

**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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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.