



A comparison of parent and staff perceptions of setting-specific and everyday stressors encountered by parents with very preterm infants experiencing neonatal intensive care



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ABSTRACT

Background: Stress responses among parents of premature infants experiencing the neonatal intensive care unit (NICU) environment are widely reported. However, less is known about how nurses perceive parents' experiences or how stressors relating to demands on family finances and practical challenges associated with infant hospitalization contribute to parental stress levels in the NICU.

Objective: 1) To compare parent and staff perceptions of the stressors facing parents experiencing neonatal intensive care; and 2) to develop a scale suitable for identifying stressors outside the NICU setting.

Methods: At infant 34 weeks, parents ($n = 21$) of very preterm infants (≤ 32 weeks GA) and NICU nurses ($n = 23$) completed the Parental Stressor Scale: NICU (PSS: NICU) and a custom-made External Stressor Scale (ESS: NICU).

Results: Nurses perceived parents to experience higher stress in the NICU than parents themselves ($ps < 0.00001$), with parents reporting low-to-moderate stress and staff rating parental stress as moderate-to-high. Parents reported slightly lower levels of stress on the ESS: NICU, with nurses again overestimating the level of parental stress ($ps < 0.00001$). Consideration of the extent of nurses' medical experience did not alter results. The ESS: NICU showed good internal reliability, with PCAs revealing all items to load onto a single component. Additional analyses demonstrated divergent validity, with no relation evident with stress responses on the PSS: NICU.

Conclusions: Periodic reassessments of staff and parent perceptions should be encouraged along with research dedicated to a fuller understanding of the range of stressors facing parents experiencing neonatal intensive care in attempts to reduce stress levels and aid integration into the unit.

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1. Introduction

For the parents of premature and/or low-birth weight infants, the physical and psychosocial environment of the neonatal intensive care unit (NICU) is often perceived as a stressful experience [1–3]. Experiences specific to the NICU setting that parents have identified as most stressful on the Parental Stressor Scale: Neonatal Intensive Care Unit (PSS: NICU; [4]) include sights and sounds of the NICU (monitors and equipment), infant behavior and appearance (illness and treatment) and perceived alteration of the parental role (extended separation from the infant and powerlessness) [5,6]. Although the degree of stress reported may be influenced by a range of infant medical, family and demographic factors [7], there is also potential for stress experienced around the perinatal and early neonatal period to negatively impact on the parent–infant relationship [8] and later child outcomes [9,10].

This has made attempts to fully understand the early stress responses of parents a key research priority, particularly in terms of parent–staff communication and NICU intervention-based efforts [11,12]. Accordingly, in the present study, we aimed to compare the perceptions of parental stress between NICU nursing staff and parents and to evaluate the feasibility of supplementing parent-report measures of stress specific to the NICU setting with items on factors associated with infant hospitalization but encountered outside of the unit that parents may also find stressful.

To date, the majority of studies on the neonatal intensive care experiences of parents with very premature infants (<32 weeks GA) have focused on understanding the contribution of setting-specific factors to stress responses. The influence of stressors encountered outside of the NICU environment has been less well documented. Researchers advocating for an ecological systems/transactional approach to the assessment of parental distress relating to infant NICU admission have suggested that the contribution of factors outside of the NICU environment such as child care arrangements [13] and practical hassles and time pressures [14] be taken into account in order to fully assess the extent and sources of parents' stress reactions in the NICU. Revisiting

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the role of “pre-existing and concurrent personal and family factors” in accounts of parental stress responses, two factors — originally proposed as one of the six major sources of stress in Holditch-Davis and Miles’s [5] Preterm Parental Distress Model, may be important in clarifying the degree to which stressors outside the NICU setting but related to the demands placed on parents by infant hospitalization contribute to specific and overall stress levels in the NICU. Although increasing numbers of studies have identified socio-familial and background characteristics such as marital status, family finance, maternal age and education, and adverse life events as key predictors of maternal and paternal stress [3,7,10,14–16], few have attempted to extend existing assessment scales to incorporate items relating to such factors. More critically, none have examined the contribution these factors might make to parent ratings of stress in the NICU, despite increased awareness of the often disadvantaged socio-familial circumstances of families with premature infants [7].

In one of the few studies to supplement the widely used PSS: NICU with items centered on the demands that infant hospitalization may place on the social and financial resources of parents, Reid, Bramwell, Booth, and Weindling [17] found that parents reported stress associated with conflicting responsibilities, time pressures and practical costs. Administered to a large sample of mothers and fathers with medically fragile infants (i.e., any new-born infants requiring intensive care) in the NICU at two time points (48–72 h and 10–14 days post-delivery), results from exploratory and confirmatory factor analysis justified the inclusion of a social/practical pressures subscale. Furthermore, the factor structure remained robust for both administrations, suggesting that timing of assessment was not critical. However, because the ‘sights and sounds’ and ‘staff communications’ subscales of the PSS: NICU were not included in analysis, the degree to which stress measured by items included in the social/practical pressures subscale related to stress specific to the PSS: NICU subscales was not fully assessed. Moreover, it is not clear as to whether the inclusion of a social and practical stressors subscale is warranted in assessments of parents with infants born very preterm, a population for the PSS: NICU was originally designed.

A second issue concerns the degree to which perceptions of nursing staff align with parents. With stress often a subjective and individual experience [18], understanding potential differences between staff and parent appraisals of the NICU experience may help to facilitate health professionals in providing parents with appropriate support and interventions. Nursing staff not only serve as members of the infants’ primary care team, providing lifesaving and stabilizing treatments [12], but they also help parents through what can be a challenging and stressful time and undoubtedly bear witness to parent distress first-hand. Despite this, studies comparing parent and staff perceptions of stressors associated with the neonatal intensive care experience are limited. Consequently, the extent to which differences and similarities might exist between parent and staff observations has not yet been sufficiently described to provide a foundation for future research, particularly for widely used measures such as the PSS: NICU [4] and Parenting Stress Index (PSI) [19].

Studies comparing staff and parent perceptions of NICU affiliated stressors have been largely restricted to opinions around NICU facility designs [20], staff competency [21] and staff perceptions of parents’ preparation for the NICU-to-home transition [3]. Two exceptions, however, include studies by Raeside [22] and Akbarbegloo and Valizadeh [23]. Using a custom made 18-item stressor scale with a sample of 12 mothers of infants born with low (>1500 g) and very low (<1500 g) birth weight and 12 nurses with a minimum of 3 months experience in the NICU, Raeside [22] found that staff tended to overestimate maternal stress levels and differed from parents in what they perceived as stressful. Specifically, for staff, the sight of “monitors attached to the baby” was considered to be most stressful for parents, while for mothers, “infant appearance” and “heat intensity” were rated as most stressful. The degree of association between reports also appeared to be dependent on the extent of staffs’ medical experience, with the ratings of more

experienced nurses being closer to maternal ratings than those of their more junior colleagues. Akbarbegloo and Valizadeh’s [23] study of 300 mothers of preterm infants (<37 weeks) and 32 NICU nurses also found staff to overestimate the degree of maternal stress reported on the PSS: NICU and to differ from mothers in their perception of stressors, rating infant behavior and appearance as most stressful, while mothers rated parental role alteration as most stressful.

Although these studies help to highlight inconsistencies between staff and parent perceptions, they are not without limitations, including restriction to maternal report and stressors specific to the NICU setting only. In addition, details around modifications made to the PSS: NICU to adapt the scale for staff report are not given. Furthermore, and in contrast to the many studies on parents’ perceptions of staff competency [21,24,25], Raeside’s study [22] remains the only one to have evaluated the extent to which nurses’ medical experience may explain differences between staff and parent perceptions of the NICU experience. The generalizability of their finding to more contemporary cohorts is, however, questionable. Continuing advances in perinatal and neonatal care contributing to improved survival rates among infants born preterm [26] indicate that periodic reassessments of parent and staff perceptions of the NICU experience may be necessary to enhance communication and the integration of parents into the unit. Against this general background, the specific objectives of this study were as follows:

1. To describe and compare the responses of nursing staff to the PSS: NICU with those of parents with very preterm infants in the NICU. Potential stressors included: sights and sounds of the NICU; infant behavior and appearance; parental role alteration; and parent–staff communications and behavior.
2. To develop and consider the reliability, validity and factor structure of a scale suitable for assessing the extent to which parents report stress associated with factors external to the NICU setting.
3. To determine the contribution of stress associated with factors external to the NICU environment to stress specific to the NICU setting.

2. Methods

2.1. Participants

Two groups of participants were included in the study. The first group was a regional sample of 11 mothers and 10 fathers of infants who were born very preterm (≤ 32 weeks’ gestation; range: 26–30 weeks’ gestation) and consecutively admitted to a level III neonatal intensive care unit (NICU) at Christchurch Women’s Hospital (New Zealand) between June 2010 and February 2011. This unit is the sole provider of neonatal intensive care services for the Canterbury region and covers approximately 20,000 km². Exclusion criteria included infant congenital abnormalities and non-English speaking parents. Of the 26 parents eligible to participate, five (19%) declined to take part, resulting in a total sample of 21.¹ Comparison of the income profile of the sample parents with national census data [27] indicated that they were representative of families with premature infants at large, in that while only approximately 18% of families in New Zealand earn <\$50,000 p.a., just over 38% of the families in our study earn <\$50,000 p.a. This finding is consistent with other research on prematurity that shows that families with premature infants are often characterized by lower family socioeconomic status [28]. The second group was a sample of 23 nursing staff working in the Christchurch Women’s Hospital NICU selected randomly from the staff roster and working during the period

¹ The 6.3 magnitude earthquake to hit Christchurch on February 22, 2011 resulted in the early termination of participant recruitment due to concerns around ethics and study validity. Only the parents (11 mothers, 10 fathers) of 13 infants who had participated in the study up to that date were retained.

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