

Difficulties of parents with infants admitted to a Neonatal Unit

Dificuldades dos pais com bebés internados numa Unidade de Neonatologia
Dificultades de los padres con niños ingresados en una Unidad de Neonatología

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Abstract

Theoretical framework: Parents with babies admitted to the Neonatology Unit (NU) experience difficulties and health professionals have knowledge of them, as observed by them and shared by parents.

Objectives: To understand the experiences of parents with babies admitted to the NU.

Methodology: An exploratory study, based on semi-structured interviews, during which we tried to identify their difficulties (n = 20).

Results: Difficulties in separating of the baby, high physical and psychological stress, generated by the emotions associated with the severity of the condition and management of numerous requests that parents are subjected throughout the hospital. Financial difficulties in dealing with the environment and procedures of the NU (vulnerability of the baby, technological apparatus, constant monitoring) and take care of the baby without help from professionals when they go home.

Conclusion: The identification of difficulties not only serves the purpose to intervene directly with the parents, seeking their resilience, but also extend the strategies to cope with the clinical condition of the baby, its treatment and hospitalization and/or present suffering.

Keywords: neonatology; parents; newborn.

Resumo

Enquadramento: Os pais com bebés internados na Unidade de Neonatologia (UN) sentem dificuldades e os profissionais de saúde têm conhecimento das mesmas, uma vez que são observadas por estes e partilhadas pelos pais.

Objetivos: Conhecer as vivências dos pais com bebés internados na UN.

Metodologia: Estudo exploratório, baseado em entrevistas semiestruturadas, durante as quais se procurou identificar as suas dificuldades (n = 20).

Resultados: Dificuldades de separação do bebé, elevado desgaste físico e psicológico, gerado pelas emoções associadas à gravidade da situação e gestão das inúmeras solicitações a que os pais estão sujeitos ao longo do internamento. Dificuldades financeiras, em lidar com o ambiente e procedimentos da UN (vulnerabilidade do bebé, aparato tecnológico, monitorização constante) e em cuidar do bebé sem ajuda dos profissionais quando vão para casa.

Conclusão: A identificação das dificuldades serve não meramente o propósito de intervir diretamente junto dos pais, visando a sua superação, mas também o alargar de estratégias para fazer face à condição clínica do bebé, seu tratamento e hospitalização e/ou ao sofrimento presente

Palavras-chave: neonatologia; pais; recém-nascido.

Resumen

Marco contextual: Los padres con bebés ingresados en la Unidad de Neonatología (UN) sienten dificultades, y los profesionales de la salud tienen conocimiento de ellas, según lo observado por estos y compartido por los padres.

Objetivos: Conocer las experiencias de los padres con bebés ingresados en la UN.

Metodología: estudio exploratorio, basado en entrevistas semiestructuradas, en las que se trató de identificar sus dificultades (n = 20).

Resultados: Dificultad en separarse del bebé; elevado desgaste físico y psicológico generado por las emociones asociadas con la gravedad de la situación y la gestión de las numerosas solicitudes a las que los padres están sujetos durante el período de internamiento; dificultades financieras en hacer frente al ambiente y a los procedimientos de la UN (vulnerabilidad del bebé, aparato tecnológico, monitoreo constante) y en cuidar del bebé sin la ayuda de los profesionales cuando se van a casa.

Conclusión: La identificación de las dificultades no solo sirve para intervenir directamente con los padres con el fin de superarlas, sino también para ampliar las estrategias para hacer frente a la condición clínica del bebé, su tratamiento y hospitalización y/o sufrimiento presente.

Palabras clave: neonatología; padres; recién nacido.

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Introduction

The birth of a child is considered one of the most important events in the lives of parents and family (Pires, 2008). It is usually experienced as a source of great satisfaction due to the personal fulfilment it causes, the new meaning assigned to the parents' life, and the proximity it may bring to the couple and family members in general (Pires, 2008). However, it may also be a source of stress due to the demands for the provision of care, and the necessary individual, marital, family and professional reorganisation (Menezes & Lopes, 2007).

When the newborn's clinical status requires hospitalisation in a Neonatal Unit (NU), the associated stress is even greater, and emotions may become intensely painful (Rocha et al., 2011). The infant's hospitalisation in an NU interrupts the attachment process (Pedro, 2007), thus representing an important change/crisis situation for parents. According to several authors, it frequently brings absolutely devastating characteristics for the parents' balance and well-being (Amaral, 2009; Gomes, Trindade, & Fidalgo, 2009; Pedro, 2007; Rocha et al., 2011). Parents have to deal with complex emotions, often beginning to manifest symptoms of anxiety and depression (Miles et al., 2007; Pedro, 2007).

Background

Referring to the couple and the pregnancy process, Pimentel (2007) cites the desire for the baby to be perfect and, simultaneously, the fear that something may be wrong with the baby. The birth of a sick newborn or a very small and fragile premature baby shatters the dream. Parents then initiate the mourning process of the idealised child, which is associated with a range of feelings and emotions: confusion, helplessness, anguish, anger, frustration, rejection of the situation, pain, sadness, fear of loss, and uncertainty and concern about the infant's future (Gronita et al., 2008; Pimentel, 2007). This is until the parents finally accept the situation (Gronita, 2007; Lindberg, 2009).

Within this scope, the parents' adaptation may occur within two extreme feelings. At one end, the feeling of guilt, which is manifested in an exclusive dedication to the baby and may lead to less appropriate forms

of interaction with the rest of the family; and, at the other end, the rejection of the baby (Pimentel, 2007). Authors such as Gronita (2007) and Lindberg and Ohrling (2008) report that these parents' disturbance and emotional lability are closely related to their beliefs about the situation that they are facing; the meaning of a baby at risk; the threats to the baby; and/or their own skills to cope with such a new and distressing situation. The performance of the first services providing support to the child has a decisive influence on the parents' emotional adjustment to the situation and, also, their acceptance of the baby (Gronita, 2007).

Research questions

Several studies have shown the importance of identifying the parents' difficulties during the hospitalisation of their child in a NU (Gomes et al., 2009; Lindberg, 2009; Pedro, 2007; Shields, Young, & McCann, 2008; Soares, Santos, & Gasparino, 2010). Exploring such difficulties allows not only to better understand the parents' behaviour and act accordingly, but also to draw up intervention strategies that best ensure the quality and humanisation of the care provided to newborns and their families (Lindberg, 2009; Pedro, 2007; Soares et al., 2010). Within this intervention, the promotion of these parents' personal resources and the expansion of their range of strategies to cope with the child's illness, diagnosis, treatment, hospitalisation, and suffering emerge as key aspects (Tamez, 2009).

The literature on this topic highlights the research on the parents' difficulties. Some empirical studies suggest that the lack of information (or lack of understanding) on the child's current health status and its implications at the level of survival and/or future development are common difficulties experienced by these parents (Soares et al., 2010). These may be supplemented by difficulties in processing information that is orally conveyed at the moment of admission, given the numerous and intense emotions felt (Lindberg, 2009; Tamez, 2009), or, for example, the overly technical language (inaccessible to parents) used by health professionals (Shields et al., 2008).

With regard to contact with the baby, difficulties may emerge in aspects such as looking at that human being

with such a strange and vulnerable appearance, often surrounded by threatening devices and instruments (Rocha et al., 2011), or recognising and reading the baby's signs (Miles et al., 2007).

At the level of emotional difficulties, strong feelings of anxiety prevail, mainly arising during the early days of the infant's life, as a result of the fear and concern for his/her survival; and the uncertainty in relation to the length of stay in intensive care and/or the necessary medical interventions (Lindberg & Ohrling, 2008; Miles et al., 2007). Subsequently, the feelings of anxiety are associated with fears concerning the baby's health and development and immaturity of growth, as well as the parents' self-assessment of lack of competence to take care of and educate a *more difficult* child (Pedro, 2007; Valente & Seabra-Santos, 2011). In relation to the mother, both fatigue and pain resulting from a sometimes traumatic birth and troubles getting rest and eating are additional difficulties (Amaral, 2009; Lindberg & Ohrling, 2008).

As for emotional expression, several difficulties may also emerge. According to Lindberg (2009), these parents are afraid to verbalise their feelings for fear that their worries become more real.

It is important to bear in mind that the main objective of this study was to identify the difficulties of parents with infants admitted to the NU of a Portuguese hospital, and then suggest some guidelines/interventions for Early Intervention in the various stages of the process: at admission, during hospital stay and in the future (at discharge and in the medium and long-term).

Methodology

This study had the participation of 20 fathers/mothers whose infant(s) had been admitted to the NU of a hospital in Northern Portugal. Of those 12 were mothers and 8 were fathers e a pague o resto que está a cor (12 of whom were couples). The mean age was 32 years: the youngest person was 22 years old and the oldest was 41 years of age. Around 1/3 of these parents (35%) had completed secondary education and only 15% had completed higher education. Their professional area was very diversified, with 45% of individuals working under the heading of artisans and industry and construction workers. The vast majority (80%) was employed and worked full-time when the

study was conducted. With regard to their family situation, 85% of interviewed parents were married. For 60% of interviewees, the baby was their first child, while 35% of respondents had two children.

All 20 participants were included in the study following the convenience sampling method. The inclusion criterion was as follows: fathers/mothers with one (or two) child(ren) hospitalised in the NU.

Data were collected through semi-structured interviews with a script including a total of nine questions. Each interview lasted approximately 30 minutes. Since this was an exploratory study, this was thought to be the most appropriate data collection methodology. During the interview, the objective was to listen to parents explaining their difficulties, concerns and needs; however, in this article, we will only share the difficulties found. Before exploring the participants' experiences, the meaning that each explored dimension had under this study was clarified. Thus, the obstacles, impediments or adversities - of either physical, material, relational or emotional nature - perceived by these fathers/mothers (or couples), and which may cause some suffering, discomfort and/or additional concerns, were considered as difficulties.

In a first stage, the study was subjected to the scrutiny of the ethics committee of the public hospital where it took place. Once authorised, the access of participants was carried out through the shift head nurse or the NU's head nurse. These liaison persons had previously assessed the availability (both physical and emotional) of the parents whose child was hospitalised at the NU at the time of data collection. Each interview was conducted at the venue indicated by the head of service. Its conditions always ensured the participants' privacy and an uninterrupted data collection process. The objectives of the study and its confidential and voluntary nature were previously explained to each participant. All interviews were recorded, upon prior signature of informed consent. Data collection was carried out individually.

During the data collection process, due care was taken to ensure full respect for hospital norms and the health care team's guidelines.

The interviews were then transcribed and their content was analysed. In addition to a qualitative analysis, a quantitative analysis of the results was carried out through the categorisation of responses and record of their frequency. Given the nature of the

data collected, the analysis was conducted using only descriptive statistics (SPSS, version 19.0 for Windows).

Results

Difficulties identified by the parents

The following results should be highlighted:

Financial difficulties - six parents (30%) reported difficulties in coping with the expenses associated with the child's hospitalisation: fuel, tolls, parking, food and parking fines. As regards the future, some of the expected difficulties related to paying rehabilitation therapies.

Difficulties in managing professional life - four parents (20%) pointed out difficulties in managing their professional lives resulting from the fact that their babies were born before they expected, which implied that they had to stop working suddenly, leaving their jobs only half done, this being most frequent among the mothers. In the specific case of the fathers (male figure), the difficulties had to do with ending the paternity leave and returning to work, while anticipating a greater demand in terms of role performance and reconciliation of schedules and routines between two (or three) life contexts: hospital/workplace/home.

Difficulties in managing family life - covering three subcategories of response: (i) management of domestic tasks; (ii) caring for the other child(ren); and (iii) time for the rest of the family (and friends). With regard to domestic chores, the difficulties were identified by four parents (20%) given the large amount of time spent at the hospital. In relation to caring for the other child(ren), three parents (15%) reported the lack of time to properly accompany them, thus being confronted with the dilemma of wanting to be with their child at the NU as much time as possible and, at the same time, not wanting to neglect their older child(ren)'s needs. Finally, one parent (5%) identified difficulties in being with relatives and friends due to the lack of time and increased need for rest after returning home from the hospital.

Difficulties in communicating with the health care team - nine interviewed parents (45%) stressed difficulties of communication with the health care team, which were divided into four distinct subcategories: (i) low availability of physicians to talk

with parents (n=2); (ii) difficulty in understanding the language used by health care professionals (n=3); (iii) lack/deficiency or delay of conveyed information (n=2); and, (iv) incongruence of conveyed information (n=2). As regards the timings or amount of information, two parents emphasised the difficulties encountered as a result of the lack of information regarding the situation of the baby or the mother. Concerning the quality of the conveyed information, the difficulties related to the complexity of the language used by health care professionals, thus becoming difficult for parents to understand as well as convey it to others. Two other parents stressed that health care professionals were *little communicative* or provided few information, being perceived as insufficient to meet their needs. The difficulties associated with *misinformation* were mentioned by the same number of individuals (n=2). They resulted essentially from the fact that the child was being accompanied by several professionals, who did not always convey consistent information.

Lack of rest - eight interviewed parents (40%) reported difficulties in resting (five of whom were mothers), as a result of the noise in the midwifery wards during the hospitalisation period in the first days after birth. The same difficulties were referred to by other parents who were already at home: thinking about the baby admitted to the NU, the routines that should be taking place, and whether the baby was alright. Approximately 1/3 of the interviewed parents (35%) reported fatigue as a difficulty, particularly due to the need to respect the rules/schedules of the NU and their willingness to participate in the babies' routines every three hours. Other reasons identified as a source of the fatigue experienced were the fact that mothers had to wake up during the night to pump and the fatigue that resulted from travelling to and from the hospital.

The mother's hospitalisation in the midwifery ward - 25% of the parents mentioned difficulties associated with the mother's stay in the midwifery ward after the baby was admitted to the NU. For those parents (both mothers and fathers), the fact that the mothers had to stay near other mothers who were next to their children was experienced with major difficulty.

Separation from the baby - almost half of the parents (n=9, 45%) reported difficulties inherent in the physical separation from the baby, both when the

child was hospitalised in the NU and the mother was in the midwifery ward, and when the mother had already been discharged and the baby remained hospitalised. Situations were also reported in which, after both had been discharged, babies had to be readmitted to the NU and parents had to return home without their children.

Confrontation with an unexpected reality - 40% of the parents (n=8) mentioned this difficulty. Three of them said that they were not prepared for what was going to happen, while three other parents attributed these difficulties to the fact that they were not psychologically prepared (given the unexpected nature of the situation) to see their child hospitalised in an NU, in some cases, involving a life-threatening situation and/or the continuous monitoring of the child's vital signs. Two parents also mentioned that the difficulties in dealing with this new reality were due to the fact that they had other plans/expectations, namely in relation to the type of delivery or the child's feeding (desire to breastfeed right from the beginning), which ended up being frustrated by the baby's increased vulnerability. For other parents, the ruin of pre-natal plans resulted in postponing their return home and the integration of the new family member in the spaces (and relationships - e.g. brothers) awaiting the child.

Dealing with the possibility of losing the son - a difficulty mentioned by five parents (25%). The fear of losing the baby, the uncertainty of the prognosis, and the anguish at the possibility that this phase of greater vulnerability could not be overcome were part of their repertoire of difficulties.

Adaptation to the environment of a NU - a difficulty mentioned by 35% of parents (n=7). For three of those parents, it arose from the fragile, vulnerable and dependent appearance of babies admitted to the NU (as a result of devices), in particular their children. Adapting to the NU routines, rules and/or procedures (e.g. having to use coats, washing their hands, and the fact that only the parents' visits were allowed) was also mentioned. Ringing alarms, the fear of touching the baby and pulling a tube or a wire, and seeing nurses give an injection to the baby were all examples of situations which created difficulties for parents, mainly arising from the idea that the baby might be suffering and/or in a situation of great risk. Finally, among the difficulties in adapting to the NU environment, two parents mentioned the NU rules,

particularly the fact that grandparents/relatives were not allowed to visit.

Difficulty in dealing with the baby's slow progress - it was also raised by one of the interviewed parents.

Emotional difficulties - within the emotional sphere, the difficulties (80% of parents, n=16) related to, in eight cases (40%), managing the multiplicity and intensity of emotions. For example, anxiety and distress towards the diagnosis; concern for their children's current and future well-being; and the fear of baby loss or relapse illustrated the *swirl* of emotions present at the time of the baby's hospitalisation or at several other moments during the hospitalisation process. According to the parents, in cases in which the baby was ill and his/her health status was not yet stable, their anxiety was lived in a particularly intense way. An evident difficulty among these parents took place when the baby was discharged and then had to go back to intensive care. Loneliness and/or isolation associated with this process, by the lack of interlocutors (including their own spouse, whom they tried to spare as much as possible) or by the difficulty in talking openly about the topic and/or managing the emotions and pressures triggered by this process were also raised by three parents. Two participants mentioned difficulties in contacting with other people, including family and friends, given the emotional pressure generated by them to get an update, even when nothing had changed. Five parents (25%) highlighted difficulties in accepting the new reality. Three of them mentioned difficulties regarding the cognitive processing of information conveyed by health care professionals, due to the *blockage* triggered by the confrontation with the baby's health problem, unexpected in these cases. Two mothers pointed out feelings of guilt associated with the baby's current health problems, as a result of behaviours which they considered to have been harmful to the child's health and intrauterine development.

Logistical difficulties - eight parents (40%) underlined these difficulties - (i) for three of them, they arose from the daily commuting home-hospital-home, particularly in cases in which they lived further away from the hospital, and/or the need to, at times, walk long distances on foot to avoid paying for parking; (ii) four parents mentioned the access to the NU (e.g. more limited access on weekends and public holidays), and, finally, (iii) one father mentioned

difficulties in quickly taking care of documents related to the mother's medical and maternity leaves at the Social Security services.

Difficulties related to the visits of relatives - one parent referred to the management of visits in the early days, as a result of the need to avoid risks of infection for the baby. Two parents considered that the extended family's expectations and pressures to meet the new member were anticipated as sources of additional difficulties.

Difficulties related to child care - three parents anticipated the difficulty in taking on those functions autonomously, after returning home, for the following reasons: fear of relapse; lack of help from health care professionals and devices to monitor the baby's vital signs; and/or lack of immediate information in response to questions that could emerge during care provision. A feeling of insecurity or incompetence to take care of the baby was also anticipated by two parents.

Discussion

The early days of a baby's life in such an artificial and strange environment as that of a NU is difficult and problematic for all parties involved, in particular for parents, who, throughout the process, experience a number of difficulties which this study has made evident, consistently with other investments in this area (Amaral, 2009; Gomes et al., 2009; Lindberg, 2009; Pedro, 2007; Soares et al., 2010). Just as it was possible to confirm through the interviewed parents' statements, which were then systemised and categorised, and the review of the literature in this area, the admission of an infant to a NU may have a significant impact not only on his/her development and well-being, but also on the parents' self-confidence and their ability to take on their parental role. It may also pose a risk for parents-baby attachment relationships; the parents' mental health and/or the family dynamics (Menezes & Lopez, 2007; Pal et al., 2008; Pedro, 2007; Valente & Seabra-Santos, 2011). Therefore, at issue are not only the quality of the experiences (very intense, painful and, sometimes, *shattering*) associated with a specific life stage of these parents - their baby's hospitalisation in the NU - but also the quality of the established attachment relationships and lived parenthood, and

the development, (physical and psychological) well-being and life journey of these children and each member of their nuclear family at the short, medium and long term.

In view of the (empirical and theoretical) scenario portrayed throughout this article, it seems clear that there is an urgent need for complementary interventions to support these parents and families, sustained on the previous mapping of their more pressing difficulties and the subsequent design of appropriate responses. The identification of difficulties, either through the parents or health care professionals who closely monitor these processes, serves the purpose of intervening directly with parents in order to overcome the difficulties found. This will be possible through the promotion of their personal resources, development of positive attitudes, greater autonomy, self-confidence to take on the responsibility of caring for the baby (who will soon be entirely to their care), and development of new strategies to cope with the baby's clinical condition, treatment, hospitalisation and/or current suffering (Gronita, 2007; Pedro, 2007). The joint pursuit of adaptive responses (starting from the family's own attributes and resources); the changes in the meanings associated with the present situation; or the promotion of these parents' role as facilitators of processes inherent to their children emerge as central aspects in this process (Gronita et al., 2008; Mendes & Martins, 2012; Pedro, 2007). Also in this process, the figure of the health care professional, namely the nurse, who deals closely with these parents, and the quality of communication established between them both are essential (Amaral, 2009; Baltazar, Gomes, & Cardoso, 2010; Mendes & Martins, 2012) not only during the hospitalisation period at the NU, but also in later stages, with a long-lasting impact (Gronita et al., 2008).

Having said that, within the scope of family-centred care and aiming at encompassing the different steps of an infant's admission process to the NU (before the delivery, during the delivery, postpartum, at admission to the NU, during the hospitalisation period, and preparation for discharge), the creation of moments of dialogue and timely clarification with parents about the present situation is considered a priority and should be a reality from pregnancy until hospital discharge (Pedro, 2007; Pimentel, 2007). In cases of high-risk pregnancies, for example, in which there is

a possibility for the child to be delivered before the expected due date or born with some type of problem that requires hospitalisation at a NU, this seems to be an urgent need (Amaral, 2009; Pimentel, 2007). One of the measures to be considered in some of these cases could be taking parents on a visit to the NU, aiming at preparing them for the most likely scenario that they will directly experience during the birth of their child(ren) (Tamez, 2009). Informing parents about the evolution of labour may also contribute to developing their confidence and will give them hope, thus also helping them to reduce stress (Tamez, 2009). The risks of this approach should, however, be duly weighted given the major distress and anxiety that they may trigger among parents.

After the baby is born and admitted to the NU, special attention should be given to the parents' first visit. In that sense, it is essential that health care professionals, particularly nurses, create a safe and welcoming environment to help parents feel that they are welcome and an active part of the team that will take care of their baby. Availability, empathy, serenity and security in the adopted posture fall within the relational environment that should be created since the first visit. Conditions should also be created within this environment for parents to feel that the professionals taking care of their baby are *fighting* for the same goal; that they are doing their best - even if, sometimes, they have no absolute certainties - and that they are *on the parents' side* (Pedro, 2007; Tamez, 2009).

At this stage, it is also essential to have clear information on what is happening and the treatment plan, thus giving some additional security to parents and/or reducing the amount of stress experienced (Pedro, 2007). It is suggested that such information (the most important one) be presented in writing in a small book that parents may carry around and read whenever they wish and that it be conveyed in a phased and progressive manner. Equal care should be taken to create the necessary conditions to ensure that the information can be repeated and explained in different ways to parents, if requested. Some of these measures aim at addressing, on the one hand, the evidence that, during the first few days, parents forget about 90% of the factual information received (Tamez, 2009) and, on the other hand, the importance of its actual understanding for a more active participation in child care and quicker use of more adaptive coping

strategies, which are adjusted to the ongoing process (Pedro, 2007).

An environment of trust, safety and protection may also facilitate some experiences of sharing and emotional ventilation. In that case, psychologists play an obviously important role (Baltazar et al., 2010). However, considering that nurses establish a very close relationship with some parents or the fact that the institution may not have a psychologist or one may not be available, nurses may often emerge as a major figure of reference and support (Amaral, 2009). Arranging for meetings with other parents who have experienced a similar situation may also be relevant (Pedro, 2007). The exchange of experiences between parents contributes, among other things, to destroy fears, clarify doubts, *normalise* their experiences and, consequently, increase security and improve confidence (Tamez, 2009). In addition, the creation of a parents' room that allows them to get together, where testimonies of preterm or ill babies may also be given, with photos of the hospitalisation period, birthdays and various activities in which children participated in the course of their development, may provide parents with the possibility to design a life project for their child.

Regarding the interaction with the baby, while he/she is still very small and immature and handling him/her is necessarily restricted, nurses may help parents to use the time spent at the NU to get to know their child, learning how to interpret signs of stress and the different behavioural states; know his/her containment and comfort positions; and enhance the discovery of their child's unique characteristics and his/her small progress (almost invisible to a more distant look) (Amaral, 2009; Pedro, 2007). This is also a way to promote an attachment relationship between the parents and the baby, as well as stimulate hope and a feeling of competence in parents (Pedro, 2007; Pimentel, 2007). When the baby is more stable, parents may be encouraged to discover how the child reacts to tactile stimulation, to the parents' voice (through *conversations* or songs), and, for example, when he/she is rocked to sleep (Pimentel, 2007; Tamez, 2009).

So that, at the moment of hospital discharge, parents are able to care for their child at home effectively and safely, the planning and teaching of care must be designed/carried out in advance (Tamez, 2009). Bearing in mind that these parents leave the hospital

with a set of meanings which are more or less realistic, rigid and open to new information and experiences, it seems extremely important to us that all these issues be addressed before discharge. In fact, several authors recommend that the preparation of discharge starts right at admission (Amaral, 2009; Lindberg, 2009; Valente & Seabra-Santos, 2011). Thus, the involvement of parents in the newborn's basic care should be facilitated and encouraged from the very beginning (or as soon as possible), so that they quickly feel more confident in their skills to care for their baby and an integral part of the treatment and recovery processes (Pimentel, 2007). Parents who have the opportunity to interact and care for their babies at the NU are better equipped to care for them after discharge and, are, therefore, more likely to achieve a successful transition from the NU to their homes (Lindberg, 2009; Pedro, 2007; Valente & Seabra-Santos, 2011).

Conclusion

In line with the previously mentioned points, which summarise not only what some authors postulate in this area, but also what we believe to be the most appropriate approach for (and with) families with babies hospitalised at a NU, our aim was to present some suggestions for intervention. Not only do these suggestions compile and synthesise some proposals of other authors who have also been working on the issue (at the research and intervention levels), but they also try to meet the difficulties that were identified by the group of parents who participated in this study. Therefore, their discourse/testimony made it possible to know more about a reality which, given its richness, complexity and intensity, deserves much of our attention and concern for dissemination and intervention.

As a result of the investment of the overall study - identification of parents' needs, problems and concerns - and in agreement with the proposed interventions, we also designed a preliminary version of an instrument that sought to compile the concerns, difficulties and needs which, according to the review of the literature on the topic and the testimonies collected, seemed to represent the most significant aspects of these parents' experiential repertoire: the *Questionário*

de preocupações, dificuldades e necessidades dos pais de bebés internados numa Unidade de Neonatologia (Questionnaire of concerns, difficulties and needs of parents with infants admitted to a Neonatal Unit).

We hope that, in some way, the proposed instrument, which has not yet been subjected to a process of psychometric validation, may contribute not only to mapping some of the experiences that make these parents more fragile, but also to designing appropriate responses. It is hoped that it may also function as a preliminary way to intervene with these parents.

This study has some limitations and constraints, which relate to the data collection process. We soon realised that interviewing fathers and mothers simultaneously could lead to a certain *contamination* in the sharing of experiences or to one of the parents stop sharing because his/her companion had already given his/her opinion. As regards health care professionals, eight of them were interviewed at the same time, due to the difficulty in reconciling schedules and aiming at not disrupting the NU's functioning. Finally, despite the high number of participants, we had to take into account that we did not interview the same number of mothers/fathers (more mothers were interviewed than fathers), nor the same number of physicians/nurses (more nurses were interviewed than physicians). This disparity led to a more thorough analysis of the data collected.

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