



Stress and distress in parents of neonates admitted to the neonatal intensive care unit for cardiac surgery



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ABSTRACT

Background: Parents of infants admitted to the Neonatal Intensive Care Unit (NICU) are at risk of psychological distress and NICU-related stress. However, parents of infants admitted to NICU for cardiac surgery are an under-researched population.

Aims: Identify levels of NICU-related stress, and levels of psychological distress, reported by parents of infants admitted to the NICU for cardiac surgery.

Study design: Observational study.

Subjects: 69 parents of infants admitted to the NICU for cardiac surgery (cardiac group) and 142 parents of healthy infants (control group).

Outcome measures: Questionnaire packs provided to parents prior to discharge (time-point 1), and at six and 12 months corrected age included: Hospital Anxiety and Depression Scale, Coping Inventory for Stressful Situations, and Family Support Scale. The Parental Stressor Scale:NICU was administered to the cardiac group at time-point 1.

Results: The cardiac group reported (i) that parental role alteration was the most stressful aspect of the NICU and (ii) higher scores for anxiety and depression than the control group at all three time-points, with the highest levels reported during the NICU stay. Correlation analyses indicated (i) stress associated with the sights and sounds of the NICU, and the appearance and behaviour of the infant in the NICU, had a significant positive association with anxiety and depression, and (ii) a significant negative relationship between anxiety and task-focused coping.

Conclusions: An individualised parent-targeted intervention aimed at reducing stress associated with the NICU and enhancing task-focused coping style may help to reduce levels of anxiety and depression within this group of parents.

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1. Background

New parents are at risk of experiencing psychological distress, including anxiety and depression [1–2]. High levels of distress may disrupt normal interactions between the parent and infant, interfere with the parent–infant attachment process [3–5], and impact negatively upon the infant's intellectual and behavioural development, educational attainment, and mental health [6–8]. It is therefore feasible that parents of infants admitted to the Neonatal Intensive Care Unit (NICU) may be at risk of additional distress. It has been reported that 40–50% of parents have reported high levels of psychological distress during the

hospitalisation of their infant in the NICU, or within the first few weeks after discharge [9–12]. Studies have shown that variables such as parental coping style, social support, and parental age are associated with psychological distress in parents of infants admitted to the NICU [13–16]. The NICU environment may also be stress-inducing for parents, including the sights of equipment, bright lights, and unfamiliar sounds, the infant's physical appearance, and the interruption to the normal parenting role [17–21]. High levels of stress associated with the NICU environment have also been reported to be associated with higher levels of parental psychological distress [22–23].

To date, a paucity of studies have assessed the NICU-related stress experienced by parents of infants with complex medical and/or surgical conditions; including cardiac surgery [24–26]. This is despite reports that the birth prevalence of congenital heart disease (CHD) worldwide is now eight in every 1000 live births, with up to 50% of such children

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requiring surgery [27,28]. Studies have tended to focus on more general levels of parental stress within this population [29]. Furthermore, few studies have examined psychological distress reported by mothers and fathers of infants admitted to the NICU for cardiac surgery, or investigated reasons why some parents report higher levels of distress than others. Such studies have also included children from a wide range of age groups [30–33]. Elevated levels of psychological distress have been reported in one-third of mothers of infants, and almost one-fifth of fathers with congenital heart disease (CHD) in the first few months following the birth [32]. A recent study also reported that 14% of parents of infants with CHD had borderline state anxiety scores, and 5% of parents had significant levels of both state and trait anxiety at the time of hospital discharge [34]. Mothers of infants with severe CHD have also been reported to have significantly higher levels of psychological distress than a control group of mothers of healthy infants at 6, 18, and 36 months postpartum [35–36]. Overall, the evidence suggests that parents of infants admitted to the NICU are at risk of psychological distress. However, parents of infants with CHD who have surgery in the neonatal period remain an under-researched population.

This study reports data from a larger project which was guided by The Double ABCX Model of Family Adjustment and Adaptation [37] and focuses on mothers and fathers of infants admitted to the NICU for cardiac surgery.

This study aimed to investigate the following:

- (1) The level of stress associated with the NICU environment reported by mothers and fathers of infants undergoing cardiac surgery.
- (2) The levels of psychological distress reported by the parents during their infant's admission to the NICU for cardiac surgery, and over time, in comparison to parents of healthy infants.
- (3) The association between coping style, social support, NICU-related stress, parent age, and psychological distress, in parents of infants admitted to the NICU for cardiac surgery.

2. Methods

2.1. Participants

The sample was recruited between 7th March 2010 and 30th June 2011 from the Grace Centre for Newborn Care at The Children's Hospital at Westmead (CHW), New South Wales, Australia. The inclusion criteria for the surgical group were parents of infants born >30 weeks gestation admitted to the NICU with a diagnosis of a congenital anomaly requiring neonatal surgery. This study reports on a sub-set of data on parents of babies admitted to the CHW for cardiac surgery which was collected as part of a larger multi-site project. Control participants were recruited from the co-located maternity unit at Westmead Hospital as this was the same geographical area serving a similar population. The inclusion criteria were parents of infants born >37 weeks gestation with no medical or health concerns. Parents were excluded if they were: (i) under the age of 16, (ii) unable to consent for themselves, (iii) non-English speaking, (iv) from inter-state or an international country. A flow diagram describing the number of participants within the study at each time-point is presented in Fig. 1.

2.2. Procedure

For the cardiac group, readiness for recruitment was determined by the clinical stability of the infant, and in collaboration with the NICU clinical team. A suitable time post-initial surgery, and prior to discharge,

was chosen for time-point 1 data collection. For the control group, recruitment and time-point 1 data collection occurred during admission to the maternity unit and questionnaires were completed within four weeks of discharge. Self-completion questionnaire packs at time-point 1 included: a demographic questionnaire, the Hospital Anxiety and Depression Scale (HADS) [38], the Coping Inventory for Stressful Situations (CISS) [39], and the Family Support Scale (FSS) [40]. The Parental Stressor Scale:NICU (PSS:NICU) [41] was only administered to the cardiac group. Medical notes were accessed to obtain infant characteristics. Postal questionnaire packs were administered when the infant was six months (demographic questionnaire, HADS, CISS and FSS), and 12 months corrected age (demographic questionnaire, HADS and FSS).

2.3. Instruments

The PSS:NICU [41] is used to measure parents' perceptions of stressors arising from the physical and psychosocial environment of the NICU (administered to parents in the cardiac group only). The Metric 2 scoring procedure (Overall Stress level) was used in the current study [41]. There are three subscales within this questionnaire for which scores can be calculated. The 'Appearance and Behaviour' subscale assesses aspects of the baby's appearance which may cause stress for the parent, such as the whether they appear to be cold and behaviours such as whether they are crying. The 'Sights and Sounds' subscale assesses how aspects of the NICU such as the sights and sounds of monitors and seeing other sick infants in the room may cause the parent to experience stress. The 'Parental Role and Relationship' subscale assesses how experiences such as not being able to hold their baby, and not being able to see the child when the parents wanted, may cause stress for the parents. The score for each subscale ranges from 1 to 5 and from 34 to 170 for Overall Stress. Higher scores are indicative of higher levels of NICU-related stress.

The HADS [38] was used as a screening measure in order to assess the levels of self-reported depression and anxiety in the parents. Scores range from 0 to 21 with higher scores indicating higher levels of anxiety or depression. Scores can also be categorised as follows: 'normal' 0–7, 'mild' 8–10, 'moderate' 11–14 and 'severe' 15–21. The CISS [39] was used to assess coping style. Coping styles are evaluated on separate subscales and include task-focused coping, emotion-focused coping, and avoidance coping. Scores for each subscale range from 16 to 80 with higher scores indicative of a greater degree of coping activity within that dimension. Social support was assessed using the FSS [40] which is a measure of how helpful different sources of support have been for families. The Total FSS Score ranges from 0 to 90 with higher scores indicative of higher perceptions of helpfulness of support. Reliability analyses were conducted for each measure used within the current study and results were satisfactory, indicating they were appropriate for use.

2.4. Statistical analyses

Differences in parental demographic characteristics between mothers and fathers in each group at time-point 1 were compared using independent *t*-tests for normally distributed variables, Kruskal-Wallis for non-normal continuous variables, and Chi-square for categorical variables (or Fisher's Exact Test if expected frequencies were less than five). Differences in demographic characteristics and questionnaire responses at time-point 1 were compared for those who responded at each time-point in the study and those who responded at time-point 1 only.

Due to the small sample size, a bootstrap technique was performed on the data and confidence intervals were calculated for the mean scores on each measure [42]. A MANOVA (Multivariate Analysis of Variance) was conducted to investigate any differences between PSS:NICU scores for mothers and fathers. Changes in anxiety and depression scores over time between parents in each group (cardiac and control) were analysed using two-way repeated measures ANOVA's. All

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