

# Parents' and nurses' perceptions of Nursing care in neonatology – an integrative review

Perceção de pais e enfermeiros sobre cuidados de Enfermagem em neonatologia: uma revisão integrativa

Percepción de padres y enfermeros sobre la atención de enfermería en neonatología – una revisión integradora

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## Abstract

**Background:** The admission of a Newborn (NB) to a Neonatal Intensive Care Unit (NICU) requires specialised skills from nurses in order to not only assess the NB's biological features, but also focus care on the NB/parents binomial.

**Objectives:** To analyse the scientific evidence on the Nursing care experienced at NICUs from the perspective of nurses and parents of NBs during their hospital stay at those units.

**Methodology:** An integrative literature review was conducted. The following databases were searched in the EBSCOhost platform: CINAHL; MEDLINE and Cochrane. Scientific studies published in databases of reference from 2004 to 2013 were selected based on previously defined inclusion and exclusion criteria.

**Results:** Nine studies which emphasised the diversity of perceptions of care were included. The analysis of these studies allowed organising the results into three themes: therapeutic relationship, humanisation of care and suffering.

**Conclusion:** The evidence obtained in this study suggest that parents of NBs admitted to NICUs experience a great emotional overload and need to receive information and support from nurses.

**Keywords:** infant, newborn; neonatal nursing; intensive care, neonatal; perception; parents

## Resumo

**Contexto:** A admissão de um Recém-Nascido (RN) numa Unidade de Cuidados Intensivos Neonatais (UCIN) requer dos enfermeiros competências especializadas, de modo a considerar não somente os aspetos biológicos do RN, mas centrando o cuidar no binómio RN/pais.

**Objetivos:** Conhecer a evidência científica sobre os cuidados de Enfermagem experienciados em UCIN, na perceção dos enfermeiros e dos pais dos RN durante o período de internação nessas unidades.

**Metodologia:** Realizou-se uma revisão integrativa da literatura. Elegeram-se a plataforma EBSCOhost e selecionaram-se as bases bibliográficas eletrónicas: CINAHL, MEDLINE e Cochrane. Os estudos científicos publicados em bases de dados de referência, entre 2004-2013, foram selecionados com critérios de inclusão e exclusão previamente definidos.

**Resultados:** Incluídos nove estudos que ressaltaram diversidade de percepções sobre os cuidados de Enfermagem. A análise destes estudos permitiu organizar os resultados em três temas: relação terapêutica; humanização dos cuidados e sofrimento.

**Conclusão:** As evidências, neste estudo, mostram que os pais que têm um RN internado em UCIN experienciam uma grande sobrecarga emocional, necessitam de receber informações e apoio dos enfermeiros.

**Palavras-chave:** recém-nascido; enfermagem neonatal; terapia intensiva neonatal; perceção; pais.

## Resumen

**Contexto:** La admisión de un Recién Nacido (RN) en una Unidad de Cuidados Intensivos Neonatales (UCIN) requiere que los enfermeros tengan competencias especializadas con el fin de tener en cuenta no solo los aspectos biológicos del RN, sino centrando la atención en el binomio RN/padres.

**Objetivos:** Conocer la evidencia científica sobre la atención de enfermería experimentada en las UCIN, en la percepción de los enfermeros y de los padres de los RN durante el período de internamiento hospitalario en estas unidades.

**Metodología:** Se realizó una revisión integradora de la literatura. Para ello, se consultó la plataforma EBSCOhost y se seleccionaron las bases bibliográficas electrónicas: CINAHL; MEDLINE y Cochrane. Los estudios científicos publicados en las bases de datos de referencia, entre 2004 y 2013, fueron seleccionados con criterios de inclusión y exclusión previamente definidos.

**Resultados:** Se incluyeron nueve estudios que resaltaron una diversidad de percepciones sobre la atención de enfermería. El análisis de estos estudios permitió organizar los resultados en tres temas: relación terapéutica, humanización de la atención y sufrimiento.

**Conclusión:** En este estudio, las evidencias indican que los padres que tienen un RN ingresado en una UCIN experimentan una gran sobrecarga emocional y necesitan recibir información y apoyo de los enfermeros.

**Palabras clave:** recién nacido; enfermería neonatal; cuidado intensivo neonatal; percepción; padres.

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## Introduction

The hospitalisation of a newborn (NB) child imposes itself as a reality with no physical or chronological boundaries, requiring a higher level of expertise from both nurses and family members. Human experiences can only be explained by how they are perceived, *i.e.* the essence of the phenomenon through the eyes of the person who experiences it. Only then will it be possible to understand human experiences, thus leading to the exploration of the phenomenon (Watson, 2002).

The equipment developed over the last decades turned the Neonatal Intensive Care Units (NICUs) of hospitals into a technologically advanced environment. Their purpose is to care for vulnerable, unstable and critically-ill NBs, who are highly at-risk and whose clinical conditions are permanently changing. Life maintenance requires intensive care and sophisticated technology, and represents a source of anxiety that is shared by both nurses and parents (Hockenberry & Wilson, 2011).

The admission of a NB to a NICU may be a traumatic event for both the NB and his/her parents. When the NB is hospitalised, he/she is invaded by invasive procedures and remains surrounded by unfamiliar sounds (monitors frequently beeping or aspiration noises), constant lights and strange people. All of this contributes to increase depersonalisation and the parents' anxiety for the baby's clinical condition. Parents experience a significant level of stress, anxiety and helplessness. Thus, uncertain of their child's future, physically uncomfortable and emotionally insecure, their reactions range from silence to cry. Many parents feel vulnerable and afraid, since hospitalisation is imbued with the constant possibility of death. Therefore, when the child is admitted to the NICU, it is essential to meet the family's needs (Hockenberry & Wilson, 2011).

The impact on the family of the NB's hospitalisation at a NICU has been widely documented in the literature (Serafim & Duarte, 2005). The adaptation to such a situation represents a complex process, with repercussions, whose success depends on several factors. It requires an almost constant effort of adaptation, in which nurses function as the support and security system and hold an essential knowledge that allows them to help people overcome difficult moments (Ferreira & Caeiro, 2005).

From this point of view, Watson emphasises that caring is the essence of Nursing, which may only be demonstrated and practiced in an interpersonal way, and necessarily involves the intentional encounter between two people with their lived experiences (Watson, 2002). It should also be noted that describing the nature of the care provided continues to be a necessary and imperative condition for the recognition of a professional identity (Ferreira & Caeiro, 2005). The gradual valorisation of Nursing is seen in the search for quality of care, which will tend to become a reality as a result of the existing scientific evidence, in which skills are increasingly more valued for the excellence of care.

When we focus our attention on the concept of care, the Anne Casey's Model of Partnership-in-Care in the literature emerges, whose theoretical assumption is to include parents in the care provided to hospitalised children (Casey, 1993). Confirming the importance of this notion, we consider this model to have guided our study, for we believe it to be very important for nurses to the extent that parents also play a role in the care process, though it focuses on the NB. The study of family-centred care has been at the centre of researchers' attention, which confirms its importance to Nursing. The various studies in this field have produced new key data for the understanding of this construct. Since this is a complex construct, understanding it and emphasising its importance requires stepping back in time. The partnership narrative dates back to the late 1980s, with Anne Casey (a nurse from New Zealand). The contribution of this author was of the utmost importance, especially because she developed the Anne Casey's Model of Partnership-in-care based on the family-centred care model. In her new model, she emphasised the parents' key role in the care provided to the hospitalised child (Casey, 1993) and emphasised a fundamental principle: the recognition that parents are the best care providers for their children.

The Anne Casey's Model of Partnership-in-Care emerged at a very peculiar moment when a change in the philosophy of health care was advocated, from care focused on the disease and biological aspects to a holistic approach to the human being. There was also a shift in the sense that people were believed to be responsible for their own health and health care (whenever possible). Therefore, the Nursing intervention to populations tended to change: it no

longer focused on the provision of direct care, but rather on forms of care that promoted autonomy. The basis of this model was the feeling of negotiation and respect for the needs and desires of the NB/family. Negotiating the partnership-in-care is considered to be the highest level of participation in the care practice: the provision of care focuses on the person, with a high level of communication between the various actors in the care process.

The Anne Casey's Model of Partnership-in-Care aims at establishing equal relationships between professionals and parents. It is, therefore, imperative that nurses provide support, education, and referral services to the family members of the ill NB.

As regards support strategies, nurses may put into action strategies that allow parents to engage in care, in order to create an environment of trust between NB/parents/health care professionals. In relation to education, nurses should engage in an educational process in which they share knowledge and teach appropriate techniques to family members so that they may effectively meet the child's needs. Finally, as regards referral services, nurses may ask for the help of other health care professionals, where necessary, in order to ensure the child's recovery and support to her/his care providers (Casey, 1993).

Therefore, this study aims at reflecting on the practice of Nursing oriented towards the following purpose: to contribute to a reflection on the Nursing care provided at NICUs with a view to improve the quality of care, based on the perception of nurses and parents of NBs on the care practices experienced at NICUs.

A protocol of integrative search of studies was designed based on a guiding question as a starting point. To answer this research question, we aim at identifying and synthesising the best scientific evidence. It is our purpose to analyse the scientific evidence on the Nursing care experienced at NICUs from the perspective of nurses and parents of NBs during their hospital stay at those units.

We assumed that, in neonatology, the harmful consequences of hospitalisation, such as the separation from parents, anxiety, and the unknown environment, may be minimised when the NB receives care from his/her parents. Thus, it is now

important to understand the methodological process involved.

## Methodological procedures of integrative review

Bearing in mind the research question and the objectives set out, an integrative review was chosen for being a broad methodological approach that enabled the inclusion of experimental and non-experimental studies and even data from the theoretical and empirical literature. This approach aimed at defining concepts, reviewing theories and evidences, as well as analysing the methodological problems of a given topic, thus enabling general conclusions to be drawn regarding a particular area of study (Whittemore & Knafl, 2005). The study followed the steps established for integrative reviews: formulation of the guiding question and objectives; definition of criteria for the selection of articles, categorisation of studies, assessment of the studies included in the review, analysis of data, and presentation of results (Whittemore & Knafl, 2005).

The search included articles published in portuguese, english and spanish between 2004 and 2013 for being chronologically closer to the current reality.

Articles were searched in the EBSCOhost platform using the following electronic bibliographic databases: CINAHL *plus with full text*; MEDLINE *with Full Text*, *Cochrane Central register of controlled trials*, *Database of abstracts of reviews of effects*, and *Cochrane Database of Systematic Reviews*. English was the preferred language and no restrictions were imposed on the type of publication. Five keywords were used: *recém-nascido* (infant, newborn; *recién nacido*); *enfermagem neonatal* (neonatal nursing; *enfermería neonatal*); *terapia intensiva neonatal* (intensive care, neonatal; *cuidado intensivo neonatal*); *percepção* (perception; *percepción*); *pais* (parents; *padres*), validated through the Health Sciences Descriptors - DeCS (compatible with the *Medical Subject Headings* - MeSH). The descriptors were combined using the boolean expressions OR and AND as follows (Table 1):

Table 1  
*Descriptors used and respective combination*

Descriptors	No. of articles
(infant, newborn* OR neonat* OR perinatal OR premature) ANDnurs* AND ("Intensive Care Unit*" OR NICU) AND (perception OR "professional-family relation*") AND parent*	209

The guiding question of this review was the following:  
*What is the scientific evidence on the Nursing care experienced at NICUs from the perspective of nurses and parents during the hospital stay at those units?*

The inclusion and exclusion criteria of the sample were selected according to a pre-defined model which included: participants, interventions, comparisons, outcomes and study design - the so-called PI[C]OD method (Table 2).

Table 2  
*Inclusion and exclusion criteria of the sample*

Inclusion criteria	Exclusion criteria
- Full-text and peer-reviewed articles;	- Being a dissertation or thesis;
- Referring to NBs or exclusively to specific groups such as parents and/or nurses;	- Being a quantitative study;
- Presenting information on the parameters considered as essential: <i>Participants</i> (Parents whose NBs had been hospitalised at a NICU/P for at least 24 hours (after the emergency procedures and initial stabilisation had occurred), nurses (working at a NICU, or both), <i>Interventions</i> (studies on the Nursing care provided at a NICU/P were selected), <i>Comparisons</i> (when applicable), <i>Outcomes</i> (perceptions on the experiences and meanings assigned to care during the hospitalisation at a NICU) and <i>Study Designs</i> (the scientific evidence has been obtained through qualitative approaches) and also the year of publication and author(s).	- Not being related to Nursing care.

Articles published between December, 2004, and January, 2013, were included. In order to expand the search for studies, the references of the studies found in the selected databases were analysed with the purpose of identifying other studies that included the research aims.

The analysis of the material was performed between February and March, 2013. In a first search refinement, descriptors were cross-compared and 209 articles were identified through the advanced search form available in the abovementioned databases. Following the reading of the abstracts and application of the pre-defined exclusion and inclusion criteria, 138 articles were excluded. Subsequently, following the reading of the full text of all articles, 62 more articles were excluded. In the end, a total of nine articles were selected. As recommended, an independent researcher participated in the analysis and selection of studies to increase the reliability and transparency of the process. In this way, nine articles were included. Bearing in mind the selection criteria listed above, the empirical evidence was analysed, assessed and synthesised.

## Results and Interpretation

With a view to a critical reflection, duly guided by our objectives, the results emerging from the phenomenon under study were discussed. Special emphasis will be given to the presentation and analysis of a set of data and information that will enable us to understand the scientific evidence on Nursing care, based on the perception of parents and nurses providing care at NICUs on the Nursing care experienced at the Unit.

Following the critical assessment of the studies in terms of data credibility and relevance, using a grid previously designed to assess the rigor and quality of results, all studies were found to have been conducted in the clinical context. The Nursing care perceived by parents and nurses was described based on the experiences of both types of participants.

Bearing in mind the research question, the inclusion criteria established that only qualitative articles should be considered as they were methodologically more suitable to provide evidence and identify significant

attributes or areas of subjectivity and intersubjectivity inherent in the attitudes and behaviours perceived by nurses and parents on the phenomenon or context of the experiences of caring for the NB.

The number of participants in the articles analysed ranged between 6 and 33 individuals. In relation to the paradigmatic guidance and sample size, no significant differences were found in the results obtained. The articles included had been published between 2004 and 2013 and were distributed as follows in relation to their country of origin: three from Brazil, one from Portugal, one from the USA, one from England, one from Norway, one from Canada, and one from

Australia. All collected studies (Table 3) presented relevant information to answer our research question, since the data obtained described the Nursing care perceived and experienced by parents whose NBs had been hospitalised at NICUs or by nurses working at these Units. Through the analysis of the different studies, the use of the interview was concluded to be predominant, as one of its main advantages was the fact that it enabled a direct contact with the individual's personal experience (Fortin, 2009). We shall now present a summary of the evidences found in each study.

Table 3

*Summary table of the selected articles, according to the PI[C]OD method*

Author(s)/ Year of Publication/ Country	Participants	Interventions	Outcomes	Design
Harbaugh, Tomlinson, and Kirschbaum (2004) USA	n=19 10 mothers 9 fathers	Semi-structured interviews were conducted to describe the parents' perceptions of the nurses' skills.	Data indicate that parents wish nurses to participate in the <i>non-technical</i> aspects of the care provided to their children.	Qualitative
Gale, Franck, Kools, and Lynch (2004) England	n=12 parents	Interviews and focus groups were conducted to explore the parents' perceptions of their baby's pain.	Two major themes were identified: infant pain as a source of parents' anguish, and the relief of the parents' suffering because of the newborn's pain.	Qualitative Exploratory
Rolim and Cardoso (2006) Brazil	n=6 nurses	Interviews were conducted to identify the team's opinion about the contribution of humanised care to the recovery of the baby at risk.	Results were organised into four themes: humanisation, sensitiveness, awareness raising and care.	Qualitative Descriptive
Silva, Barroso, Abreu, and Oliveira (2009) Portugal	n=12 10 mothers 2 fathers	Data were collected through semi-structured interviews that aimed at identifying the needs and coping mechanisms of parents with NB children.	The following categories of analysis emerged: feelings developed during the NB's hospitalisation, the day-to-day of the family with a hospitalised NB and the support/resources available during the NB's hospitalisation.	Qualitative Exploratory Descriptive
Fegran and Helseth (2009) Norway	n=18 6 mothers 6 fathers 6 nurses	Interviews and participant observations were conducted to explore the relationships established between parents and nurses.	The proximity between parents and nurses is desirable at the NICU; however, the emotional load of such proximity seems to be rarely problematised.	Exploratory with hermeneutic approach
Reis, Rempel, Scott, Brady-Fryer, and Van Aerde (2010) Canada	n=10 9 mothers 1 father	Semi-structured interviews were conducted to explore the parents' experience and their satisfaction with the care provided at the NICU.	The analysis of the reports suggests that the nurses/parents relationship is the factor that most influences the parents' satisfaction. Parents value the roles of educator and facilitator inherent in the nurses/parents interaction.	Qualitative
Fontoura, Fontenele, Cardoso, and Sherlock (2011) Brazil	n=16 parents	Semi-structured interviews were conducted to understand the experience of being the parent of a preterm child hospitalised at an NICU.	Results were organised into two themes, with their respective categories: parents' experience (happiness, confidence, indecision and fear), doubts and expectations (sequel, survival and discharge).	Qualitative Exploratory- Descriptive

Merighi, Jesus, Santin, and Oliveira (2011) Brazil	n=7 nurses	Semi-structured interviews were conducted to understand how nurses experienced the care provided to NBs in the presence of their parents.	The following categories emerged: recognising the parents' needs, experiencing difficulties in an emergency situation, being the link that joins both children and parents.	Qualitative Phenomenological
Trajkovski, Schmied, Vickers, and Jackson (2012) Australia	n=33 nurses	Interviews and focus groups were conducted to explore nurses' perspectives about their role in facilitating family-centred care at the NICU.	Four dominant themes emerged: getting to know parents and their wishes, involving family in the day-to-day care, finding a <i>bappy</i> medium, and transitioning support across the continuum.	Qualitative

The perception of the lived experiences allows for an understanding of different ways of seeing the world. Greater knowledge of the patient's experiences may help Nursing gain a deeper understanding of his/her health and disease processes, and thus provide a more solid basis for health care or even lead to new Nursing interventions. Nurses may improve the quality of care by listening to the other. For this reason, it is important for them and other members of the health care team to know what the newborns' parents truly experience during their child's hospital stay at NICUs.

The synthesis process was based on a thematic analysis: the exploratory reading of each article to develop an understanding of the content and context of the evidence; content analysis with the identification of recurring or prominent themes in the different studies; and comparative analysis of the recurring themes with the interpretative integration of results into new thematic categorisations that encompass and transpose the meanings of the studies included in the sample (Whittemore & Knaff, 2005). The studies analysed the Nursing care provided at NICUs based on the perceptions of nurses and parents of NBs. This was followed by a comparison of the evidence found in the articles, searching for common themes, sentences and concepts.

Among the studies which revealed the presence and importance of the nurse as a caregiver of newborns admitted to NICUs, his/her role was evident in areas related to the relationship and information/education, and was considered to be either positive or negative. Thus, this skill was identified in four studies, and a true relationship was established and applied through the analytical categories: support to the family during the NB's hospitalisation, proximity between parents and nurses at the NICU, recognition of nurses as the liaison person between children and parents, involvement of parents

in the day-to-day provision of care, and support in the transition process. Three studies focused on the professional domain, including behaviours and attitudes that contributed to a personalised care, such as the support to the meaning of Nursing care; while the remaining two studies focused on aspects inherent in the NB's hospitalisation, in a situation of suffering, which was imposed on parents as a complex adaptation process.

In view of the above, a first theoretical model of interpretation emerged from our analysis. This model showed that the parents' main focus of attention was the NB and that the nurse's role covered all those aspects. Following further analysis, the categories found were reformulated and three even more abstract categories were created to describe the factors found in the studies related to the perceptions of parents and nurses on Nursing care at NICUs. This process was based on the pervasive nature of the themes and concepts present in all studies. Finally, the similarities were transformed into representative synthetic constructions of the entire body of evidence to produce a synthesis integrated into a clear theoretical framework for all studies. Therefore, the common evidence was gathered into three themes: therapeutic relationship; humanisation of care; and suffering.

### Theme 1 - Therapeutic relationship

While performing their role, nurses focus their intervention on the person/environment relationship bearing in mind that the environment includes different aspects (both human and physical). Aware of the relationship that they build with patients and family members, their training and experience in clinical practice facilitate the understanding and respect for others. In that sense, the therapeutic relationship promoted within the professional Nursing practice is characterised by the partnership

with patients, in compliance with their skills and the enhancement of their role. This relationship is developed and strengthened through a dynamic process that aims at helping patients be proactive in achieving their health project. In practice, within the scope of child health Nursing, this partnership should be established by involving significant persons, as suggested in Anne Casey's Model of Partnership-in-Care, *i.e.* parents/family. Thus, when the family entity and patients are observed as a whole and are the target of Nursing care, free of value judgments, they are optimised by a change in behaviour that becomes compatible with health promotion. Collaborating with the family requires a relationship involved in ideas, resources, values and ways to solve problems, established jointly by nurses and parents. In this context, this attitude converges to a model of family interaction where nurses are able to work with family members in health promotion, and the prevention and treatment of diseases.

Therefore, in relation to the therapeutic relationship, the nurse's role next to the family of the hospitalised NB was identified at the relationship and education/information levels.

Somehow, the role of the relationship between nurses and parents was evidenced by both its positive and negative natures (Silva, Barroso, Abreu, & Oliveira, 2009; Fegran & Helseth, 2009; Merighi, Jesus, Santin, & Oliveira, 2011; Trajkovski, Schmied, Vickers, & Jackson, 2012). The findings of some authors highlight the direct and intense relationship between parents and nurses during the periods of hospitalisation (Silva et al., 2009; Fegran & Helseth, 2009; Merighi et al., 2011; Trajkovski et al., 2012).

In studies on the relationship and experience of parents with NBs hospitalised at NICUs, one of the themes that emerged from the interviews was the positive relationship between nurses, parents and NBs (Silva et al., 2009; Fegran & Helseth, 2009; Reis, Rempel, Scott, Brady-Fryer, & Van Aerde, 2010). However, the relationship of health care professionals was not always considered positive or rewarding; there were parents who reported a poor relationship, although this was more commonly referred to during the initial period of hospitalisation (Gale, Franck, Kools, & Lynch, 2004; Silva et al., 2009; Fegran & Helseth, 2009).

In studies on the experience of parents with NBs admitted to NICUs, one of the themes that emerged

from the interviews and that reflected the essence of their experience was the perception of the Nursing team's behaviour in the provision of care. Parents reported that they felt well taken care of, that the professionals' empathy helped them communicate, that professionals conveyed feelings of security, trust and peace, and that the team was professional in mastering their specific skills (Silva et al., 2009; Fegran & Helseth, 2009; Reis et al., 2010). These results were in line with those found in another study, in which the participants' reports indicated that the care received at NICUs was satisfactory and participants recognised the Nursing team's concern to communicate with them, emphasising the nurses' gaze, presence and touch (Fegran & Helseth, 2009).

Among the participants who revealed the presence and importance of nurses, there was evidence of somehow superficial relationships of little engagement, mainly during the periods of admission. These relationships evolved significantly during the hospital stay. By engaging more closely with the family and NB, nurses provided more emotional support, facilitated information and guided some procedures.

In practice, family Nursing in child health care should be carried out in collaboration and cooperation with families. The collaboration with the family of a NB requires a type of relationship involved in values and ways to solve problems, established jointly by the nurse and the family.

It cannot be said that many education-related expressions were extracted from the reports of parents with hospitalised NBs. The nurses' role in conveying information could indeed be confirmed, which is also in line with the evidence found in another study (Reis et al., 2010). Their role as facilitators and guiders was also expressed by participants. This may refer to a process of education in which parents are provided with information to better care for their hospitalised child (Reis et al., 2010).

Some concerns were also expressed about the sources of support and both their effectiveness, and, insufficient or ineffective response, thus sometimes emphasising their state of loneliness (Silva et al., 2009). Therefore, the most relevant support emerged from within the nuclear family, namely the spouse, *i.e.* the main caregiver, usually the mother, found help and comfort in her spouse - the father. The evidence also showed that grandparents were the extended family's relatives whom parents most resorted to and

assumed to be able to rely on. In view of the above, the conclusion may be drawn that Nursing found guidance for care in the emergence of the concept of therapeutic relationship, which provided a new perspective on human relationships. It is in that sense that such perspective is a key reference in the development of this study.

### **Theme 2 - Humanisation of care**

The construct of humanisation has been increasingly used in the context of health care. As the word itself indicates, humanising means making care and relationships human. Therefore, we may conclude that humanisation lacks a reflection on the values and principles guiding the professional practice, implying a new ethical approach that permeates all professional activities and institutional work processes, in addition to implying the provision of a dignified, supportive and welcoming nursing treatment and care to the nurses' main subject of work, *i.e.* NBs and their parents, who are fragile beings. From this perspective, nurses seem to be increasingly looking for answers to ensure the human dimension of professional relationships, especially those associated with autonomy, justice and the need to respect the person's dignity.

Nurses should take into account the human being as a whole, integrating the relational dimension into their practice as a clear form of humanisation, thus caring for the NB with dignity, a person with his/her own value and a unique and unrepeatable human being, while, simultaneously, providing him/her with possible health gains. If nurses aim at providing Nursing care of excellence, it should be emphasised that they need to profoundly humanise care, in accordance with the provisions of Article 89 (a) of the Code of Ethics for Portuguese Nurses (OE, 2005): "being responsible for the humanisation of nursing care, the nurse has a duty to: while providing care, give attention to the person as a whole and integrated within a family and a community".

The evidence pointed out to the importance of the lack of staff and the resulting significant mobility. In the long term, these aspects may have negative consequences due to work overload and failures at the level of integration that reveal inexperience and mistakes not only in the technical-practical components, but also in the partnership with the patient and family, and in the humanisation, continuity and quality of care (Rolim & Cardoso, 2006).

The intensive care environment was also mentioned in the studies by some participants. Based on their experiences, two distinct themes were found: the technological environment and behaviour in Nursing care.

Although the technological environment at the NICU benefits the biological balance, it is physically and psychologically aggressive to both parents and NBs. NBs have a high risk of developing stress-related behavioural, physical and emotional disorders and the environment at the NICU may significantly contribute to those changes (Harbaugh, Tomlinson, & Kirschbaum, 2004; Rolim & Cardoso, 2006; Trajkovski et al., 2012). One of such harmful interactions referred to the level of noise, light and movement. The NICUs were described as a technological symphony, especially due to the high level of activity, sounds of equipment and alarms, telephones, and professionals' voices. The technological environment was described as unpleasant (Harbaugh et al., 2004; Rolim & Cardoso, 2006; Trajkovski et al., 2012).

### **Theme 3 - Suffering**

Nursing procedures provided to hospitalised NBs often cause pain or discomfort and are, consequently, a cause of suffering and anxiety for parents. This anxiety may be due to a combination of stressful factors inherent in the environment of the NICU, but it also makes us reflect on the suffering which is often expressed by parents during hospitalisation.

Based on the results of the articles analysed, parents' experienced their NB's hospitalisation at NICUs in different ways.

Emotions played an important role in the process of disease and healing. The psychological and emotional experience was strongly focused on several articles and mentioned by participants as negative experiences usually associated with death. Even though death was a common event at NICUs, the threat of and confrontation with such a reality, in addition to the death of others, were a constant presence in the patient's experiences at NICUs (Gale et al., 2004; Rolim & Cardoso, 2006; Silva et al., 2009; Fontoura, Fontenele, Cardoso, & Sherlock, 2011; Merighi et al., 2011; Trajkovski et al., 2012). In this line of thought, participants used metaphors that referred to the reality of death: "I didn't even know if he would survive", "will he get better, will he make it?", "I'm very afraid that he doesn't leave (the Unit)", which

revealed death as a frightening experience (Fontoura et al., 2011).

Situations of terror, anxiety and panic were also mentioned by study participants (Gale et al., 2004; Rolim & Cardoso, 2006; Silva et al., 2009; Fontoura et al., 2011; Merighi et al., 2011; Trajkovski et al., 2012). Complaints, such as panic attacks and anxiety, were strongly associated with such situations of terror and experienced as frightening, thus involving strong emotions that were manifested through expressions such as "I want to die" (Rolim & Cardoso, 2006). Feelings of uncertainty, powerlessness, fear, insecurity (Rolim & Cardoso, 2006; Silva et al., 2009; Fontoura et al., 2011; Merighi et al., 2011), psychological suffering, and a feeling of inability to cope with the situation (Fontoura et al., 2011; Trajkovski et al., 2012) were also mentioned by the parents of NBs admitted to NICUs.

The presence of pain led to a substantial increase in discomfort. Physical suffering and pain were also expressed by participants (Gale et al., 2004; Rolim & Cardoso, 2006; Silva et al., 2009; Fontoura et al., 2011; Merighi et al., 2011; Trajkovski et al., 2012). In another study, in addition to pain, physical sensations such as the presence and removal of the endotracheal tube, presence of chest drains and invasive monitoring lines were also described as painful experiences (Fontoura et al., 2011). In the abovementioned studies, the experiences of parents of NBs undergoing mechanical ventilation were also described as touching and frightening. It was common for the parents of hospitalised children to express feelings of fear, anxiety and frustration. The evidence of another study revealed that those manifestations were minimised when teams considered parents to be key elements in their child's care, parents held information about what to expect, and knew what was expected of them and how they could participate in care (Fontoura et al., 2011).

## Conclusion

The evidence indicated the themes of therapeutic relationship, humanisation of care and suffering as relevant in the care provided to NBs at NICUs and important for the scientific basis of Nursing knowledge. In practice, nurses should hold such knowledge. Through this integrative literature

review, we intended to deepen knowledge and answer the question that guided our research, ensure the relevance of the study, clarify and contextualise its topic, and guide the research design. This study brought us relevant evidence about the Nursing care provided at NICUs, based on the perceptions of nurses and parents of NBs during the period of hospitalisation at the units. However, expectations have not yet been fully explored, thus we believe it to be relevant to further update the research on this topic.

In order to achieve these aims, nine scientific studies were analysed, which were guided by a qualitative paradigm. Based on the literature review conducted, there is a clear divergence in the efforts that have been made to update and humanise Nursing care. The results of these studies showed that although the overall experience of parents of NBs hospitalised at NICUs was negative, their perception of the practice of Nursing care was positive. The first related to death, concern of possible future cognitive or physical changes, discomfort due to the presence of invasive devices in the child, difficulty in sleeping, pain, anxiety, and fear. The evidence expressed by professionals pointed out to the lack of staff and the resulting significant mobility. These aspects may have a negative impact on the technical-practical components, the partnership with the patient and family, and the humanisation, continuity and quality of care. The positive impact was associated with the security provided by the constant presence of nurses. The nurse's role next to the family of the NB was identified at the relationship and education/training levels. The nurses identified the therapeutic relationship through the partnership established with the patient, while respecting his/her skills and enhancing his/her role.

This study contributed to identifying the scientific evidence on Nursing care at NICUs, which enabled us to make recommendations regarding the need for Nursing interventions targeting NBs to involve the parents, thus assuming the NB as a relational being. All of this contributes to building an intervention model to humanise neonatal care.

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