please visit the [online registration portal](#)

As the nominated contact for this submission you will receive all correspondence and are responsible for communicating this information to your co-presenters and/or author(s).

If you have any queries please do not hesitate to contact the [Conference Organisers](#).

We look forward to welcoming you to the Unique International Trauma Conference.

Kind regards

Joe Tuoci
CEO
Australian Childhood Foundation

CONFERENCE PROGRAMS

NOTE:

This appendix is included on pages 308-314 of the print copy of the thesis held in the University of Adelaide Library.

PUBLICATIONS FROM THIS THESIS

P01-259 - SUPPORTING THE NEONATAL INTENSIVE CARE PARENT - RESEARCH INTO PARENTAL SUPPORTS AND PERCEPTIONS OF THE INTENSIVE CARE EXPERIENCE IN AUSTRALIA

M. Turner

Discipline of Psychiatry, University of Adelaide, Adelaide, SA, Australia

Objective: In 2008 a new support group based on psycho-educational principles, attachment theory and neurodevelopmental practice, began at the Womens and Childrens Hospital (WCH) in South Australia. This group caters for parents, grandparents and other carers, who have children in neonatal intensive care and special care nurseries.

2 years of research have been done to evaluate the parent experience of neonatal intensive care and the support networks available for parents.

Method: Qualitative interviews have been performed with parents who have attended the group. The 1st set taken when their babies were in the nursery and then 5 months post discharge. Interviews with nursing staff who work within the nursery were also completed in 2009. A survey study using the PSS-NICU is underway at present and will conclude in late 2010.

Results: The parent interviews were reviewed with framework analysis and indicated a number of themes. The main theme was the loss of control of the parental relationship and the distress at sharing their child with nursing staff. Nursing staff interviews were analysed with framework analysis and the main theme was of chronic parental distress and difficulties managing the parental grief.

Conclusions: These results indicate that psychological support should be focussed on 1. the attachment relationship in trauma and 2. dealing with grief at deviating from the normal parenting experience. These results were used to provide modifications to our parent group and to structure education and support for nursing staff in the intensive care unit.

Keywords: Prematurity, early-intervention, attachment.

Turner, M., Winefield, H. & Chur-Hansen, A. (2013) The emotional experience and supports for parents with babies in a neonatal nursery.
Advances in Neonatal Care, v. 13(6), pp. 438-446

NOTE:

This publication is included on pages 317-325 in the print copy of the thesis held in the University of Adelaide Library.

It is also available online to authorised users at:

<http://doi.org/10.1097/ANC.0000000000000030>

Turner, M., Chur-Hansen, A. & Winefield, H. (2012) Examining the experience of parents and staff in the neonatal nursery.

Presented at: International Association for Child and Adolescent Psychiatry and Allied Professions (IACAPAP) World Congress, 22 July, Paris, France

NOTE:

This publication is included on pages 326-327 in the print copy of the thesis held in the University of Adelaide Library.

Turner, M., Chur-Hansen, A. & Winefield, H. (2014) The neonatal nurses' view of their roles in emotional support of parents and its complexities.

Journal of Clinical Nursing, v. 23(21-22), pp. 3156-3165

NOTE:

This publication is included on page 328 in the print copy of the thesis held in the University of Adelaide Library.

It is also available online to authorised users at:

<http://doi.org/10.1111/jocn.12558>

PARENT INFORMATION RELATED TO THE
HOSPITAL SUPPORT GROUP

NOTE:

This appendix is included on pages 339-344 of the print copy of the thesis held in the University of Adelaide Library.