

# Parents' experience during the hospitalisation of the preterm infant

Vivência dos pais durante a hospitalização do recém-nascido prematuro

Experiencia de los padres durante la hospitalización del recién nacido prematuro

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## Abstract

**Theoretical framework:** The birth of preterm infants is increasing and parents are faced with several difficulties and constraints, especially when the premature baby requires hospitalisation.

**Objectives:** To identify the feelings experienced by parents at the anticipated birth of a child and demonstrate the influence of hospitalisation on the adaptation to parenthood.

**Methodology:** Qualitative exploratory-descriptive study, using a non-probability sample of 12 parents whose children had been admitted to neonatal intensive care units. Semi-structured interviews were used and their contents were analysed.

**Results:** Seven categories emerged: Impact of premature birth; Parents' feelings/ emotions; Parenting given the child's hospitalisation; Significant events for parents related to the newborn; Support received by parents; Parents' opinion regarding hospitalisation; and Institutional aspects to be improved.

**Conclusion:** We believe that the results found help us understand the difficulties and meanings attributed to the parents' experience, so as to strengthen measures to humanise the processes of adaptation to illness and promote parenting, thus optimising Nursing care.

**Keywords:** infant, premature; parents; life change events; Nursing care; hospitalization.

## Resumo

**Enquadramento:** Assiste-se ao aumento do nascimento de bebés prematuros e os pais são confrontados com várias dificuldades e constrangimentos, principalmente se o prematuro requer hospitalização.

**Objetivos:** Identificar os sentimentos vivenciados pelos pais perante o nascimento antecipado de um filho; demonstrar a influência da hospitalização na adaptação à parentalidade.

**Metodologia:** Estudo qualitativo, exploratório-descritivo, numa amostra não probabilística constituída por 12 pais que tiveram o filho internado em cuidados intensivos neonatais. Utilizámos a entrevista semiestruturada e efetuámos análise de conteúdo.

**Resultados:** Emergiram sete categorias: Impacto do nascimento prematuro; Sentimentos/ emoções dos pais; Parentalidade face à hospitalização de um filho; Acontecimentos marcantes para os pais relacionados com o recém-nascido; Apoios recebidos pelos pais; Opinião dos pais face à hospitalização; Aspectos institucionais a melhorar.

**Conclusão:** Acreditamos que os resultados nos ajudam a compreender as dificuldades e significados atribuídos à vivência dos pais, no sentido de se fortalecerem medidas de humanização dos processos de adaptação à doença e promoção da parentalidade, otimizando os cuidados de Enfermagem.

**Palavras-chave:** prematuro; pais; acontecimentos que mudam a vida; cuidados de Enfermagem; hospitalização.

## Resumen

**Marco contextual:** Somos testigos del aumento del nacimiento de bebés prematuros y los padres se enfrentan a diversas dificultades y limitaciones, especialmente si el prematuro requiere hospitalización.

**Objetivos:** Identificar los sentimientos experimentados por los padres ante el nacimiento anticipado de un hijo; demostrar la influencia de la hospitalización en la adaptación a la parentalidad.

**Metodología:** Estudio cualitativo, exploratorio y descriptivo en una muestra no probabilística formada por 12 padres que tenían al hijo ingresado en cuidados intensivos neonatales. Se utilizó la entrevista semiestructurada y se realizó un análisis de contenido.

**Resultados:** Surgieron siete categorías, el impacto del nacimiento prematuro; sentimientos/emociones de los padres; parentalidad ante la hospitalización de un hijo; hechos relevantes para los padres relacionados con el recién nacido; apoyos recibidos por los padres; opinión de los padres ante la hospitalización; aspectos institucionales por mejorar.

**Conclusión:** Creemos que los resultados nos ayudan a entender las dificultades y los significados atribuidos a la experiencia de los padres con el fin de reforzar las medidas de humanización de los procesos de adaptación a la enfermedad y la promoción de la parentalidad, optimizando así la atención de enfermería.

**Palabras clave:** prematuro; padres; acontecimientos que cambian la vida; atención de enfermería; hospitalización.

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## Introduction

The birth of a child represents the continuity of the family, and is a moment awaited and desired by parents and relatives. However, when an anticipated birth requiring hospitalisation in neonatal intensive care units occurs, parents experience intense suffering (Centa, Moreira, & Pinto, 2004). Silva (2010) points out that the need for the hospitalisation of premature newborns is common for nurses, but distressing for parents and family members, causing fear of the unknown.

In line with these ideas, Santos, Moraes, Vasconcelos, and Araújo (2007) consider that the premature birth and hospitalisation imposed by the newborn's clinical condition lead parents to experience this phase with anguish and fear. The image of the real child is very different from that of the imagined child, making the adaptation to parenthood difficult. In addition, the physical separation and contact with the hospital environment hamper the development of the emotional bond between parents and the newborn. Within this scope, nurses play a significant role through their practices, providing a greater proximity between parents and the baby and adopting various procedures that facilitate the adaptation to parenthood in the case of prematurity.

As it is an area of care that concerns us, the present study was developed with the following objectives: To identify the feelings experienced by parents at the anticipated birth of a child; To demonstrate the influence of hospitalisation on the adaptation to parenthood.

The purpose of this study is to contribute not only to the reflection on and improvement of procedures that facilitate the adaptation to parenthood in the case of prematurity, but also to the enhancement of the quality of care provided. The nurses' role is to help parents in the transition processes throughout the life cycle, as is the case with the birth of a premature child.

## Background

### Impact of prematurity on parents

Being born premature is a risk that is intrinsic to life and corresponds to an abrupt exit from a cosy and safe environment, the mother's womb, to an aggressive

and new environment, the extra-uterine environment (Santos et al., 2007).

Over time, several authors have shown interest in the study of prematurity and how it interferes with the family structure. Martins, Silva, Aguiar, and Morais (2012) consider that the birth of a baby at risk is characterised as a time of family crisis and vulnerability.

The biological immaturity and vulnerability of these babies have implications in the family adaptation processes and may interfere with the interactive and attachment processes. On the other hand, as a result of extreme prematurity, families face moments of struggle since childbirth, not only by trying to understand the child's diagnosis, but also by being unexpectedly faced with his/her health problems (Arruda & Marcon, 2010).

Thus, the arrival of a premature child creates an extremely stressful and challenging experience for families, which may profoundly change their own dynamics and personal relationships, since parents experience a moment of mourning for their imagined child (Santos et al., 2007).

Silva (2010) also mentioned that, for parents, the idealised child does not correspond to the child who is now before them, *i.e.* a small baby, with many tubes, wires and lights. The neonatal intensive care unit represents a scary environment, where parents are no longer in control.

Carvalho, Araújo, Costa, Brito, and Souza (2009) observed that parents with hospitalised children experience emotions which are translated by fear, anguish, anxiety, and loneliness that alternate with faith, joy and hope.

In the same line of thought, Scarabel (2011) referred that the experience of being a mother following a premature birth is marked by an ambivalence of feelings, particularly the fact that the baby is born with life and being able to touch him/her is good, but it is also *sorrowful* not being able to be with him/her all the time, or take him/her home, having to go to the hospital on a daily basis, and dealing with the anxiety caused by the baby's clinical evolution.

In his study, Inácio (2011) sought to identify and understand the meanings assigned by parents to the hospitalisation of their premature child in the neonatal period. Through a qualitative research study, the author found that *living in uncertainty* was the central category, given that parents considered

hospitalisation to be both a *difficult transition* and a *rewarding experience*. The support of grandparents and the spouse, the relationship of trust with the team, the favourable clinical evolution and the parents' involvement in care are some aspects which facilitated the transition that they had to deal with at the birth of a premature child. However, the fact of having another child to care for, the unit's physical environment, the separation from the child, and the feelings of guilt, fear and sadness were challenging aspects of this transition.

The impact of prematurity on parents is, therefore, reported in different ways and depends on the available support.

Barradas (2008) pointed out that the family support is essential because it may facilitate the parents' stay at the hospital, while their commitments with their other children or daily tasks are still met. The author emphasised the siblings' participation in child care, through their visit to the unit, as it promotes the opportunity to bring the family children closer together, allowing for an affective natural, spontaneous and safe relationship.

Scarabel (2011) mentions that hope, as well as the support from the family and health care team, and the proximity to the child help to cope with the day-to-day life. Bloch, Lequien, and Provasi (2006) ensure that it is imperative for neonatology nurses to help parents experience and face this moment of crisis, as it is a period of personal and family growth. According to Silva (2010), it is the responsibility of neonatology nurses to help parents know, understand and accept their child. Furthermore, it is their responsibility to provide the conditions for parents to be able to care for the child later on, thus establishing with them a partnership of care. In his study, Botêlho (2011) found that health care professionals need to better welcome mothers to minimise the difficulties resulting from hospitalisation and guide them in caring for their babies at home. Traditionally speaking, the maternal figure is still prevalent in some studies, but nowadays the father's role is preponderant in the baby's attachment and development process, not separating itself from the mother/father and child binomial. It is recognised that Nursing plays a significant role by providing a sense of closeness between parents and the baby, thus contributing to relieve the family stress, helping parents adapt to their real child instead of their

imagined child, and mitigating the trauma caused by hospitalisation (Santos et al., 2007). Silva (2010) emphasises the nurses' role in recognising the needs of each newborn/family so as to establish effective measures for the promotion of the parents/baby attachment, prepare parents to welcome their child at home, and plan with each of them an appropriate care plan to promote the continuity of care.

## Research questions

The research questions that guided our research were:

- What experiences influenced the parents during the hospitalisation of their preterm child?
- What were the feelings experienced at the premature birth of a child?
- How did the hospitalisation of the premature child influence their adaptation to parenthood?

## Methodology

Taking into account the concerns that led to the development of this study, the methodological option fits into the qualitative exploratory-descriptive research method of phenomenological nature. Our methodological choice was based on Fortin (2009), who mentioned that the use of the qualitative research method aims at understanding the phenomenon under study from a broad perspective, and on Streubert and Carpenter (2002, p. 20), when the authors stated that "the purpose of phenomenology is to explore the lived experiences of individuals and [that] it provides researchers with the framework for discovering what it is like to live that experience". Therefore, we focused on the parents' testimonies and reports using semi-structured interviews, which were audio recorded and then transcribed and analysed.

For the selection of participants, a non-probability intentional sample was used to obtain answers to the most specific and differentiated questions. For this reason, it was necessary to create inclusion criteria, namely: participants had to be parents of newborns with gestational ages of less than 34 weeks, hospitalised for more than one month, in the period between 2010 and 2012. In order to obtain a wider sample that would allow for data saturation, we

included the births that had occurred in the two years prior to this study, because a reduction in the number of births had been observed with repercussions on the decreasing number of hospitalisations. The study sample was composed of parents who accepted to participate in the study on a voluntary basis: eight mothers and four fathers who attended an outpatient consultation in February, 2013. Permission was granted by the President of the Board of Directors of the hospital, following the favourable opinion of the Ethics Committee. All participants signed an informed consent to participate in the study, after being explained its objectives and guaranteed data anonymity and confidentiality. The interviews took place in a quiet setting, free from disturbance, and lasted 10 minutes on average.

To support the understanding and meaning of data, the content analysis technique was used, based on Amado (2000), Bardin (2009) and some aspects mentioned by Streubert and Carpenter (2002). Thus, as interviews were conducted and prior to their transcription, a code was given to each participant (M1 to M8 for mothers, and F1 to F4 for fathers). Then, each interview was carefully read, and finally re-read to discover the meanings and drawing up of the categories and subcategories that emerged. Each interview was analysed individually, since each included a valid and sustained idea and opinion. At the same time, it was our concern to thoroughly

register the symbols and meanings expressed in both verbal and non-verbal manifestations, in particular between quotation marks and underline blocs of text for the participants' discourse and the suspension points for breaks in speech. Upon the completion of this step, we tried to understand the essential relationships and make a representative drawing of the phenomenon, which was used to guide the data analysis process. To confirm and validate the process, the study participants could have been contacted once again and asked to read the interviews, but since, on the one hand, we perceived a strong emotional load on parents as they relived the birth and hospitalisation of their premature child and, on the other hand, interviews were fully transcribed and what parents said and expressed was totally respected, parents were not further involved at this stage.

## Results and Discussion

The data obtained were based on the parents' experiences and events that marked their lives during the hospitalisation of their premature child. From the content analysis performed on the parents' interviews, seven categories, subcategories and indicators emerged, as may be observed in the following table.

Table 1

*Categories, subcategories and indicators of the parents' experience during the hospitalisation of the preterm infant*

Categories	Subcategories	Indicators (Units of Enumeration)
Impact of premature birth		Restructuring of life/family life (12)
		Physical characteristics of the newborn (10)
		Environment surrounding the newborn (9)
		Milestone in personal/family life (5)
		Vitality of the newborn (2)
Parents' feelings/emotions	Negative feelings/emotions	Fear (16)
		Sadness (13)
		Uncertainty (8)
		Suffering/pain (8)
		Anxiety (6)
		Concern (5)
		Despair/anger (3)
		Impotence (2)
		Guilt (2)
	Positive feelings/emotions	Happiness/ tranquillity (14)
		Hope (2)

Parenting given the child's hospitalisation	Constraints to attachment/relationship (13) Mother/Father and child bond (10) Aspects facilitating the attachment/relationship (9) Development of parenting skills (4)
Significant events for parents related to the newborn	Hemodynamic changes/worsening of the clinical status (7) Returning home with the newborn (5) Communication of bad news (4) Interaction of the newborn with his/her parents (4) Favourable clinical evolution (4) Ponderal growth of the newborn (2)
Support received by parents	Support from professionals (23) Support from relatives (12) Support from other parents and friends (2) Being with the newborn (2)
Parents' opinion regarding hospitalisation	Satisfaction (6)
Institutional aspects to be improved	Physical environment and resources of the Neonatal and Paediatric Intensive Care Unit (6) Outside the Neonatal and Paediatric Intensive Care Unit (4)

## Analysis of the category *per se*:

### Impact of premature birth

The first category *impact of premature birth* revealed that, in their discourses, parents recognised that the birth of a premature child led to the restructuring of family life and constituted a milestone in the personal/family life of those families. The expression used by M6 illustrated this category: "my life was never the same again, nor my family's life (...) Our plans were completely different". In addition, Fraga and Pedro (2004) refer that a whole change occurs in the family following the premature birth, with the existence of a contradictory reality that may hamper the coming together of parents and children. In the same line of thought, Tronchin and Tsunehiro (2005) consider that the birth of a child always brings changes to the personal life and society.

The physical characteristics of the newborn and the surrounding environment were emphasised, because the impact caused on parents, who were not prepared to deal with this reality, was significant. "(...) it had more to do with seeing that little thing there, so tiny, I wasn't expecting it to be so small" (M3, M7, F2).

Santos et al. (2007) also refer that the physical characteristics of the newborn impress the parents, since they are not expecting to find such a small baby and it does not match the expectations created throughout pregnancy, thus impairing the establishment of the affective bond between parents and the baby.

### Parents' feelings/emotions

The expression of feelings/emotions was also clear in the parents' reports and showed how they needed an environment that normalised the families' functioning as much as possible, in a context in which the nurse cared for not only the baby but also the parents. Through the answers given, both negative and positive feelings emerged. There is an ambivalence of feelings in parents, which alternated between negative feelings, as may be seen in the following expressions: "every time I had to enter the unit, I was always afraid of what was going to happen" (M2); "at the beginning, it's that doubt whether the baby will survive or not" (M3, M8); "It's a pain, it's a pain that goes away, but it takes time." (M5); "it seems like we are the ones who failed, it seems that it was our fault (...) I felt that maybe it was my fault that he was born like this" (M4). However, positive feelings were also revealed, as it was clear in the following expressions: "there was some joy also" (M2, M4, M6, M8, F2, F3, F4); "it gave me some tranquillity, I was more calm, it gave me confidence" (F2). These expressions reflect joy and hope, which are so important in times of crisis. Centa et al. (2004) concluded that families with hospitalised premature newborns go through moments of anguish, sadness and fear, which require a humanitarian care practice from Nursing. Carvalho et al. (2009) also found that parents with hospitalised children experience emotions such as fear, anguish, anxiety and loneliness that alternate with faith, happiness and hope.



### Parenting given the child's hospitalisation

With the birth of a child, new roles emerge for both the man and the woman who have just become parents and assumed the parental role. With this new role, a whole readjustment of family life and affective bonds between family members and the new member - the child - is observed. However, in this case, the child appears before the expected time, changing the planning of future parents. Should the birth of the premature baby require hospitalisation, then the return home is delayed and it is understandable that the parental role is compromised. This was portrayed in the *parenting given the child's hospitalisation* category. We observed that hospitalisation interfered with the adaptation to parenthood because it impeded the mother/father and child relationship and bond, as evidenced by this mother: "we couldn't hold, touch, kiss, embrace (...) we couldn't do what other parents with a normal baby could" (M1). Indeed, in the case of an ill child, in a strange environment and exposed to the observation of others, parents have no power over the care provided to their child and feel insecure about it. In the same category, the findings reinforce the nurses' role in this area, particularly in terms of the parents' involvement in care and their preparation to take care of the child at home when we observed that parents underlined the *aspects facilitating the attachment/relationship process and development of parenting skills*. The nurses' role was relevant in bringing parents closer to their child by encouraging them to touch or hold the baby in their arms. M6 referred that "I felt that I had a strong relationship with her because she felt it when she was in my arms and it calmed her down, she liked it and I liked holding her".

The possibility of the mother remaining hospitalised and being closer to the child facilitates the attachment as M7 underlined: "If I had left the hospital and gone home (...) it would have caused a certain distance, it wouldn't have been the same thing as being there and whenever... whenever I missed him or whenever I felt like it, I could be there".

Santos et al. (2007) also observed that the separation between the newborn and the family due to hospitalisation intensifies the parents' feelings.

The touch is another facilitating aspect of the attachment process mentioned by Schmidt, Sassá, Veronez, Higarashi, and Marcon (2012). It is considered important for both parents and the newborn and it

is essential to teach parents when and how to touch their child, so as to promote a pleasant experience. In addition to the safety that it conveys, the touch can become a positive stimulus to develop the attachment between parents and the baby.

### Significant events for parents related to the newborn

In the *significant events for parents related to the newborn* category, and due to the fact that hospital stay was often long, parents recognised that they were affected by the instability of the premature child's clinical evolution. Indeed, while observing the hemodynamic changes, especially when the clinical condition worsened, parents realised the vulnerability of their child and attached importance not only to the skills needed for the interventions that aimed at the fragile and immature newborn, but also to the communication skills, interpersonal relationships and ethical responsibility needed during the transmission of information on the premature child.

Parents' described the meaningful situations as follows:

(...) it was the day after her head surgery (...) her saturation levels were low, very low indeed, I thought she was going to die (...) the stimulus was enough for her to reduce the saturation levels, I wanted to touch her, but I couldn't" (M3);

She was OK, lying there... normal and, suddenly, her saturation levels and heart rate started to drop (...) I saw her turning purple and then the monitor (...) we saw the heart rate, the saturation levels really low and her heart rate was dropping (M6);

"(...) what struck me most was when we got to a point where he started to regress instead of progress, so when there was a downturn in his clinical situation (...)" (F1)

The communication of bad news, which is closely related to the worsening of the clinical situation and diagnosis, was the third most common indicator.

The moment of returning home with the newborn is also a significant event because it is something that is very awaited and desired, as mentioned by participant M1: "discharge is really the most memorable moment". Significant events were also identified by Tronchin and Tsunehiro (2005). For the authors,

negative experiences related to events associated with the baby's health condition during hospital stay and also at home. However, they also experienced positive moments, such as the adequate development of their child and the moment of hospital discharge.

Santos et al. (2007) observed that fear is intensified and relates to the fact that the newborn remains hospitalised, the worsening of the his/her clinical condition, and the presence of risk signs and symptoms, which are all related to the risk of death that influences parents in an intense way.

### Support received by parents

During the child's hospitalisation, parents spend a lot of time at the hospital, leaving their daily lives behind. This experience brings with it major changes and, therefore, they need support. The *support received by parents* was expressed in their discourses, with the support received from health care professionals playing a significant role. Parents also mentioned family support in a positive way; and often considered health professionals as *family* for all the time spent at the unit and the relationship established in extended hospitalisations, such as highlighted in the following expressions: "we end up establishing a friendship (...) it's as if it was family" (M1, M3).

With this support, participants stated that "I felt supported, very supported" (M2, M3, M5, M8) and emphasised that "they always explained things calmly, with affection and attention, it was very good" (M7, M8). It should be noted that they kept good memories: "overall, we were nurtured (...) there were explanations, a special warning, sensitivity to the more difficult moments, (...) I have very good memories" (F2).

Support from family members was highlighted, which was not surprising since family is always very important in these situations, as may be seen: "my sister helped me a lot (...) my mother, my parents, my husband" (M1), "My parents were my main support (...) they gave me the strength to continue" (M2).

The support from other parents and friends was referred to twice and an example was the following: "it helps us if we exchange ideas with the parents of other kids who were/are also in the same situation" (F1).

Gomes, Trindade, and Fidalgo (2009) refer that the spouse is the person from whom women expect to receive more unconditional support. They also expect to receive it from close family members and friends.

However, since the newborn is in a closed unit with visit restrictions, parents feel a lack of support from family and friends, which is mitigated by the support of the spouse and health professionals who keep them informed about their child's health status.

Inácio (2011) found that there is a relationship of trust between parents and professionals that relates to professional skills and is established in such a way that parents rely on the team of professionals. A mother even characterised the professionals as a family, as we found in our study.

### Parents' opinion regarding hospitalisation

In the *parents' opinion regarding hospitalisation* category, we found that, in general, parents were satisfied with the care and services provided at the unit, comparing them to "a five-star hotel" (F1). One of the mothers mentioned: "I think it has everything to be a good team" (M4).

Another mother mentioned the unit's norms regarding visits: "I think I wouldn't change a thing, I think I'd keep it as it is. (...) I thought it was very good for only mother and father to be there at the beginning and, only later, we could bring another person, I totally agree with it because it avoids complications (M3). Another aspect emphasised was "being able to take pictures, I think it's important (...) it helps us to be closer to the baby at home, to look at it" (F2). All these aspects confirm the effort that has been made towards the humanised care of the baby but also the parents.

### Institutional aspects to be improved

The *Institutional aspects to be improved* was another category that parents did not left out and that showed the need to give more attention to the physical environment and material resources of the unit.

In our reality and according to the interviewees' suggestions, it would be important to improve the conditions for rooming-in care so as to provide parents with a pleasant experience and help them adapt to their child. Let us take this interview excerpt as an example: "The mothers' rooms should be closer" (to the unit) (M7) "there should be a separate room just for preterm infants (...) the nurses of the other unit, I think that they also have no preparation, sensitivity to these cases" (when referring to rooming-in care) (F2). The need for a bigger unit aiming at the creation of different spaces was also highlighted. In those areas,

parents could be with their child without having to leave when something happened to another baby in the same room due to the lack of space and conditions to maintain total privacy. F1 mentioned that “it would be desirable to have more space to better accommodate parents (...) the unit is a bit small (...) I just think that the space is a bit too tiny”.

Most data corroborated other mentioned studies and reinforced the importance of considering that the parents of preterm infants live the first days of their small child in an environment in which the adaptation to parenthood is compromised. The tranquillity in the baby’s growth and development is not always as desired, thus the parents felt the need for and valued the support from health care professionals and family members. We believe that the care partnership is emerging, because it not only promotes the parents/child attachment, but also empowers them to take care of their child at home.

We recognise that this study referred to a single unit, which means that we cannot generalise the results to other neonatal units. However, given that it relates to the only unit in the Autonomous Region of Madeira, we may infer that the results obtained are representative of this island.

Considering the richness of the interviewees’ discourses, it was not easy to summarise the information collected and organise it into categories, subcategories and indicators.

Given that the researcher was part of the unit’s health care team where this study was conducted and in order to minimise possible constraints, we decided to interview parents after the discharge of their newborns. We found that mothers verbalised more easily than fathers what they had felt and experienced, which is the reason why most interviews’ excerpts are from mothers.

## Conclusion

Aware of the importance of understanding how parents perceive the experience of hospitalisation of a preterm infant, we conducted this qualitative study to help us identify the feelings experienced by parents towards the preterm birth of a child and demonstrate the influence of hospitalisation in adapting to parenthood. Based on this evidence, we may conclude that the impact of hospitalisation causes ambivalent

feelings/emotions, with a predominance of negative feelings, the parental role is compromised by hospitalisation, parents feel powerless about meeting their newborn’s needs, and significant events for the family life occur as a result of the experience of hospitalisation. These aspects confirm the demand for integral and individualised care in which nurses should adopt the care partnership model.

We believe that the care provided by nurses to these parents will be further enriched with the team sharing and reflection on the findings of this research. It is important for professionals to be prepared to recognise these parents as vulnerable, providing them with safety, affectivity, humanised care and accurate information on the baby’s health status.

On the one hand, we felt that parents appreciated this opportunity to talk about their experiences and, on the other hand, we aimed at expanding the existing perspectives on this experience. In view of this problem, it is possible to conduct further studies to find out other realities and contexts in Portuguese neonatal intensive care units in order to compare results. Furthermore, identifying the nurses’ perception of parents’ experiences is a new area of research that, in our opinion, seems to be relevant and which would help to raise the awareness of health care professionals about this issue. It would also be interesting to assess the training and empowerment process of parents with premature children so as to contribute to strengthening and systematising the actions, attitudes and resources at the unit.

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