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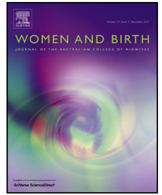

ORIGINAL RESEARCH – QUANTITATIVE

The assessment of parental stress and support in the neonatal intensive care unit using the Parent Stress Scale – Neonatal Intensive Care Unit

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ABSTRACT

Problem: Parental stress in the neonatal intensive care unit (NICU) has been reported, however identifying modifiable stress factors and looking for demographic parent factors related to stress has not been well researched.
Aim: This study aims to identify the most stressful elements for parents in the neonatal intensive care unit.
Methods: Parents of babies in an Australian neonatal intensive care unit ($N = 73$) completed both the Parent Stress Scale – Neonatal Intensive Care Unit and a survey of parent and baby demographic and support experience variables (Parent Survey) over an 18-month period.
Findings: Older parental age, very premature birth and twin birth were significantly associated with a higher Parent Stress Scale – Neonatal Intensive Care Unit score. Having a high score in the Relationship and Parental Role scale was strongly associated with attendance at the parent support group.
Conclusion: These results indicate the variables associated with stress and this knowledge can be used by teams within hospitals to provide better supportive emotional care for parents.
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1. Introduction

There were 301,617 births registered in Australia in 2011.[1] Of these births approximately 8% of babies were delivered pre-term, referred to as a premature birth.[1] Neonatal intensive care units (NICUs) 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 neonate in the NICU is stressful[2,3] and the effects of the NICU experience may continue beyond the acute admission and influence subsequent family functioning and parent mental health.[4]

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.[5,6] Lam[7] found that psychologically informed support is indicated in NICU environments. To provide this support a range of programmes has been trialled, and includes Buddy programmes,[8] recorded information via CD or booklet[9] and support groups run by professional hospital staff.[10] 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.

1.1. 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.

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2. Literature review

2.1. Parent support groups in the NICU

Group support for NICU parents has been initiated in a number of hospitals throughout the world.[10,11] The various methods of NICU support groups include structured closed groups, open groups, groups run by volunteers and groups run by parents.[12] Provision of a one 45 min support session for parents has previously shown improvement in PSS subscale stress scores.[13]

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, approximately 8 to 12 parents attended each session. 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 range of topics 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.

2.2. Identifying parental stress

To assess parental distress, the PSS NICU was developed from the Parental Stressor Scale: Paediatric ICU (PSS: PICU) by Carter[14] and Miles.[15] It was further refined by Miles et al. in 1993[16] 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,[17] from which the subscale of Communication with Staff was excluded after revision[18] has been used. This scale has had its validity and internal consistency confirmed in the USA[19] and the UK.[18]

In previous research,[20] 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.[21] 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. Participants and 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 in 2009/2010. Ethics approval was obtained from the local Ethics committee at the hospital concerned as well as from the institutional Human Research Ethics Committee both meeting NHMRC guidelines; anonymity was preserved for all participants. 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. Methods – measures

3.2.1. Measuring parent stress

The PSS NICU[17] 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[16] 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[16] and Sweet and Mannix[22] best describes levels of parental stress due to the total NICU environment.

3.2.2. 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. Methods – procedure

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.

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