

Emotional support for parents with premature children admitted to a neonatal intensive care unit: a qualitative phenomenological study

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ABSTRACT

Background and objectives. Parents who have a premature child in neonatal intensive care units (NICUs) are in a stressful situation. The aim of this paper is to analyze the emotional support received by parents with premature children admitted to NICUs.

Methods. A phenomenological qualitative study with an explanatory and interpretative approach was employed.

Results. The findings are: 1) The experience and emotions of a premature delivery; showing sadness, guilt and despair, stress, anxiety, and uncertainty over the future of their child. 2) The emotional support received by the father/mother of the partner; discussion of how their partner is cared for, as well as the care given to the premature child and other children in the family; the stress that this causes them on not being able visit all at once. 3) The emotional support offered by the health professionals (doctors, nurses, etc.); parents indicate that they have received very strong support from the nurses, but also that they were not always asked about their feelings when in the NICU. 4) The informal emotional support of relatives and parents in the NICU. After talking with other *support mothers*, the mothers then felt less guilty.

Conclusion. As regards premature birth, the mothers showed feelings of sadness and guilt, asked themselves where they had failed and what they had done wrong.

Key words: premature infant, low birth weight, emotional support, NICU, qualitative research.

Premature birth is that which occurs before week 37 of gestation or before 259 days counting from the first day of the last menstruation¹, or as other authors indicate, before the organs are sufficiently mature to permit normal post-natal survival.² Premature birth is a crisis process for mothers. In 2000, Caplan et al.³ found feelings of anticipated grief in these mothers as well as a sense of failure associated with the birth of the baby before full term.

Stressful situations described in the literature to which parents may be subjected are diverse. The birth of a premature child can lead to a strong imbalance of roles, which may subsequently give rise to a situational crisis.⁴⁻⁶ When a baby is admitted to a Neonatal Intensive Care Unit (NICU), this can be a very stressful moment for the parents, for whom the main concern is the diagnosis and prognosis of their child.⁶ Additional to this is the fear of not being able to be with the baby, as well as the disconcerting factor of the advanced technology and the general environment in the NICU itself.⁴ In these units, health professionals focus their attention on the care of the patient, in many

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cases ignoring the other family members.⁷

It should be remembered that the parents can be on an emotional roller-coaster, where the birth of the baby is presented as something surprising and unexpected, for which they were not prepared.⁸

Other stressors can be added to the experience of premature birth, such as the separation from contacts and friendships, loss of intimacy present in the home, in addition to conflict between couples that can end up in separation or divorce.⁹

In view of all this, emotional support is as a key factor in promoting an adaptive approach for mothers and fathers when faced with the birth of a premature child. On the other hand, the complex interactions among issues such as prematurity and paternity, the stressful nature of the environment, and personal circumstances give rise to a wide range of emotional responses.¹⁰

Several sources of emotional support to parents are described, among them, that of the nurses of the unit. In this respect, the majority of parents in the study by O'Brien et al.⁶, reported having received a high level of support from the nurses in the Irish NICU. However, emotional support scored lowest in the functional support provided by the neonatal nursing staff. An important part of nurses' responsibility is to provide support to parents. After observing their child's condition, parents often start seeking hope and feel anxious when encouraging comments from nurses and doctors are not forthcoming; in this context, a sense of desperation is one of the most stressful factors reported by most parents, since any glimmer of hope provides them with the emotional strength to continue the struggle.⁵

The family-centered care of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) has in current times changed its aims towards ensuring a quality paradigm focusing on the means of promoting family well-being and on parents' participation from the birth of the child.⁸

Family-centered care in the NICU entails the active participation of both parents in the daily care of the premature newborn.^{8,11} Its basic principles are dignity and respect, and sharing information¹¹ This philosophy of care should therefore facilitate the establishment of individualized patient attention, meaning that the mother and father feel more secure, reducing anxiety by establishing a therapeutic relationship with the nursing team.¹²

Another source of emotional support is from other parents with premature infants admitted to the unit. These parents-friends (peers) are an aid for promoting an adaptive approach on the part of the parents. Mothers from a culture other than the prevailing one are often geographically distant from their own parents and members of their extended family. However, even when social support was available in their own language, mothers often experienced a feeling of failure, isolation, and a lack of understanding on the part of family and friends to whom they normally feel close. Instead of this usual support network, such mothers tend to talk with fathers-mothers-friends who have already had similar experiences to their own.¹⁰

We aimed to analyze the emotional support received by the parents with premature children admitted into the Neonatal Intensive Care Unit (NICU).

Material and Methods

Design

We present a phenomenological qualitative study having an explanatory and interpretative approach. It aims to determine the sources of emotional support for parents of premature infants and the importance that these parents give to such sources. It facilitates the study of the phenomena in the natural context in which they are produced and to understand the corresponding social reality by sharing and interpreting the importance of the individuals involved.¹³ The study sees the individual as integrated within the environment; the

individual is the only source of information for responding to the question posed. In the study that concerns us here, this individual is the mother and father of the premature baby.¹⁴

Participating population

The participants were the mothers and fathers of premature infants admitted into the NICU.

Inclusion criteria:

- Fathers/ mothers of infants admitted into the NICU.
- Speakers of Spanish or Catalan (or else understand one or both).

Exclusion criteria:

- Parents with cognitive or behavioral disorders
- Mothers admitted for causes other than childbirth
- Denial of consent to record their voice during the interview.

The sample was theoretical, non-probabilistic, intentional and reasonable. Sample units were chosen on the basis of the representation of discourse variability. Individuals capable of providing a good response to the study questions were looked for, as well as the

possibility that they were familiar with the study phenomena. To this end, a decision tree was drawn up providing those profiles that a priori would be explored (Fig.1).

It was additionally considered that the sample would be accumulative and sequential, that is to say, the sampling ended with the saturation of data, as well as flexible, circular and reflexive, meaning that the sampling decision could lead to the discovery of new aspects that would need to be studied, or in order to ascertain whether distinct informants were more suitable.

The sampling was performed through a recruiter, who was provided with the characteristics required of the informant.

Data collection

Data were collected between April 2016 and February 2018. Data collection was carried out by nurses working in the NICU who are also researchers in this study, collecting data from informants whose children were not awarded to these professional’s care collaborators working in the NICU, collecting data from the informants whose children were not awarded to these workers’ care.

The interview used was in depth, semi-structured and individual, with a script of the

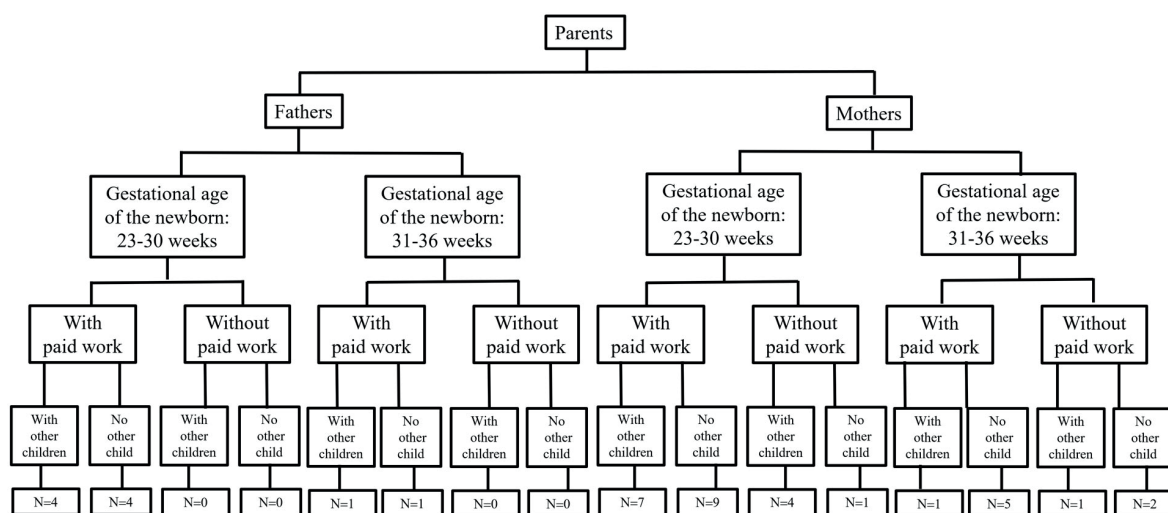


Fig. 1. Decision tree showing the profiles examined and the number of participants in each subgroup.

basic aspects to explore, open, and focused on the aims of the study. A pilot interview was previously carried out with a mother, the results of which have not been included in this study. The interview script evolved as the interviews were carried out and as the data analysis from these interviews was undertaken, thus shaping the content of all subsequent interviews. They were carried out in a setting that was private, had good lighting conditions and was free from noise and other interruptions. The nursing office of the NICU was made available for this purpose. The interview lasted about 60 minutes. The investigator had a notebook in which his/her observations and impressions during the interview were recorded.

There was a total number of 40 interviews, of which 10 were with men and 30 with women. The profile of men without paid work was not left pending further research as it was not possible to find fathers that fulfilled these characteristics.

The data collection was deemed to be terminated when there was saturation of information, that is to say, when the interviews with new parents did not provide data different to that already collected.

Data analysis

Data analysis was performed at the same time as collection. The interviews were recorded in audio and were transcribed literally, after which they were returned to the participants for them to read, confirm or rectify anything that did not reflect their experiences.

Following receipt of the source documents, these were protected by removing all elements that could identify the participants and other individuals that appeared in the conversation, and by assigning fictitious names to the participants (maintaining gender).

Subsequently, the transcriptions were analyzed, first, by reading the text repeatedly so that the investigator became familiar with the conversation, preparing pre-analytical

intuitions and coding the findings that appeared in the interviews that were then grouped into categories and families. Once finalized, an explanatory framework was created, and the findings of the analysis were contrasted with the original data.

As an aid to analysis the Atlas Ti 6.2 computer program was used.

With the aim of increasing the validity and consistency of the results obtained, a triangulation was performed by the investigators and specialists. The data were analyzed independently by two investigators not connected to the NICU in order to subsequently reach a consensus on the findings. The findings were then presented to specialists for their validation (Table I).

Ethical and legal aspects

Permission to conduct the study was requested from the Neonatology Unit. The study was approved by the Ethics Committee of the Vall d'Hebron Research Institute, Barcelona, Spain. PR(AMI) 342/2015.

An informative document was written for the participating parents. Informed consent was requested prior to the data collection, and are available to those who require them. The transcriptions were stored electronically and password protected; access to these documents was exclusive to the research team.

Participants were informed of the relevant data that had been obtained during the course of the study. This information has been communicated to those that expressed a wish to have it; in the case of preferring not to be informed, this decision was respected.

Results

The field work was carried out in the Neonatal Intensive Care Unit (NICU) of the Hospital Universitario Vall d'Hebron, Barcelona, Spain, which is a third-level, high-technology hospital.¹⁵ The Neonatal Unit has 25 critical

Table I. Guba Rigor Criteria based on Pla M, 1999 (reference: 14).

Criteria	Description	Procedures
Credibility	True value of an investigation to the extent that it may be credible	Data collection technique is explicit Extensive and intensive observations are made The data are triangulated by investigators and experts Feedback is obtained from the informants The collections of data and the analysis are concomitant The data are presented with examples (verbatim)
Transferability	Degree in which the discoveries of the investigation can be applied to other subjects or contexts	Profiles to explore are prepared in order to ensure the homogeneity and heterogeneity of the sample The sample is described (see Table I, sociodemographic aspects)
Dependency or consistency	Stability of the data	The status and the role of the investigators are described The physical, social and interpersonal context of the informants are described Information collection techniques are described
Confirmability	Makes reference to the neutrality	Particular registers are collected, textual transcriptions and direct quotes are made The suppositions are checked with the participants The information is collected by direct recording The position of the investigator is explained

beds, 20 semi-critical beds, and 24 basic-care beds. There were 970 admissions in this unit throughout 2017. This NICU is an open unit, allowing 24/7 access to the parents of the babies admitted. Parents of diverse nationalities and ethnic groups, as well as different academic profiles, were interviewed. The characteristics of the participants are shown in Table II. An elevated mean age was observed in both the fathers (38.8 years) and in the mothers (35.05 years).

The present study shows distinct categories and families: 1) the experience and emotions of a premature delivery; 2) the emotional support received by the father/mother of the spouse in the event of a premature delivery, and that offered by their spouse/partner; 3) the emotional support offered by the health professionals (doctors, nurses, etc.); 4) the informal emotional support offered by relatives and other fathers/mothers in the NICU undergoing the same situation. The emerging category 'emotional distance' appears throughout this study. The

informed consent was signed both by the informant and the researcher before recording the interview.

The experience and emotions of a premature delivery

Regarding the event of a premature birth, participants experienced feelings of sadness and guilt (parents of the newborn), as well as disappointment and anxiety for not having achieved a full-term pregnancy (mothers).

Cristina (aged 37), explains her experiences and opinions in the following way:

"She was very small; just when you start to see something more of the pregnancy... I've got a bigger tummy and then suddenly... it's not there. Other mums say: "I just can't wait any longer for this baby! I'm so heavy, everything's a real pain"...I didn't have the time to feel like this...it's like when you have something and then they take it away from you. It's taken for granted that it should be super-nice and super-happy, but this is more like a wake,

Table II. Sociodemographic data of the participating parents.

Mothers (n=30)	Fathers (n=10)
Mean age: 35.05 years	Mean age: 38.8 years
20-29 years, n=5	20-29 years, n=1
30-39 years, n=17	30-39 years, n=5
40-49 years, n=8	40-49 years, n=3
50-59 years, n=0	50-59 years, n=1
Nationality	Nationality
Spanish, n=24	Spanish, n=9
Romanian, n=2	Ecuadorean, n=1
Pakistani, n=1	
Ecuadorean, n=1	
Moroccan, n=1	
Uruguayan, n=1	
Ethnicity	Ethnicity
Caucasian, n=25	Caucasian, n=9
Muslim, n=2	South American, n=1
South American, n=2	
Gypsy, n=1	
Births	Births
Twins, n=8	Twins, n=2
Single, n=22	Single, n=8
Level of studies	Level of studies
Primary, n=5	Primary, n=1
Secondary, n=11	Secondary, n=5
University, n=14	University, n= 4
Duration of gestation	Duration of gestation
23- 30 weeks, n=21	23- 30 weeks, n=8
31-36 weeks, n=9	31-36 weeks, n=2
Work situation	Work situation
Active paid work, n=22	Active paid work, n=10
Without paid work, n=8	Without paid work, n=0
Number of children	Number of children
Have 1 child, n=17	Have 1 child, n=5
Have more than 1 child, n=13	Have more than 1 child, n=5

or a feeling of sadness, of guilt...I wasn't up to the demands of the delivery, or the birth of a child at full-term... It doesn't even have a name, my poor little thing"

Emma (aged 43) explains her experience of the premature delivery of a twin pregnancy:

"I'd already thought about prematurity... I said, well, just hang on until week 29 or 30, to the end

of December or the beginning of January. I was expecting to have two premature babies but nothing so extreme, week 25. It was a real shock to be operated on for this... 'Save my children', that was the only thing that interested me, I wasn't worried that that my blood pressure was high, nothing bothered me". Just that fear, the fear that they wouldn't survive".

In the account given by some of the participants, because an explanation for the premature

delivery is not available, this lack is attributed to God's will.

Rafaela (aged 36) explains her experience of pregnancy by insemination and her premature delivery in the following way:

"God knows why it has happened, why it had to be born this way. Of course, you end up saying; "if it had been two or three months more inside me, this would not have happened. It's... well, you've gone and left your heart there. I thought that when the artificial insemination was carried out, I might have had a miscarriage in the first few months, but this didn't happen. What actually happened never ever came into my mind before; it was only later that I learned about artificial insemination being one of the causes of pre-eclampsia".

Maria (aged 30) explains her pregnancy and her daughter's premature birth. Other cultures also reveal the same feelings of guilt by the mother for not having made things better for the baby during pregnancy, and because of the premature delivery itself.

"Really, I just don't know what happened, I think that it was my fault, I was very stressed in the last 3-4 months because of things at home, family things... One day I wanted to quit work, nobody understood me. I told them I wanted to quit work and they told me, OK, do what you want, but in reality they wanted me to continue working. In the previous pregnancy I did not look after myself, I didn't know how to, but in this one, I looked after myself very well, my husband has always made lunch, dinner, for me, he gave me fruit, because my husband knew that the other child was born with low weight, and wanted the daughter to be born safely (...). I know my husband says that it's not my fault; but I know that it's all down to me, because I didn't do things right, I worked, did work around the house, I put on weight...I called my husband and told him to come quickly, I was very scared: she's very small, I don't know what's going to happen, I don't know if she'll make it, don't know what's going to happen. I was crying, praying, I was in surgery for 3-4 hours. I just don't know what is going to happen..."

Oriol (aged 29), talks about his partner's pregnancy and his daughter's premature birth:

"You're worried about what might happen, the first 4-5 hours are very important, their first seconds, how to react... well, yes, the NICU is quite impressive, because it's a unit that, I mean, listen, things are more serious in here and especially it's like how my wife said, I can't do anything. You feel impotent on not being to do anything. It's all new, I don't know how to react. We are first-time parents, we have to take it all in...at first it was a shock, not severe, very severe, very sudden and very bad...We have to move forward".

Gloria (aged 42) explains her pregnancy and the premature delivery of her twin daughters, as well as her feelings of guilt.

"I felt guilty, it might have been my age that influenced thing, but here, there's a lot of young people in the same situation as us, so if it happens to you, it just happens and that's that..."

Emotional distance

In our study, some mothers and fathers explain situations that we identify as emotional distance. Emotional distance can be defined, in the case that concerns us here, as a distant view taken with regard to the current problem, that is to say, after the birth of the premature baby and its admission into the NICU. This emotional distance leads to a situation in which the parents do not feel as if they were the parents of their newborn child and, consequently, delegate the care and attention of their baby to professionals, showing ambivalent feelings about the new situation.

Cristina (aged 37) explains the emotional distance she felt towards her daughter.

"You feel any connection, but it's your baby...yes, I see her more as a person that you need to bring up, I don't have this baby feeling, all cuddles and baby-talk... I see her more like just a person".

Gloria (aged 42), explains the emotional distance with her daughters.

"There is like a kind of, like a...an emptiness inside, no? There is like a kind of distance. Whereas you say it's mine, of course...that as long as you do not touch it and let a few days or hours pass by, well... The connection, that these are my own daughters, really is present, of course. But I'm not sure what to think. Can they survive, so small? That's what I think... it's what was in my head at that time".

Rafaela (aged 36), explains her emotional roller-coaster.

"No, I believe that hormonally it is also a roller coaster... the emotions and all the moods. You are making normal progress. At first you cannot stop crying, later on talking, you remember and you are still emotional..."

Formal emotional support received by the parents from the professionals (nurses, doctors and psychologists)

Neonatal nurses are expected to show competence and a willingness to involve mothers and fathers as soon as possible in the care of their baby, and also to be open to developing a relationship of confidence with the parents.

Abel (aged 38) describes the help received from the nurses.

"They [the nurses] didn't ask me about my emotions or feelings. I think my wife needed help, because I gave her support. I helped her to cry, because all of this was stored up inside and yes, she did need a professional to help her."

Yolanda (aged 34) describes the help she received from the nurses in the Unit.

"And later, where I got a lot of support, it was with the nurses. Sometimes I was a little... I don't know, they help you, they explain things to you... they even explain things to you later on, when you're at home, what will happen... for example, me with

breastfeeding... they really have helped a lot. They gave me real encouragement, above all. So that I don't get obsessed with things".

Rebeca (aged 34) comments the following on the psychological support that she received.

"Well, the psychologist is there... but for me, it was better talking to the mums than with the psychologist. M. is a really good person; she came specially to look for me so we could talk about things..."

Gerardo (aged 33) describes the psychological support that he received.

"Professional psychological support? No, professional no, because you know what you have to come to terms with anyway. You just have to get your head around it, you've drawn the short straw... when things are fine, then... you just tell it like an anecdote and that's it. I didn't need a psychologist. I talked it over with whoever I needed to, my parents, my sister and that's that. You know, I just don't need to explain it to anybody else".

Clara (aged 28) recalls the psychological support that she received

"On the other hand... the psychologist did come round. But, well, if you don't really believe in psychologists... we were on the floor above where the baby was admitted, there were a few very bad days and she came to see me twice, the next time I went down to see her. I never saw her again; she came and told me that I seemed fine."

Carlos (aged 37) describes the help received from the nurses.

"They offered us psychological support several times. And finally, one day when I saw my missus in a bit of a state and that, I said "if you want, come and talk to her sometime. Let's see if you can help us with anything". And, well, she came along one day to talk to us, but from my point of view, I don't really think it helped me much. Because what I'm going through I have go through anyway. And to talk about it, well, I'll talk to someone that I know and trust and I'll tell them everything I would have told her anyway".

Informal emotional support offered / received by their partner / husband

Due to the distressing situation experienced by the fathers in NICU, the health care systems have changed their objectives towards the quality of care paradigm, promoting well-being centered on the family, and in the continued and maintained participation by the fathers. The benefits that are observed from this active participation by the fathers in the care are: reduction in the stay, improved well-being of the fathers, and an improved neuro-behavioral development of the baby. However, the concerns expressed by the fathers are about the well-being of their partner and their baby.⁸

Luis (aged 31), discusses the pregnancy and premature delivery of his son, and how he cared for his wife

“You have to try, poor thing [his wife], to be as affectionate as possible at that moment and explain to her that, look, everything’s fine, it’s okay, you know with the tubes and all that. I’ve seen him and he looks just great, he’s a little fighter. And anyway, at that moment you couldn’t really tell her even if there was something wrong, you just can’t give her any bad news, poor thing (...). So, well, you just try to cheer her up”.

Emotional support received by first-time parents from other parents whose child is in the same NICU.

The participants’ conversation mentions the help received by parents from other support parents whose own children have also been admitted into the NICU. The place used for the exchange of experiences was “the milk room”, where the extraction of milk is carried out. This was a meeting point where both positive and negative experiences were exchanged.

Rebeca (aged 34), describes the help she received from other support mothers with infants admitted to the NICU.

“It’s far easier for me to talk to the other mums than to the psychologist”. *“The milk room is an*

interesting place.... I had the chance to speak to other mums there (...), of course, you always meet the same mums there. You end up explaining your worries and you can let off steam. Or maybe you meet other mums who tell what’s happened to them and that’s just as good. They cheer you up, they tell you what’s easier and what works really well...”

Josefa (aged 43), describes her own experience of this help.

“Well, it’s really good and you get to know people in the NICU. For example, in the milk room, there’s lots of different experiences. Some people speak more positively than others. Other times they start talking and all you get are only problems, pain and misery, and you so end up saying that your milk has run out.... For example, people who have already experienced this situation have a bit of perspective and can explain it. Lots of mums are alone, because they’re from other places, probably the husband can’t be there with them because he’s working. We give each other emotional support, but if we needed any other kind of help, we would ask for it. On the trips home and back again, my husband and I talked about how we were both managing”.

Clara (aged 28), talks about the help received by other support mothers with infants admitted in the NICU.

“It’s just like being at the hairdresser’s when you’re in the milk room. People are always asking you things like ‘how are you doing?’; ‘How many weeks ago was your baby born?’; ‘How much does he weigh?’; ‘How are you coping with all the stuff?’; ‘How long have you been here?’. You hear about everything in the milk room, about benefits, how they work them out, things you have to hand into get them, all of that, and that’s a big plus (...). It’s been really useful for me, yes... you share these moments, you say, if there’s anything here, there’s a bit of humanity, and that’s not easy to find in other situations. You connect, you feel supported and comforted. You feel like you’re not the only one going through all of this. And later, you get help from the mums who have more time and then you help the new mums”

Diana (aged 32) considers the help that she received through social networks;

"There is a group of mothers called "Vall d'Hebron prematures", on Facebook. I gave it a like. It has been good for me because you end up reading other cases. And the other day I read an article by one of the girls and I could really identify with that. You know? I also had my child here. I've been helped here by other mums and dads who've got through all of this..."

José (aged 51), talks about the help received from other support mothers/fathers.

"D. [another father] told me that he was in the Vall d'Hebron prematures group on Facebook; I took part in this group, too. I have been in contact with parents who had a premature child, even with one of my friends, who I knew has two 11-year-old twins of 11 years and one of them was monitored at home, what a drag..."

However, some parents comment on the fact that they were unaware of the social network support groups for parents with premature infants.

Raquel (aged 41) discusses not knowing about the social network groups, adding that the support received from other mothers with infants in the Unit was sufficient.

"I haven't been to any support group, and I didn't know about the Vall d'Hebron prematures group on Facebook, I did not read any of the comments from other parents (...). But I really liked the milk room, it is the place where most of the mums go to. I got to talk to other mums about my children, and they talked to me about theirs. The milk room was really useful for me, basically because you talk to other mums about their situation, and sometimes you say, well, things aren't so bad for me. And we also talk about our personal situations and things"

Discussion

The mothers in this study showed feelings of guilt and sadness, searching for the causes that triggered premature delivery, in addition to a sense of fear regarding the prognosis and survival of their baby. In his text on crisis intervention, Roberts¹⁵ highlights the prior conditions for

crisis: the most important precipitating factor is a stressful or dangerous event. However, two other conditions are also required: (a) the subject's perception that the stressful event will lead to considerable unease; and (b) the subject's inability to resolve the disruption through the coping methods being used to that end.^{10,15} Other authors report a profound change in social roles and expectations. In the case that concerns us, the mother finds herself with a baby in a critical state, instead of being able to take up the expected role of a mother with her full-term baby. This experience can lead to post-traumatic stress disorders^{10,16}

When mothers do not receive enough support from the staff that looks after their child, they turn to God. We agree with the observation by Heidari⁵ which states that parents are searching for hope and hoping to talk with the doctors and nurses. When these needs are not satisfied, they resort to God and to prayer to cope with the stress.

According to Borrero¹⁷, a suitable *management* of these feelings should be carried out by the nurse responsible, a nurse trained in family relationships. Care is required in such circumstances that is based on listening to experiences, information, in accordance with a guide on participation, and directed towards stabilizing the role of the mother as soon as possible so as to reduce stress.

On the other hand, we must take into account that in the NICU, nurses have responsibilities that go further than caring for the newborn child, such as the commitment to the parents, especially the mother, to accompany them in the first visits to the NICU, inform on the condition of the baby, answer questions, give emotional support, encourage the visit and the contact, participate in the nursing care and inform about the procedures and treatments performed.¹²

The findings of this present study, as regards the feelings expressed by mothers on premature delivery, are in agreement with that reported by Frello et al.¹² On the admission of their

child to an NICU, mothers feel a sense of guilt, disappointment and anxiety, as well as the need for emotional support at this difficult time.

As reported by Shin and White-Traut¹⁸, negative feelings on the health of the baby and a lack of confidence in the medical team lead to a higher level of stress than the simple fact of having a baby in the NICU. Our study's findings differ from those of Heidari⁵ and Shin et al.¹⁸, since we observed few signs of any lack of confidence in the doctors and nurses in the department; stress in our study is identified more with uncertainty about the future and about the baby's development and progress and is also linked to a lack of knowledge regarding the causes of the premature delivery. In view of all this, we infer that frequent and open communication by the nursing staff, based on empathy, active listening and the handling of topics on which parents show concern, could contribute to a reduction in the anxiety felt by these parents and to facilitate a more relaxed experience of their child's hospitalization.

In 2017, Heidari⁵ showed that when the parents become anxious due to having a baby in the NICU, they look for alternative ways to improve their child's health and its chances of survival. This action in itself helps the parents to cope better and to gain a little control over the situation. For many parents, constant praying may offer them a sense of calm, hope, and acceptance. These findings can help to improve both clinical performance and quality of care through a focus on considering the parents' emotional state and through enabling nurses to communicate with the parents in keeping with their behavior and spiritual needs.

In our study, the fathers stated that they were not always asked about their emotions and feelings during their stay in the NICU. According to Frello et al.¹², nurses may forget that fathers need support and emotional guidance, thereby undermining the interpersonal relationships that are seen as one of the challenge in the movement towards humanizing care. Health professionals are concerned with perfecting

their technical abilities, in some cases neglecting the care of individuals. A failure to recognize the importance of the mother and to include her needs in nursing care is seen as indifference.

Parents subjected to the stressful situation of a premature birth can show emotional distance and also reveal themselves to be, in effect, on an emotional roller-coaster, that is to say, they are characterized by marked emotional ups and downs. The results of this study coincide with the findings of Ionio et al.¹⁹ who suggested that, during the mother-child interaction, mothers of premature infants are more distant than are mothers of full-term infants. They also find it easier to withdraw from interacting with their baby. On the other hand, the fathers of pre-term babies are more prone to resilience than stress. Likewise, those mothers showing stress, negative feelings (anxiety, depression, and anger), as well as post-traumatic symptoms, showed a maternal behavior of distancing themselves from the infant during their interactions. Ionio et al.¹⁹ found that the perception of a dysfunctional mother-child interaction from the point of view of the mothers could have an influence on greater distancing during the interaction. This shows that if the mother does not perceive the child as appropriate to her expectations and to the interactions, the infant does not reinforce the mother's own sense of being mother and probably may be more distance in the interaction with her baby.¹⁹

O'Brien et al.⁶ pointed out the time of admission of the premature infant into the NICU as a stressful time and full of anxiety for the parents. They pointed out the concerns for the diagnosis and the highly technological environment and worries about a change in their functions as parents. We have not found authors describing the sense of separation felt by the parents from their hospitalized baby and the feeling, also described by the parents in the present study, on a lack of bonding with the baby possibly determined by the circumstances of birth and restrictions on contact with their child and any decision-taking involved.

The informants identified the attention received from the nurses as 'very good'; however, in some of the conversations, deficiencies in communication were noted, as well as in the psychological care given to fathers. As indicated by certain authors, it is essential that the NICU team welcomes parents and establishes effective therapeutic communication with them, avoiding the use of technical terms distinct from maternal reality, which only serve to mark professionals as withholders of knowledge.¹²

Our study also enquires into the emotional support provided by the psychologist assigned to the NICU. The conversations reveal a rejection of the help provided by this healthcare professional, this being associated with the social connotations of mental illness that such professional support involves.

There is evidence in the literature that nurses provide most of the communication on emotional support for the parents in NICUs, and that this type of support is appreciated by parents.²⁰

Of the studies that consider the relationship established between nurses and mothers with babies admitted to the NICU, it is possible to perceive that there is margin for improvement, despite the effort recognized.^{10,12}

The information and observations provided by the informants in this study was in agreement with that expressed by certain authors. Ardal et al.¹⁰, showed that mothers felt less guilty, less anxious, and had more confidence, after talking with their support mother-friend. The support parents-friends reduced the sense of isolation felt in relation to the birth; similarly, the conscientious use of the support mother-friend experience itself, in response to the concerns of the first-time mother, seemed to have a profound impact on this situation.

As well as that which has previously been mentioned, other sources of emotional support were identified, such as social networks and *WhatsApp* groups. In this case, support is

derived from the discovery that one's own story is not unique, which will then lead to a better acceptance of the situation.

The findings of the present study show the importance of support among peers, that is to say, among parents going through a similar situation. This support becomes key in overcoming the problem, the distress and the pressure of having a newborn child who has been admitted into an NICU. This coincides with the views reported by Ardal et al.¹⁰, which highlights the importance of mutual support for vulnerable parents.

In conclusion, in the context of a premature birth, mothers expressed feelings of sadness and guilt, asking themselves where they had failed and what they did wrong. Mothers and fathers are both afraid that their child, with a low birth weight and related immaturity problems due to prematurity (sometimes extreme), may not survive which is sometimes extreme.

In light of this stressful situation, parents undergo an emotional roller coaster and have ambivalent feelings about this new situation. As a defense mechanism, they adopt emotional distance, delegating the care of their baby to the health professionals so as to process the situation being faced, and for which they were not prepared. Consequently, parents require emotional support that may come from the health professionals themselves, but may also be in the shape of informal support.

In the ambit of professional-emotional support, parents identify the nurses as a key part, since they accompany the parents, inform them, and instruct them in childcare. Nurses must therefore take an interest in the process being undergone, attempting to give support and help to parents according to their expressed needs.

Another source of professional-emotional is that provided by the NICU psychologist, which was shown to be factor that was not determining, almost certainly due to the social connotations that psychological treatment entails.

As regards non-professional support, parents identified as very beneficial the exchange of experiences with other mothers and fathers whose children had also been admitted into the Unit, as well as support groups on social networks, and the use of WhatsApp groups in which they can give voice to their worries and compare their experiences with other parents who are possibly going through a similar experience, or whose child has overcome prematurity.

The nurse needs to know about these sources of support and should guide families towards them, in order for them to understand their emotions when facing the situation, they are experiencing with their children.

Among the limitations there is the difficulty of the father taking part in the interview, as studies have shown the difficulty of combining work, caring for the hospitalized wife, for other children and for the premature child; for all of these reasons, there are still profiles in this study that require fuller exploration.

Other limitations are those common to qualitative methodology as regards the generalization of data. For this reason, this qualitative-research study cannot be extrapolated to all communities.

Finally, an additional limitation was that the informants did not provide all the information that was actually available to them, due to the fact that the researchers were from the service area in which their child had been admitted; they therefore retained whatever information that might be conflictive in such cases.

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