



Inês Baía Ribeiro Baltazar Dias

**Orientadora:**

Doutora Susana Silva

Instituto de Saúde Pública da Universidade do Porto

Departamento de Epidemiologia Clínica, Medicina Preditiva e Saúde Pública, Faculdade de Medicina da Universidade do Porto

**Coorientadora:**

Doutora Elisabete Alves

Instituto de Saúde Pública da Universidade do Porto

Departamento de Epidemiologia Clínica, Medicina Preditiva e Saúde Pública, Faculdade de Medicina da Universidade do Porto

## **Prematurity and parental perspectives in Neonatal Intensive Care Units**

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## **LIST OF ABBREVIATIONS**

BMI - Body Mass Index

CI – Confidence Interval

MOSAIC - Models of Organising Access to Intensive Care for very preterm births

NICU – Neonatal Intensive Care Unit

WHO - World Health Organization

## RESUMO

A prematuridade representa 75% da mortalidade perinatal e é a principal causa de mortalidade neonatal, constituindo o parto muito pré-termo um dos três principais determinantes de morbidade infantil na Europa. Daí o notório investimento na tradução de conhecimento em práticas baseadas na evidência no caso de crianças muito pré-termo internadas em Unidades de Cuidados Intensivos Neonatais (UCIN). Importa incorporar as perspectivas dos pais na organização dos cuidados e nas intervenções em saúde, sendo o conhecimento sobre as respetivas necessidades e stresse essencial para a implementação de cuidados de saúde centrados na família. Contudo, a investigação sobre conhecimento e papéis parentais no contexto da prematuridade é escassa, e não existe evidência sobre a influência do período de recolha de dados no reporte de necessidades e stresse parentais em UCIN.

Esta dissertação tem como objetivo geral avaliar as experiências parentais em UCIN e o efeito de diferentes opções metodológicas no planeamento do estudo sobre necessidades e stresse de mães e pais de crianças muito pré-termo internadas em UCIN. De seguida descrevem-se, sucintamente, os objetivos específicos de cada estudo, assim como a respetiva metodologia e principais resultados.

1. Rever sistematicamente a literatura acerca das experiências e perspectivas de mães e pais de crianças prematuras internadas na UCIN, tendo em conta os seus significados, conhecimento e emoções.

Pesquisaram-se as bases de dados eletrónicas Pubmed, ISI WoK and PsycINFO para identificar artigos originais com dados empíricos sobre as perspectivas dos pais quanto às suas experiências, conhecimento e tomada de decisão na UCIN. Incluíram-se 19 estudos, emergindo quatro temas iterativos e dinâmicos: fatores contextuais, necessidades parentais, emoções contraditórias, e estratégias de *coping*. Na UCIN, os pais têm que lidar com a vulnerabilidade da criança num ambiente sociotécnico não familiar, que impõe restrições à prestação de cuidados, e com a necessidade de estabelecer relações com os profissionais de saúde, procurando informação, orientação, confiança e suporte social. Simultaneamente, os pais lidam com emoções complexas e assumem, ativa e/ou passivamente, a responsabilidade pela criança através do recurso a crenças religiosas e adoção de uma atitude positiva.

2. Avaliar o efeito do período de recolha de dados no reporte de necessidades e stresse parental, comparando pais entrevistados 8 a 14 dias após a admissão do seu filho na UCIN, com aqueles entrevistados 15 a 22 dias após esse evento.

Entre Janeiro e Setembro de 2013, 22 mães e 17 pais foram entrevistados, consecutivamente, 8 a 14 dias ou 15 a 22 dias após a admissão do seu filho numa UCIN de nível III na região Norte de Portugal. Os dados foram recolhidos através de questionários autoadministrados, usando-se o Inventário de Necessidades da Família e a Escala de Stress Parental na UCIN. As necessidades mais valorizadas pelos pais foram a confiança e a proximidade. Comparada com a avaliação 8 a 14 dias após admissão na UCIN, observou-se a valorização da perceção do suporte social como muito importante na avaliação 15 a 22 dias. Os pais entrevistados mais tarde consideraram mais frequentemente a alteração no papel parental e aparência e comportamento do bebé como extremamente stressante. Não houve recusas no segundo momento de avaliação.

Os resultados desta investigação evidenciam o parto prematuro como um acontecimento disruptivo, revelando a complexidade dessa experiência na vida de mães e pais. A literatura tem-se focalizado nas respostas emocionais dos pais de crianças prematuras, a nível individual, em detrimento da análise dos procedimentos de avaliação cognitiva e da compreensão dos fatores socio-estruturais que influenciam a vivência do internamento em Unidades de Cuidados Intensivos Neonatais. Conhecer as perspetivas e necessidades parentais, assim como as fontes de stresse, é essencial durante o período de internamento, de modo a detetar eventuais lacunas nos serviços de saúde e poder melhorar a respetiva qualidade, adequando os cuidados às necessidades de mães e pais. Importa ainda reconhecer os pais como elementos integrantes da prestação de cuidados à criança, promovendo o seu envolvimento e garantindo a circulação contínua de informação precisa.

Compreender as perspetivas de mães e pais no contexto da hospitalização em Unidades de Cuidados Intensivos Neonatais é fundamental para assegurar a qualidade dos cuidados de saúde e orientar investigação futura que contemple a análise de variáveis socio-estruturais. Esta dissertação pode contribuir para sustentar o desenho de intervenções em saúde centradas na família, promovendo o suporte e a educação de mães e pais para lidar com o nascimento, e conseqüente internamento, de um filho prematuro.

## ABSTRACT

Prematurity accounts for 75% of perinatal mortality and constitutes the single largest cause of neonatal mortality, and very preterm birth remains as one of the three major determinants of childhood impairment across Europe. Thus, there is a strong focus on the translation of scientific knowledge into evidence-based practice when dealing with preterm infants hospitalized in Neonatal Intensive Care Units (NICU). The incorporation of parents' perspectives with respect to the organization of care and technical interventions is needed, and knowledge about parental needs and stress is essential for the implementation of family-centered care in NICU. However, research on parenthood and embodied knowledge in the context of prematurity is scarce, and there is no evidence on how the period of data collection may introduce reporting bias when assessing self-reported parental needs and stress in NICU.

Overall, this thesis aims to study parental experiences in NICU and the effect of different methodological options in planning the study of parental needs and stress of mothers and fathers of preterm infants hospitalized in NICU. The next paragraphs briefly describe the specific objectives pursued in each study, as well as the methodology adopted and main results.

1. To systematically review the experiences and views of mothers and fathers of preterm infants admitted to NICU described in the literature, regarding meanings, knowledge and emotions.

The electronic databases Pubmed, ISI WoK and PsycINFO were searched to identify original articles providing empirical data on perspectives of parents regarding their experiences, knowledge and decision making in NICU. Four iterative and dynamic themes emerged from 19 publications: contextual factors, parental needs, mixed emotions and coping strategies. In NICU, parents are challenged to deal with the infant's vulnerability in an unfamiliar sociotechnical environment, which imposes restraints on the performance of usual caregiving activities and the need to establish relationships with health professionals, while looking for information and guidance, assurance and support. Simultaneously, parents grapple with complex and mixed emotions and enact action by active and/or passive forms of assuming responsibility for the infant, using religious beliefs, and being positive.

2. To assess the effect of the period of data collection on the self-reported parental needs and stress, by comparing those interviewed 8 to 14 days after the hospitalization of their child with those interviewed 15 to 22 days after that event.

Between January and September 2013, 22 mothers and 17 fathers were consecutively interviewed 8 to 14 days or 15 to 22 days after admission, in a level III NICU in the North of Portugal. Data were collected through a self-administered questionnaire comprising the NICU Family Needs Inventory and the Parental Stress Scale in NICU. Assurance and proximity were the most valued needs. Comparing to the assessment 8 to 14 days after admission, an increase in parental perception of support as very important was observed 15 to 22 days. Those interviewed later considered the change in parental role and baby looks and behaves as extremely stressful more often. No refusals occurred in the second moment.

The main results of this thesis point out preterm delivery as an acute life event for both mothers and fathers, highlighting the complexity of such multifaceted parental experience. Current literature focus on emotional responses at an individual level, at the expense of cognitive appraisals, as well as socio-structural factors influencing the experience of having a preterm infant hospitalized in NICU. The identification of parental perspectives, needs and sources of stress is essential along the continuum of care, not only to allow the detection of possible gaps in health services but also to improve their quality and adequacy. Also, it is important to recognize mothers and fathers as healthcare partners in infants' care, promoting their involvement and continuous sharing of accurate information.

Understanding mothers' and fathers' perspectives during hospitalization in NICU is an important step in improving the quality of care and guiding future research, which needs to include social and structural levels of analysis. The present thesis may assist health professionals in designing holistic, family-centered, supportive and educational interventions for parents, helping them to deal with the unexpected experience of having a premature child.

# 1. INTRODUCTION

## 1.1. Prematurity: definition, prevalence and causes

Preterm delivery refers to that occurring before 37 completed weeks of gestation, or earlier than 259 days since the first day of a woman's last menstrual period. According to gestational age - less than 28 weeks, between 28 and 31 weeks, between 32 and 33 weeks or between 34 and 36 weeks, delivery can be classified as extremely preterm, very preterm, moderate preterm or late preterm, respectively (Figure 1).

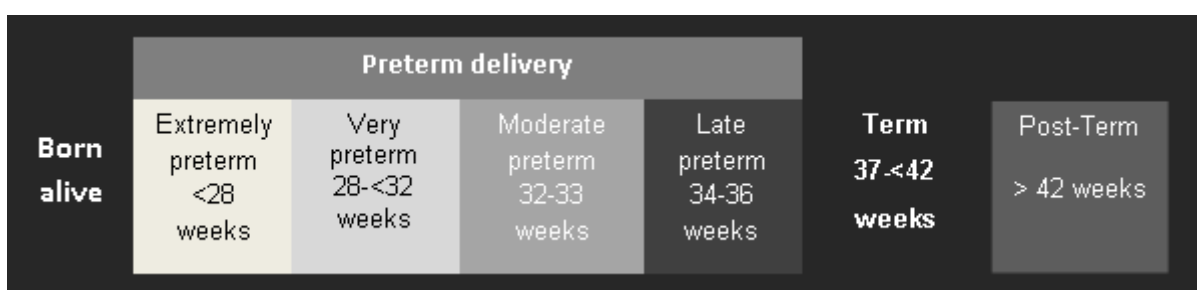


Figure 1 – Classification of preterm delivery (adapted from WHO (1)).

While spontaneous preterm delivery can result from preterm labor with intact fetal membranes or preterm rupture of the fetal membranes, provider-initiated preterm delivery is defined by early induction of labour or caesarean section before term, for fetal or maternal indication. In high-income countries, approximately 40% to 45% of preterm births follow preterm labor, 25% to 40% follow preterm premature rupture of the fetal membranes and 30% to 35% are indicated deliveries (2). Although most of preterm deliveries occur spontaneously, several high-income and middle-income countries have increasingly numbers of provider-initiated preterm births (3).

The WHO global survey on preterm birth rates, which was based on 184 countries worldwide, points to a global average of preterm birth rate of 11.1% in 2010, representing a total of 14.9 million infants (Figure 2). Over the last two decades, many countries worldwide have reported increased preterm birth rates (3-6). Time trends were estimated for 65 Developed, Latin America and Caribbean countries, with the mean preterm birth rate rising from 7.5% in 1990 to 8.6% in 2010. Reasons contributing for these increase include the rise of multiple pregnancies associated with fertility treatments, and changes in population risk factors such as older maternal age at first birth and higher maternal body mass index (BMI) (6).

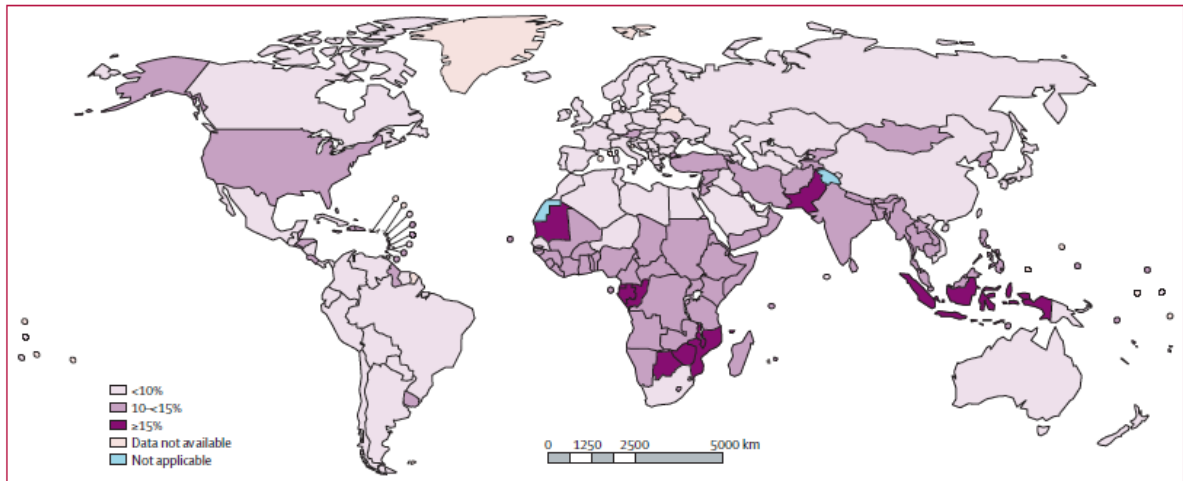


Figure 2 – Estimated preterm birth rates by country, 2010 (3).

There are wide differences in the prevalence of preterm birth across Europe. In fact, between 2004 and 2010, rates of preterm live births increased in Luxembourg, Brussels/Belgium, the Czech Republic, Portugal, Northern Ireland and Italy, but declined in Norway, Scotland, Germany, England and Wales, Denmark and Sweden, as shown by the European Perinatal Health Report (7).

Preterm delivery results from the interplay of multiple factors, with the precise causes being unidentified in up to all of births (8). There are maternal and fetal characteristics associated to preterm delivery, including maternal sociodemographic characteristics, nutritional status, pregnancy history, pregnancy characteristics, psychological characteristics, adverse behaviors, pregnancy complications and biologic and genetic markers (9, 10). Individual or family history of preterm delivery have been described as strong risk factors, along with older maternal age, single marital status, low socioeconomic and educational status, tobacco use, type of work, level of physical activity, absence of a strong supportive economic and social safety net, and also maternal health problems, namely obesity, diabetes and high blood pressure, previous preterm premature rupture of membranes, previous cervical surgery or laceration, a short cervix ultrasound, genetic connective tissue disorders, infections and multiple pregnancy (1, 3).

Infection is one of the most important potentially preventable causes of early preterm birth, but other conditions such as pre-eclampsia, placental abruption, uterine rupture, uteroplacental ischemia or hemorrhage, inflammation, uterine over distension, cervical insufficiency, fetal distress, fetal growth restrictions, stress and other immunologically mediated processes have also been associated with higher risk of preterm delivery (9). Although the etiologies of preterm birth are complex and multifactorial, smoking cessation, progesterone treatment and cervical cerclage have shown some success as preventive interventions for preterm delivery (2).

## 1.2. Prevalence and outcomes of very preterm delivery

Extremely and very preterm births, occurring before 32 weeks of gestational age, account for about 1% of live births and represent a proportion of 15.6% of all preterm births (Table 1) (1). In Portugal, 846 very preterm infants were born in 2013, representing 1% of all births and a proportion of 10.2% of preterm births (11).

Table 1 – Worldwide distribution of preterm births according to gestational age, 2010 (n= 131,296,785 live births).

	Gestational age	Proportion of all <37 weeks (% , 95% CI)
Extremely preterm	<28 weeks	5.2% (5.1–5.3)
Very preterm	28–<32 weeks	10.4% (10.3–10.5)
Moderate or late preterm	32–<37 weeks	84.3% (84.1–84.5)

SOURCE: Meta-analysis developed by WHO (1).

In 2003, the MOSAIC study (Models of OrganiSing Access to Intensive Care for very preterm births) estimated very preterm birth rates in 10 European regions, ranging from 0.8% in Eastern and Central Netherlands to 1.4% in Trent, in United Kingdom (12). In 2010, the European Perinatal Health Report showed a similar range in very preterm delivery rates, from 0.7% to 1.4% (Figure 3). Lower rates of very preterm live births were described for Iceland (0.7%), Malta (0.8%), Finland (0.8%), Wallonia/Belgium (0.9%), Lithuania (0.9%) and Sweden (0.9%). Rates were higher in Hungary (1.4%), Brussels (1.4%), Germany (1.3%), Austria (1.3%), Slovenia (1.2%), Romania (1.2%) and United Kingdom (1.2%) (7).

Over the past three decades, significant medical and technological advances have reduced perinatal mortality for these infants from 35% to 15%, approximately (13, 14). However, very preterm birth remain as one of the three major determinants of perinatal death and childhood impairment across Europe, along with fetal growth restriction and congenital anomalies (7). Very preterm infants are at particular high risk of infant death, respiratory and gastrointestinal complications, and neurodevelopmental impairment, including cerebral palsy, mental retardation sensory loss (such as visual and auditory deficits) and dysfunction in cognitive areas, as attention, academic progress and executive function, important in a child's cognitive functioning, behavior, emotional control, and social interaction (6, 15, 16).

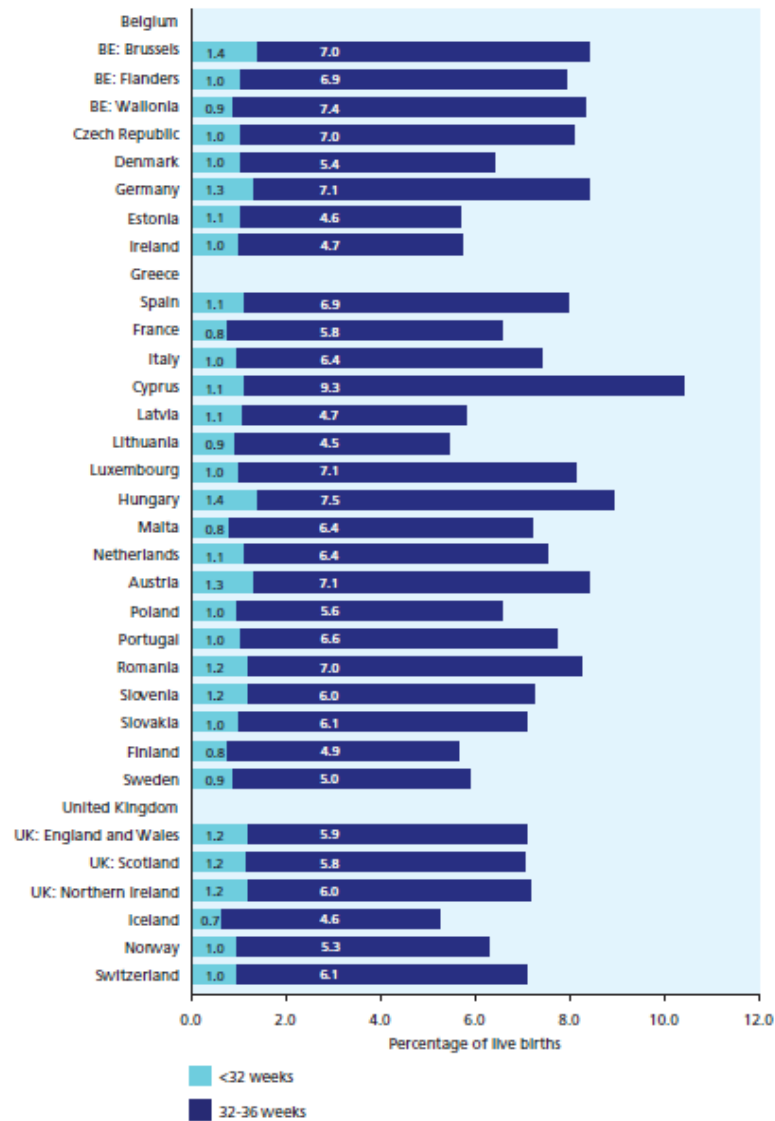


Figure 3 – Percentage of live births with a gestational age <32 weeks and between 32-36 weeks in European countries, 2010 (7).

These infants are highly dependent of intensive care after birth, mainly regarding feeding, constant monitoring, and early treatment of neonatal problems, such as breathing difficulties, infections and jaundice (2, 15, 17). Outcomes of very preterm infants concerning survival rates, mortality, and neurological and respiratory morbidity differ between neonatal intensive care units (NICU) and European regions, according to varied uses of medical interventions and several approaches to the organization of care (12, 18). The MOSAIC study showed crude in-hospital mortality rates ranging from 7.9% to 24.7% between 10 European regions, presenting an average rate of 14.2%. The Northern of Portugal had a rate of in-hospital mortality of very preterm infants of 15.9%, lower than the regions of

Flanders/Belgium, Lazio/Italy, and Wielkopolska and Lubuskie/Poland, but higher than Hesse/Germany, the Northern of the United Kingdom, and the Eastern Denmark (5).

Very preterm delivery represents a public health concern with significant disparities in preterm birth across populations. Also, very preterm infants generate substantial emotional and economic costs in their families and communities and have a disproportionate impact on health service utilisation (19). The societal burden of very preterm delivery is also relevant, with many families experiencing the sudden loss of a very preterm baby or a stressful hospital stay, sometimes for months, adding that at discharge from hospital, frequently unknown prognosis and uncertain future health needs of their child (3).

Thus, the birth of a very preterm infant is an unexpected outcome of pregnancy, which constitutes a disruptive and acute adverse life event with impact on parents' health and well-being (20). Parental stress, anxiety, depression and several psychopathological symptoms are higher among families with a very preterm infant and have been associated with poorer child behavioral and health outcomes (13, 14, 20).

### **1.3. Family-centered care in Neonatal Intensive Care Units**

Family-centered care is a philosophy of care grounded in support and respect for family participation in the child's care that acknowledges that the family has the greatest influence over an infant's health and well-being (21, 22). This approach is characterized by respect, collaboration and open communication between health care professionals and families. It is an important component of neonatal care, highlighting the importance of acknowledging and accepting family support in promoting improved infant outcomes (22).

Enhancing family presence in NICU, through parental involvement in care and decision-making, and respecting parental perceptions is part of this partnership. Therefore, assessing parents' perspectives and experiences, including their needs and stress, is an important element for promoting quality family-centered care in NICU, which may help families dealing with stress, fear and altered parenting roles that emerge from the delivery of a preterm infant and its subsequent hospitalization in NICU.

### **1.3.1. Parental Needs**

A family need is defined as “a requirement, which if supplied, relieves or diminishes their distress or improves their sense of adequacy or well-being” (21). After the birth of a very preterm infant and during his/her hospitalization in NICU parents face particular needs of information, assurance, proximity, comfort and social support (23), which may place them at an increased risk of developing parental stress and several psychopathological symptoms (20, 24). Empirical studies, examining the perspective of parents regarding their experiences during infant’s hospitalization in NICU, highlight the need of obtaining information and guidance (25), trusting in the healthcare team (26), and experiencing support from staff members and the partner (27). The importance attributed to several needs, especially information, assurance and proximity, is in alignment with the parents’ attempt to develop a sense of meaning about a new reality shaped in an unknown sociotechnical environment (28, 29).

In NICU, health professionals have an important role as the main source of information for parents, since they are the ones in charge of their infants (26, 28). A good and effective communication between parents and health care providers empowers parents and helps them to develop caregiving competencies (28, 30). As demonstrated by previous studies, parents describe the provision of frequent and accurate information as essential to know and be aware of their infant’s health status (31), contributing also to involvement in decision making (27), an increased sense of control (25) and participation in child’s care (28). Parents also recognize the need for ongoing explanations regarding the infant’s appearance and behavior, feeling more involved in the decision-making process if this exchange of information with healthcare professionals about infant’s condition is clear and understandable (25, 27). Also, the provision of infant-related information by healthcare professionals may facilitate the attachment between parents and their child, by allowing parents to focus on infants’ well-being, and contributing for overcoming some physical and psychological barriers (31, 32).

The development of positive and trustful relationships between parents and health professionals allows them to feel welcome in the unit and gain control over the situation (28, 33). Moreover, when the bond established with the health staff is perceived as trustful, parents feel more secure and capable, which will consequently contribute for the development of feelings of pride and enhanced self-esteem (26). As the process of bonding between parents and their infants is perceived as more vulnerable, the need for supportive relationships with healthcare professionals increases (34). Therefore, a positive relationship

with medical staff tends to, simultaneously, empower parents to connect their infants and facilitates the establishment of parental competence (35). In fact, confidence in health care providers helps parents to leave their infants and deal with the worrisome nature of NICU experience (26).

During hospitalization, parents also express needs of proximity in order to overcome the initial and unexpected separation of their infant (36-38). Physical and emotional closeness facilitates parent-infant relations, as well as their involvement in infant's care, through caregiving actions such as visual contact, touching, soothing and holding, and physical care like feeding, bathing and diapering (30, 39). Besides, the participation of both mothers and fathers in infant's care contributes to positive neurobehavioral and development outcomes for children, which enhances parents' confidence and capacity to provide care for their infants (39-41).

The importance of support needs, during hospitalization in NICU, may reflect parental search for assistance, either from healthcare professionals, to learn and practice skills for taking care of their infant, and from family and friends, for assistance with household tasks (33), care of other children and emotional support (42) in order to reduce parental burden. Availability of social and emotional support for mothers and fathers can promote their well-being and encourage parent-infant bonding (31). In addition, social support is revealed as a coping strategy for parents and helps them feel less alone and more hopeful while going through the NICU experience (27). Along with support, there is also a need to ensure that someone is concerned about maternal and paternal health and comfort. The assurance of parental comfort is related both with physical and psychosocial issues, in order to provide comfortable and resting spaces in NICU, guarantying that parents can express their emotions and feelings in privacy or can have the support of other person if preferred (31). Literature has been showing a higher relevance of infant related priorities, which may mask parents' need for support and comfort (31, 43).

Studies also describe the need for parents to share their experiences with other parents with infants hospitalized in NICU (25), along with the need of physical help provided by the partner, for sharing parental responsibilities regarding, for example, breastfeeding (26) and physical contact (25), and support from the government (44). Nevertheless, the emotional "roller-coaster" (38) experienced by parents limits the means of verbally expressing their individual needs and taking control in the situation (36).

Noteworthy is the fact that satisfaction of parental needs can reduce the negative impact of a preterm birth and promote parental well-being (31). Thus, the identification of parental perspectives and needs may help healthcare professionals, particularly the NICU staff, to define strategies to help the parents cope with preterm birth and premature parenthood.

### 1.3.2. Parental Stress

The delivery of a very preterm infant and his/her subsequent hospitalization in NICU is often described as a stressful moment for parents (45), implying a redefinition and adaptation of their expected parenting roles, while dealing with the loss of an expected healthy neonate (46), and with the loss of the “phantasy self-as-mother”, an idealized state where no mistakes are ever made (47). Additionally, research suggests that the NICU experience is associated with posttraumatic stress disorder, beyond the period of hospitalization (38, 48, 49). Therefore, evaluation of parental stress during infants’ hospitalization in NICU is needed to improve quality of care and identify parents at risk for immediate and extended physical and emotional consequences (49).

Parents with very preterm infants hospitalized in NICU encounter multiple stressors, such as the medical condition of the child, the complexity of NICU environment, the perceived vulnerability of the infant, along with stressors related with the normal transition process to parenthood (38, 50). Personal and family factors, such as parental age, ethnicity, socioeconomic status and previous experiences with illness, as well as prior prenatal and perinatal experiences may also be considered as direct sources of parental stress (38).

The unknown sociotechnical environment of the NICU, with specific smells and lights and noisy life support and monitoring equipment, can be a major factor contributing to parents’ distress (51, 52). At the same time, the immature and vulnerable appearance of the child, surrounded by medical devices, along with abnormal breathing and less responsiveness to social interactions affects parent-infant relationship and lessens the families’ role in caregiving activities (51-53). Other factors contributing to parental stress are the concern that the healthcare team would misunderstand the child’s needs and the lack of information on the diagnosis or treatment (53).

Throughout the hospitalization of the infant in NICU, parents are unable to assume the role as primary caregivers of their infant, so high levels of stress arouse from alterations on parental roles (33, 51, 54). The lack of privacy (30), the incubator (55), and the constant presence of healthcare professionals (49) emerge as the main challenging elements for parental roles. In fact, the physical and symbolic barriers for touching and holding the child (55), the technological equipment crucial for infants’ viability (53), as well as the impossibility to protect the child from harm and to perform caregiving activities (37, 53) can lead parents to feel less confident, more alienated from their infants and incompetent in their parental roles (37).

Thus, the delivery of a very preterm infant may be considered as an event of biographical disruption, where expected development of interactive skills for both the parent and the infant are interrupted (56). After birth, feelings of self-blame and guilt experienced by parents, particularly by mothers, also contribute to their levels of stress (29, 47). In this context, parents may assume the responsibility for the premature birth and for possible complications in child's growth and development (43), feeling guilty of putting their child through pain (57).

A discrepancy between parents' social representation of their child and the real premature infant, who is vulnerable, immature and whose survival is dependent upon medical and technological intervention, respiratory support and close monitoring, is frequently described in the literature (28, 47). The difference between what is expected from very preterm infants compared to other infants regarding size, weight, neurobehavioral development and interaction with mothers and fathers may lead to increased levels of stress in parents of very preterm infants hospitalized in NICU (29, 47).

Parents' recognition of the child's cues and ability to touch and handle the babies reduce stress and facilitate positive parent-child interactions (51). Thus, clear communication and careful explanations geared to parental comprehension capability may reduce parental anxiety and improve both parental health and parenting involvement and behavior (49). Designing tailored interventions that focus parents' needs, not only in terms of informational and educational support, but also regarding feelings of self-blame and low self-efficacy (58), may reduce parental stress, facilitating the opportunities for active participation in the care and nurturing of their child, and fostering the philosophy of family-centered care in NICU (51). As well, the assessment of parental needs and stress provides health professionals with individualized measures that may be used to evaluate care and provide benchmarks for quality improvement (49).

#### **1.4. Socially robust quantitative methodologies in Neonatal Intensive Care Units**

The respect for the principles of autonomy, non-maleficent, beneficence and justice is essential in public health research (59). It means that participants must be fully informed about the purposes and procedures of the research, and its potential benefits and risks, before freely deciding to be involved in the study and signing the informed consent. Additionally, researchers must minimize potential harms while maximizing potential benefits to individuals and society, designing fair and just research strategies in order to achieve an

equal individual distribution of the potential benefits of the study (59, 60). Regarding the assessment of parental perspectives and experiences in NICU, researchers must minimize the burden to mothers and fathers of hospitalized infants and to lessen the intrusion into their private and stressful experiences (59), being careful about confidentiality, privacy and anonymity.

Considering that parental perspectives may change across child's hospitalization (46), researchers and health professionals must be aware of the relevance of the period of assessment and its effects on results, as well as on counselling and clinical practice. In addition, the quality of data and response rates may be influenced by mode of selecting participants (61), setting (62), mode of questionnaire administration (63) and validity of self-reported information (64).

Researchers need to guarantee parents' safety throughout the process of data collection (65), by assuring that it occurs in physical and socioethical environments where the interviewees, as well as the researchers, feel protected and comfortable (66). The investment on trained interviewers with adequate attributes (e.g., gender, age, ethnic group and empathy) facilitates the establishment of trustworthy relationships (59) and the disclosure of personal information (67).

Thus, researchers and health professionals must be aware of potential effects of methodological decisions regarding data collection on the interpretation of results, while minimizing the burden to participants and lessening the intrusion in their private experiences.

## 2. OBJECTIVES

Although the improvement in the quality of antenatal and neonatal care led to a decrease in perinatal mortality and morbidity in the last three decades (15, 16), prematurity still accounts for 75% of perinatal mortality and constitutes the single largest cause of neonatal mortality, contributing to 35% of neonatal deaths (17) and more than half of long-term morbidity (9). Preterm infants require specialized, demanding and planned care, to ensure their stability and survival, despite their immaturity and vulnerability. The birth of a preterm infant and his/her hospitalization in NICU is a stressful and traumatic experience for parents (57), who have to deal with a lot of unusual information, contradictory emotions of excitement and fear, and uncertainty (51). Thus, preterm birth is an event of public health significance, with health and social impacts on infants and their families, especially on mothers and fathers (3, 19). However, there is a strong focus on the translation of scientific knowledge into evidence-based practice when dealing with preterm infants hospitalized in NICU, contrasting with scarce literature on parents' perspectives with respect to the organization of care and technical interventions (68, 69).

Research on mothers and fathers' perspectives, roles and needs is needed and, to our knowledge, there is no evidence on how the period of data collection may introduce reporting bias when assessing self-reported parental needs and stress in NICU. Overall, this thesis aims to study parental experiences in NICU and the effect of different methodological options in planning the study of parental needs and stress of mothers and fathers of preterm infants hospitalized in NICU.

The specific objectives are:

1. To systematically review the experiences and views of mothers and fathers of preterm infants admitted to NICU described in the literature, regarding meanings, knowledge and emotions.
2. To assess the effect of the period of data collection on the self-reported parental needs and stress, by comparing those interviewed 8 to 14 days after the hospitalization of their child with those interviewed 15 to 22 days after that event.

### **3. CHAPTER 1**

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# **Parents' perspectives on hospitalization of preterm infants in Neonatal Intensive Care**

## **Units: a review of literature**

Elisabete Alves<sup>1,2</sup>, Mariana Amorim<sup>1</sup>, Inês Baía<sup>1,2</sup>, Susana Silva<sup>1,2</sup>

<sup>1</sup>Institute of Public Health – University of Porto (ISPUP), Porto, Portugal;

<sup>2</sup>Department of Clinical Epidemiology, Predictive Medicine and Public Health, University of Porto Medical School, Porto, Portugal.

### **Corresponding author:**

Elisabete Alves

Institute of Public Health – University of Porto (ISPUP)

Rua das Taipas nº 135

4050-600 Porto, Portugal

Telephone: +351 222 061 820

Fax: +351 222 061 821

e-mail: ealves@med.up.pt

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## **ABSTRACT**

This literature review intended to synthesize the repertoire of meanings, knowledge, and emotions actualized by parents of preterm infants during hospitalization in a Neonatal Intensive Care Unit (NICU). The electronic databases Pubmed, ISI WoK and PsycINFO were searched to identify original articles providing empirical data on perspectives of parents regarding their experiences, knowledge and decision making in NICU. Four iterative and dynamic themes emerged from 19 publications: contextual factors, including the impact of the sociotechnical environment, alterations in the expected parental roles, parents-professionals relationships and awareness on infant vulnerability; parental needs of information, guidance, assurance and support; mixed emotions, from hope and love to worrisome, guilty and lack of control; and coping strategies through which parents enact action in NICU. Current literature focus on emotional responses at an individual level, at the expense of cognitive appraisals and socio-structural factors influencing the experience of having a preterm infant hospitalized in NICU.

**Keywords:** Intensive Care Units, Neonatal; Premature Birth; Parents; Child, Hospitalized; Patient-Centered Care.

## **BACKGROUND**

In the last years, there has been an increasing interest in studying the cognitive and motor development, as well as the long-term adverse consequences for health and quality of life of infants born prematurely, before 37 weeks of gestation (Leversen et al. 2011; van Lunenburg et al. 2013). These children are at increased risk of neurodevelopmental impairments and respiratory and gastrointestinal complications (Saigal and Doyle 2008), being highly dependent of intensive care after birth. Prematurity is the worldwide leading direct cause of neonatal death and short- and long-term morbidity (March of Dimes et al. 2012), but outcomes concerning survival rates, mortality and morbidity differ between countries (Liu et al. 2012; Saigal and Doyle 2008) and by level of neonatal care (Phibbs et al. 2007).

Time is ripe to develop optimal evidence-based treatment for effective perinatal intensive care (EPICE 2014), standardizing the uses of medical interventions and approaches to the organization of care, especially in the case of prematurity (Milligan 2010). Family-centered care (Malusky 2005), defined as provision of care that is respectful of and responsive to individual parents preferences, needs, and values, is essential for a successful design and implementation of evidence-based practices in Neonatal Intensive Care Units (NICU) (European Commission 2012; WHO 2007). In fact, literature has been shown that the maternal psychological stress associated with very preterm birth (Meijssen et al. 2011; Singer et al. 1999), maternal sensitivity to baby's cues (Forcada-Guex et al. 2006), and mother-infant interaction factors (Benzies et al. 2013) are predictive of infant development and long-term outcomes (Kaarsen et al. 2006).

The vulnerability of preterm infants, as well as unique challenges posed by the NICU's sociotechnical environment (Singer et al. 1999) interfere with the development of the

bonding between parents and infants, and with the expression of feelings of competence regarding parental role (Aagaard and Hall 2008; McCarter-Spaulding and Kearney 2001). A preterm birth may influence the family environment several years later (Treyvaud et al. 2010) through multiple pathways. During and shortly after the infant's hospitalization, the prioritization of child's health and well-being over parent's personal needs and health (Flacking et al. 2006) may condition changes in patterns of life styles, such as smoking, alcohol intake, physical exercise and/or dietary habits, that have a considerable impact on health (Ezzati et al. 2002; Mozaffarian et al. 2012). Also, the reconfiguration of parental roles under the NICU adverse conditions (e.g. physical separation from the child, structured and controlled opportunities of interaction, difficulty in feeling part of infant's care, and the fear for his/her survival and future development) place mothers and fathers at an increased risk of developing parental stress (Davis et al. 2003; Holditch-Davis and Miles 2000) and several psychopathological symptoms, such depression and anxiety (Garel, Bahuaud and Blondel et al. 2004; Vigod et al. 2010), with repercussions on their quality of life.

The strong focus on the translation of scientific and medical knowledge into evidence-based practice aiming the standardization and rationalization of the healthcare system may contribute to suppress parents' voices with respect to the organization of care, clinical practices and technical interventions in NICU (Jacono et al. 1990; Timmermans and Berg 2003). In fact, studies surrounding the health care of preterm births tend to analyze the frequency, causes, and mechanisms leading to premature deliveries (Goldenberg et al. 2008; Simmons et al. 2010); how prematurity accounts for perinatal mortality rates and morbidity (Draper et al. 2009; Milligan 2010; Zeitlin et al. 2008); treatment options (De Leeuw et al. 2000); staff (neonatologists and nurses) attitudes, views and practices regarding ethical decision-making in NICU (Cuttini et al. 2009; Rebagliato et al. 2000); and the management of staff-parents relationships (Alderson, Hawthorne and Killen et al. 2006; Vermeulen 2004).

Literature on co-constitution of parenting (both mothering and fathering) and medical technologies, as well as the biomedical and embodied knowledge in the context of prematurity is scarce, focusing on the following main domains: informed consent practices and perceptions of risk (Alderson et al. 2006); information and communication needs (De Rouck and Leys 2009); parental stress (Howe et al. 2014); psychopathological symptoms (Garel et al. 2004; Vigod et al. 2010); meanings of acceptable quality of future life (of offspring) and legitimacy of end-of-life decisions (Vermeulen 2004); and breastfeeding (Alves et al. 2013).

While parents' perspectives is a core need for family-centered care and ethics in clinical practice, there is not a literature review regarding the experiences and views of mothers and fathers of children born prematurely and admitted to the NICU. This paper fills this gap, contributing for mapping out and for synthesizing the repertoire of meanings, knowledge, and emotions actualized by the mothers and fathers of preterm infants in their experiences during hospitalization in NICU.

## DATA AND METHODS

The electronic databases PubMed, ISI Web of Knowledge and PsycINFO were searched to identify original articles providing empirical data on perspectives of parents of preterm babies regarding their experiences, knowledge and decision making actualized during hospitalization in NICU. The search covered the full range of publication dates from inception until 15 May 2014, with the expression: "Parents" AND ("perspective\*" OR "experience\*" OR "Knowledge" OR "Decision Making") AND "Intensive Care Units, Neonatal". In PubMed, search terms were included as Medical Subject Heading (MeSH) terms. Two hundred and twenty four publications were identified.

The flowchart showing the literature review process is presented in Figure 1. Two reviewers independently evaluated the studies, following *a priori* defined criteria for exclusion: (1) not written in English, French, Spanish or Portuguese; (2) case reports, editorials, comments or reviews; (3) studies focusing parents of specific groups of preterm newborns or non-preterm newborns; (4) studies that evaluate parents' perspectives, experiences, knowledge and decision making regarding situations after discharge from NICU.

Firstly, 143 studies were excluded based on title and abstract assessment. Whenever the abstract of a particular article was not available, full text was considered for evaluation. The full texts of the 81 selected articles were then evaluated to decide on their eligibility and availability of relevant data. The bibliographic references of the 15 eligible publications were screened to identify potentially articles, being included four additional papers (Cardoso et al. 2006; Holditch-Davis and Miles 2000; Hughes and McCollum 1994; Padden 1997). The decisions regarding the selection of the studies were made by two independent reviewers, who also extracted and synthesized the data from the 19 publications included in this review.

Descriptive data for studies' characterization was retrieved: information about the authors and publication year, the type of study (qualitative, quantitative, and mixed-methods), period and country of data collection, techniques and time of assessment, setting where the study was developed, and sample size (Table 1).

Based on the protocol for content analysis developed by Stemler (2001), the first two authors identified, independently, quotation by quotation, all the perspectives of parents of preterm babies regarding their experiences, knowledge and decision making actualized during hospitalization in NICU. These quotations were then synthesized into categories, defined as “a group of words with similar meaning and connotations”, and the number of papers where each category emerged was recorded. Such categories were then grouped in four main themes by the first and the last authors, according to the protocol for thematic analysis developed by Mays *et al.* (2005): “contextual factors”, which included the sociotechnical environment, alterations in the expected parental roles, parents-professionals relationships and awareness on infant vulnerability; “parental needs” and “mixed emotions”, when quotations pointed out the needs and feelings identified by mothers and fathers, respectively; and their “coping strategies” to deal with the experience of having an infant hospitalized in NICU.

Disagreements in abstractions were discussed and resolved by consensus. An almost perfect strengthen of agreement between reviewers was achieved (>0.80) (Stemler 2001).

## RESULTS

### *Study Characteristics*

The main characteristics of the 19 studies included in this literature review are presented in Table 1. The studies were published between 1990 and 2013, with 14 being published in the 2000s. Studies were conducted in USA (n=9), Canada (n=4), Brazil (n=3), Sweden (n=2) and England (n=1). Thirteen were qualitative, four were quantitative and two used mixed methods. Semi-structured interviews were the most common method for collecting qualitative data. Quantitative studies used more frequently psychosocial scales for assessing acute stress, postnatal depression, anxiety, psychological well-being, perception of uncertainty, and family-provider relationships.

Only five studies reported information regarding the period of data collection, which ranged from 8 days to 2 years and 4 months. The timing of data collection was also highly variable across the studies, going from 4 days after infant's birth until 6 months of infant's corrected age, with three publications not specifying the moment during the hospitalization in NICU and other three not providing any information regarding the timing of data collection. The setting also varied between the studies, with only seven studies including more than one NICU.

The sample size ranged from 6 to 23 couples, 10 to 55 mothers, 6 to 17 fathers, and 6 to 76 mothers and 3 to 74 fathers, according to the groups of participants included: couples (n=4), only mothers (n=8), only fathers (n=3) and mothers and fathers (n=4), respectively.

The eligibility criteria of the participants were heterogeneous but, in general, mothers and fathers who were able to speak the native language, without maternal illness, who had a baby admitted in NICU at least 12 hours with no congenital malformation or severe illness, were included in the studies.

### *Perspectives of parents*

Table 2 depicts the four iterative and dynamic themes that emerged from the studies on the perspectives of parents of preterm infants regarding their experiences, knowledge and decision making actualized during hospitalization in NICU. Contextual factors included the sociotechnical environment, alterations in the expected parental roles, parents-professionals relationships and awareness on infant vulnerability, and were assessed in 14 studies. Parental needs were mentioned in 12 studies, describing the need of obtaining information and guidance, to trust in the health care team, and to experience supportive staff members and support from partner and the government. The mixed emotions revealed during the experience of having a preterm infant hospitalized in NICU were analyzed in 11 papers, ranging from hope and love to worrisome, fear, guilty and self-blame, lack of control, stress and anxiety. Coping strategies, as to be responsible for the infant, religious beliefs and being positive, were the focus on 11 studies.

### *Contextual factors (Table 3)*

The technology surrounding the baby and “many other foreign components” (Pepper et al. 2012), the high level of expertise, a new language and established schedules were perceived by parents as unfamiliar elements located in an unfamiliar atmosphere limiting their “ability to develop a relationship with their babies” (Boucher et al. 2011). Having privacy and appropriate hospital furniture emerged as factors that help to deal with the experience of having a baby in NICU (Blomqvist et al. 2013). However, the impossibility of performing “all expected maternal experiences with a newborn infant” (Holditch-Davis and Miles 2000), like hold, feed and bath, as well as the imposed “parents’ physical separation from their infant” (Bernaix et al. 2006) and the need to negotiate the infant care with the staff (Flacking et al.

2006) were the major factors contributing for alterations in the expected parental roles, with mothers experiencing more stress related to this circumstance than did fathers (Miles, Funk and Kasper et al. 1992).

Parents, in particular mothers, reported that trustful, early and positive family-centered relationships with the staff, specially the “partnership with nurses” (Heermann et al. 2005), improve their satisfaction with healthcare, as well as their security and “psychological well-being” (Van Riper 2001), and help them to gain “some control and power” (Pepper et al. 2012) over the child hospitalization. On the contrary, a distrustful or disrespectful parents-professionals relationship results in the expression of feelings of “insecurity, submissiveness and shame” (Flacking et al. 2006).

Infant’s vulnerability, comprising the small, fragile, tiny and sick appearance of the babies (Cardoso, Souto and Oliveira et al. 2006; de Carvalho et al. 2009; Heermann, Wilson and Wilhelm et al. 2005; Holditch-Davis and Miles 2000), as well as their “susceptibility to illness and cot death” (Padden 1997), constitutes another contextual factor influencing parents’ perspectives on their experiences during hospitalization in NICU, mainly highlighted by mothers.

#### *Parental needs* (Table 4)

Parents mentioned the need to obtain clear and consistent information and guidance about their infant’s health status, and also their need to ear and share experiences with other parents of infants hospitalized in NICU. Fathers, specifically, also referred the importance of disseminating information to others outside NICU (Arockiasamy, Holsti and Albersheim et al. 2008). They valued “the style and the frequency with which the health care team communicated” (Arockiasamy et al. 2008) with them, emphasizing the nurses as the main source of information and support for families, while “communication with doctors was

generally limited to opportunistic conversation” (Padden 1997). To have access to information and guidance increase parents’ sense of control, allowing them to believe that they could make appropriate decisions about their infants’ care (Arockiasamy et al. 2008).

Mothers and fathers also reported the need to trust in the health care team “to be able to leave their infant and deal with worrisome nature of the experience” (Bernaix et al. 2006). Confidence in those caring for their child in NICU is ensured by the establishment of “genuine relationships between the staff and the parents” (Pepper et al. 2012) and the recognition of the technical capacities and competence of the staff (de Carvalho et al. 2009; Holditch-Davis and Miles 2000).

According to the parents’ perspectives, such interactions should be grounded on supportive staff members, who should be aware of the parents’ and infants’ needs and wishes and to act without judging, to encourage without pressure, to supply relevant knowledge, and to treat the mother and infant as persons (Flacking et al. 2006). For that purpose, parents suggested the possibility of visiting the NICU prior the birth and the importance of participating in decisions regarding the treatment options in collaboration with health professionals “through directive counseling” (Pepper et al. 2012). The studies stated that parents also feel the need of emotional support and physical help provided by the partner, sharing parental responsibilities regarding breastfeeding (Bernaix et al. 2006) and physical contact (Arockiasamy et al. 2008). One study highlighted the importance of having support from the government (Blomqvist et al. 2013).

#### *Mixed emotions* (Table 5)

Hospitalization in NICU is described by one mother as a “roller-coaster ride from hell” (Holditch-Davis and Miles 2000). Overall, it generated an emotional chaos (Flacking et al. 2006) and feelings of lack of the control (Arockiasamy et al. 2008). Such emotions

coexisted with hope and love, experienced at their infants' first sign (Padden 1997) and as their health improved (Cardoso et al. 2006).

Parents felt worrisome and fear about the threat of the infants' death and of adverse outcomes (Flacking et al. 2006), as well as of the infant becoming attached to others (Padden 1997). Both mothers and fathers reported stress and anxiety, especially in the first week of admission (Hughes and McCollum 1994) and when they had to go home to take care of other children (Padden 1997). The time spent in the NICU by mothers and fathers with other children also "made them feel guilty about the lack of time spent with their other children" (Bernaix et al. 2006). Additionally, mothers indicated that they felt guilty for the preterm delivery, wondering "what they had done to deserve it" (Hughes and McCollum 1994).

#### *Coping strategies (Table 6)*

Literature described three main coping strategies developed by parents in order to support sense of mothering and fathering (Bernaix et al. 2006), claim the babies as their own (Heermann et al. 2005), gain control over the environment (Arockiasamy et al. 2008, Pepper et al. 2012) and deal with the experience of having a premature baby admitted to NICU. The most frequently reported was assuming responsibility for the infant, both through active forms of coping, such as monitoring the infant's condition, comforting, visiting, breastfeeding, bathing, diapering and touching the infant, as through passive forms, like deriving comfort by being with the baby, developing emotional attachment to the baby and making the environment more homelike (Hughes et al. 1994, Pepper et al. 2012, Bernaix et al. 2006).

Religious beliefs and being positive were also used as ways to cope with infant's hospitalization in NICU. Religious beliefs influenced the overcome of suffering and the guidance of parents in decision-making for their infant care (Arockiasamy et al. 2008). Mothers reported to feel lucky by having a baby and "used downward social comparisons to

support this feeling” (Padden 1997). Moreover, mothers tended to see something positive coming out of this experience (Padden 1997), accepting the need of the treatment and assigning symbols of life, recovery and security to the NICU (Tronchin and Tsunehiro 2005).

## DISCUSSION

The repertoire of meanings, knowledge, and emotions actualized by mothers and fathers of preterm infants during hospitalization in NICU is grounded on four main iterative and dynamic themes: contextual factors influencing their experiences, parental needs, mixed emotions and coping strategies. In NICU, parents are challenged to deal with the infant's vulnerability in an unfamiliar sociotechnical environment, which imposes restraints on the performance of usual caregiving activities and the need to establish relationships with health professionals, while looking for information and guidance, assurance and support. Simultaneously, parents grapple with complex and mixed emotions and enact action by active and/or passive forms of assuming responsibility for the infant, using religious beliefs, and being positive, in order to support sense of parental identities and gain control over the environment throughout the experience of having a premature infant admitted to NICU. The main results of this paper support that this acute life event is a complex and multifaceted experience for parents, and shows that current literature focus mainly on the emotional responses at an individual level, at the expense of cognitive appraisals and social and structural factors.

Delivering a preterm infant may be considered as an event of biographical disruption, where expected developmental of interactive skills for both the parent and the infant is interrupted (Browne and Talmi 2005), with impacts on their life trajectories and identities. In the short-term, particularly during infant's hospitalization, the foreign, enclosed, and controlled sociotechnical environment of the NICU poses specific challenges to parents' health and well-being. The discomfort brought by the heat, lights, noises, smells, monitoring equipment, and the lack of privacy on the unit, are often highlighted by parents (Bouet et al. 2012; Mendelsohn 2006). The spatial and procedural restrictions of the unit are also

mentioned by parents as frequently creating obstacles to close involvement in the care of the infant, namely the distance to the boarder rooms, the impossibility of mothers to sleep beside their infants and the restriction of extended family members visits (Wiebe and Young 2010).

Fathers, but particularly mothers, report the need to redefine and adapt their parenting roles, while dealing with the loss of an expected healthy neonate (Lubbe and Bornman 2005), and with the loss of the “phantasy self-as-mother”, an idealized state where no mistakes are ever made (Mendelsohn 2006). Parents of preterm infants admitted to NICU tend to perceive changes in parental role ground on their own embodied experience of feeling unable to perform usual caregiving activities, such as breastfeeding or bathing, or protect the infant from harm. The supportive role and genuine encouragement from health professionals constitute a facilitator for parental early contact (Alderson et al. 2006) and active engagement in caregiving activities (Smith et al. 2012). Therefore, health professionals’ commitment with family-centered care emerges as a way of helping parents to support sense of mothering and fathering, claim the babies as their own, and gain control over the environment.

Besides the sociotechnical environment of NICU, the parents-professionals relationships, and changes in parental roles, it has been described that, for parents, the overwhelming sight of so many very small babies in incubators constitutes a relevant feature in NICU, remaining in parents’ minds long after discharge (Mendelsohn 2006). The importance of size beyond hospitalization may represent a symbolic projection of the fears about the child's development throughout life, taking into account that social influences may become literally embodied into psycho-anatomic characteristics that influence health (Krieger and Davey Smith 2004). Therefore, the difference between what is expected from preterm infants compared to other infants regarding size, weight, neurobehavioral development and interaction with mothers and fathers may lead to an increase on stress levels concerning baby looks and behaves (Shin and White-Traut 2007).

This review shows how parental needs of information, assurance, guidance, and support during infants' hospitalization in NICU emerge frequently in the literature as an attempt to gain control and develop a sense of meaning about mothering and fathering in an unknown sociotechnical environment (Shin and White-Traut 2007). Parents need to trust in the care provided to their child, and feel involved in decision-making and caregiving activities (Feeley et al. 2013; Wigert et al. 2006), as well as to obtain continuous and accurate information on infants' health status (Bialoskurski et al. 2002; Feeley et al. 2013). Since most parents did not have the expertise to evaluate the medico-technical procedures and practices in NICU, they appraised the care based on active non-corporeal and verbal demonstrations of concern for the baby's well-being (Wiebe and Young 2010). Also, parents need to look for support, either from healthcare professionals, to learn and practice skills for taking care of their infant (Smith et al. 2012), and from family and friends, including emotional (Bialoskurski et al. 2002) and instrumental support, such as meal preparation, assistance with household tasks or the care of other children (Feeley et al. 2013). Therefore, parents empowerment in NICU includes the repetition of oral information and the provision of written information (Lubbe and Bornman 2005), as well as the establishment of respectful, trustful and effective relationships with the health professionals (Pepper et al. 2012), in which teaching by demonstration and taking time to explain are essential features (Wiebe and Young 2010).

During the hospitalization of a premature infant, parents must cope with intense and confusing emotions (Lubbe and Bornman 2005), in a context where feelings of self-blame and guilt emerge before the uncertainty regarding the specific causes underlying the multifactorial etiology of preterm birth, including parental socio-demographic, psychological, biogenetic, clinical and obstetric characteristics (Holditch-Davis and Miles 2000; Hughes and McCollum 1994). Coping strategies, including assuming the responsibility for the infant, religious beliefs

and a positive attitude towards such experience, constitute processes that parents use to handle adversity. Data from a recent prospective study conclude that, during hospitalization in NICU, parents adopt 5 primary coping strategies to handle the NICU experience: participation in care, getting away from the NICU, gathering information, involvement of friends and family, and engagement with other NICU parents (Smith et al. 2012). In such sociotechnical environment, parents develop a technoscientific identity, which will generate new modes of social relations (Clarke et al. 2013). These new identity emerge through the application of science and technologies directly to parents' bodies and histories, and may constitute an effective way to deal with infant's hospitalization.

Parents' perspectives regarding their experiences, knowledge and decision making actualized during the hospitalization of a preterm infant in NICU are essential to sustain the design and implementation of quality family-centered care (Malusky 2005), wherein spaces, environments, and health professionals are organized around parents' needs and values. While the incorporation of parents' perspectives into healthcare delivery needs to consider the sociocultural and technical specificities of the setting, this review identifies 4 common themes among studies, pointing to the existence of factors that should constitute a privileged target for intervention.

In conclusion, literature regarding parents' perspectives on hospitalization of preterm infants in Neonatal Intensive Care Units highlights the multifaceted nature of such experience, characterized by heterogeneities and complexities that shape the relationships between parents' agency and emotions, medical knowledge production and the design of technical practices and sociotechnical environments. Understanding mothers and fathers perspectives' regarding their infant hospitalization in NICU is an important step in improving the quality of care and guiding future research, which needs to include social and structural levels of analysis. The present study may assist health professionals in understanding what parents do

to handle the NICU experience, informing efforts to integrate parental support. Providing holistic, family-centered, developmentally supportive care and open communication with parents during hospitalization is essential. In fact, the identification of parents' perspectives may help the NICU staff to establish strategies to help the parents to cope with such event. Such approach may optimize the engagement of mothers, fathers and health professionals on family-centered care in NICU.

Table 1. Main characteristics of the studies, according to the type of study (n=19)

Authors, year of publication	Data collection					
	Country	Period	Techniques	Time of assessment	Setting	Sample size
<i>Qualitative studies</i>						
Casteel 1990	USA	NR	Semi-structured interviews	5 days after birth	Special care nursery	18 mother-father dyads
Padden 1997	England	NR	Semi-structured interviews	4-9 days after birth	3 NICU's of a north west of England (2 general hospitals and 1 regional hospital)	36 mothers
Holditch-Davis and Miles 2000	USA	NR	Semi-structured interviews	Mothers were interviewed when the infant was 6 months corrected for prematurity	Tertiary university-based NICU	31 mothers
Heermann et al. 2005	USA	NR	Open-ended interviews	NR	32-bed Level III NICU at academic health science center in the Midwestern United States	15 mothers
Tronchin and Tsunehiro 2005	Brazil	1999-2001	Participant observation Semi-structured interviews	After discharge	NICU of São Paulo University hospital	6 couples (interview)
Bernaix et al. 2006	USA	NR	Semi-structured interviews	Within 1 to 2 weeks of the infant's admission to the unit	52-bed, tertiary-care NICU in a free standing Paediatric hospital that is part of an Academic Medical Centre	9 mother-father pairs
Cardoso et al. 2006	Brazil	14 <sup>th</sup> – 22 <sup>nd</sup> January 2005	Interviews	During the NICU admission	25-bed level III NICU of an university hospital in Ceará	6 fathers
Flacking et al. 2006	Sweden	January 2001 - May 2003	In-depth interviews	At least 4 weeks after discharge from the unit	7 NUs spread geographically all over Sweden, 3 at university hospitals and 4 at country hospitals	25 mothers
Arockiasamy et al. 2008	Canada	NR	Semi-structured interviews	During the NICU admission	Level III NICU – Women's Hospital in Vancouver	16 fathers
de Carvalho et al. 2009	Brazil	May - August 2008	Semi-structured interviews	During the NICU admission	2 NICU's of public maternity hospital of Natal	17 fathers
Boucher et al. 2011	Canada	NR	Semi-structured interviews	NR	Level III NICU in a large urban hospital	10 mothers
Pepper et al. 2012	Canada	NR	Semi-structured interviews	At 6 months adjusted age of infant	A regionalized tertiary care NICU in a large western Canadian city	2 couples and 3 mothers

Hurst et al. 2013	USA	NR	Semi-structured interviews	2 weeks x and 4 to 6 weeks after delivery	76-bed tertiary care and 68-bed level II NICU in southeastern Texas	14 women
<b>Quantitative Studies</b>						
Miles et al. 1992	USA	NR	Questionnaires (Parental Stressor Scale: NICU; The Parent Perception of Uncertainty tool; The State-Trait Anxiety Inventory)	Within a week of infants' admission and approximately a week later	14-bed level III NICU and a 14-bed intermediary care nursery in a Southeastern university medical center, a 24-bed level II NICU in a Midwestern community hospital	23 mother-father dyad
Van Riper 2001	USA	NR	Questionnaires (Family-provider Relationships Instrument; 18-item version of Ryff's measure of psychologic well-being; General scale of the family assessment measure)	NR	5 different NICUs in Midwestern EUA	55 mothers
Blomqvist 2012	Sweden	NR	Questionnaire design by authors	Shortly after infant's discharge	Two level III NICUs in Swedish university hospitals	76 mothers and 74 fathers
Jubenville et al. 2012	Canada	16 <sup>th</sup> February - 16 <sup>th</sup> May 2008	Questionnaires (Acute Stress Disorder Interview; Stanford Acute Stress Reaction Questionnaire; Edinburgh Postnatal Depression Scale)	7 to 10 days after birth	65-bed level III tertiary NICU located in Alberta	40 mothers
<b>Mixed Methods Studies</b>						
Hughes and McCollum 1994	USA	NR	Semi-structured interviews Survey (Ways of Coping Questionnaire; Neonatal Morbidity Scale)	Mothers and fathers were interviewed separately within 3 weeks of their infant's birth	Level III NICU in a large metropolitan hospital	32 mothers and 25 fathers
Hughes et al. 1994	USA	NR	Semi-structured interviews Survey (5-point likert-type rating scale for assess the stressfulness of the NICU experience)	Mothers and fathers were interviewed separately within 3 weeks of their infant's birth	Level III NICU in a large metropolitan hospital	32 mothers and 25 fathers

Table 2. Themes and categories regarding parents' perspectives on hospitalization of preterm infants in NICU

Themes	Categories	Studies
Contextual Factors	Sociotechnical environment	(Boucher et al. 2011, Blomqvist et al. 2013, de Carvalho et al. 2009, Heermann et al. 2005, Holditch-Davis and Miles 2000; Hughes and McCollum 1994; Hurst et al. 2013, Miles et al. 1992, Padden 1997, Pepper et al. 2012)
	Alterations in the expected parental roles	(Bernaix et al. 2006, Boucher et al. 2011, Flacking et al. 2006, Holditch-Davis and Miles 2000, Hughes and McCollum 1994, Hurst et al. 2013, Miles et al. 1992)
	Parents-professionals relationships	(Casteel 1990, (Flacking et al. 2006, Heermann et al. 2005, Pepper et al. 2012, Van Riper 2001)
	Awareness on infant vulnerability	(Blomqvist et al. 2012, Cardoso et al. 2006, de Carvalho et al. 2009, Heermann et al. 2005, Hughes and McCollum 1994, Holditch-Davis and Miles 2000)
Parental needs	To obtain information and guidance	(Arockiasamy et al. 2008, Blomqvist et al. 2012, Boucher et al. 2011, de Carvalho et al. 2009, Holditch-Davis and Miles 2000, Hughes and McCollum 1994; Pepper et al. 2012)
	To trust in the health care team	(Bernaix et al. 2006, Cardoso et al. 2006, de Carvalho et al. 2009, Holditch-Davis and Miles 2000, Padden 1997, Pepper et al. 2012)
	To experience supportive staff members	(Arockiasamy et al. 2008, Flacking et al. 2006, Holditch-Davis and Miles 2000, Hughes et al. 1994, Padden 1997, Pepper et al. 2012)
	Support from significant others	(Arockiasamy et al. 2008, Bernaix et al. 2006, Blomqvist et al. 2012, Holditch-Davis and Miles 2000, Hughes and McCollum 1994, Hughes et al. 1994, Pepper et al. 2012)
	Support from government	(Blomqvist et al. 2012)
Mixed emotions	Worrisome and Fear	(Bernaix et al. 2006, Cardoso et al. 2006, Casteel 1990, de Carvalho et al. 2009, Flacking et al. 2006, Holditch-Davis and Miles 2000, Padden 1997, Tronchin and Tsunehiro 2005)
	Stress and Anxiety	(Bernaix et al. 2006, de Carvalho et al. 2009, Hughes and McCollum 1994, Jubinville et al. 2012, Padden 1997)
	Hope and Love	(Cardoso et al. 2006, Casteel 1990, de Carvalho et al. 2009, Padden 1997)
	Guilty and Self-Blame	(Bernaix et al. 2006, Hughes and McCollum 1994, Padden 1997)
	Lack of Control	(Arockiasamy et al. 2008, Cardoso et al. 2006, Flacking et al. 2006)
Coping strategies	To be responsible for the infant	(Bernaix et al. 2006, Blomqvist et al. 2012, Boucher et al. 2011, Flacking et al. 2006, Heermann et al. 2005, Hughes et al. 1994, Hurst et al. 2013, Pepper et al. 2012)
	Religious beliefs	(Arockiasamy et al. 2008, de Carvalho et al. 2009, Hughes and McCollum 1994, Pepper et al. 2012, Tronchin and Tsunehiro 2005)
	Being positive	(Arockiasamy et al. 2008, Padden 1997, Tronchin and Tsunehiro 2005)

Table 3. Parents' perspectives on the contextual factors influencing their experiences during infants' hospitalization in NICU

Category	Excerpts
Sociotechnical environment	<p>- "Overwhelmed by the technology of the unit and the expertise of the nurses. (...) The mothers' first reaction to their infants was frequently as stranger or visitor (outsider)." (Heermann et al. 2005)</p> <p>- "The unfamiliar environment and its new language were distressing for parents. (...) A world they had not really know existed, a world dependent on technology: incubators, ventilator, intravenous pumps, monitors, x-rays, and many other foreign components." (Pepper et al. 2012)</p> <p>- "Some parents were never offered the opportunity to stay overnight with the infant at the NICU (...). Several parents missed comfortable armchairs and beds for KMC [Kangaroo Mother Care]." (Blomqvist et al. 2013)</p> <p>- "Mothers anticipated that breastfeeding would be less challenging [at home] because of the less stressful home atmosphere, more opportunities for rest, a more flexible feeding schedule, and having their infants nearby." (Boucher et al. 2011)</p>
Alterations in the expected parental roles	<p>- "This loss of parental role affected the ability of mothers to advocate and make decision for their infant. (...) Another related loss was of the ability to hold, feed, and bathe the baby, all expected maternal experiences with a newborn infant." (Holditch-Davis and Miles 2000)</p> <p>- "Separation between mother and infant mediated insecurity in the self and in the maternal role [because] the separation resulted in feelings of being unimportant and being just a visitor. (...) Doing things with the infant always have to be negotiated with the individual staff member in a continuous wish/demand approval situation." (Flacking et al. 2006)</p> <p>- "Mothers reported experiencing more stress related to alterations in the expected parental role than did fathers." (Miles et al. 1992)</p>
Parents-professionals relationships	<p>- "Mothers who wanted and believed they had positive family-centered relationships with [health care] providers were more satisfied with the care received and reported higher levels of psychological well-being." (Van Riper 2001)</p> <p>- "When the bond [between the staff and the mother] was perceived as trustful or almost collegiate, the mothers felt secure and capable and felt like good mothers, with consequent feelings of pride and enhanced self-esteem. When mothers encountered disrespectful or forceful behavior, a distrustful relationship arose and in some cases resulted in insecurity, submissiveness and shame" (Flacking et al. 2006)</p> <p>- "The early relationships built between the parents and the healthcare team helped the parents gain some control and power over the impending delivery and admission of their premature infant to the NICU." (Pepper et al. 2012)</p>
Awareness on infant vulnerability	<p>- "Dealing with the appearance of a small and sick premature infant was also difficult for mothers" (...)...seatbacks are traumatic for mothers." (Holditch-Davis and Miles 2000)</p> <p>- "Most common worry about the future related to their infants' development or susceptibility to illness or cot death." (Padden 1997)</p> <p>- " [The] category (infant's appearance, health, and course of hospitalization - illness, complications, medical procedures) was named (...) half (52%) of [times by] the fathers [in comparison to mothers]." (Hughes and McCollum 1994)</p>

Table 4. Parents' perspectives on their needs during infants' hospitalization in NICU

Category	Excerpts
To obtain information and guidance	<p>- "The fathers described the theme information in the following two ways: the amount of information that they received about their infant and the information that they delivered to others. (...) The consistency (being able to speak to an identified primary communicator) of communication and the communication skills of the NICU staff had an impact on how much control the fathers felt." (Arockiasamy et al. 2008)</p> <p>- "The action of health care providers that had the most negative effect on mothers was failure to communicate clearly. (...) Mothers were aware that health care providers didn't always agree." (Holditch-Davis and Miles 2000)</p> <p>- "Communication with doctors was generally limited to opportunistic conversation. (...) "the nursing staff were the main source of information and support for families, and parents highly valued this aspect of care." (Padden 1997)</p>
To trust in the health care team	<p>- "The parents' confidence in their infants' healthcare providers helped them to be able to leave their infant and deal with the worrisome nature of the experience." (Bernaix et al. 2006)</p> <p>- "It was the [genuine] relationships that developed between themselves [parents] and the staff that allowed them to trust that their infant was good hands." (Pepper et al. 2012)</p> <p>- "Six women said they did not trust the staff to care for their infants as well as they would wish, or were worried about some aspects of care." (Padden 1997)</p>
To experience supportive staff members	<p>- "Parents identified the importance of knowing what to expect (...) If neonatologists and nurse practitioners have the opportunity to provide these explanations to parents before the birth of their premature infant, this might ease the transition to the foreign NICU environment. If possible, seeing the NICU prior to the birth of their infant might help to alleviate the stress and foreignness felt when their child is admitted there." (Pepper et al. 2012)</p> <p>- "All mothers experienced some supportive staff members who were aware of the mothers' and infants' needs and wishes and acted without judging, encouraged without pressure, supplied relevant knowledge, and treated the mother and infant as persons." (Flacking et al. 2006)</p>
Support from significant others	<p>- "Four of the nine couples made comments that demonstrated a mutual commitment to provide breast milk to their respective premature infant. (...) These same couples shared the responsibilities of establishing "their" milk supply." (Bernaix et al. 2006)</p> <p>- "Many mothers reported that their physical and emotional health prevented them from doing many of the tasks that they had done before the birth and they relied more heavily on their spouse for physical help and emotional support." (Hughes and McCollum 1994)</p>
Support from government	<p>- "The parents also mentioned the government as a supportive factor as it provided both parents with temporary parental benefit during the infants' entire NICU stay." (Blomqvist et al. 2013)</p>

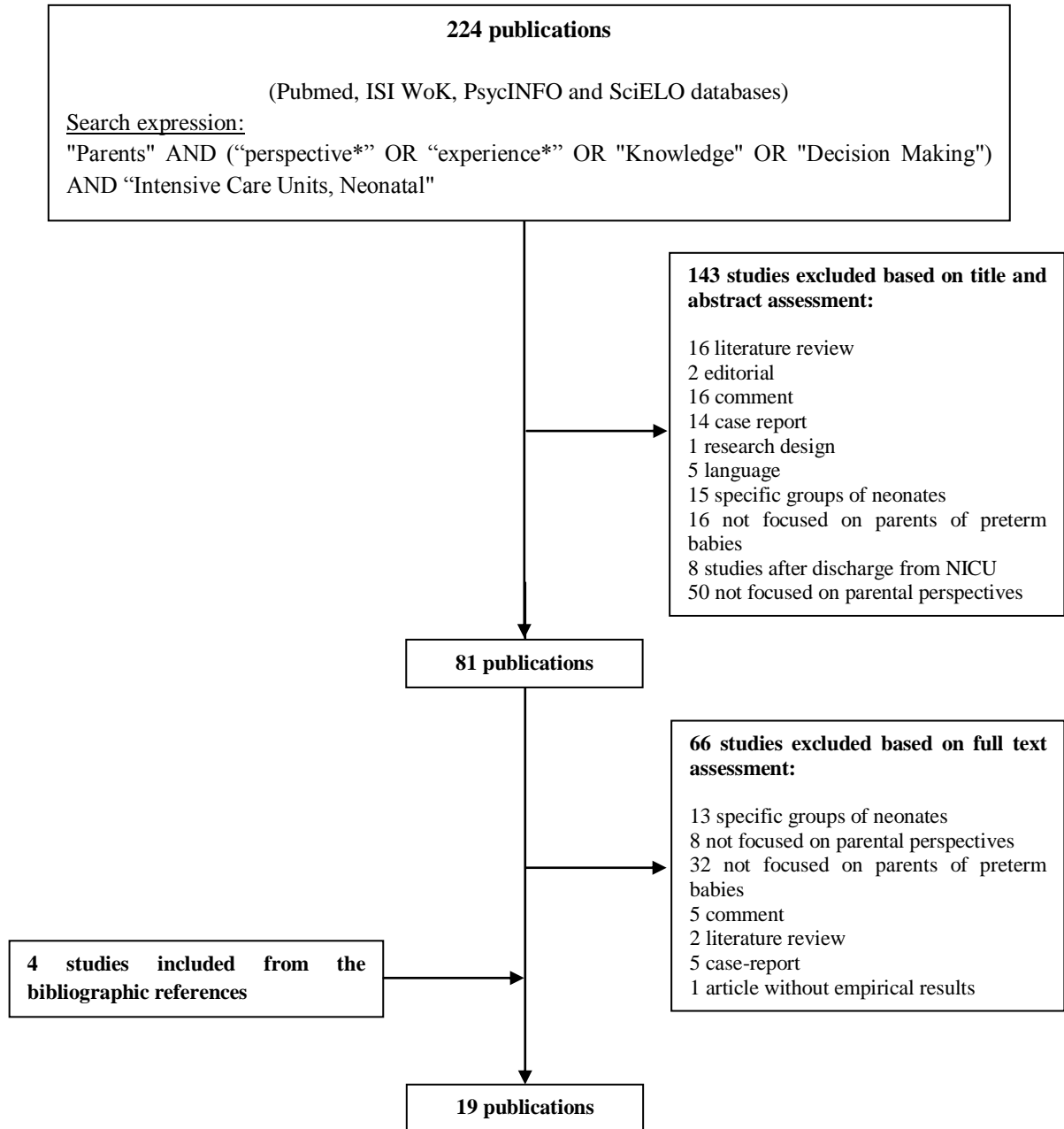
Table 5. Parents' mixed emotions during infants' hospitalization in NICU

Category	Excerpts
Worrisome and Fear	<ul style="list-style-type: none"> <li>- "One mother described this worry about the infants' outcome as a roller-coaster ride from hell" (Holditch-Davis and Miles 2000)</li> <li>- "There was some expression of jealousy, or fears of the infant becoming attached to others."(Padden 1997)</li> <li>- "The unexpected delivery and the threat of the infant's death led to emotional chaos in which the mothers felt frightened, sad, disappointed, and worthless, or a failure."(Flacking et al. 2006)</li> </ul>
Stress and Anxiety	<ul style="list-style-type: none"> <li>- "Both mothers and fathers reported that having an infant in the NICU was stressful."(Bernaix et al. 2006)</li> <li>- "Anxiety levels indicated that these parents were highly anxious during the first week after admission but were significantly less anxious a week later."(Hughes and McCollum 1994)</li> <li>- "Mothers who had to leave their infant to go home to care for other children or partners were very stressed by this."(Padden 1997)</li> </ul>
Hope and Love	<ul style="list-style-type: none"> <li>- "Positive affects noted in the data were amazement, confidence, love, and well-being."(Casteel 1990)</li> <li>- "[First sight of the infant:] relief and happiness (...) [Present feelings:] thrilled and pleased." (Padden 1997)</li> </ul>
Guilty and Self-Blame	<ul style="list-style-type: none"> <li>- "Mothers indicated that they either felt guilty in some way about having caused the premature birth or they wondered what they had done to deserve it." (Hughes and McCollum 1994)</li> <li>- "For parents with other children, the time spent in the NICU made them feel guilty about the lack of time spent with their other children."(Bernaix et al. 2006)</li> </ul>
Lack of Control	<ul style="list-style-type: none"> <li>- "The universal response of the fathers to having an infant in the NICU was their feeling that the situation was "out of my control"."(Arockiasamy et al. 2008)</li> <li>- "The emotional chaos limited the means of verbally expressing the individual needs and taking control in the situation."(Flacking et al. 2006)</li> </ul>

Table 6. Parents' coping strategies during infants' hospitalization in NICU

Category	Excerpts
To be responsible for the infant	<p>- "As parents settled into the NICU, they identified ways to gain a sense of control over their new environment. One couple decorated the twin's bedsides with pictures and items from home in an attempt to render the environment more familiar, more homelike."(Pepper et al. 2012)</p> <p>- "Many parents reported that they coped by focusing on the infant. In particular, this strategy consisted of both active forms of coping (e.g., monitoring the infant's condition, comforting the infant, visiting the infant) and more passive forms (deriving comfort by being with the baby, developing and emotional attachment to the baby)."(Hughes et al. 1994)</p> <p>- "Providing breast milk was one thing they [mothers] did that supported their sense of mothering."(Bernaix et al. 2006)</p> <p>- "As they become more comfortable in the NICU as their babies' medical conditions improved, they were more likely to claim the babies as their own"(Heermann et al. 2005)</p> <p>- "you know, you really do take this on [pumping milk] as your duty and it's almost therapeutic. This is what I can do. This is my job." (Hurst et al. 2013)</p>
Religious beliefs	<p>- "Religious belief was also cited as an important influence on their sense of control (...) this statement provided the direction that helped guide the father in decision-making for his infant care, increasing his sense of control." (Arockiasamy et al. 2008)</p> <p>- "Decisions were made through a variety of means that differed from family to family; information sharing spiritual and religious beliefs; personal values (...)" (Pepper et al. 2012)</p>
Being positive	<p>- "In spite of having a baby in a NICU, a majority of women felt lucky, and used downward social comparisons to support this feeling. They also tended to have seen something positive coming out of their experience."(Padden 1997)</p>

Figure 1. Literature review flowchart



## REFERENCES

- Aagaard, Hanne and Elisabeth O.C. Hall. 2008. "Mothers' experiences of having a preterm infant in the neonatal care unit: a meta-synthesis." *Journal of Pediatric Nursing* 23(3):e26-36.
- Alderson, Priscilla, Joanna Hawthorne, and Margaret Killen. 2006. "Parents' experiences of sharing neonatal information and decisions: consent, cost and risk." *Social Science & Medicine* 62(6):1319-29.
- Alves, Elisabete, Carina Rodrigues, Sílvia Fraga, Henrique Barros, and Susana Silva. 2013. "Parents' views on factors that help or hinder breast milk supply in neonatal care units: systematic review." *Archives of Disease in Childhood Fetal and Neonatal* edition 98(6):F511-7.
- Arockiasamy, Vincent, Liisa Holsti, and Susan Albersheim. 2008. "Fathers' experiences in the neonatal intensive care unit: a search for control." *Pediatrics* 121(2):e215-22.
- Benzies, Karen M., Joyce E. Magill-Evans, K. Alix Hayden, and Marilyn Ballantyne. 2013. "Key components of early intervention programs for preterm infants and their parents: a systematic review and meta-analysis." *BMC Pregnancy and Childbirth* 13 Suppl 1:S10.
- Bernaix, Laura W., Cynthia A. Schmidt, Patricia A. Jamerson, Lorraine Seiter, and Joan Smith. 2006. "The NICU experience of lactation and its relationship to family management style." *MCN, American Journal of Maternal Child Nursing* 31(2):95-100.
- Bialoskurski, Maria M., Cox Carol L., and Richard D. Wiggins. 2002. "The relationship between maternal needs and priorities in a neonatal intensive care environment." *Journal of Advanced Nursing* 37(1):62-9.

- Blomqvist, Ylva Thernstrom, Lovisa Frölund, Christine Rubertsson, and Kerstin Hedberg Nyqvist. 2013. "Provision of Kangaroo Mother Care: supportive factors and barriers perceived by parents." *Scandinavian Journal of Caring Sciences* 27(2):345-53.
- Boucher, Camille A., Paola M. Brazal, Cynthia Graham-Certosini, Kathryn Carnaghan-Sherrard, and Nancy Feeley. 2011. "Mothers' breastfeeding experiences in the NICU." *Neonatal Network : NN* 30(1):21-8.
- Bouet, Kary M., Norma Claudio, Veronica Ramirez, and Lourdes Garcia-Fragoso. 2012. "Loss of parental role as a cause of stress in the neonatal intensive care unit." *Boletín de la Asociación Médica de Puerto Rico* 104(1):8-11.
- Browne, Joy V. and Ayelet Talmi. 2005. "Family-based intervention to enhance infant-parent relationships in the neonatal intensive care unit." *Journal of Pediatric Psychology* 30(8):667-77.
- Cardoso, Maria, Kely Souto, and Márcia Oliveira. 2006. "Compreendendo a experiência de ser pai de recém-nascido prematuro internado na unidade neonatal." *Rev RENE* 7(3):49-55.
- Casteel, JK. 1990. "Affects and cognitions of mothers and fathers of preterm infants." *Maternal Child Nursing Journal* 19(3):211-20.
- Clarke, Adele, Janet Shim, Sara Shostak, and Alondra Nelson. 2013. "Biomedicalising genetic health, diseases and identities". Pp. 21-40 in *Handbook of Genetics and Society: Mapping the New Genomic Era*, edited by P. Atkinson, P. Glasner, L. Margaret. New York: Routledge.
- Cuttini, Marina, Veronica Casotto, Umberto de Vonderweid, Micheline Garel, Louis A. Kollée, and Rodolfo Saracci. 2009. "Neonatal end-of-life decisions and bioethical perspectives." *Early Human Development* 85(10 Suppl):S21-5.

- Davis, Leigh, Helen Edwards, Heather Mohay, and Judy A. Wollin. 2003. "The impact of very premature birth on the psychological health of mothers." *Early human development* 73(1-2):61-70.
- de Carvalho, Jovanka B., Ana C. Araujo, Iris C.C. Costa, Rosinelde S. de Brito, and Nilba L. de Souza. 2009. "[Social representation of fathers regarding their premature child in the Neonatal Intensive Care Unit]." *Revista brasileira de enfermagem* 62(5):734-8.
- De Leeuw, Richard, Marina Cuttini, Michael Nadai, István Berbik, Gesine Hanson, Audrunas Kucinskas, Sylvie Lenoir, Adik Levin, Jan Persson, Marisa Rebagliato, Margaret Reid, Marco Schroell, Umberto de Vonderweid, and other members of the EURONIC study group. 2000. "Treatment choices for extremely preterm infants: an international perspective." *The Journal of pediatrics* 137(5):608-16.
- De Rouck, Sofie and Mark Leys. 2009. "Information needs of parents of children admitted to a neonatal intensive care unit: A review of the literature (1990-2008)." *Patient Education and Counseling* 76(2):159-173.
- Draper, Elizabeth S., Jennifer Zeitlin, A C Fenton, T Weber, J Gerrits, G Martens, B Misselwitz, G Breart and MOSAIC research group. 2009. "Investigating the variations in survival rates for very preterm infants in 10 European regions: the MOSAIC birth cohort". *Archives of disease in childhood Fetal and neonatal edition* 94(3):F158-63.
- EPICE. 2014. "Effective Perinatal Intensive Care in Europe: translating knowledge into evidence-based practice." In. <http://www.epiceproject.eu/pt/> Accessed 22nd February 2014.
- European Commission. 2012. "Eurobarometer Qualitative Study." Patient Involvement. Aggregate report.

- Ezzati, Majid, Alan D. Lopez, Anthony Rodgers, Stephen Vander Hoorn, Christopher JLMurray, and Comparative Risk Assessment Collaborating G. 2002. "Selected major risk factors and global and regional burden of disease." *Lancet* 360(9343):1347-60.
- Feeley, Nancy, Elana Waitzer, Kathryn Sherrard, Linda Boisvert, and Phyllis Zelkowitz. 2013. "Fathers' perceptions of the barriers and facilitators to their involvement with their newborn hospitalised in the neonatal intensive care unit." *Journal of Clinical Nursing* 22(3-4):521-30.
- Flacking, Renée, Uwe Ewald, Kerstin H. Nyqvist, and Bengt Starrin. 2006. "Trustful bonds: a key to "becoming a mother" and to reciprocal breastfeeding. Stories of mothers of very preterm infants at a neonatal unit." *Social Science & Medicine* 62(1):70-80.
- Forcada-Guex, Margarita, Blaise Pierrehumbert, Ayala Borghini, Adrien Moessinger, and Carole Muller-Nix. 2006. "Early dyadic patterns of mother-infant interactions and outcomes of prematurity at 18 months." *Pediatrics* 118(1):e107-14.
- Garel, M., M Bahuau, and B Blondel B . 2004. "[Consequences for the family of a very preterm birth two months after discharge. Results of the EPIPAGE qualitative study]." *Archives de pediatrie: organe officiel de la Societe francaise de pediatrie* 11(11):1299-307.
- Goldenberg, Robert L., Jennifer F. Culhane, Jay D. Iams, and Roberto Romero. 2008. "Epidemiology and causes of preterm birth." *Lancet* 371(9606):75-84.
- Heermann, Judith A., Margaret E. Wilson, and Patricia A. Wilhelm. 2005. "Mothers in the NICU: outsider to partner." *Pediatric Nursing* 31(3):176-81, 200.
- Holditch-Davis, Diane and Margaret S. Miles. 2000. "Mothers' stories about their experiences in the neonatal intensive care unit." *Neonatal network: NN* 19(3):13-21.

- Howe, Tsu-Hsin, Ching-Fsn Sheu, Tien-Ni Wang, and Yung-Wen Hsu. 2014. "Parenting stress in families with very low birth weight preterm infants in early infancy." *Research in developmental disabilities* 35(7):1748-56.
- Hughes, Mary-Alayne and Jeanette McCollum. 1994. "Neonatal Intensive Care. Mothers' and Fathers' Perceptions of What Is Stressful." *Journal of Early Intervention* 18(3):258-268.
- Hughes, Mary-Alayne, Jeanette McCollum, D. Sheftel, and G. Sanchez. 1994. "How parents cope with the experience of neonatal intensive care." *Child Health Care* 23(1):1-14.
- Hurst, Nancy, Joan Engebretson, and Jane S. Mahoney. 2013. "Providing mother's own milk in the context of the NICU: a paradoxical experience." *Journal of human lactation : official journal of International Lactation Consultant Association* 29(3):366-73.
- Jacono, John, G Hicks, C Antonioni, K O'Brien, and M Rasi. 1990. "Comparison of perceived needs of family members between registered nurses and family members of critically ill patients in intensive care and neonatal intensive care units." *Heart & lung : the journal of critical care* 19(1):72-8.
- Jubenville, Jodi, Christine Newburn-Cook, Kathleen Hegadoren, and Thierry Lacaze-Masmonteil. 2012. "Symptoms of acute stress disorder in mothers of premature infants." *Advances in neonatal care : official journal of the National Association of Neonatal Nurses* 12(4):246-53.
- Kaarsen, Per I., John A. Ronning, Stein E. Ulvund, and Lauritz B. Dahl. 2006. "A randomized, controlled trial of the effectiveness of an early-intervention program in reducing parenting stress after preterm birth." *Pediatrics* 118(1):e9-19.
- Krieger, Nancy and George D. Smith. 2004. "'Bodies count,' and body counts: social epidemiology and embodying inequality." *Epidemiologic reviews* 26:92-103.

- Leveresen, Katrine T., Kristian Sommerfelt, Arild Rønnestad, Per Ivar Kaaresen, Theresa Farstad, Janne Skranes, Ragnhild Støen, Irene Bircow Elgen, Siren Rettedal, Geir Egil Eide, Lorentz M. Irgens, and Trond Markestad. 2011. "Prediction of neurodevelopmental and sensory outcome at 5 years in Norwegian children born extremely preterm." *Pediatrics* 127(3):e630-8.
- Liu, Li, Hope Johnson, Simon Cousens, Jamie Perin, Susan Scott, Joy E. Lawn, Igor Rudan, Harry Campbell, Richard Cibulskis, Mengying Li, Colin Mathers, Robert E. Black, and for the Child Health Epidemiology Reference Group of WHO and UNICEF. 2012. "Global, regional, and national causes of child mortality: an updated systematic analysis for 2010 with time trends since 2000." *Lancet* 379(9832):2151-61.
- Lubbe, Welma and Juan Bornman. 2005. "Early intervention care programme for parents of neonates." *Curationis* 28(5):73-82.
- Malusky, Sheila K. 2005. "A concept analysis of family-centered care in the NICU." *Neonatal network :NN* 24(6):25-32.
- March of Dimes, PMNCH, Save the Children, WHO. 2012. "Born too soon: The Global Action Report on Preterm Birth." Geneva: World Health Organization.
- McCarter-Spaulding, Deborah E., and Margaret H. Kearney. 2001. "Parenting self-efficacy and perception of insufficient breast milk." *Journal of obstetric, gynecologic, and neonatal nursing: JOGNN / NAACOG* 30(5):515-22.
- Meijssen, D E, M J Wolf, K Koldewijn, A G van Wassenaer J H Kok, and A L van Baa. 2011. "Parenting stress in mothers after very preterm birth and the effect of the Infant Behavioural Assessment and Intervention Program." *Child: care, health and development* 37(2):195-202.

- Mendelsohn, Annette. 2006. "Recovering reverie: Using infant observation in interventions with traumatised mothers and their premature babies." *Infant Observation: International Journal of Infant Observation and Its Applications* 8(3):195-208.
- Miles, Margaret S., Sandra G. Funk, and Mary A. Kasper. 1992. "The stress response of mothers and fathers of preterm infants." *Researching in Nursing & Health* 15(4):261-9.
- Milligan, David W. 2010. "Outcomes of children born very preterm in Europe." *Archives of disease in childhood Fetal and neonatal edition* 95(4):F234-40.
- Mozaffarian, Dariush, Ashkan Afshin, Neal L. Benowitz, Vera Bittner, Stephen R. Daniels, Harold A. Franch, David R. Jacobs Jr, William E. Kraus, Penny M. Kris-Etherton, Debra A. Krummel, Barry M. Popkin, Laurie P. Whitsel, Neil A. Zakai, on behalf of the American Heart Association Council on Epidemiology and Prevention, Council on Nutrition, Physical Activity and Metabolism, Council on Clinical Cardiology, Council on Cardiovascular Disease in the Young, Council on the Kidney in Cardiovascular Disease, Council on Peripheral Vascular Disease, and the Advocacy Coordinating Committee. 2012. "Population approaches to improve diet, physical activity, and smoking habits: a scientific statement from the American Heart Association." *Circulation* 126(12):1514-63.
- Padden, Tilly and Sheila Glenn. 1997. "Maternal experiences of preterm birth and neonatal intensive care." *Journal of reproductive and infant psychology* 15:121-139.
- Pepper, Dawn, Gwen Rempel, Wendy Austin, Christine Ceci, and Leonora Hendson. 2012. "More than information: a qualitative study of parents' perspectives on neonatal intensive care at the extremes of prematurity." *Advances in neonatal care : official journal of the National Association of Neonatal Nurses* 12(5):303-9.

- Phibbs, Ciaran S., Lawrence C. Baker, Aaron B. Caughey, Beate Danielsen, Susan K. Schmitt, and Roderic Phibbs. 2007. "Level and volume of neonatal intensive care and mortality in very-low-birth-weight infants." *The New England journal of medicine* 356(21):2165-75.
- Rebagliato, Marisa, Marina Cuttini, Lara Broggin, István Berbik, Umberto de Vonderweid, Gesine Hansen, Monique Kaminski, Louis A. A. Kollée, Audrūnas Kucinskas, Sylvie Lenoir, Adik Levin, Jan Persson, Margaret Reid, and Rodolfo Saracci, for the EURONIC Study Group. 2000. "Neonatal end-of-life decision making: Physicians' attitudes and relationship with self-reported practices in 10 European countries." *JAMA: the journal of the American Medical Association* 284(19):2451-9.
- Saigal, Saroj and Lex W. Doyle. 2008. "An overview of mortality and sequelae of preterm birth from infancy to adulthood." *Lancet* 371(9608):261-9.
- Shin, Hyunjeong and Rosemary White-Traut. 2007. "The conceptual structure of transition to motherhood in the neonatal intensive care unit." *Journal of advanced nursing* 58(1):90-8.
- Simmons, LaVone E., Craig E. Rubens, Gary L. Darmstadt, and Michael G. Gravett. 2010. "Preventing preterm birth and neonatal mortality: exploring the epidemiology, causes, and interventions." *Seminars in Perinatology* 34(6):408-15.
- Singer, Lynn T, Ann Salvator, Shenyang Guo, Marc Collin, Lawrence Lilien, and Jill Baley. 1999. "Maternal psychological distress and parenting stress after the birth of a very low-birth-weight infant." *JAMA: the Journal of the American Medical Association* 281(9):799-805.

- Smith, Vincent C., Gillian K. Steelfisher, Carmel Salhi, and Li-Ye Shen. 2012. "Coping with the neonatal intensive care unit experience: parents' strategies and views of staff support." *The Journal of Perinatal & Neonatal Nursing* 26(4):343-52.
- Timmermans, Stefan and Marc Berg. 2003. *The Gold Standard: The Challenge of Evidence-Based Medicine and Standardization in Health Care*. Philadelphia: Temple University Press.
- Treyvaud, Karli, Vicky A. Anderson, Katherine J. Lee, Lianne J. Woodward, Carol Newnham, Terrie E. Inder, Lex W. Doyle, and Peter J. Anderson. 2010. "Parental mental health and early social-emotional development of children born very preterm." *Journal of Pediatric Psychology* 35(7):768-77.
- Tronchin, Dayse M. and Maria Alice Tsunehiro. 2005. "The experience of becoming parents of a premature infant: an ethnographic approach." *Revista Brasileira de Enfermagem* 58(1):49-54.
- van Lunenburg, Afra, Sylvia M. van der Pal, Paula van Dommelen, Karin M. van der Pal-de Bruin, Jack Bennebroek Gravenhorst, and Gijsbert H.W. Verrips. 2013. "Changes in quality of life into adulthood after very preterm birth and/or very low birth weight in the Netherlands." *Health and Quality of Life Outcomes* 11:51.
- Van Riper, Marcia. 2001. "Family-provider relationships and well-being in families with preterm infants in the NICU." *Heart & Lung: The Journal of Critical Care* 30(1):74-84.
- Vermeulen, Eric. 2004. "Dealing with doubt: making decisions in a neonatal ward in The Netherlands." *Social Science & Medicine* 59(10):2071-85.
- Vigod, Simone N., Leon Villegas, Cindy-Lee Dennis, and Lori E. Ross. 2010. "Prevalence and risk factors for postpartum depression among women with preterm and low-birth-

weight infants: a systematic review.” *BJOG: An International Journal of Obstetrics and Gynaecology* 117(5):540-50.

World Health Organization. 2007. *People-Centred Health Care: a policy framework*. World Health Organization, Geneva.

Wiebe, Adrienne and Brenda Young. 2010. “Parent perspectives from a neonatal intensive care unit: a missing piece of the culturally congruent care puzzle”. *Journal of Transcultural Nursing* 22(1):77-82.

Wigert, Helena, Renée Johansson, Marie Berg, and Anna Lena Hellström. 2006. “Mothers' experiences of having their newborn child in a neonatal intensive care unit.” *Scandinavian Journal of Caring Sciences* 20(1):35-41.

Zeitlin, Jennifer, Elizabeth S. Draper, Louis Kollée, David Milligan, Klaus Boerch, Rocco Agostino, Ludwig Gortner, Patrick Van Reempts, Jean-Louis Chabernaud, Janusz Gadzinowski, Gérard Bréart, Emile Papiernik, and the MOSAIC research group. 2008. “Differences in rates and short-term outcome of live births before 32 weeks of gestation in Europe in 2003: results from the MOSAIC cohort.” *Pediatrics* 121(4):e936-44.

#### **4. CHAPTER 2**

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## **Needs and stress in parents of very preterm infants hospitalized in Neonatal Intensive Care Units: the effect of data collection period**

**Running title:** Needs and stress in NICU: data collection period

Inês BAÍA<sup>1</sup>, Elisabete ALVES<sup>2</sup>, Mariana AMORIM<sup>3</sup>, Sílvia FRAGA<sup>4</sup>, Susana SILVA<sup>5</sup>

<sup>1</sup> BSc, Research Fellow, Department of Clinical Epidemiology, Predictive Medicine and Public Health, University of Porto Medical School, Porto, Portugal (FMUP); Institute of Public Health – University of Porto (ISPUP), Porto, Portugal

<sup>2</sup> PhD, Postdoctoral Researcher, Institute of Public Health – University of Porto (ISPUP), Porto, Portugal; Department of Clinical Epidemiology, Predictive Medicine and Public Health, University of Porto Medical School, Porto, Portugal (FMUP)

<sup>3</sup> MSc, Research Fellow, Institute of Public Health – University of Porto (ISPUP), Porto, Portugal

<sup>4</sup> PhD, Postdoctoral Researcher, Institute of Public Health – University of Porto (ISPUP), Porto, Portugal; Department of Clinical Epidemiology, Predictive Medicine and Public Health, University of Porto Medical School, Porto, Portugal (FMUP)

<sup>5</sup> PhD, Research Assistant, Institute of Public Health – University of Porto (ISPUP), Porto, Portugal; Department of Clinical Epidemiology, Predictive Medicine and Public Health, University of Porto Medical School, Porto, Portugal (FMUP)

**Corresponding author:**

Susana Silva

Institute of Public Health – University of Porto (ISPUP)

Rua das Taipas n° 135

4050-600 Porto, Portugal

Telephone: +351 222 061 820

Fax: +351 222 061 821

e-mail: [susilva@med.up.pt](mailto:susilva@med.up.pt)

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**Conflicts of Interest**

No conflict of interest has been declared by the authors.

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## **Abstract**

**Aim:** To assess the effect of data collection period on self-reported needs and stress among parents of very preterm infants hospitalized in NICU.

**Background:** The assessment of parental needs and stress is essential for the implementation of quality family-centered care in NICU. In this context it is important to minimize the burden to parents of very preterm infants admitted to NICU and to lessen the intrusion into their private experiences, which reinforce the importance of being aware of the relevance of the moment of data assessment.

**Design:** Cross-sectional study.

**Methods:** Between January and September 2013, 22 mothers and 17 fathers were consecutively interviewed 8 to 14 days or 15 to 22 days after admission, in a level III NICU in the North of Portugal. Data were collected through a self-administered questionnaire comprising the NICU Family Needs Inventory and the Parental Stress Scale in NICU.

**Results:** Assurance and proximity were the most valued needs. Comparing to the assessment 8 to 14 days after admission, an increase in parental perception of support as very important was observed 15 to 22 days (31.6% vs. 45.0%). Those interviewed later considered the change in parental role (21.1% vs. 55.0%) and baby looks and behaves (10.5% vs. 25.0%) as extremely stressful more often. No refusals occurred in the second moment.

**Conclusion:** Parental needs and stress evolve throughout hospitalization. Their continuous monitoring is needed to design family-centered care interventions.

**Keywords:** Needs Assessment; Stress, Psychological; Parents; Intensive Care Units, Neonatal; Nursing.

## **Summary Statement**

### **Why is this research needed?**

- The assessment of parental needs and stress is essential for the implementation of quality family-centered care in NICU.
- Researchers and health professionals must be aware of the relevance of the moment of assessment and its effects on results, as well as on counselling and clinical practice.

### **What are the key findings?**

- Assurance and proximity were the most valued needs.
- A longer hospitalization was related with a higher relevance attributed to support.
- Stress on parental role and baby looks and behaves increases during hospitalization.

### **How should the findings be used to influence policy/practice/research/education?**

- Parental continuous monitoring is needed to design family-centered interventions.
- Researchers and health professionals must be aware of potential effects of methodological decisions regarding the moment of data collection on the interpretation of results.

## **Introduction**

The assessment of parental needs and stress is essential for the implementation of quality family-centered care in NICU (Gooding et al. 2011) wherein parents actively contribute to decision making and to infant's care. Considering that parental perceptions of needs and stress may change across child's hospitalization (Lubbe and Bornman 2005) researchers and health professionals must be aware of the relevance of the moment of assessment and its effects on results, as well as on counselling and clinical practice.

## **Background**

The birth of a very preterm infant, before 32 weeks of gestation, (World Health Organization) and his/her subsequent hospitalization in a Neonatal Intensive Care Unit (NICU), constitute an acute adverse life event with impact on parents' health and well-being (Jubenville et al. 2012). During the hospitalization period, parents face particular needs of information, assurance, proximity, comfort and support (Ward 2001), which may place them at an increased risk of developing parental stress and several psychopathological symptoms (Jubenville et al. 2012). Empirical studies, examining the perspective of parents regarding their experiences during infant's hospitalization in NICU, highlight the need of obtaining information and guidance (Arockiasamy et al. 2008), trusting in the healthcare team (Bernaix et al. 2006), and experiencing support from staff members and the partner (Pepper et al. 2012). In the presence of alterations in the expected parental roles and infant's vulnerability, parents also reveal a set of mixed emotions, from hope and love to worrisome (Bernaix et al. 2006), fear, guilty (Obeidat et al. 2009) and lack of control (Arockiasamy et al. 2008), towards a technological environment.

Beyond the respect for the ethical principles of autonomy, non-maleficent, beneficence and justice (Dickson-Swift et al. 2008) the assessment of parental needs and stress in NICU

raises methodological issues like minimizing the burden to mothers and fathers and lessening the intrusion into their private experiences, which reinforce the importance of being aware of the relevance of the moment of data assessment.

To our knowledge there is scarce evidence on how data collection period may influence the assessment of self-reported issues in the NICU setting.

### **Aim**

This study aims to assess the effect of data collection period on self-reported needs and stress among parents of very preterm infants hospitalized in NICU, by comparing those interviewed 8 to 14 days after child's admission with those interviewed 15 to 22 days after that event.

## Methods

In the present study participants were mothers and fathers of very preterm infants born between January and September 2013 and hospitalized in a level III NICU located in the North of Portugal. This Unit has the largest number of very preterm infants in Portugal. The study protocol was approved by the National Data Protection Commission and the Ethics Committee of the hospital where the study was performed and written informed consent was obtained from all participants.

Only parents with infants born before 32 weeks of gestation and still hospitalized in the abovementioned NICU at the time of the interview were consecutively invited to participate in the study by a health professional. Parents with serious illness that precluded NICU visitation (e.g. cancer), families who were absent in NICU during the hospitalization period, and parents whose infants were discharged or transferred to other hospital were excluded from the present study (Alves et al. 2014).

During data collection period, there were 35 pairs of mothers and fathers of very preterm infants, and 28 were eligible and invited to integrate the study (Figure 1). In order to assess the effect of data collection period on self-reported parental needs and stress, mothers and fathers of infants born between 1<sup>st</sup> January and 15<sup>th</sup> May of 2013 were interviewed 8 to 14 days after their child's admission, while parents of infants born between 16<sup>th</sup> May and 30<sup>th</sup> September 2013 were interviewed 15 to 22 days after child's birth.

From 16 eligible pairs invited 8 to 14 days after admission, 12 accepted to participate, being included 10 mothers and 9 fathers. Four pairs have refused mainly because of lack of time to participate (n=3) or psychological unavailability (n=1). In this period, 2 mothers were missed due to medical complications and lack of time, and 3 fathers were absent due to professional commitments. All the pairs invited and interviewed 15 to 22 days after the birth

of the infant accepted to participate (n=12), being included 12 mothers and 8 fathers. In this period, 4 fathers were missed due to professional commitments.

Trained interviewers were responsible for conducting face-to-face interviews, using structured questionnaires, to mothers and fathers, separately. Data on demographic and socioeconomic characteristics, personal medical history, gynecologic and obstetric history and lifestyles were collected through self-report.

Clinical records were reviewed by interviewers to retrieve data on pregnancy complications which included infectious, placental, hemorrhagic and cardiovascular complications, twin pregnancy, and mode of delivery (vaginal or instrumental and caesarean). Data on neonatal characteristics was also recovered, such as sex, birth weight and gestational age. According to World Health Organization definitions very low birth weight and extremely premature infants were defined as birth weight below 1500 grams and gestational age under 28 weeks, respectively (World Health Organization 1992).

Mothers and fathers were, additionally, asked to fill the NICU Family Needs Inventory (Ward 2001) and the Parental Stressor Scale: Neonatal Intensive Care Unit (Souza et al. 2012). The NICU Family Needs Inventory is a self-administered scale, consisting in 56 need statements designed to measure the importance of family needs. The 56 items are grouped into 5 subscales: “assurance”, “proximity”, “information”, “comfort” and “support” and each item range from 1 to 4: (1) Not important, (2) Slightly important, (3) Important and (4) Very important. The Parental Stressor Scale: Neonatal Intensive Care Unit measures parental perception of sources of stress arising from the environment of the NICU (Souza et al. 2012). It is a self-administered scale, with 26 items that cover 3 dimensions: Sights and Sounds (6 items), Baby Looks and Behaves (13 items) and Change in Parental Role (7 items) and each is rated in a five-point scale, ranging from 1 (not at all stressful) to 5 (extremely stressful). A Portuguese version of NICU Family Needs Inventory, which is being culturally adapted and

validated in Portugal, and a validated Portuguese version of the Parental Stressor Scale were used (Souza et al. 2012).

Statistical analysis was performed using Stata 11.0 (College Station, TX, 2009). Sample characteristics are presented as counts and proportions and were compared using the fisher's exact test. To assess the effect of data collection period, needs and stress subscales were presented as medians and interquartile range (IQR) and compared using the Mann-Whitney test. Additionally, due to the low variability in the response scale, parental needs were categorized as very important or not very important (combining the answers not important, slightly important and important). Therefore, for each subscale, very important was defined as scoring on average 3.5 or more and not very important as scoring on average less than 3.5. Regarding parental stress, and since a wider range of responses was observed, the distribution of parental perception on each stress subscale was presented, according to the time of interview.

## Results

The characteristics of participants according to the time of interview are summarized in Table 1. The mean (standard deviation) time of infants' hospitalization at the moment of interview was, in the first period of data collection, 9.2 days (0.9) and 18.0 days (2.3) in the second one. Overall, more than half of participants were female and 69.2% were aged below 35 years. Almost 65% of the parents had more than 9 years of education. Regarding sociodemographic variables there were no statistically significant differences between mothers and fathers who participated in the two moments of data collection.

This was the first pregnancy for nearly 58% of the women. The proportion of women with pregnancy complications and with caesarean sections was higher in the first moment of assessment than in the second one, although not reaching statistical significance (50.0% vs. 33.3%,  $p=0.680$ ; and 83.3% vs. 63.6%,  $p=0.371$ ; respectively). In the present study, there were 3 twin pregnancies, 1 in the first moment and 2 in the second. Mothers interviewed 8 to 14 days after their child's admission delivered more frequently female babies than those interviewed 15 to 22 days (75.0% vs. 16.7%;  $p=0.012$ ). Three quarters of the deliveries resulted in very low birth weight infants in both periods. There were 5 extremely premature deliveries, 2 in the first moment and 3 in the second.

Overall, parents classified, on average, all items of NICU Family Needs Inventory as important or very important (Table 2). Needs of assurance and proximity were the most valued by parents of very preterm babies hospitalized in NICU, independently of the time of interview. Despite the lack of statistically significant differences, parents interviewed 15 to 22 days after their child's admission tended to attribute higher importance to all needs, except for assurance. In fact, comparing to the perception assessed 8 to 14 days after admission, an increase in parental perception of support and comfort needs as very important was observed 15 to 22 days after admission (31.6% vs. 45.0%; 36.8% vs. 40.0%, respectively), while the

appreciation of assurance (100% vs. 85.0%), proximity (94.7% vs. 85%) and information needs (84.2% vs. 75.0%) has decreased (Figure 2).

Regarding the distribution of stress perception by subscale, the analysis of stress inventory showed higher levels of stress among parents interviewed 15 to 22 days of their child's admission, when compared with those interviewed 8 to 14 days, especially on subscale change in parental role (median (IQR): 4.5 (4.0-4.7) and 3.7 (3.0-4.3), respectively,  $p=0.082$ ) (Table 2). Parents interviewed in the second week of their child's admission reported more frequently the sights and sounds as extremely stressful (10.5% vs. 0.0%), while those interviewed during the third week were more likely to consider the baby looks and behaves (10.5% vs. 25.0%), and change in parental role (21.1% vs. 55.0%) as extremely stressful (Figure 3).

## **Discussion**

The results of the present study revealed that, independently of the time of interview, needs of assurance and proximity were the most valued by mothers and fathers of very preterm infants hospitalized in NICU. A longer hospitalization period was related with a higher relevance attributed to support needs, as well as an increase on stress levels regarding change in parental role and the baby looks and behaves. One major contribution of this study is the simultaneous evaluation and analysis of parental needs and stress, in parents of very preterm infants hospitalized in NICU, taking into account the influence of the period of data collection in the assessment of such topics.

The findings regarding assurance and proximity needs are supported by other studies that included parents of preterm but also term infants, interviewed at child's admission and at discharge (Ward 2001, Mundy 2010). The importance attributed to assurance and proximity needs independently of the time of interview seems to align with the parents' attempt to develop a sense of meaning about a new reality shaped in an unknown sociotechnical environment (Shin and White-Traut 2007). In order to regain some control of the situation and be closer to the expected roles in the field of parenthood, parents need to ensure the development of assurance and proximity, through confidence in the care provided to their child, involvement in decision-making and caregiving activities (Feeley et al. 2013), as well as trusting that the information about infants' health status is accurate (Bialoskurski et al. 2002). Other studies (Arockiasamy et al. 2008, Bialoskurski et al. 2002 Cox & Bialoskurski 2001) emphasized information and communication needs as the priority for parents whose infants were admitted to NICU, which is frequently considered an adaptive strategy to handle with that experience (Arockiasamy et al. 2008). It has been proposed that an ongoing communication with the parents as well as the provision of infant-related information by healthcare professionals may facilitate the attachment between parents and their child, by

focusing on infants' well-being, and may contribute for overcoming some physical and psychological barriers in NICU (Cox & Bialoskurski 2001).

Despite the relevance of assurance and proximity needs of parents throughout their very preterm infant's stay in NICU, the results corroborate the existence of different needs at different stages along with the adaptation to NICU's environment and to premature parenthood (Lubbe and Bornman 2005). Our study described an increase on overall needs in the third week after child's admission, when needs of support emerge as more relevant than in the second week. The importance given to support needs in the second moment of parents' interviews may reflect a growing parental search for assistance, either from healthcare professionals, to learn and practice skills for taking care of their infant (Cleveland 2008), and from family and friends, for assistance with household tasks (Feeley et al. 2013), care of other children and emotional support (Cleveland 2008), in order to reduce parental burden (Feeley et al. 2013). In fact, it has been previously described that in the first two weeks of infants' hospitalization parents feel more like bystanders (Heermann et al. 2005), becoming to feel more active in their child's care and to strength trustworthy relationships with healthcare professionals after that period of time (Obeidat et al. 2009). Furthermore, in the first two weeks of child's hospitalization in NICU, infant priorities such as diagnosis, therapeutic and prognosis information, along with his/her care and protection may mask parents' own need for support and comfort (Obeidat et al. 2009, Bialoskurski et al. 2002).

Change in parental role emerges as the greatest stressor for parents, especially 15 to 22 days after their child's admission to NICU. These results are corroborated by previous research conducted with parents of premature but also term infants (Busse et al. 2013, Dudek-Shriber 2004). According to the literature, during hospitalization in NICU, parental roles are challenged by different elements of the environmental context of NICU (Sikorova and Kucova 2012), in particular the lack of privacy (Heermann et al. 2005), the incubator (Jackson

et al. 2003), and the constant presence of healthcare providers (Busse et al. 2013). In fact, the physical and symbolic barriers for touching and holding the child (Jackson et al. 2003), the instruments surrounding him/her (Sikorova and Kucova 2012), the continuous noise, characteristic smells and lights of NICU (Sikorova and Kucova 2012), along with the impossibility to protect the child from harm and performing caregiving activities (Feeley et al. 2013) may justify the higher stress levels regarding change in parental role. Furthermore, delivering a very preterm infant may be considered as an event of biographical disruption, where expected developmental of interactive skills for both the parent and the infant is interrupted (Browne and Talmi 2005). Therefore, feelings of self-blame and guilt experienced by parents, particularly by mothers, also contribute to their levels of stress regarding their role as parents (Shin and White-Traut 2007, Mendelsohn 2005).

After the occurrence of a preterm birth, there is, frequently, a discrepancy between parents' social representation of their child and the real infant, who is vulnerable, immature and whose survival is dependent upon medical and technological intervention, respiratory support and close monitoring (Mendelsohn 2005). The difference between what is expected from very preterm infants compared to other infants regarding size, weight, neurobehavioral development and interaction with mothers and fathers may lead to the increase observed in stress levels concerning baby looks and behaves of parents interviewed in the second moment (Shin and White-Traut 2007, Mendelsohn 2005).

The results from the present study provide relevant information for the design and implementation of rigorous methodologies in the study of parents' experiences inside NICU, with implications on clinical practice and counselling. In studies that involve self-reported data and the assessment of parental needs and stress in parents of very preterm infants during hospitalization, researchers and health professionals must be aware of potential effects of methodological decisions regarding the moment of data collection on the interpretation of

results, while minimizing the burden to participants and lessening the intrusion in their private experiences.. The lack of refusals in the second moment of data collection, as well as a deeper awareness of parents-centered needs (support and comfort) and change in parental role may support the idea that the third week of hospitalization may constitute a socioethically appropriate moment for data assessment for research purposes. For clinical practice, these results demonstrate the need for implement family-centered care in NICU, promoting counselling and involvement of parents during hospitalization, incorporating their needs in the care and providing them assurance and support.

Despite the innovative nature of the present study, some limitations should be discussed. Data was collected in a single NICU and the sample size was quite small, which may limit the generalizability of the results. However, the results suggest a differential effect by period of data collection that should not be markedly different in other Units with similar conditions. Also, data was collected during an extended recruitment period of nine months and participants were consecutively and systematically invited to participate.

Overall, our findings highlight the importance of the moment of data collection for assessing parental needs and stress in NICU, demonstrating that there are differences in needs and sources of stress reported by parents, according to the time of interview. Also, this study contributes for a deeper and grounded understanding of how parental needs and stress evolve throughout hospitalization, which is fundamental for clinical practice where parental monitoring should be continuous for designing and implementing interventions that promote parental guidance and support.

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## References

- ALVES, E., AMORIM, M., FRAGA, S., BARROS, H. & SILVA, S. 2014. Parenting roles and knowledge in neonatal intensive care units: protocol of a mixed methods study. *BMJ open*, 4, e005941-e005941.
- AROCKIASAMY, V., HOLSTI, L. & ALBERSHEIM, S. 2008. Fathers' experiences in the neonatal intensive care unit: a search for control. *Pediatrics*, 121, e215-22.
- BERNAIX, L. W., SCHMIDT, C. A., JAMERSON, P. A., SEITER, L. & SMITH, J. 2006. The NICU experience of lactation and its relationship to family management style. *MCN Am J Matern Child Nurs*, 31, 95-100.
- BIALOSKURSKI, M. M., COX, C. L. & WIGGINS, R. D. 2002. The relationship between maternal needs and priorities in a neonatal intensive care environment. *J Adv Nurs*, 37, 62-9.
- BOWLING, A. 2005. Mode of questionnaire administration can have serious effects on data quality. *J Public Health (Oxf)*, 27, 281-91.
- BROWNE, J. V. & TALMI, A. 2005. Family-based intervention to enhance infant-parent relationships in the neonatal intensive care unit. *J Pediatr Psychol*, 30, 667-77.
- BUSSE, M., STROMGREN, K., THORNGATE, L. & THOMAS, K. A. 2013. Parents' Responses to Stress in the Neonatal Intensive Care Unit. *Critical Care Nurse*, 33, 52-60.
- CLEVELAND, L. M. 2008. Parenting in the neonatal intensive care unit. *J Obstet Gynecol Neonatal Nurs*, 37, 666-91.
- COX, C. & BIALOSKURSKI, M. 2001. Neonatal intensive care: communication and attachment. *British journal of nursing (Mark Allen Publishing)*, 10, 668-76.
- DEMAREST, S., VAN DER HEYDEN, J., CHARAFEDDINE, R., DRIESKENS, S., GISLE, L. & TAFFOREAU, J. 2013. Methodological basics and evolution of the Belgian health interview survey 1997--2008. *Arch Public Health*, 71, 24.
- DICKSON-SWIFT, V., JAMES, E. L. & LIAMPUTTONG, P. 2008. *Undertaking Sensitive Research in the Health and Social Sciences*, United Kingdom Cambridge University Press.
- DUDEK-SHRIBER, L. 2004. Parent Stress in the Neonatal Intensive Care Unit and the Influence of Parent and Infant Characteristics. *American Journal of Occupational Therapy*, 58, 509-520.
- EVENSON, K. R., CHASAN-TABER, L., SYMONS DOWNS, D. & PEARCE, E. E. 2012. Review of self-reported physical activity assessments for pregnancy: summary of the evidence for validity and reliability. *Paediatr Perinat Epidemiol*, 26, 479-94.
- FEELEY, N., WAITZER, E., SHERRARD, K., BOISVERT, L. & ZELKOWITZ, P. 2013. Fathers' perceptions of the barriers and facilitators to their involvement with their newborn hospitalised in the neonatal intensive care unit. *J Clin Nurs*, 22, 521-30.
- GOODING, J. S., COOPER, L. G., BLAINE, A. I., FRANCK, L. S., HOWSE, J. L. & BERNS, S. D. 2011. Family Support and Family-Centered Care in the Neonatal Intensive Care Unit: Origins, Advances, Impact. *Seminars in Perinatology*, 35, 20-28.
- GUILLEMIN, M. & GILLAM, L. 2004. Ethics, Reflexivity, and "Ethically Important Moments" in Research. *Qualitative Inquiry*, 10, 261-280.
- HEERMANN, J. A., WILSON, M. E. & WILHELM, P. A. 2005. Mothers in the NICU: outsider to partner. *Pediatr Nurs*, 31, 176-81, 200.
- JACKSON, K., TERNESTEDT, B. M. & SCHOLLIN, J. 2003. From alienation to familiarity: experiences of mothers and fathers of preterm infants. *Journal of Advanced Nursing*, 43, 120-129.
- JUBINVILLE, J., NEWBURN-COOK, C., HEGADOREN, K. & LACAZE-MASMONTEIL, T. 2012. Symptoms of acute stress disorder in mothers of premature infants. *Adv Neonatal Care*, 12, 246-53.
- LUBBE, W. & BORNMAN, J. 2005. Early intervention care programme for parents of neonates. *Curationis*, 28, 73-82.
- MENDELSON, A. 2005. Recovering reverie: Using infant observation in interventions with traumatised mothers and their premature babies. *Infant Observation*, 8, 195-208.
- MILLER, D. R., CLARK, J. A., ROGERS, W. H., SKINNER, K. M., SPIRO, A., LEE, A. & KAZIS, L. E. 2005. The influence of place of administration on health-related quality-of-life assessments: findings from the Veterans Health Study. *J Ambul Care Manage*, 28, 111-24.

- MUNDY, C. A. 2010. Assessment of family needs in neonatal intensive care units. *Am J Crit Care*, 19, 156-63.
- OBEIDAT, H. M., BOND, E. A. & CALLISTER, L. C. 2009. The parental experience of having an infant in the newborn intensive care unit. *J Perinat Educ*, 18, 23-9.
- PEPPER, D., REMPEL, G., AUSTIN, W., CECI, C. & HENDSON, L. 2012. More than information: a qualitative study of parents' perspectives on neonatal intensive care at the extremes of prematurity. *Adv Neonatal Care*, 12, 303-9.
- SHIN, H. & WHITE-TRAUT, R. 2007. The conceptual structure of transition to motherhood in the neonatal intensive care unit. *Journal of Advanced Nursing*, 58, 90-98.
- SIKOROVA, L. & KUCOVA, J. 2012. The needs of mothers to newborns hospitalised in intensive care units. *Biomedical Papers-Olomouc*, 156, 330-336.
- SOUZA, S. R. D., DUPAS, G. & BALIEIRO, M. M. F. G. 2012. Adaptação cultural e validação para a língua portuguesa da Parental Stress Scale: Neonatal Intensive Care Unit (PSS:NICU). *Acta Paulista de Enfermagem*, 25, 171-176.
- WARD, K. 2001. Perceived needs of parents of critically ill infants in a neonatal intensive care unit (NICU). *Pediatr Nurs*, 27, 281-6.
- WORLD HEALTH ORGANIZATION. <http://www.who.int/mediacentre/factsheets/fs363/en/> [Online]. [Accessed 25th January 2014].
- WORLD HEALTH ORGANIZATION 1992. International statistical classification of diseases and related health problems, tenth revision. *World Health Organization, Geneva*.

Table 1. Participants' characteristics according to the time of interview.

	Total n (%)	Interview after admission		p
		8 to 14 days n (%)	15 to 22 days n (%)	
<b>Sociodemographic Characteristics</b>	<b>39</b>	<b>19</b>	<b>20</b>	
<b>Sex</b>				
Male	17 (43.6)	9 (47.4)	8 (40.0)	0.751
Female	22 (56.4)	10 (52.6)	12 (60.0)	
<b>Age (years)</b>				
<35	27 (69.2)	12 (63.2)	15 (75.0)	0.501
≥35	12 (30.8)	7 (36.8)	5 (25.0)	
<b>Education (years)</b>				
≤9	14 (35.9)	4 (21.1)	10 (50.0)	0.096
>9	25 (64.1)	15 (78.9)	10 (50.0)	
<b>Mothers' Obstetric Characteristics</b>	<b>24</b>	<b>12</b>	<b>12</b>	
<b>Gravidity</b>				
1	14 (58.3)	6 (50.0)	8 (66.7)	0.680
>1	10 (41.7)	6 (50.0)	4 (33.3)	
<b>Pregnancy Complications</b>				
Yes	14 (58.3)	6 (50.0)	4 (33.3)	0.680
No	10 (41.7)	6 (50.0)	8 (66.7)	
<b>Mode of delivery</b>				
Vaginal/Instrumental	6 (26.1)	2 (16.7)	4 (36.4)	0.371
Caesarean	17 (73.9)	10 (83.3)	7 (63.6)	
<b>Twin pregnancy</b>				
Yes	3 (12.5)	1 (8.3)	2 (16.7)	1.000
No	21 (87.5)	11 (91.7)	10 (83.3)	
<b>Sex of the baby</b>				
Male	12 (50.0)	3 (25.0)	9 (75.0)	0.012
Female	11 (45.8)	9 (75.0)	2 (16.7)	
Male & Female	1 (4.2)	0 (0.0)	1 (8.3)	
<b>Very low birthweight delivery<sup>‡</sup></b>				
Yes	18 (75.0)	9 (75.0)	9 (75.0)	1.000
No	6 (25.0)	3 (25.0)	3 (25.0)	
<b>Extremely preterm delivery*</b>				
Yes	5 (22.7)	2 (18.2)	3 (27.3)	1.000
No	17 (77.3)	9 (81.8)	8 (72.7)	

<sup>‡</sup> <1500g

\* < 28 gestational weeks

Table 2. Participants' needs and stress perception, according to the time of interview.

	Interview after admission		p
	8 to 14 days	15 to 22 days	
<b>NICU Family Needs Inventory</b>			
<b>Subscales</b>	<b>Median (IQR)</b>	<b>Median (IQR)</b>	
Assurance	3.9 (3.9-4.0)	3.9 (3.7-4.0)	0.055
Proximity	3.8 (3.6-3.9)	3.9 (3.7-4.0)	0.578
Information	3.7 (3.5-4.0)	3.8 (3.5-3.9)	0.854
Comfort	3.3 (3.1-3.7)	3.4 (3.1-3.7)	0.932
Support	3.1 (2.9-3.6)	3.3 (3.2-3.8)	0.122
<b>Parental Stress</b>			
<b>Subscales</b>	<b>Median (IQR)</b>	<b>Median (IQR)</b>	<b>p</b>
Sights and Sounds	2.5 (2.0-3.0)	2.7 (2.1-3.2)	0.410
Baby looks and behaves	3.4 (2.6-4.0)	3.6 (2.6-4.5)	0.583
Change in parental role	3.7 (3.0-4.3)	4.5 (4.0-4.7)	0.082
<b>Overall Stress</b>	<b>4.0 (3.0-5.0)</b>	<b>4.0 (3.0-5.0)</b>	<b>0.787</b>

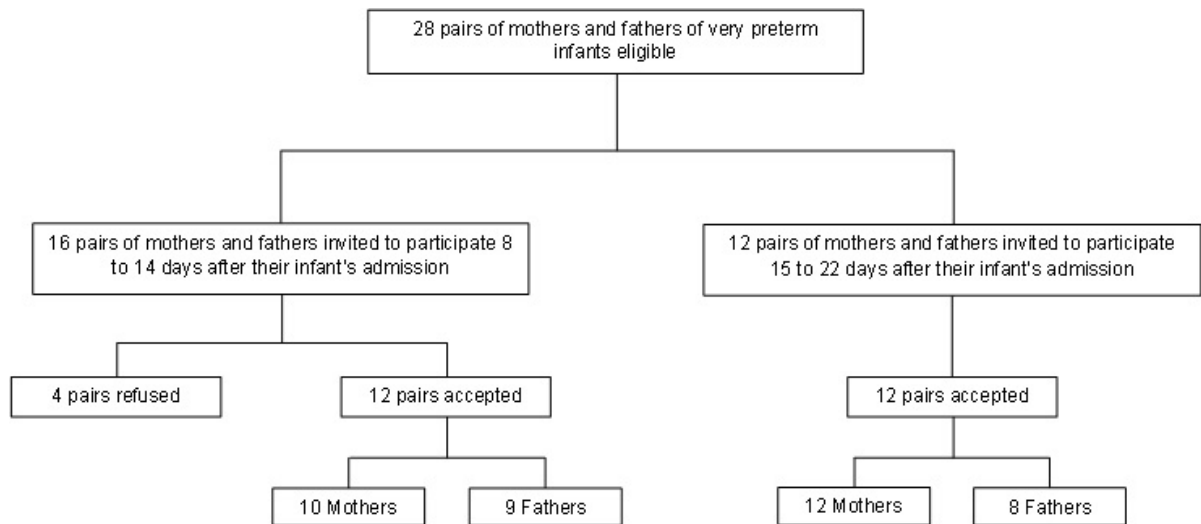


Figure 1 – Selection of participants.

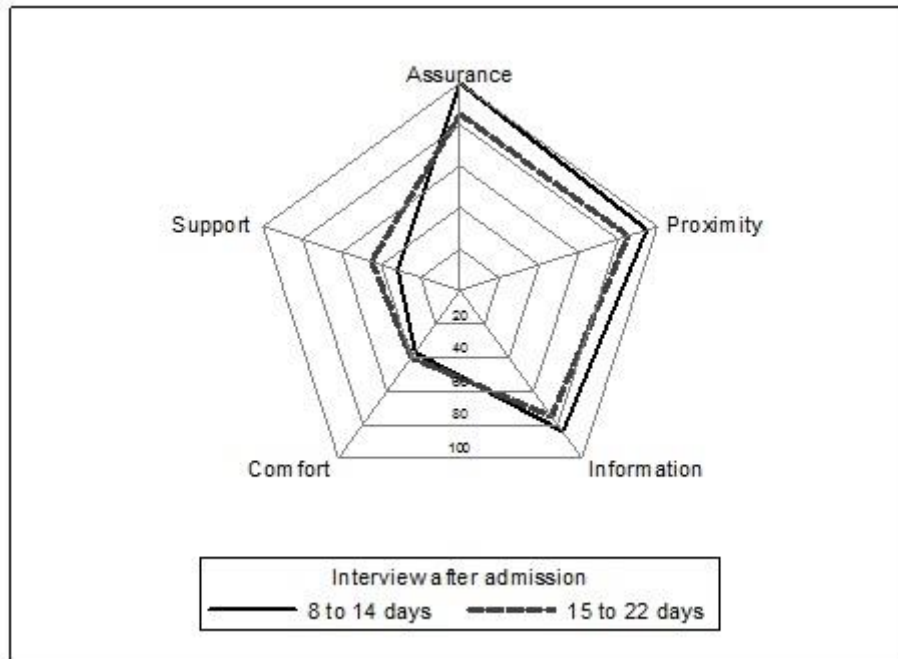


Figure 2 – Classification of parental needs subscales as very important, according to the time of interview (%).

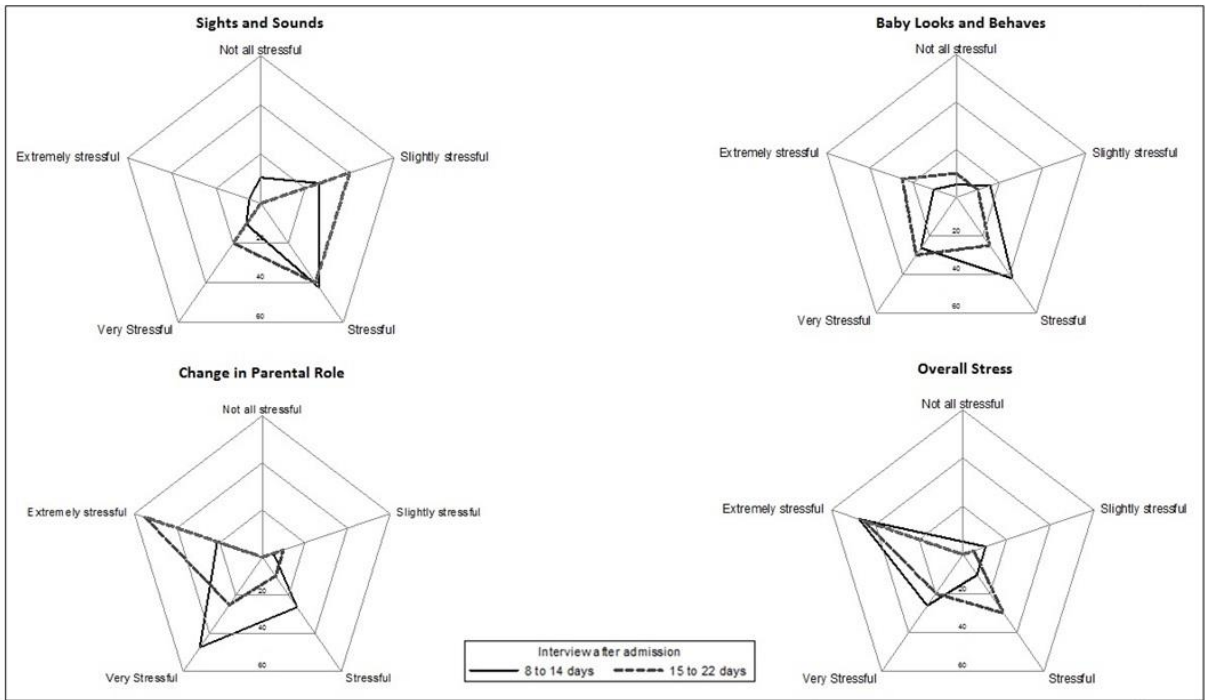


Figure 3 - Classification of parental stress subscales, according to the time of interview (%).

## 5. CONCLUSION

The main results of this thesis point out preterm delivery as an acute life event for both mothers and fathers, highlighting the complexity of such multifaceted parental experience. The repertoire of meanings, knowledge, and emotions actualized by mothers and fathers of preterm infants during hospitalization in NICU is grounded on four main iterative and dynamic themes: contextual factors, parental needs, mixed emotions and coping strategies. In NICU, parents are challenged to deal with the infant's vulnerability in an unfamiliar sociotechnical environment, which imposes restraints on the performance of usual caregiving activities and the need to establish relationships with health professionals, while looking for information and guidance, assurance and support. Simultaneously, parents grapple with complex and mixed emotions and enact action by active and/or passive forms of assuming responsibility for the infant, using religious beliefs, and being positive. Overall, there is an emphasis on the study of the emotional responses at an individual level, at the expense of cognitive appraisals and social and structural factors.

The importance of the period of data collection for assessing parental needs and stress in NICU is demonstrated by the observed differences in the report of needs and sources of stress, according to the time of interview. Despite the relevance of assurance and proximity needs throughout the very preterm infant's hospitalization in NICU, the results corroborate the existence of different needs at different stages along with the adaptation to NICU's environment and to premature parenthood. In fact, a longer hospitalization period was related with a higher relevance attributed to support needs, as well as an increase on stress levels regarding changes in parental role and baby looks and behaviors.

The identification of parental perspectives, needs and sources of stress is essential along the continuum of care, not only to allow the detection of possible gaps in health services but also to improve their quality and adequacy. Also, it is important to recognize mothers and fathers as healthcare partners in infants' care, promoting their involvement and continuous sharing of accurate information, using simple language, adapted to parental knowledge.

For clinical practice, these results demonstrate the need for implementing family-centered care in NICU, promoting counselling and involvement of parents during hospitalization, incorporating their voices and needs into care and providing them assurance and support. Family-centered care is an important element in helping families dealing with stress, fear and altered family or parenting roles that they experience, improving parental skills and sense of control. For health research, especially the one that involves self-reported data and sensitive topics such as the assessment of parental needs and stress in parents of

very preterm infants during hospitalization, this study highlights the importance of being aware of potential effects of methodological decisions regarding the period of data collection on the interpretation of results, while minimizing the burden to participants and lessening the intrusion in their private experiences.

While addressing the “traditional” issue of prematurity, which remains as a global public health problem with major implications for individuals, families and societies, the innovative nature of this study relies on the focus given to parents’ experiences, needs and stress during their preterm infants’ stay in NICU, taking into account methodological questions posed in this context. Understanding mothers’ and fathers’ experiences, roles, emotions and needs during hospitalization in NICU is an important step in improving the quality of care and guiding future research, which needs to include social and structural levels of analysis. The present thesis may assist health professionals in designing holistic, family-centered, supportive and educational interventions for parents, helping them to deal with the unexpected experience of having a premature child.

## REFERENCES

1. World Health Organization. Born too Soon: The Global Action Report on Preterm Birth. Geneva: WHO, 2012.
2. Simmons LE, Rubens CE, Darmstadt GL, Gravett MG. Preventing preterm birth and neonatal mortality: exploring the epidemiology, causes, and interventions. *Semin Perinatol.* 2010 Dec;34(6):408-15. PubMed PMID: 21094415. Epub 2010/11/26. eng.
3. Blencowe H, Cousens S, Oestergaard MZ, Chou D, Moller A-B, Narwal R, et al. National, regional, and worldwide estimates of preterm birth rates in the year 2010 with time trends since 1990 for selected countries: a systematic analysis and implications. *The Lancet.* 2012 //;379(9832):2162-72.
4. Chang HH, Larson J, Blencowe H, Spong CY, Howson CP, Cairns-Smith S, et al. Preventing preterm births: analysis of trends and potential reductions with interventions in 39 countries with very high human development index. *Lancet.* 2013 Jan 19;381(9862):223-34. PubMed PMID: 23158883. Pubmed Central PMCID: Pmc3572865. Epub 2012/11/20. eng.
5. Zeitlin J, Draper ES, Kollee L, Milligan D, Boerch K, Agostino R, et al. Differences in rates and short-term outcome of live births before 32 weeks of gestation in Europe in 2003: results from the MOSAIC cohort. *Pediatrics.* 2008 Apr;121(4):e936-44. PubMed PMID: 18378548. Epub 2008/04/02. eng.
6. Zeitlin J, Szamotulska K, Drewniak N, Mohangoo AD, Chalmers J, Sakkeus L, et al. Preterm birth time trends in Europe: a study of 19 countries. *BJOG : an international journal of obstetrics and gynaecology.* 2013 Oct;120(11):1356-65. PubMed PMID: 23700966. Epub 2013/05/25. eng.
7. EURO-PERISTAT project in collaboration with SCPE Ea, EURONEOSTAT. Health and Care of Pregnant Women and Babies in Europe in 2010. European Perinatal Health Report. 2013.
8. Menon R. Spontaneous preterm birth, a clinical dilemma: Etiologic, pathophysiologic and genetic heterogeneities and racial disparity. *Acta Obstetrica Et Gynecologica Scandinavica.* 2008 2008;87(6):590-600. PubMed PMID: WOS:000257910700002.
9. Goldenberg RL, Culhane JF, Iams JD, Romero R. Epidemiology and causes of preterm birth. *Lancet.* 2008 Jan 5;371(9606):75-84. PubMed PMID: 18177778. Epub 2008/01/08. eng.
10. Berkowitz GS, Papiernik E. Epidemiology of preterm birth. *Epidemiologic Reviews.* 1993 1993;15(2):414-43. PubMed PMID: WOS:A1993MY67600008.
11. Instituto Nacional de Estatística. Available at <http://www.ine.pt> [11th June 2014].
12. Field D, Draper ES, Fenton A, Papiernik E, Zeitlin J, Blondel B, et al. Rates of very preterm birth in Europe and neonatal mortality rates. *Archives of disease in childhood Fetal and neonatal edition.* 2009 Jul;94(4):F253-6. PubMed PMID: 19066186. Epub 2008/12/11. eng.
13. Huhtala M, Korja R, Lehtonen L, Haataja L, Lapinleimu H, Rautava P, et al. Parental Psychological Well-Being and Behavioral Outcome of Very Low Birth Weight Infants at 3 Years. *Pediatrics.* 2012 Apr;129(4):E937-E44. PubMed PMID: WOS:000302541700011.
14. Garel M, Dardennes M, Blondel B. Mothers' psychological distress 1 year after very preterm childbirth. Results of the epipage qualitative study. *Child Care Health and Development.* 2007 Mar;33(2):137-43. PubMed PMID: WOS:000243973200005.

15. Saigal S, Doyle LW. Preterm birth 3 - An overview of mortality and sequelae of preterm birth from infancy to adulthood. *Lancet*. 2008 Jan 19;371(9608):261-9. PubMed PMID: WOS:000252471900029.
16. Marlow N. Neurocognitive outcome after very preterm birth. *Archives of Disease in Childhood*. 2004 May;89(3):F224-F8. PubMed PMID: WOS:000221195500010.
17. Lawn JE, Kerber K, Enweronu-Laryea C, Cousens S. 3.6 Million Neonatal Deaths-What Is Progressing and What Is Not? *Seminars in Perinatology*. 2010 Dec;34(6):371-86. PubMed PMID: WOS:000285527800002.
18. Milligan DWA. Outcomes of children born very preterm in Europe. *Archives of Disease in Childhood-Fetal and Neonatal Edition*. 2010 Jul;95(4):F234-F40. PubMed PMID: WOS:000279281900002.
19. Mattison DR, Damus K, Fiore E, Petrini J, Alter C. Preterm delivery: a public health perspective. *Paediatric and Perinatal Epidemiology*. 2001 Jul;15:7-16. PubMed PMID: WOS:000170483900003.
20. Jubinville J, Newburn-Cook C, Hegadoren K, Lacaze-Masmonteil T. Symptoms of acute stress disorder in mothers of premature infants. *Advances in neonatal care : official journal of the National Association of Neonatal Nurses*. 2012 Aug;12(4):246-53. PubMed PMID: 22864005. Epub 2012/08/07. eng.
21. Mundy CA. Assessment of family needs in neonatal intensive care units. *American journal of critical care : an official publication, American Association of Critical-Care Nurses*. 2010 Mar;19(2):156-63. PubMed PMID: 20194612. Epub 2010/03/03. eng.
22. Malusky SK. A concept analysis of family-centered care in the NICU. *Neonatal network : NN*. 2005 2005;24(6):25-32. PubMed PMID: MEDLINE:16383182.
23. Ward K. Perceived needs of parents of critically ill infants in a neonatal intensive care unit (NICU). *Pediatric nursing*. 2001 May-Jun;27(3):281-6. PubMed PMID: 12964668. Epub 2003/09/11. eng.
24. Doering LV, Dracup K, Moser D. Comparison of psychosocial adjustment of mothers and fathers of high-risk infants in the neonatal intensive care unit. *Journal of perinatology : official journal of the California Perinatal Association*. 1999 Mar;19(2):132-7. PubMed PMID: 10642975. Epub 2000/01/22. eng.
25. Arockiasamy V, Holsti L, Albersheim S. Fathers' experiences in the neonatal intensive care unit: a search for control. *Pediatrics*. 2008 Feb;121(2):e215-22. PubMed PMID: 18182470. Epub 2008/01/10. eng.
26. Bernaix LW, Schmidt CA, Jamerson PA, Seiter L, Smith J. The NICU experience of lactation and its relationship to family management style. *MCN The American journal of maternal child nursing*. 2006 Mar-Apr;31(2):95-100. PubMed PMID: 16523034. Epub 2006/03/09. eng.
27. Pepper D, Rempel G, Austin W, Ceci C, Hendson L. More than information: a qualitative study of parents' perspectives on neonatal intensive care at the extremes of prematurity. *Advances in neonatal care : official journal of the National Association of Neonatal Nurses*. 2012 Oct;12(5):303-9. PubMed PMID: 22964607. Epub 2012/09/12. eng.
28. Padden T, Glenn S. Maternal experiences of preterm birth and neonatal intensive care. *Journal of Reproductive and Infant Psychology*. 2007;15(2):121-39.
29. Shin H, White-Traut R. The conceptual structure of transition to motherhood in the neonatal intensive care unit. *Journal of Advanced Nursing*. 2007 Apr;58(1):90-8. PubMed PMID: WOS:000245230600010.

30. Heermann JA, Wilson ME, Wilhelm PA. Mothers in the NICU: outsider to partner. *Pediatric nursing*. 2005 May-Jun;31(3):176-81, 200. PubMed PMID: 16060580. Epub 2005/08/03. eng.
31. Bialoskurski MM, Cox CL, Wiggins RD. The relationship between maternal needs and priorities in a neonatal intensive care environment. *J Adv Nurs*. 2002 Jan;37(1):62-9. PubMed PMID: 11784399. Epub 2002/01/11. eng.
32. Cox C, Bialoskurski M. Neonatal intensive care: communication and attachment. *British journal of nursing (Mark Allen Publishing)*. 2001 2001 May 24-Jun;10(10):668-76. PubMed PMID: MEDLINE:12048467.
33. Feeley N, Waitzer E, Sherrard K, Boisvert L, Zekowitz P. Fathers' perceptions of the barriers and facilitators to their involvement with their newborn hospitalised in the neonatal intensive care unit. *Journal of clinical nursing*. 2013 Feb;22(3-4):521-30. PubMed PMID: 23186388. Epub 2012/11/29. eng.
34. Bruns DA, McCollum JA. Partnerships between mothers and professionals in the NICU: caregiving, information exchange, and relationships. *Neonatal network : NN*. 2002 2002;21(7):15-23. PubMed PMID: MEDLINE:12514985.
35. Aagaard H, Hall EOC. Mothers' experiences of having a preterm infant in the neonatal intensive care unit: a meta-synthesis. *Pediatric Research*. 2010 Nov;68:256-. PubMed PMID: WOS:000208479700499.
36. Flacking R, Ewald U, Nyqvist KH, Starrin B. Trustful bonds: a key to "becoming a mother" and to reciprocal breastfeeding. *Stories of mothers of very preterm infants at a neonatal unit. Social science & medicine (1982)*. 2006 Jan;62(1):70-80. PubMed PMID: 15992983. Epub 2005/07/05. eng.
37. Flacking R, Lehtonen L, Thomson G, Axelin A, Ahlqvist S, Moran VH, et al. Closeness and separation in neonatal intensive care. *Acta Paediatrica*. 2012 Oct;101(10):1032-7. PubMed PMID: WOS:000308206300015.
38. Holditch-Davis D, Miles MS. Mothers' stories about their experiences in the neonatal intensive care unit. *Neonatal network : NN*. 2000 2000-Apr;19(3):13-21. PubMed PMID: MEDLINE:11949060.
39. Goulet C, Bell L, Tribble DS, Paul D, Lang A. A concept analysis of parent-infant attachment. *Journal of Advanced Nursing*. 1998 Nov;28(5):1071-81. PubMed PMID: WOS:000077280700032.
40. Sannino P, Plevani L, Bezze E, Cornalba C. The 'broken' attachment between parents and preterm infant: how and when to intervene. *Early human development*. 2011 Mar;87 Suppl 1:S81-2. PubMed PMID: 21288664. Epub 2011/02/04. eng.
41. Davis L, Mohay H, Edwards H. Mothers' involvement in caring for their premature infants: an historical overview. *Journal of Advanced Nursing*. 2003 Jun;42(6):578-86. PubMed PMID: WOS:000183279900011.
42. Cleveland LM. Parenting in the neonatal intensive care unit. *Journal of obstetric, gynecologic, and neonatal nursing : JOGNN / NAACOG*. 2008 Nov-Dec;37(6):666-91. PubMed PMID: 19012717. Epub 2008/11/18. eng.
43. Obeidat HM, Bond EA, Callister LC. The parental experience of having an infant in the newborn intensive care unit. *The Journal of perinatal education*. 2009 Summer;18(3):23-9. PubMed PMID: 20514124. Pubmed Central PMCID: Pmc2730907. Epub 2010/06/02. eng.
44. Blomqvist YT, Frolund L, Rubertsson C, Nyqvist KH. Provision of Kangaroo Mother Care: supportive factors and barriers perceived by parents. *Scandinavian journal of caring sciences*. 2013 Jun;27(2):345-53. PubMed PMID: 22816503. Epub 2012/07/24. eng.

45. Forcada-Guex M, Borghini A, Pierrehumbert B, Ansermet F, Muller-Nix C. Prematurity, maternal posttraumatic stress and consequences on the mother–infant relationship. *Early human development*. 2011 1//;87(1):21-6.
46. Lubbe W, Bornman J. Early intervention care programme for parents of neonates. *Curationis*. 2005 Dec;28(5):73-82. PubMed PMID: 16509099. Epub 2006/03/03. eng.
47. Mendelsohn A. Recovering reverie: Using infant observation in interventions with traumatised mothers and their premature babies. *Infant Observation*. 2005 2005/12/01;8(3):195-208.
48. Olshtain-Mann O, Auslander GK. Parents of Preterm Infants Two Months after Discharge from the Hospital: Are They Still at (Parental) Risk? *Health & Social Work*. 2008 Nov;33(4):299-308. PubMed PMID: WOS:000261034700007.
49. Busse M, Stromgren K, Thorngate L, Thomas KA. Parents' Responses to Stress in the Neonatal Intensive Care Unit. *Critical Care Nurse*. 2013 Aug;33(4):52-60. PubMed PMID: WOS:000323070600005.
50. Miles MS, Funk SG, Kasper MA. The stress response of mothers and fathers of preterm infants. *Research in nursing & health*. 1992 Aug;15(4):261-9. PubMed PMID: 1496151. Epub 1992/08/01. eng.
51. Dudek-Shriber L. Parent Stress in the Neonatal Intensive Care Unit and the Influence of Parent and Infant Characteristics. *American Journal of Occupational Therapy*. 2004;58:509-20.
52. Franck LS, Cox S, Allen A, Winter I. Measuring neonatal intensive care unit-related parental stress. *Journal of Advanced Nursing*. 2005 Mar;49(6):608-15. PubMed PMID: WOS:000227315200006.
53. Sikorova L, Kucova J. The needs of mothers to newborns hospitalised in intensive care units. *Biomedical Papers-Olomouc*. 2012 2012;156(4):330-6. PubMed PMID: WOS:000312983100008.
54. Hughes M, McCollum J. Neonatal Intensive Care: Mothers' and Fathers' Perceptions fo What is Stressful. *Journal of Early Intervention*. 1994;18(3):258-68.
55. Jackson K, Ternestedt BM, Schollin J. From alienation to familiarity: experiences of mothers and fathers of preterm infants. *Journal of Advanced Nursing*. 2003 Jul;43(2):120-9. PubMed PMID: WOS:000183894900001.
56. Browne JV, Talmi A. Family-based intervention to enhance infant-parent relationships in the neonatal intensive care unit. *Journal of pediatric psychology*. 2005 Dec;30(8):667-77. PubMed PMID: 16260436. Epub 2005/11/02. eng.
57. Arnold L, Sawyer A, Rabe H, Abbott J, Gyte G, Duley L, et al. Parents' first moments with their very preterm babies: a qualitative study. *BMJ open*. 2013;3(4). PubMed PMID: 23550091. Pubmed Central PMCID: 3641451. Epub 2013/04/04. eng.
58. Montiroso R, Provenzi L, Calciolari G, Borgatti R, Grp NAS. Measuring maternal stress and perceived support in 25 Italian NICUs. *Acta Paediatrica*. 2012 Feb;101(2):136-42. PubMed PMID: WOS:000298914000016.
59. Dickson-Swift V, James EL, Liamputtong P. *Undertaking Sensitive Research in the Health and Social Sciences*. United Kingdom Cambridge University Press; 2008.
60. Coughlin SS. Ethical issues in epidemiologic research and public health practice. *Emerging themes in epidemiology*. 2006 2006 Oct;3:16-. PubMed PMID: MEDLINE:17018147.

61. Demarest S, Van der Heyden J, Charafeddine R, Drieskens S, Gisle L, Tafforeau J. Methodological basics and evolution of the Belgian health interview survey 1997--2008. *Arch Public Health*. 2013 Sep 18;71(1):24. PubMed PMID: 24047278. Epub 2013/09/21. Eng.
62. Miller DR, Clark JA, Rogers WH, Skinner KM, Spiro A, Lee A, et al. The influence of place of administration on health-related quality-of-life assessments: findings from the Veterans Health Study. *J Ambul Care Manage*. 2005 Apr-Jun;28(2):111-24. PubMed PMID: 15923945. Epub 2005/06/01. eng.
63. Bowling A. Mode of questionnaire administration can have serious effects on data quality. *J Public Health (Oxf)*. 2005 Sep;27(3):281-91. PubMed PMID: 15870099. Epub 2005/05/05. eng.
64. Evenson KR, Chasan-Taber L, Symons Downs D, Pearce EE. Review of self-reported physical activity assessments for pregnancy: summary of the evidence for validity and reliability. *Paediatr Perinat Epidemiol*. 2012 Sep;26(5):479-94. PubMed PMID: 22882792. Pubmed Central PMCID: Pmc3419488. Epub 2012/08/14. eng.
65. Parker B, Ulrich Y. A protocol of safety - research on abuse of women. *Nursing Research*. 1990 Jul-Aug;39(4):248-50. PubMed PMID: WOS:A1990DQ48700016.
66. Paterson BL, Gregory D, Thorne S. A protocol for researcher safety. *Qualitative Health Research*. 1999 Mar;9(2):259-69. PubMed PMID: WOS:000078743800008.
67. Rosenbaum A, Rabenhorst MM, Reddy MK, Fleming MT, Howells NL. A comparison of methods for collecting self-report data on sensitive topics. *Violence and victims*. 2006 2006-Aug;21(4):461-71. PubMed PMID: MEDLINE:16897913.
68. Jacono J, Hicks G, Antonioni C, O'Brien K, Rasi M. Comparison of perceived needs of family members between registered nurses and family members of critically ill patients in Intensive-Care and Neonatal Intensive Care Units *Heart & Lung*. 1990 Jan;19(1):72-8. PubMed PMID: WOS:A1990CL09600011.
69. Timmermans S, Berg M. *The Gold Standard: The Challenge of Evidence-based Medicine and Standardization in Health Care*: Temple University Press; 2010.

## APPENDIX





- 32** – Ter cadeiras confortáveis ao lado do berço ou incubadora do meu bebé. \_\_\_\_\_
- 33** – Darem-me material para ler sobre a situação médica do meu bebé. \_\_\_\_\_
- 34** – Explicarem-me as coisas de tal forma a que eu as compreenda. \_\_\_\_\_
- 35** – Sentir que os profissionais do hospital cuidam do meu bebé. \_\_\_\_\_
- 36** – Permitirem-me ajudar nos cuidados físicos prestados ao meu bebé. \_\_\_\_\_
- 37** – Ser informada dos planos de transferência enquanto estão a ser feitos. \_\_\_\_\_
- 38** – Receber informação sobre o meu bebé pelo menos uma vez por dia. \_\_\_\_\_
- 39** – Ver o meu bebé frequentemente. \_\_\_\_\_
- 40** – Ser informada sobre aspetos específicos relativos ao progresso do meu bebé. \_\_\_\_\_
- 41** – Ter uma sala de espera perto da UCIN. \_\_\_\_\_
- 42** – Ser reconhecida como importante na recuperação do meu bebé. \_\_\_\_\_
- 43** – Receber ajuda para responder às reações dos irmãos do meu bebé. \_\_\_\_\_
- 44** – Poder conversar com outros pais cujo bebé esteja na UCIN ou que tenham passado por uma situação semelhante. \_\_\_\_\_
- 45** – Ser permitida a visita dos irmãos do meu bebé. \_\_\_\_\_
- 46** – Ter a liberdade de escolher ficar ou sair durante a realização de procedimentos dolorosos ao meu bebé. \_\_\_\_\_
- 47** – Ter um espaço para dormir perto da UCIN. \_\_\_\_\_
- 48** – Saber porque é que fizeram algo ao meu bebé. \_\_\_\_\_
- 49** – Ligarem-me para casa quando há mudanças importantes na situação clínica do meu bebé. \_\_\_\_\_
- 50** – Saber que o meu bebé está a receber medicação para a dor. \_\_\_\_\_





**Comece agora** – Em baixo apresenta-se uma lista de várias IMAGENS E SONS frequentemente experienciados numa UCIN. Estamos interessados em saber a sua opinião sobre quão stressantes estas imagens e sons são para si. Circule o número que melhor representa o seu nível de stress.

### IMAGENS E SONS

1. A presença de monitores e equipamentos	NA	1	2	3	4	5
2. Os barulhos constantes de monitores e equipamentos	NA	1	2	3	4	5
3. Os barulhos repentinos dos alarmes dos monitores	NA	1	2	3	4	5
4. Os outros bebés doentes na sala	NA	1	2	3	4	5
5. O grande número de pessoas que trabalham na unidade	NA	1	2	3	4	5
6. Ver uma máquina (ventilador) respirar pelo meu bebé	NA	1	2	3	4	5

Em baixo apresenta-se uma lista de vários itens que podem descrever a APARÊNCIA E O COMPORTAMENTO DO SEU BEBÉ na UCIN, bem como alguns dos TRATAMENTOS que viu serem realizados ao seu bebé. Nem todos os bebés tiveram estas experiências ou têm esta aparência. Circule NA se não passou pela experiência ou não observou o item em questão. Se o item reflete algo que já experienciou, indique quão stressante ou perturbadora essa experiência foi para si, circulando o número apropriado.

### APARÊNCIA E COMPORTAMENTO DO BEBÉ

1. Tubos e equipamentos no meu bebé ou perto dele	NA	1	2	3	4	5
2. Nódos negros, cortes ou incisões no meu bebé	NA	1	2	3	4	5
3. A cor anormal do meu bebé (por exemplo: pálido ou amarelado)	NA	1	2	3	4	5
4. Respiração pouco usual ou anormal do meu bebé	NA	1	2	3	4	5
5. O tamanho pequeno do meu bebé	NA	1	2	3	4	5
6. A aparência enrugada do meu bebé	NA	1	2	3	4	5
7. Ver agulhas e tubos colocados no meu bebé	NA	1	2	3	4	5
8. O meu bebé ser alimentado por uma sonda ou tubo intravenoso	NA	1	2	3	4	5
9. Quando o meu bebé parece estar em sofrimento	NA	1	2	3	4	5
10. Quando o meu bebé parece estar triste	NA	1	2	3	4	5
11. A aparência flácida e frágil do meu bebé	NA	1	2	3	4	5
12. Movimentos bruscos ou inquietos do meu bebé	NA	1	2	3	4	5
13. O meu bebé não ser capaz de chorar como os outros bebés	NA	1	2	3	4	5

