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How parents and health professionals experience prematurity in neonatal intensive care: a Grounded Theory study

INTRODUCTION

Premature births are approximately 11% of birth worldwide (Liu et al., 2016). However, **this evidence** varies across countries due to different methods **of** gestational age evaluation (Vogel et al., 2018). The **World Health Organization (WHO)** report defines premature as birth weight below 2500 g. and gestational age less than 37 weeks (Spong, 2013; WHO, Dimes, Maternal, Health, & Children, 2012). Although survival-to-discharge rates for premature and highly premature children have been continuously increasing, health complications are still a significant concern in the development of premature newborns representing the leading cause of death in the first weeks of life.

In addition to the newborn's critical conditions and related medical needs, premature birth is highly distressful from an emotional perspective. Parents are suddenly (and too soon) faced with challenges they had not pictured in their dreams of parenthood (Rieves, Petty, & McCarroll, 2016), which interferes with their plans to develop family identity (Kantrowitz-Gordon, 2013). For many parents, the Neonatal Intensive Care Unit (NICU) may represent the place of shattered expectations (Lasiuk, Comeau, & Newburn-Cook, 2013) as well as a period of loss of control over their child's care.

The evidence suggests emerging unmet needs on behalf of the parents, such as being recognized as a part of their child's care and **confirmed in** their parental role.

In these regards, it is crucial to consider **the parental system (whether composed of mother-father dyads or single mothers/fathers)** since most of the studies involved just the mothers' point of view (Turner, Chur-Hansen, & Winefield, 2015; Welch et al., 2016). Only recently, publications started **including** fathers (Edwards et al., 2020; Mörelius, Brogren, Andersson, & Alehagen, 2021; Premji et al., 2020). Such considerations, however, provide only a partial

perspective on the overall psycho-social process around premature births, which also involves other actors, such as **healthcare professionals (HPs)** operating around a premature child. In the literature, few studies address the experience of HPs involved **in** the NICU (Broom, Parsons, Carlisle, Kecskes, & Thibeu, 2017; Voie, Tunby, & Strømsvik, 2018).

So far, studies from the literature on prematurity have limited their scope to distinct perspectives, leaving the interplay of relevant actors – in terms of psycho-social process – out of the picture.

For constructing a dedicated pathway for prematurity care management, the team of an Italian NICU **explored this process** involving both parents' and HPs' perspectives to improve the care response using key individuals' information.

METHODS

Design and setting

We followed the Grounded Theory (GT) method to construct a theoretical model. Semi-structured interviews were **conducted** to generate the data. According to the study's aim, we **followed** Charmaz's constructivist GT (Charmaz, 2014), a broad-ranging interpretative research approach used in the social sciences to define psychological and sociological processes (Charmaz, 2014).

The participants were recruited in a Neonatology hub ward **of the** main provincial hospital (Northern Italy). **This** is the only tertiary Neonatology service within the province; it includes 20 beds: 6 NICU beds, a sub-intensive area (11 beds), and three isolation beds, managed according to clinical conditions and needs of premature/at term newborns. The staff **includes** 11 physicians (**10 pediatricians with specialties in neonatology working in NICU, one pediatrician working on territory**), 34 **registered nurses**, two psychologists, and two physiotherapists. The multidisciplinary team covers all three areas by rotation shifts. The number of annual ward admissions is approximately 350 newborns: more than a third are

premature children under 37 weeks. As to NICU, the average length of stay is around 70 days (ranging from 20 days to 6 months, depending on the child's clinical conditions). Generally, the first contact with parents occurs at the child's admission. Nonetheless, in case of severe prematurity, NICU staff already know parents during the pregnancy and assess and care for them before their child's birth.

Sample and sampling procedure

The study carried out an initial sample involving:

- parents (preferably dyads) of a premature newborn surviving to discharge, entailing at least 15 days of NICU stay (Lee, Bennett, Schulman, & Gould, 2013; Maier et al., 2018; Seaton et al., 2019).
- According to the parents, key informants played a significant role in the care process. Parents could indicate HPs like pediatricians, neonatologists, but also gynecologists since, in the Italian context, they support midwives during the delivery.

To explore further aspects as they emerged from the analysis, we extended the sampling to additional participants (theoretical sampling) until theoretical saturation was reached. We asked for participation couples whose prematurity experience occurred earlier than the initially sampled parent to understand the role of time within the developing theoretical model. The study did not include parents whose child was still in critical conditions.

Data collection

Two pre-planned interview schemes, varied according to interviewees' roles (parents and professionals), were prepared jointly by all coauthors to guide the interviews in a semi-structured data collection (Table 1).

Researchers conducted face-to-face interviews with a colleague acting as an observer to collect non-verbal and para-verbal behaviors of participants concerning their interaction (Morgan, Ataie, Carder, & Hoffman, 2013). **The participants decided the time and place for the interview.** The advantages of dyad interviewing include i) the possibility to collect different views on the same topic and ii) to allow participants to stimulate each other's ideas that might not have been either recognized or remembered (Morgan et al., 2013). On the contrary, a bias may arise in terms of answers perceived to be acceptable to the partner or are consistent with the partner's perceived (or known) position (Taylor & de Vocht, 2011). As to our data collection, there were no conflicting views expressed during the interviews by the parents.

INSERT HERE TABLE 1

Data analysis

The analysis occurred concurrently with the data collection so we could apply the theoretical sampling to confirm and saturate the provisional categories (Charmaz, 2014). The interviews were digitally recorded and verbatim transcribed by interviewers/observers (CG, CP, PC, AM) for enriching transcripts with comments, memos, and observational notes on respondents' behaviors. MM, RC, and SC checked, alternatively, the transcriptions for accuracy.

The coding process entailed a three-step analysis: open, focused, and theoretical. We indexed the interviews using open codes, which we grouped into conceptual categories, identifying concepts at a higher level of abstraction. All the researchers created memos to record and share the first analysis. Focused coding was concurrently performed with the theoretical sampling, which helped us corroborate and saturate the provisional categories. Then, we defined the model during theoretical coding, highlighting the relationships between the conceptual categories. Researchers stopped recruiting participants when the analysis reached theoretical saturation (Charmaz, 2014).

Reflexivity and rigor

They were aided in designing and conducting the study by two GT experts (LG, SDL). At least two researchers conducted every step of the data collection and analysis. As to reflexivity, we should note that the principal investigator (PI) was a NICU **registered nurse (RN)**. She was not involved in interviews to limit social desirability. Researchers have diverse scientific backgrounds. It consented to clarify possible research bias and enrich the interpretation of the results.

Moreover, to assess GT validity, credibility, originality, resonance, and usefulness are the suggested criteria (Charmaz, 2014). Credibility was obtained by collecting adequate data to substantiate the theoretical explanation of the process. Originality was reached by outlining the participants' meanings. As to resonance, saturation achieved in our analysis permitted a comprehensive picture of the experience within a specific cultural setting. Finally, we valued the usefulness of this study as it can offer consistent practice implications.

Ethical considerations

The Ethical Committee of the Local Health Authority approved this study (in-house prot. n. 2017/71438). The PI obtained written informed consent from all the participants before commencing the interviews.

FINDINGS

Overall, researchers conducted 27 interviews: 7 parental couples interviewed as dyads (5 first-child, 2-second child as premature) with recent NICU experience, two mothers who had given birth 2-6 years before the study, and 11 HPs (6 **RNs**, four neonatal physicians, one pediatrician). In two interviews, **two mothers participated without their partners. Single parents or same-sex**

parents were not included in the final sample as they did not access the NICU during the study.

All participants were interviewed in a hospital private room outside the NICU.

Participants' characteristics are shown in Table 2. The second phase of theoretical sampling further involved two parents of siblings, two parents of premature children at 2 and 6 years, and a pediatrician. Interviews lasted between 15 and 45 minutes (mean of 33' for parents, 17' for HPs). Transcripts were available upon request (Table 2) to allow member check.

INSERT HERE TABLE 2

Our analysis led to a theoretical model, which explains what was going on around the premature birth of a child. The model can be described as a two-fold process: on one side, the behaviors, emotions, and feelings of the parental couple; on the other, the activities and reactions of the HPs. These two parts influence each other, generating and supporting each other towards the final goal of managing the prematurity event. Figure 1 illustrates the theoretical model.

INSERT HERE FIGURE 1

We identified four main phases within the categorized process: 1) the initial breakup; 2) the floating family; 3) event processing; 4) reconstruction of a new family. The significance of each phase and conceptual category is explained below. Table 3 lists the theoretical phases, the conceptual categories, and the most representative quotations from participants for each phase (Table 3)

INSERT HERE TABLE 3

The initial breakup

In the first phase, we conceptualized data about the impact of receiving the news concerning the premature birth of a child. What occurred here was the breaking of expectations the parental couple had. Our data revealed the parents' peaceful minds until the birth event. All the pregnancy narratives gathered during the interviews were described as "normal" or "without problems" and experienced within a shared vision of the ideal family.

Within the interview data, we generated four main characteristics defining the initial breakup: accomplishing a family project, the couple's needs, the sudden change, and the intervention/assistance of HPs.

All the dyads described having children as the natural path toward building their ideal family. Among the elements that characterized the new family (parents and child), participants expressed a distinct sense of protection and attention towards their partner, the need to be together, and the support of grandparents if present. The **physician's** suspicion of a medical problem of the yet unborn child, the sudden hospitalization, and the unexpected birth marked a moment of transition that shattered their expectations. This feeling of shattered expectations remained vivid in the minds after the event (theoretically sampled participants).

Another recurrent theme among parents concerned "feeling lucky." Dyads emphasized how lucky they had been to have the **physician recognize** the problems promptly. After hospitalization, this feeling was incredibly vivid once they could compare their situation with others in the ward: "I believe I was lucky (...) I put myself in the parents' shoes". "We were very happy."

As to the participants involved on the other side of the event, HPs described the situation revolving around their technical tasks. HPs reported that their main concern focused on prompt clinical action. **RNs** and neonatologists said they were interested only in managing the newborn's unstable clinical situation. **They did not search for any prior information on the pregnancy.** HPs described the situation limitedly to their job tasks and reported job-related aspects with technical jargon and in detail from a linguistic perspective. They expressed a

positive attitude towards the case, as they were confident of their actions and approached these events as “business as usual”: “If she should not breathe, I might have to intubate her.” At times they were frustrated by the technical limits of care for the newborn. HPs did not report on relational matters with parents or family members, as **their felt** priority was the physical well-being of the premature child and thus their work towards that goal. From **RNs’** and physicians’ point of view, the child’s stabilization was a priority; the information and relationship with parents occurred in the free time around events when possible and left to the sensitivity of the HP, rather than following a structured format or timing.

The floating family

After delivery, the dyads went through what we categorized as “suspension” when they perceived their family vision had been broken. It had been put on hold as they waited to go home together. This second phase of awaiting was characterized by the search for positivity, a sense of isolation, the support **given** by HPs, and **delicate** communication.

In describing what happened, dyads did not use the term “prematurity” but rather “the thing” or “the procedure.” However, the parents interviewed tended to describe the procedures on their child (i.e., intubation, oxygen saturation) positively, which we interpreted as a need to focus on positivity to contrast the critical situation they were living. In addition, the relationship with the care team was always described in favorable terms. **Even if entering the first time in NICU** was experienced as a challenging moment, parents said they could rely on HPs and their honest and complete communication.

Nonetheless, couples felt alone in dealing with the situation in the ward. This feeling was also intensified by not being involved in caring practices in which families expected to have a role: “I arrive, and the child has been already washed and fed: I should have done it.”

While relatives were considered a valuable resource, couples described getting connected with friends as fatiguing: the “floating family” emerged as concentrated on its “shifting” (from

initially strong to fragile and then searching for inner resources to cope and come back to life. The shared perception of the family's "suspended" state was constant throughout the interviews, as confirmed by our analyses.

From the HPs' perspective, this period (when dyads felt "floating" in their new condition) was recalled as when they provided empathic listening and support. **RNs** and neonatologists, in most cases, reported they were aware of parents' intense feelings experienced during this phase. They said they tried to be careful when communicating the newborn's clinical condition: "I tried to convey information delicately (...)". However, analyses evidenced that attention to emotional aspects and establishing a relationship of trust occurred only once the clinical conditions of the newborns had stabilized.

Event processing

The third phase of the process, which we named "event processing," identifies an intermediate step from the "floating" state towards reconstructing a revised idea of family. This phase was characterized by four categories: feeling fatigued, **recuperating** the parental role, counseling from HPs, and experiencing satisfaction.

The parents interviewed described another waiting time. They perceived this new stand-by to rebuilding the family as a chance to reflect and process both the premature birth and the break from previous expectations. They described feelings of uncertainty due to the complexity of the circumstances as well as mental fatigue: "I can't handle it." This discomfort was particularly intensified upon seeing other mothers/parents in the hospital room with their at-term newborns. Eventually, when parents saw their newborn growing, feeding at the mother's breast, they began re-connecting to the child and going back where they left off in starting their family project, recovering the parental role they were used to during pregnancy.

From the perspective of the HPs, their activities within this phase regarded counseling and support in all the aspects entailed with a newborn. On the one hand, HPs stated that they tried

to reassure parents and inspire them to feel secure about the NICU. On the other hand, HPs reported this phase as rewarding. They said they received personal gratification from their parents; they thought they made a difference in the parents' coping with prematurity. Some **RNs** reported that parents met years after the child's discharge and wanted to tell how the family is now and thank them for their care at the NICU. All HPs expressed satisfaction, representing a relevant category that promoted motivation to work in the NICU: "it's so satisfying seeing a child grow together with its family (...) small steps together".

Reconstruction of a new family

This phase concludes the process of dealing with prematurity. It is informed by the interviews carried out with the **parents** who had dealt with premature birth years earlier and the pediatrician. **Even if planned to involve dyads, only mothers gave their availability to participate in this phase with no partners present at the interview. They reported they felt stronger after** re-signifying, ex-post, the meaning given to prematurity and nurturing their new family identity: "I feel stronger...now I can think everything over more clearly...". The **interviewed** pediatrician confirmed this outcome and described he could not forget "the tears" of joy shed by parents when they realized their premature child was growing and developing healthily.

DISCUSSION

Managing prematurity within a NICU is a negotiated process where different actors' behaviors, feelings, and activities impact each other.

Parents and HPs act differently, in a complementary way. While parents were experiencing premature birth as a moment of shattered expectations (*breakup*), HPs responded with support in this unexpected event with technical and emotional skills. While the breakup phase can be

tracked in the literature (Howe, Sheu, Wang, & Hsu, 2014; Labrie et al., 2021; Lasiuk et al., 2013; Rieves et al., 2016), this study adds the HPs feedback and role, which could also inform the underlying motivations of communicative dynamics reported by Labrie and colleagues (Labrie et al., 2021). Parents need to search for positivity about what is happening in this first phase, confirming their fragility, which has already emerged in other studies (Edwards et al., 2020; Labrie et al., 2021; Mörelius et al., 2021; Premji et al., 2020). Couples felt alone in this situation, which is confirmed by previous studies (Kusters, van der Pal, van Steenbrugge, den Ouden, & Kollée, 2013; Lakshmanan et al., 2017). Dyads may feel a suspension of their family project, intensified by not being involved in caring practices during the ward stay, as reported by other studies (Gallegos-Martínez et al., 2013; Labrie et al., 2021; Turner et al., 2015). However, HPs reinforce the psychological construction of a “new” parental identity. This role in guiding the family through this phase is perceived as a gratifying aspect of the medical and nursing profession, triggering parents’ satisfaction in return (Labrie et al., 2021).

Then, this study highlights how the parents rebuild their identity with new strength without forgetting the experienced feelings. This finding may challenge the long-term trauma of social isolation and repercussions on the quality of life, even after years, as reported by Lakshmanan and colleagues (Lakshmanan et al., 2017). This process can be sustained by a positive participant interaction which, as noted by Franck and colleagues (Franck et al., 2017), cannot be taken for granted in the NICU settings.

In agreement with previous studies (Ireland, Ray, Larkins, & Woodward, 2019; Rieves et al., 2016; Turner et al., 2015), our findings confirm that feelings of being catapulted into parenting arise within the context of NICU. Here HPs have to deal with parents’ high levels of stress and anxiety (Howe et al., 2014; Treyvaud, 2014; Welch et al., 2016).

The understanding by HPs, **mainly registered nurses** – as also recognized by Green and colleagues (Green, Darbyshire, Adams, & Jackson, 2015) – in dealing with parental distress **was evident in the data**. Although HPs appear to be cautious in the initial stages, during which

they abide by their clinical duties, they are more open to establishing a relationship with the parents after the most immediate and critical medical issues are solved. Active listening, the attention to the family as a whole, and the multidisciplinary team giving coherent answers help construct the care relationship (Jones, Taylor, Watson, Fenwick, & Dordic, 2015). In this regard the authors of a recent systematic review reinforce the pivotal role of relationship and parent-provider communication in the NICU, as a decisive determinant for parental well-being and satisfaction with care, during and following infant hospitalization (Labrie et al., 2021).

Practice Implication

To the best of our knowledge and comforted by a recent systematic review collecting studies on parent-provider communication during NICU care (Labrie et al., 2021), this is the first GT study about prematurity involving multiple perspectives.

The study's results permit understanding a process characterized by dyads' fragility, which can be contrasted by promoting a family-centered approach in neonatal care (Erdei, Inder, Dodrill, & Woodward, 2019).

Limitation

The theoretical explanation reported is informative for the research setting.

It is derived from only a setting, an obstacle to transferability (Charmaz, 2014). Nonetheless, as a GT study, abstract conceptualizations may fit (Charmaz, 2014) and explain a variety of similar NICU settings. Therefore, continuing the study could involve other parents, families, and settings to strengthen the findings and extend the investigation.

CONCLUSION

Perinatal care would benefit from the following suggested practical implications: i) reducing feelings of separation and solitude by integrating diverse professionals (psychologists, primary care practitioners, future pediatricians) around the family systems; ii) expediting prematurity-related changes (expectations' break, sense of loss, reconstruction of family identity) through peer-support during hospitalization and attention to rooms' organization; iii) enhancing information exchange **between all HPs involved in the care of dyads/parents and newborns, starting since the pregnancy and continuing after the child's birth by implementing multidisciplinary meetings or appropriate care pathways.**

This study suggests promoting a family-centered approach as fundamental in neonatal and pediatric services. **Paying attention to the team's communication with the parents is particularly significant. Being open in listening, coherent in the given answers, and knowing the entire process and story of being suddenly parents of a premature child can make the difference in the future definition of a new family.**

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Tables and figures

Table 1 - Topic guide and prompts

Topic area	Prompts for parents	Prompts for Health Professionals
<i>Introductory questions</i>	Could you tell me about how your family is composed? Could you tell me about your experience with prematurity? Are there other experiences of prematurity in the family or through acquaintances?	Could you tell me about the care process of NN and his/her family?
<i>Pregnancy</i>	What were your thoughts during pregnancy? Could you tell me how your pregnancy went?	What were your thoughts during her pregnancy [in case of professional involvement, e.g., gynecologist, or in case of being informed about the pregnancy]? Could you tell me how you assisted her during her pregnancy? And what about the family members?
<i>Prematurity</i>	Could you tell me about the first time you knew your child would be born before the term? How did you feel? Could you tell me about the information you had concerning prematurity? What kind of reactions did you notice from significant others? How was meeting your child for the first time?	Could you tell me what you did when you knew their child would be born before the term? How did you feel? Could you tell me how you handled the situation?
<i>Hospitalization</i>	Could you tell me what information you received from the staff the first time you accessed the NICU? Did you have questions? How did the team answer your questions? What helped you during your NICU stay? How did you experience the relationship with the staff? What did you like to do once you left the ward?	Could you tell me what kind of information you gave to the parents when they accessed the ward? How did you feel about communication?
<i>Concluding questions</i>	Do you have any further thoughts to share? Thank you for sharing your experience with us.	Do you have any further thoughts to share? Thank you for sharing your experience with us.

Table 2 - Participants' characteristics

Interviewee	Kinship/Gender (code)	Age Range	Nationality	Education *	Profession	Family members	N° children	N° premature children	Child gender	Gestational age (week)	Weight (grams)	NICU stay (at the interview date)
Parents	Mother (MF1)	25-30	Italian	Secondary	Housewife	4	2 (twins)	2 (twins)	Male	33+3	1400-1799	15 days
	Father (FF1)	25-30		Tertiary	Policeman				Male	33+3	1000-1399	
	Mother (MF2)	25-30	Italian	Secondary	Shop assistant	3	1	1	Female	28	1000-1399	23 days
	Father (FF2)	25-30			Worker							
	Mother (MF3)	25-30	Extra UE	Secondary	Employee	3	1	1	Male	25+5	600-999	52 days
	Father (FF3)	25-30	Italian		Self-employee							
	Mother (MF4)	41-45	Italian	Secondary	Computer programmer	4	1	1	Female	30+6	600-999	32 days
	Father (FF4)	36-40										
	Mother (MF5)	31-35	Italian	Secondary	Teacher	4	1	1	Male	32+4	1800-2000	40 days
	Father (FF5)	31-35			Worker							
	Mother (MF6)	25-30	Extra UE	Secondary	Dancer	3	1	1	Male	25	600-999	83 days
	Father (FF6)	31-35			Self-employee	4	2					
	Mother (MF7)	36-40	Italian	Secondary	Undeclared	4	2	1	Male	33+5	1400-1799	30 days
	Father (FF7)	31-35										
HPs	Mother (MF8)	41-45	Italian	Secondary	Housewife	5	3	2 (twins)	Male	26+5	600-999	130 days
	Mother (MF9)	41-45	Italian	Tertiary	Nurse	4	3	1	Female	32	1800-2000	21 days
	Male (M1)	46-50	Italian	Tertiary	Physician	/	/	/	/	/	/	/
	Female (IA1)	36-40	Italian	Tertiary	Nurse	/	/	/	/	/	/	/
	Female (M2)	31-35	Italian	Tertiary	Physician	/	/	/	/	/	/	/
	Female (IA2)	41-45	Italian	Tertiary	Nurse	/	/	/	/	/	/	/
	Female (IB2)	41-45	Italian	Tertiary	Nurse	/	/	/	/	/	/	/
	Male (M3)	31-35	Italian	Tertiary	Physician	/	/	/	/	/	/	/
	Female (IA3)	31-35	Italian	Tertiary	Nurse	/	/	/	/	/	/	/
	Female (IA4)	41-45	Italian	Tertiary	Nurse	/	/	/	/	/	/	/
	Female (IA5)	46-50	Italian	Tertiary	Nurse	/	/	/	/	/	/	/
	Female (M4)	31-35	Italian	Tertiary	Physician	/	/	/	/	/	/	/
	Male (M10)	>50	Italian	Tertiary	Pediatrician	/	/	/	/	/	/	/

* Education was clustered by attended school type:

- Primary education = elementary and middle school or junior high school.
- Secondary education = high school or any kind of secondary school.
- Tertiary education = university or any post-graduate program.

Table 3 – Phases, conceptual categories, and meaningful quotations from participants

Phase	Category	Meaningful questions	Participants	
			HPs	Parents
The initial breakup	The project of a family	“We wanted them (the children)”		(FF1)
		“We had decided to build our family”		(FF2)
	The characterizing elements	“I was maintaining relationships; she was trying to recover”		(FF2) (FF4)
		“I was more scared for her than for the baby”	(M1)	
		“The twins were holding each other’s hand”		(FM1)
		“I’m going, home and we’re leaving them here”		(FM2)
		“It tried us immediately”	(IB2)	
		“It turned out well considering what you see in the ward”		(FM1)
		(grandparents) “There was a direct line, they supported us”		(FM1) (FF1)
		“The idea of a solid family ready for everything... but it wasn’t true”		(FM8) (FM8)
		“I’m trying to put it behind me, we were in complete darkness”		
		“I thought...how it would be when I went to see here”		
		“I was watching and was afraid to do some things”		
	The changes	“Were ecstatic”; (...) then the gynecologist noticed that (...)”		(FM1) (FF2)
		“It was all going well until (...)”		(FM8)
		“We didn’t even have time to realize it”		(FM1)
		“It was all at once”		
	The technical/clinical response from HPs	“I gave him a bit of help with the oxygen in the first moments, then he breathed with C-PAP”	(M1) (IA2)	
		“It was a very sudden thing, not like the usual cases of premature births we have here when they are just a bit early”	(IA3)	
		“Finding yourself with these tiny babies so small and underweight and all of this with two parents who were not prepared (...)”	(M2) (IB2)	
		“The nervousness, the anxiety associated to the critical emergency situation”	(M4) (M3)	
		“We always feel sorry intervening on a small baby, but we always hope everything will turn out fine”	(IA4)	
		“When things are going well, I feel good too”		
		“We had a hard time intubating, linked to the new endotracheal tubes”		
		“I knew the mom had gestosis and her blood pressure was too high”		
	Searching for positivity	“Days seemed as months... every day that went by was felt as a goal”		(FM9) (FM1)
		“I saw them intubated...but it was only air”		(FF2)
		“They kept her only a few days”		(FF4)
		“They helped her a bit with breathing, but they didn’t intubate her”		(FF5) (FF6)
		“Saturation falls every now and then (...) it’s quite normal”		
		“(...) she only needed some air; she was receiving C-PAP”		
The floating family	Sense of isolation	“I found myself in a room alone waiting”		(FF1)
		“We weren’t in the mood of seeing people”		(FF6)
		“Every time we had to explain everything all over again (...)”		(FM2) (FF4)
	Support given by HPs	“I had to wait two days before seeing her”		
		“I was the first to put her in her lap...I could sense so much anxiety on behalf of the mom...she was crying, but I reassured here ... and then a detail, I took their picture”	(IA4)	
		“We started with the pouch, and they were concentrating on the monitor... so then I turned it off -youOve got the baby there with you and you can feel it, he’s alive, put your hand on his back and you’ll feel him breath”	(IA3)	

Event processing	Delicate communication	“They had always told us about the risks”	(FM1)
		“They had been very exhausted”	(FF1)
		“They update us on the baby’s health status”	(FM4)
		“I want to know everything”.	(FF2)
		“I was reassuring, I explained them what was expecting us, and what would have happened, what is normal for us and what isn’t for them”	(M3)
		“I told them that their baby had been a good girl, that she hadn’t needed any assistance, except for the mask to breath better”	(M2)
		“The father wanted true information (...), this leads to be more objective. More scientific”	(M3) (M2)
	Feeling fatigued	“I’m not sure what the parents remember from those moments, maybe, more than lots of words, it’s the gestures, the smiles...”	
		“Staying in the hospital (...) with other moms who have their babies in the room, it is devastating”	(FM7)
		“(the physician) shattered all my hopes altogether (...) – you’ll never get to the end”	(FM4)
Event processing	Uncovering the parental role	“The pain of not being able to stay with her (...) it’s not exactly the moment you imagine”	(FM4)
		“I get there, and the baby had already been changed (...) they had already fed her, what was I supposed to do?”	(FM9)
		“Now we’re waiting for the baby to come home”	(FM1)
		“When I saw here, I felt completely helpless”	(FM4)
		“I had to be guided also on where to put my hands”	(FM5)
		“Guilt knocked at my door”	(FM8)
		“It was then that we decided we didn’t want to see them”	(FM8)
		“You see here intubated, with all those sensors, so you can’t touch her”	(FM2)
	Counseling from HPs	“I was the first to put the baby in her lap, I felt a lot of anxiety (...) she left with a smile.”	(IA4) (IB2)
		“They are people who highly trust our work (...) it’s really important”	(IA3)
		“We established a relationship based on hope and trust, no longer of fear (...)”	
Reconstruction	Experiencing satisfaction	“I get to the end of the day fully gratified, ...bushed, but I go home with a smile on my face knowing I’ve given something”	(IA3)
		“The father came to my office: -you are the physician that took G. on the night of her birth-, those are important words”	(M2) (IB2)
		“When you get to the delivery, that baby is special to you. Seeing it now grow, feeding on his mom’s breast seeing his parents peaceful is a great sense of achievement”	
		“The birth was an opportunity”	(FM8)
		“Now I feel stronger, a unique courage”	(FM8)
		“Having understood that my kids are a blessing”	(FM8)
		“The families will always consider these kids preemies, there are no official protocols on premature babies.... it’s up to the family pediatrician to make sure the path is as smooth and peaceful as possible, ...”	(FM8)
		“A large family, a home...”	(FM8)
		“I will not forget the tears, the joy, and the uncertainties”	(M10)
		“It’s incredible that you might even miss those hard times...”	(FM9) (FM9)
		“There’s a good environment, you know they are watched over and monitored...”	(FM8)
		“They stayed by our side moment by moment”	
		“I consider them guardian angels; we entrust ourselves to them”	(FM9)
		“Thinking that there are people working for us, for our daughter (...) – also in a difficult time like this – is uplifting”	

Figure 1

