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Parenting very preterm infants and stress in Neonatal Intensive Care Units

Inês Baía [a,b,1], Mariana Amorim [a,c,1], Susana Silva [a], Michelle Kelly-Irving [d,e], Cláudia de Freitas [a,f], Elisabete Alves [a,*]

[a] ISPUP-EPIUnit, Universidade do Porto, Rua das Taipas, nº 135, 4050-600 Porto, Portugal
[b] Faculdade de Medicina, Universidade do Porto, Rua Doutor Plácido da Costa, 4200-450 Porto, Portugal
[c] Global Public Health Doctoral Programme, Instituto de Saúde Pública, Universidade do Porto, Portugal
[d] INSERM UM1027, F-3100 Toulouse, France
[e] Université Toulouse III Paul Sabatier, UM1027, F-3100 Toulouse, France
[f] Centre for Research and Studies in Sociology (CIES), University Institute of Lisbon, Portugal

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ABSTRACT

Background: Assessing parental stress during infants' hospitalization in Neonatal Intensive Care Units (NICU) is essential to identify parents at risk for immediate and extended physical and emotional burden.
Aims: To identify sources of stress in mothers and fathers of very preterm infants hospitalized in NICU, and their association with sociodemographic, obstetric and infants' characteristics.
Study design: Observational and cross-sectional study conducted between July 2013 and June 2014.
Subjects: Parents of very preterm infants hospitalized in all level III NICU in the Northern Health Region of Portugal were consecutively and systematically invited to participate in this study, being included 120 mothers and 91 fathers (participation rate: 98.6%).
Outcome measures: The Portuguese version of the Parental Stressor Scale: Neonatal Intensive Care Unit was used.
Results: The overall experience of hospitalization was classified as more stressful than the median for the subscales. "Change in parental role" was classified as the most stressful subscale by mothers (Median (P25–P75): 4.1(3.2–4.7)) and fathers (Median (P25–P75): 3.2(2.4–4.0)). Mothers scored significantly higher in all subscales. For mothers, multiple pregnancy was associated with lower levels of stress regarding "change in parental role" ($\beta = -0.597$; 95% CI $= -1.020$ to -0.174) and "overall stress" ($\beta = -0.603$; 95% CI $= -1.052$ to -0.153). Being ≥30 years old was found to be a significant predictor for decreased fathers' stress.
Conclusions: This study raises awareness for the need to develop sensitive instruments that take notice of gender, social support and family-centered care. The implementation of interventions focused on reducing parental stress is crucial to diminish disparities in family health.

1. Introduction

The delivery of a very preterm infant, occurring at <32 gestational weeks [1], and his/her subsequent hospitalization in a Neonatal Intensive Care Unit (NICU), is often described as an emotional roller-coaster [2] and a stressful and disruptive life event for mothers and fathers [3]. Parenting a preterm infant' implies a continuous redefinition and adaptation of expected parental roles [4,5], while dealing with the loss of hope to give birth to a healthy neonate as well as of the "phantasy self-as-mother", an idealized state where no mistakes are ever made [6].

Throughout the hospitalization of very preterm infants in NICU, parents encounter multiple stressors that may interfere with the parent-infant relationship. First, the infant's medical condition and immaturity and his/her appearance, abnormal breathing and lower responsiveness to social interactions [4,7,8]. Second, the impediments to the development of interaction skills by both parents and the infant (e.g. the limited availability of the infant, parents' inability to focus on the infant's cues and to recognize his/her behaviors) that preclude changes in parental roles [9]. Third, the concern that the healthcare team may misunderstand the child's needs and the parents' feeling of lack of information on the diagnosis or treatment [8]. Fourth, the stressors related with the transition process to parenthood [2,10], alongside feelings of self-blame and guilt for putting the child through pain [11], which is

* Corresponding author at: ISPUP-EPIUnit, Universidade do Porto, Rua das Taipas, nº 135, 4050-600 Porto, Portugal.
E-mail addresses: inesbaia@med.up.pt (I. Baía), mariana.amorim@ispup.up.pt (M. Amorim), susilva@ispup.up.pt (S. Silva), michelle.kelly@inserm.fr (M. Kelly-Irving), claudia_defreitas@yahoo.com (C. de Freitas), elisabete.alves@ispup.up.pt (E. Alves).
[1] Equal contributing authors.

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particularly experienced by mothers [6,9]. Finally, the complexity of the NICU environment, with unknown specific smells and lights, noisy life support and monitoring equipment [4,7], lack of privacy [12] and the constant presence of healthcare professionals [13].

Several studies show that parental stress in NICU is influenced by a range of sociodemographic, obstetric and infant characteristics. These include parental age, ethnicity, socioeconomic status [14] and exposure to other stressful life events [15], as well as pregnancy planning and previous pregnancy loss, maternal trait anxiety and mental health history, severity of infant illness [2,10,16] and previous experience of infant's hospitalization in NICU [17]. However, the results of these studies are inconsistent. Moreover, most studies exclude fathers, offering a one-sided perspective that fails to approach the impact of NICU hospitalization on the parents and in the family. Furthermore, there are very few studies focusing on sources of stress among parents of very preterm infants and those that exist were mainly conducted in the United States of America [16].

Previous research also suggests that parents' experiences in NICU are associated with posttraumatic stress disorder beyond the period of hospitalization [2,13], with a very preterm birth influencing the family environment several years later. Studies report poorer family functioning and higher family burden 2 and 7 years after birth among preterm families when compared to families of term born infants [19]. Stressful family environments, stress experienced among couples and the potential long-term consequences of stress on parenting and child health over time may be exacerbated by the socioeconomic milieu [20]. Considering the association between social adversity across the life course and the development of non-communicable diseases [18,21], experiencing a very preterm delivery can have a longer impact on parents' health and well-being [18].

The assessment of sources of parental stress during infants' hospitalization in NICU and its associated factors is essential to identify parents at risk for immediate and extended physical and emotional burden. Knowledge about such stress sources and factors may help healthcare professionals to develop and implement measures and interventions aiming to provide benchmarks for quality improvement in NICU [13] and to promote family-centered care [22]. This study aims to help achieve these goals by identifying sources of stress in mothers and fathers of very preterm infants hospitalized in NICU, and their association with sociodemographic, obstetric and infant's characteristics.

2. Methods

This observational and cross-sectional study is based on a cohort of mothers and fathers of very preterm infants, which protocol has been previously described elsewhere [23]. The study was approved by the Portuguese Data Protection Authority and the Ethics Committees of all hospitals where the study was performed and written informed consent was obtained from all participants.

Briefly, all mothers and fathers of very preterm infants born between 1st July 2013 and 30th June 2014 and hospitalized in all level III NICU located in Northern Health Region of Portugal, 7 in total, were consecutively and systematically invited to participate in the study. Parents were approached during the hospital stay by a NICU health professional (neonatologist or nurse), who was responsible for the study presentation and invitation. A total of 201 very preterm infants were born, corresponding to 165 families (130 single pregnancies, 34 twin pregnancies and 1 triplet). After excluding families whose infants were not hospitalized in NICU at the time of the interview, due to discharge, transfer to another hospital or dead (n = 27), families with serious illness that precluded NICU visitation (e.g., severe chronic conditions) (n = 4), families who were not present in NICU during the baby's hospitalization period (n = 6), and those who did not read Portuguese (n = 2), 126 families were eligible to integrate the study. Among these, 122 (98.6%) accepted to participate. The study included 120 mothers and 91 fathers. Refusals were justified by lack of time to participate (n = 3) and psychological unavailability (n = 1). During data collection, 2 mothers were missed due to medical complications and 31 fathers were absent due to professional commitments or emigration.

Trained interviewers were responsible for conducting face-to-face interviews, 15 to 22 days after birth (Mean (SD) = 17.6 (2.3)), using structured questionnaires, to mothers and fathers, separately. Data on sociodemographic characteristics (gender, age, marital status, education and income), previous pregnancies and previous children (biological/adoptive vs. no children) were collected through self-report. Social support was assessed by the Multidimensional Scale of Perceived Social Support (MSPSS) [24] which measures the perceived adequacy of social support received from a significant other, from family and friends. Afterwards, mothers and fathers were asked to fill the validated Portuguese version of the Parental Stressor Scale: Neonatal Intensive Care Unit [25], a self-administered scale consisting of 26 items designed to measure parental perception of sources of stress arising from the environment of the NICU. Each item ranges from 1 (not at all stressful) to 5 (extremely stressful), being grouped into 3 dimensions: “Sights and Sounds” (6 items), “Baby Looks and Behaves” (13 items) and “Change in Parental Role” (7 items). Also, at the end of the questionnaire there is a question about “Overall stress”. The score of each of the abovementioned dimensions of the stress scale is calculated as the mean of the group of the respective individual items. It ranges from 1 to 5, with higher values indicating higher levels of parental stress.

Clinical records were reviewed by interviewers to retrieve data on pregnancy complications (which included infectious, placental, haemorrhagic and cardiovascular complications), multiple pregnancy (yes/no), and mode of delivery (vaginal or instrumental and caesarean). Data on the infant's sex, birth weight and gestational age were also collected. Extremely low birth weight and extremely premature infants were defined as birth weight bellow 1000 g [1] and gestational age under 28 weeks [1], respectively.

Statistical analysis was performed using Stata 11.0 (College Station, TX, 2009). Sample characteristics are presented as counts and proportions. The overall score of each subscale, stratified by gender, was presented as medians and percentiles (P25-P75) and compared using the Mann-Whitney test. Mean differences (β) in sources of stress and the respective 95% confidence intervals (95% CI) adjusted for age, educational level and all variables significantly associated with each subscale, were estimated by multiple linear regression models, stratified by gender.

3. Results

The characteristics of the study participants are summarized in Table 1. Almost 70% of the mothers and >75% of the fathers had 30 or more years of age. Most participants were married and this was the first pregnancy for >50% of them. <40% of the participants stated a household monthly income above 1500€, with approximately 40% of the mothers and 30% of the fathers reporting an educational level above 12 years. Pregnancy complications were described by >40% of mothers and fathers, caesarean was the most frequent mode of delivery and almost a quarter of pregnancies were multiple. Approximately 30% and 20% of pregnancies resulted in an extremely low birth weight delivery and in an extremely premature delivery, respectively.

Mothers of very preterm infants hospitalized in NICU classified the overall experience of hospitalization as very stressful (Median (P25–P75): 4.0 (3.0–5.0)), while fathers perceived such situation as stressful (Median (P25–P75): 3.0 (3.0–4.0)) (Table 2). Despite gender differences in the importance attributed to parental stressors, with mothers quoting significantly higher in all subscales, “change in parental role” was classified as the most stressful both by mothers (Median (P25–P75): 4.1 (3.2–4.7)) and fathers (Median (P25–P75): 3.2 (2.4–4.0)).

Tables 3 and 4 present mothers' and fathers' parental stressor subscales scores according to sociodemographic, obstetric and infants' characteristics, respectively. Women with multiple pregnancies reported