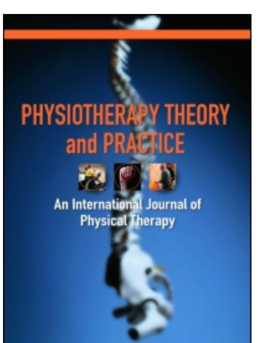

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Experiences and coping strategies of preterm infants' parents and parental competences after early physiotherapy intervention: qualitative study

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ABSTRACT

Background: Birth before term is a stressful experience for parents because of the unexpected delivery or admission to the neonatal intensive care unit.
Objective: This research aimed to evaluate the impact of the early PT intervention on preterm infants' parents' experiences, and also to obtain knowledge about parents' experiences and perceived difficulties during preterm infants' care.
Methods: This qualitative study is based on the methods of phenomenology. In the first phase, open interviews were developed to allow researchers to immerse themselves in the context of the study and refine the questions for the semi-structured interviews. Data collected from the semi-structured interviews were analyzed through content analysis.
Results: The results were summarized around three themes: 1) parental competence; 2) difficulties during preterm infants' care; and 3) coping strategies. Each theme was divided into two sub-themes.
Conclusion: Mothers and fathers of preterm infants experienced difficulties when caring for their babies. Parents that received the early physiotherapy intervention felt empowered to take care of their babies and to enhance infants' development. These parents were more capable of developing coping strategies after the intervention. Parents that did not receive the early physiotherapy intervention expressed difficulties when caring for their preterm babies.

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Introduction

Birth before term is a stressful experience for parents because of the unexpected delivery or the admission to the neonatal intensive care unit (NICU) (Al Maghaireh et al., 2016; Puthussery et al., 2018). In such circumstances, in addition to various emotions (i.e. guilt, shame, and low self-esteem), these parents can experience anxiety, uncertainty, social isolation, difficulty sharing their experience, lack of support, and helplessness (Baum, Weidberg, Osher, and Kohelet, 2012; Benzies, Magill-Evans, Hayden, and Ballantyne, 2013; Ewald, Hedberg, and Starrin, 2006; Premji et al., 2017; Toral-López et al., 2016).

Furthermore, preterm infants and their parents usually do not have sufficient interaction and associated physical and psychological proximity. This deficiency might cause emotional distress and discomfort on parents and also on their parental role, especially before infants' term-equivalent age, subsequently affecting the parents' bond with the infant and interrupting the development of a healthy parent-infant relationship (Al Maghaireh et al., 2016; Granero-Molina et al., 2018; Halpern, Brand, and Malone, 2001; Provenzi et al., 2016; Singer et al., 2006; Watson, 2011). However, it is known that parental support as part of healthcare or medical assistance can increase the level of adaptation to the new situation (Benzies, Magill-Evans, Hayden, and Ballantyne, 2013; Granero-Molina et al., 2018; Håkstad, Obstfelder, and Øberg, 2016).

Family-centered care (FCC) is a traditional approach of care within the NICU. Combined with collaboration, partnership, and responsiveness to parents' needs, FCC is associated with better parental and child psychosocial wellbeing and higher levels of parental satisfaction with their experience (Campbell, Palisano, and Orlin, 2012; Miyagishima et al., 2017;

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Reis et al., 2010). In the literature, the contributions that parents make to the development of preterm infants have been highlighted as empowering (Spittle, Treyvaud, and Hons, 2016). However many of these parents express difficulty developing parental competences due to a lack of knowledge about caring for a preterm baby (Premji et al., 2018). In this line, Al Maghaireh et al. (2016) conducted a systematic review to synthesize the evidence about parental experiences in the NICU. The authors reported the need for further research exploring the parental coping process during the hospitalization period and studies about strategies to support parents with infants in the NICU.

The role of the physiotherapist within the frame of FCC is to support parents' needs to engage with their infants and to facilitate the infants' development with the parents' collaboration (Campbell, Palisano, and Orlin, 2012; Dusing, Murray, and Stern, 2008; Miyagishima et al., 2017). It is known that involving parents in therapeutic activities and providing them information helps them to better understand their infant's development and learn how to take part in their child's care (Håkstad, Obstfelder, and Øberg, 2016). Other qualitative studies conducted to gain knowledge regarding parents' perceptions after administering a specific program reported that parents have more confidence in caring for their infants (Premji et al., 2018), and that they experienced a sense of empowerment, autonomy, and a more intense parent-infant bonding (Øberg et al., 2018). However, further research that describes parents' perception and appraisal regarding these interventions within the scope of physiotherapy (PT) and FCC is needed. This might allow health professionals to understand parents' experiences and to develop interventions adapted to support the parental coping process.

This qualitative study aimed to evaluate the impact of the early PT intervention on preterm infants' parents' experiences. The study also aimed to obtain knowledge about parents' experiences and perceived difficulties during preterm infants' care, both at the hospital and after discharge. To adequately support tailored FCC interventions, it is essential to conduct research to highlight the participants' features in the NICU, their experiences regarding the intervention and how they felt participating in it. Therefore, the following research questions were formulated: 1) what do parents of preterm infants experience and perceive when taking care of their babies; and 2) what are the needs and perceptions that preterm infants' parents express with or without early PT intervention?

Theoretical framework

The transactional model theory of stress and coping proposed in 1978 and 1984 by Lazarus has been widely used to study strategies of coping by parents of preterm infants. Stress and coping concepts provide a unique framework to understand parents' expressed perceptions, experiences, and needs regarding their competence to care and interact with their preterm baby (Lau and Morse, 2001).

Coping is an intention to manage stress, and, as reported by the theory of the transactional model, it aims to alleviate the emotions or distress produced by the stressors (emotion-focused coping), and to manage the stressor (problem-focused coping) (Lamontagne, Johnson, and Hepworth, 1995; Lau and Morse, 2001; Lazarus, 1993). From a process perspective, coping changes over time depending on the situational contexts in which it is developed (Lazarus, 1993); nonetheless, both forms of coping are likely to be used during a stressful event (Lamontagne, Johnson, and Hepworth, 1995). Indeed, the theory frames that it is an ongoing process aiming to mitigate the general stressors and reduce high negative emotions to manageable levels (Lau and Morse, 2001; Seideman et al., 1997).

Parents of preterm infants have been shown to use both forms of coping with different strategies. The coping strategies that parents adopt depend upon how parents perceive the event, the stressor degree, and their belief about their competence (Lau and Morse, 2001). Therefore, personal (i.e. age, gender, ethnicity, anxiety, and self-control) and situational factors (i.e. physical and environmental characteristics) influence how the event is appraised (Lamontagne, Johnson, and Hepworth, 1995; Lau and Morse, 2001). In the early stages of preterm birth, parents encounter stressors and difficulties that challenge their ability to take care of their babies. The coping theory states that in this period parents might use emotion-focused such as focusing on their infant and problem-focused coping like feeling part of a community strategies (Lau and Morse, 2001). However, when parents are unable to deal with the difficulties or when coping is related to non-adaptive processes (ineffective strategies), they might have difficulties developing their parental competences. This might contribute to maladaptive parenting and a higher risk for parental-child problems, including overprotectiveness, failure to thrive, and child abuse (Lau and Morse, 2001; Lazarus, 1993). For example, mothers of preterm babies might experience intense feelings of loss and grief over the

last part of the pregnancy and the natural contact with their baby (Ewald, Hedberg, and Starrin, 2006). In such cases, not coping with the loss of "the ideal child" can aggravate the residual guilt that mothers feel, hindering mothers' competence to take care of the baby and generating attitudes of overprotection or obsessive monitoring of the child's psychomotor development (Granero-Molina et al., 2018).

The theory affirms that many parents are better able to develop coping strategies during the NICU period when they take an active part in the care of their babies before discharge (Lamontagne, Johnson, and Hepworth, 1995; Lau and Morse, 2001). This involvement allows them to feel useful and more competent and, importantly, to gain experience in the handling of their tiny infant (Lau and Morse, 2001; Reid, 2000). Consequently, it reduces parents' feelings of helplessness, increases their confidence and self-esteem, and makes it easier to deal with the difficulties during the NICU stay (Håkstad, Obstfelder, and Øberg, 2016; Lau and Morse, 2001; Spittle, Treyvaud, and Hons, 2016).

Methods

Study design

The present study is based on qualitative methods of phenomenology. The focus of this methodology is based on experiences and meanings and attempting to identify what was unique about participants' meanings. This methodological approach was chosen to understand a wide range of topics related to parents' lived experiences and perceptions after having a preterm infant (Green and Thorogood, 2018; Rodriguez and Smith, 2018; Starks and Brown Trinidad, 2013).

The study was developed in two stages; a first phase was carried out through individual open interviews (OI) to refine the questions that would constitute the interview guide for the second phase. The first phase also allowed researchers to immerse themselves in the context of the study. In the second phase, individual semi-structured interviews (SSI) were conducted to address the research questions of the present study. The entire study was carried out between July 2018 and February 2019. This article presents the results of the second phase.

Following the principles of the World Medical Association Declaration of Helsinki, the study protocol was approved by the Ethics and Research Committee of the University of Vic – Central University of Catalonia (Reference Number: 50/2018). Date of approval: 18th of June 2018. The participants' consenting process was conducted in two stages: verbal (by phone call) and written. All identifying information of participants was removed before analysis, and data were anonymized.

Context of the study

The present study included parents of preterm infants admitted at the NICU of the Sant Joan de Deu Barcelona Children's Hospital (Spain), between December 2017 and May 2018. This facility is a third level hospital, with the neonatal unit open 24 hours. As usual care, the hospital provides the Newborn Individualized Developmental Care and Assessment Program (NIDCAP), which is based on the concept of newborn or child's competence and focuses on respecting the individuality of the very tiny human being and his or her family. The hospital also encourages breastfeeding and parents' involvement during childcare. The hospital provides support to the families during the NICU stay through a multidisciplinary team, consisting of neonatologists, nurses, psychologists, social workers, and physiotherapists. The usual physiotherapy care offered during the NICU stay includes at least one visit aimed at guiding parents during the daily activities in the neonatal unit. Before hospital discharge, parents are invited to a session called "*going home*", where a nurse and a physiotherapist provide specific reminders of the basics of infant care at home.

Between December 2017 and May 2018, in addition to usual- and NIDCAP-based care, some parents and their children were randomly chosen to receive an early PT intervention program during the NICU stay and after discharge. The early PT program was designed as a preventative approach directed toward healthy preterm infants and aimed to enhance the parent-infant relationship, teach parents about preterm infants' cues and management strategies, and improve preterm infants' motor development. This PT program commenced after infants' 32 weeks post-menstrual age, once the preterm infants were medically stable (i.e. no need for invasive mechanical ventilation and no active sepsis). During this period, parents received information regarding preterm infants' development and management strategies (i.e. daily care as a diaper change, feeding, bath, sleep, and postural changes) through six individual sessions with the physiotherapist. Additionally, parents were actively involved in performing the tactile/kinesthetic stimulation to the baby. Based on Fucile and Gisel (2010), the stimulation was administered for 15 minutes (10 minutes tactile and 5 minutes kinesthetic) twice a day, for 10 days. Following the hospital discharge, the program continued at the family home, from term-equivalent age until 2 months corrected age. During this period, the physiotherapist

presented parents a program of activities for the children involving them actively in the intervention. These activities were designed to be included in each family's daily routines and to provide the preterm infants with opportunities to experience different positions and movements appropriate for their development. Activities such as holding the infant while gently encouraging to bring his or her hands to their midline and "tummy time" were included. The follow-up consisted of 3–4 visits at home.

Participants and recruitment

For both phases of the study, the same procedure was developed. Through a purposive sampling approach, as described by Green and Thorogood (2018), parents with a diverse background were selected to ensure the presence of demographic variability within the data. All parents that responded to the phone calls and were willing to meet the interviewer were invited to participate. Before accepting, both parents were invited to participate together in the interviews, with the option of being interviewed separately.

The total sample represented 15 mothers and fathers of 14 preterm infants born with a gestational age between 28–34 weeks and birthweight within 1000–2200 g. They were parents with a varying number of children (1–2), as well as different education levels and origins (Europe, Africa, and Latin America). Some of the interviewed parents received the early PT intervention program (11/15), and others did not (4/15).

To develop the first phase of the study, six parents of four infants (including one set of twins) were invited to participate and only one father declined to participate because of a lack of availability, thus there were five parents included in this phase. In the second phase, 14 parents of ten infants including three sets of twins were selected to participate, and four fathers declined to cooperate because of a lack of availability, thus in this second phase there were ten parents. The demographics of the parents and the infants enrolled in both phases are shown in Tables 1 and 2.

Data collection

At the infants' 3 months corrected age, the interviewer contacted the selected parents by telephone. After receiving parents' verbal acceptance, they arranged a mutually convenient date, time, and place to carry out the interviews.

In the first phase, data were collected using OI, as it allowed the interviewee enough time to develop their account of the issues important to them (Green and Thorogood, 2018). During these interviews, some topics

Table 1. Characteristics of parents and their preterm infants (open interviews).

Interview number	Participant	M/F	Parent age	Parent education level	Parent origin	Infants' gestational age at birth (in weeks)	Infants' birth weight (in grams)	Number of children	Early PT intervention program	Type of interview
01	1	M	28	High School	Argentina	28–32	1000–1250	1	Yes	OI
01	2	F	29	High School	Spain	28–32	1000–1250	1	Yes	OI
02	3	M	33	High School	Spain	28–32	1250–1400	2 (no twins)	Yes	OI
02	4	F	33	High School	Spain	28–32	1250–1400	2 (no twins)	Yes	OI
03	5	M	38	University	Spain	28–32	1250–1400	2 (twins)	No	OI

*M: mother; F: father; OI: open-interview

Table 2. Characteristics of parents and their preterm infants (semi-structured interviews).

Interview number	Participant	M/F	Parent age	Parent education level	Parent origin	Infants' gestational age at birth (in weeks)	Infants' birth weight (in grams)	Number of children	Early PT intervention program
001	01	M	37	High School	Spain	28–32	1400–1800	2 (twins)	Yes
001	02	F	37	High School	Spain	28–32	1400–1800	2 (twins)	Yes
002	03	M	31	High School	Spain	32–34	1800–2200	1	Yes
003	04	M	34	University	Morocco	32–34	1800–2200	2 (twins)	Yes
004	05	M	27	University	Spain	28–32	1400–1800	2 (twins)	No
004	06	F	29	High School	Spain	28–32	1400–1800	2 (twins)	No
005	07	M	30	University	Spain	32–34	1400–1800	1	Yes
006	08	M	37	University	Spain	32–34	1400–1800	2 (no twins)	Yes
006	09	F	39	High School	Spain	32–34	1400–1800	2 (no twins)	Yes
007	10	M	39	High School	Bolivia	32–34	1400–1800	2 (no twins)	No

*M: mother; F: father; SSI: semi-structured interview

of interest for the research were used (Appendix 1). The purpose of this phase was, in addition to plunging into the research context, to refine the questions from the interview guide for the next phase. In the second phase, seven mothers and three fathers were interviewed through SSI. The researcher started the conversation by asking open-ended, follow-up questions to gain more significant insights into the parents' experiences (Appendix 2). This approach enabled participants to share detailed descriptions about their experiences and reflect on the reality of caring for their preterm child (Green and Thorogood, 2018; McIntosh and Morse, 2015). When data saturation was accomplished, because no new information emerged from the interviews, those were concluded, and the sample size was considered achieved.

All the interviews were carried out by the first author and occurred face-to-face at the family home or the hospital respecting parents' preferences. Each participant was invited only once since no second interviews were needed. Both parents preferred to be interviewed together in cases where both the mother and father were participating. The interviews were conducted in the Spanish language, and no translation was needed. The interviewer, also the first author (MOA), is a physiotherapist external from the hospital staff. She responded in a supportive manner, by reassuring or calming to the interviewees if they became distressed during the interview.

The conversations were audio-recorded with the written permission of the participants and then transcribed verbatim by the interviewer with all identifying information removed. Observational field notes about parents' behaviors and field notes registered by the interviewer were included in the transcriptions as "comments". Final transcripts were returned to participants to ensure accuracy of the data.

Data analysis

Data collected from the SSI were analyzed through a content analysis, with a focus on participants' lived experiences. This qualitative analysis form offers an accessible and systematic approach to identifying typical responses and "themes" in the data (Green and Thorogood, 2018; Hsieh and Shannon, 2005). In line with the steps described by Green and Thorogood (2018) transcripts from the second phase were first read and re-read to familiarize the authors with the data. Subsequently, the primary themes of interest were generated, by removing data not related to the topic of interest for the research. Once a provisional list of themes had been identified, they were organized into a set of "codes". The provisional codebook derived from the first analysis was applied to the transcripts. Following this, themes emerged based upon the generated codes and the entire data set. Finally, codes and themes and sub-themes were organized into the results.

The first and the second authors performed the detailed analysis independently, challenging, and supplementing each other's interpretations, leading to further refinement of the analysis. The Atlas.ti qualitative analysis software was used to sort codes, themes, and sub-themes.

Reflexivity

The first author is an experienced pediatric physiotherapist, with knowledge of the field, and has background teaching PT students as an associate professor at the university. The second author is a qualified nurse, experienced in primary health care and qualitative analysis. In particular, the authors assume that their different backgrounds and experience might have influenced their perspective, and subsequently, their analyzes. The authors think that the multidisciplinary approach could have affected the analysis positively in order to obtain the most efficient results.

Results

Through the analysis process of the semi-structured interviews, we found that all parents voiced consistent responses when describing their perceptions about the NICU experience and the impact of early PT intervention (Figure 1). The following three themes emerged from the data when evaluating parents' perceptions: 1) parental competence; 2) difficulties during preterm infants' care; and 3) coping strategies.

In the presentation of the results, some quotations from the interviews are displayed to support the findings. Each quote is coded with the number of the interview (also presented in Table 2), followed by information including who the parent was, number of children, and participation status in the PT program.

Theme 1: parental competence

Subtheme 1: empowerment

Parents that received the early PT intervention program responded in a very uniform manner about the topic. The seven interviewed parents underlined the intervention as helpful and favorable to feel more capable of handling their baby. For example, being taught regarding preterm infants' management and providing the tactile and kinesthetic stimulation to the baby was

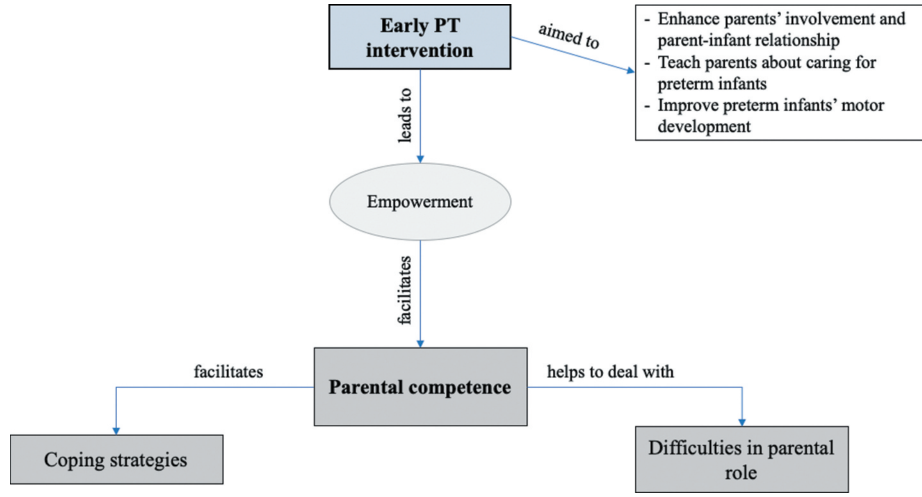

Figure 1. Concept framework of the main research findings.

helpful to lose the fear of harming him/her. In this regard, two mothers described it as "learning" a way to help them to increase competency related to the care of their infant.

> *Now (when asking about the early intervention) I am sure that the way I stimulate him is the correct (...) so, we are trained parents. When we came back home, we were trained. We were confident to do things (...) very positive, very. I mean, our word is: learning. (07 – mother, one child, PT program)*

> *To know how to play or which activities ... how to act in certain situations (...) maybe, now I know what to do if there is something that they don't know how to do. Well, perhaps I am more prepared to carry out what they need (...) to help them, with some activities, to develop what they need. (04 – mother, twins, PT program)*

Accordingly, another mother shared that she felt that the PT intervention empowered her to develop the attachment with her twin preterm children. She added that after the intervention, she felt more confident in enhancing her children's development.

> *For example, I feel that there is a stronger bond because I have been doing things from the program with them and I already took it as a routine, I am more aware, playing .. . to have a mix between play, do activities, and so, that's it. (01 – mother, twins, PT program)*

The participants repeatedly expressed the positive impact of the early PT intervention in the daily care of the baby, principally because of the knowledge they had gained, and its utility to become more aware of adapting the environment to the preterm infant. Also, a father explained that having all the information written had helped him to be more constant when performing the program.

> *So, I think that everything was positive. I mean, in my opinion, all the support is very helpful (...) the advice regarding how to manage her, how to carry her, how to bath her ... I don't know, everything. I think that all the information was very helpful. (08 – mother, two children, PT program)*

As a negative point, a mother of twins shared that sometimes it was challenging to find a slot in their daily routines, because of the lack of time and fatigue.

> *I try to do what the program has taught us, but sometimes it is difficult, because of tiredness and lack of time, sometimes I can´t. But, when I have little moments, I try to play with them, adapting the environment for them, as the program taught us. (01 – mother, twins, PT program)*

Subtheme 2: necessities

This subtheme included parents' perceptions regarding their necessities in order to complete their parental role and to enhance their preterm baby's development. All the participants agreed in their desire to get more information about the prematurity and strategies to improve their child's development. The parents stated that they preferred receiving the information at a slow pace (rather than all at once), not to feel overwhelmed. Interestingly, two mothers proposed that it would have been helpful to receive more information about prematurity and preterm infants' care in the childbirth preparation classes.

> *I think that it would be helpful to give some information in the childbirth preparation classes (...) in the same way that you talk about the delivery and cesarean section (...) it could be helpful to have some classes, I don't know, like a speech or information classes about how to manage a preterm infant. (04 – mother, twins, PT program)*

> *That, information about the preterm babies, because you don't have any idea. You have no idea of … nobody comes to you and tells you "look, a preterm infant is like this" (…) the childbirth preparation classes should talk about it. These classes or the doctor. (03 – mother, one child, PT program)*

> *Well, I would like to have a little more information. Well, not for me because I've already been through it and I've lived it all. But for the other families who really need it, yes. It would be good (…) I would like to … and I would like them to give some speech to parents (…), so they could be prepared. (10 – mother, two children, NO PT program)*

Both mothers that did not receive the early PT intervention program responded in a very consistent manner about their necessities. These mothers highlighted that they went through some challenging situations when handling and caring for the preterm infant during the NICU stay and after discharge.

> *When I had to change his diaper, I felt very strange … because he was so small and nothing fitted him … and I was so scared, because, of course, he was so … small. I couldn't, you know? I couldn't do it during lots of days; I had to ask the nurse to do it. (10 – mother, two children, NO PT program)*

Although they received the usual care (including physiotherapy), both mothers emphasized that they would have preferred to receive more assistance or physiotherapy from the hospital. Even months after discharge, they sometimes felt that they did not know how to deal with some problems, feeling helpless and stressed. An issue mentioned by these mothers was their need to be taught about the management of their premature children. They also needed help to understand and enhance their infants' development and increase their competence to care for the baby.

> *I needed to have a little more information about how to hold them. How to care of them (…) the physiotherapist came, but … it was only once. I felt that … I would need that … she (physiotherapist) came more often, that she could help us more about how to hold them, how to position them (…) during the hospital stay. And to take all this information to home and have it at home. A part of the physiotherapy with them, I mean, a direct intervention, but also to share the information with us to be able to put it into practice. I missed this, something like "how to take care of a preterm infant at home" you know? How to take care, how to hold, how to give … (05 – mother, twins, NO PT program)*

Regarding the health care services offered by the hospital, some participants in both groups expected to receive more visits from the physiotherapist during the NICU stay, as well as more scheduled follow-up visits at the hospital after discharge. These parents felt that this would help them to feel accompanied and secure regarding their child's development.

> *That's what I see that the hospital should have a follow-up. He has been so long at the NICU (…), but after discharge, they have not done any control (referring child's development). This is what I miss now. (03 – mother, one child, PT program)*

> *As I said, they told us that we were going home and then we were alone, we no longer had a person (nurse) who knows how to take care of him 24 hours … however, we were alone at home. (10 – mother, two children, NO PT program)*

Finally, when participants talked about other requirements to perform better in their parental role, some stated that it might be helpful for them to have a professional with which they could consult (e.g. by telephone), especially after hospital discharge.

Theme 2: difficulties during preterm infants' care

The difficulties perceived by the participants regarding infants' care originated in different factors. Principally, the results were organized in two main origins: 1) personal situation; and 2) health services.

Subtheme 1: difficulties related to personal situations

During the hospital period, participants voiced experiencing mixed feelings regarding their preterm child's care (e.g. frustration, insecurity, or fear) and other positive emotions (e.g. hope, gratitude, confidence, and love).

The most significant difficulty described by mothers was related to feeling like a mother, especially during the first days in the NICU. They shared the challenge of feeling like a real mother without being in charge of the daily care of their baby in the NICU and the feeling of not being able to do anything. Also, they reported experiencing difficulties when it came to bonding with their child.

> *In the NICU, you can't feel like a mother. Because he is there, in a little box. So, you can't take care of him; you can't do anything. Everything is done by the nurses. Then, no … you don't feel like a mother. You can't close the bond with your baby, because he is there, he feels abandoned, you feel that you have left him (…) you feel like an abandonment. (03 – mother, one child, PT program)*

For example, during the early period in the NICU, mothers felt insecure when handling or caring for their preterm babies by themselves, especially those that did not receive the early PT intervention. Because of the small size of the new-born, mothers describe that they felt afraid of harming the baby. Sometimes, they saw the

child as too fragile and delicate, and the presence of the invasive lines was not pleasant either, which increased their insecurity. Due to these feelings, they had to deal with the senses of being an observer or incompetent.

Mothers with twins or other children found it challenging to deal with hospitalization in the NICU. For example, one participant felt frustrated when her twins could not be placed in the same room because one of them needed to be taken care of in the NICU while the other was more stable and was transferred to the intermediate care unit. Also, those parents with older children at home felt as if they were abandoning one of the children when they were with the other one.

> *That was the hardest thing (to have the other sibling at home), it was like ... you want to be on both sides, and you can't. Then, you feel frustrated because you can't be with both of them. (08 – mother, two children, PT program)*

Other difficulties that the participants emphasized regarding their infants' care at home were related to the lack of support from their partners. All the interviewed mothers were the child's primary caregivers, and all the fathers, except one (who was also the primary caregiver), had returned to their jobs after approximately 5 weeks. Mothers expressed that in the early days at home, they felt fear and overwhelmed because of the lack of support to take care of the baby.

> *When he (partner) went back to work, and I stayed 100% alone with her ... I had very critical 2-3 weeks, but not for taking care of her ... well ... yes, yes, I was afraid to be alone with her ... everything was a world (...) so, I had a few weeks feeling very overwhelmed. (07 – mother, one child, PT program)*

Finally, some mothers reported difficulties in understanding concepts related to prematurity. For instance, understanding the difference between the corrected age and chronological age was complicated for some of them, and their social environment. Therefore, it also increased parents' anxiety.

> *I don't know if other mothers have the same problem, but for my family and me, the corrected age is the most challenging thing to understand. We don't understand. He was born on that day, and you can't understand that he has two ages. That was and still is something hard for me. Because, for me, he is 4 months old, he is going to have 5 the next week, and I don't understand that actually, he is 3 (...) I feel anxiety; it makes me feel anxious, the corrected age, the chronological age ... (03 – mother, one child, PT program)*

Subtheme 2: difficulties related to health services

Regarding difficulties related to the health professionals and the hospital, although many participants described the hospital staff's assistance as supportive and helpful, some mothers experienced some issues associated with the daily life or routines of healthcare professionals. For example, one mother shared that she felt that the bedside nurse was usually very busy, which made her feel helpless. Also, some mothers expressed different unpleasant events with some nurses. Generally, they felt that nurses pressured them to decide about breastfeeding. They also felt that some nurses were not empathetic enough, which led to them feeling guilty and more frustrated.

> *What the nurse told me, if I was going to decide about the breastfeeding ... I am the first that wants to feed my son, I don't need anyone to tell me (...) she told me that I was doing it wrong! That I didn't feel like taking my milk, and that's why I couldn't draw it. (03 – mother, one child, PT program)*

Some parents expressed their uncertainty when they found that some health professionals gave them different information, in particular, between the hospital professionals and the primary care staff. This increased their uncertainty regarding their child's care. For example, a mother shared that she felt helpless because of the discordance of the information given by the pediatricians and nurse (post-hospital discharge, at the primary health area).

> *What is more "difficult" for me (when asking about the difficulties) is the issue of food, which is what they (the doctors) just don't agree with. Because the pediatrician tells me something, and the nurse another thing, and it depends with whom I have the appointment. So, the information is very different and it's the only thing that I have not quite clear (...) and it's a bit frustrating. (05 – mother, twins, NO PT program)*

> *The issue of the weight. That also annoyed us a lot, because they told us ... each doctor told us something different about the weight. The pediatrician tells me one thing, the nurse tells me another thing (...) so, you think ... "well, finally you are the one who decides" (...), and I felt ... I felt a little bit unprotected. (07 – mother, one child, PT program)*

An additional issue mentioned by the participants was regarding the lack of knowledge about preterm infants and their care, explicitly referring to the primary health care service. Some parents found that the public health service lacked knowledge about the care and health of the preterm child. This issue made them feel more frustrated and insecure.

Concerning the hospital, some mothers explained that they experienced difficulties related to the hospital routines. These mothers found that hospital routines were rigorous and very repetitive so that they felt like they were living the same day repeatedly, which increased their anxiety. In this regard, one mother stated that she felt very occupied with the hospital routine care,

such as diaper changing. As a consequence, she felt that it was complicated to enjoy her daughter as much as she wanted and needed.

> *The stay at the hospital was very hard. It was very very intense. It was as we were in a kind of loop, every day was the same, at the same time, the same routines, the nurses (...) with the same schedules ... it was as if we had entered into a kind of loop and it was always the same day. Take their weight, breastfeed them, the thermometer, change the diaper ... everything every 3 hours. (05 – mother, twins, NO PT program)*

> *Sometimes I felt that ... I couldn't enjoy her a lot. Because ... I enjoyed feeding her, but, I don't know, it isn't the same to holding her, telling her things, isn't it? So, I felt it was like: "change the diaper", "cure the navel", and start it again, you know? And, sometimes I said "I have the feeling that I am having little moments to say: I care for her, I hold her, I pamper her". (07 – mother, one child, PT program)*

Theme 3: coping strategies

The findings presented in this section were centered around parents' coping strategies developed at the NICU to be able to deal with the situation and adapt themselves to the preterm infant's care.

Subtheme 1: problem-focused strategies

The problem-focused strategies (such as seeking support from the health professionals, the social network, or on the internet; and problem-solving) were most often highlighted by the parents. For example, during the first days in the NICU, they had to deal with the senses of being observers. The participants described two main things that helped them to cope with the frustration and the difficulty of feeling like a mother: experiencing that they were allowed to touch and hold their baby and being involved in their child's care. Most of the participants expressed positive emotions remembering the day when they were allowed to take care of their infant through skin-to-skin holding. They described this experience as the first most crucial moment between them and their baby.

> *The feeling is like ... I don't know how to explain it. They have been born, and you haven't had "that" contact (touch), it was like ... very surreal. I mean, until I touched them, I was not there, you don't believe it. It's different (...) the experience. Because you have been waiting to go home with your babies and ... you go alone, you are alone (...) Because I hold the first of my babies 2-3 days after giving birth. So, there has been more contact. However, with the other baby, it took like a month for me to be able to hold him. It was like giving him birth again. It was the same feeling. (04 – mother, twins, PT program)*

> *When I already was able to take him, change his diaper, see him ... I started to feel like a real mother. (03 – mother, one child, PT program)*

Most of the parents, even those who had had another child before, described how being helped and involved by bedside nurses had helped them to feel more secure.

> *There was a nurse, who taught me everything, everything in the unit. She was who told me "come, I'm going to teach you how to change his diaper, clean him with serum, (...)" so, she taught me many things like how to contain them, how to change their diaper ... it makes you feel like a mother, you know? (01 – mother, twins, PT program)*

> *Let's see ... you had that fear of hurting her. I was like, "we are going to do everything with great care". And, although she was my second child, I often asked nurses to help. (...) I needed more security. And it was also the satisfaction of being able to do it. I said, "I am the one who is being able to do it". So, you have that feeling that you are able to care of her. And you feel useful with her. (08 – mother, two children, PT program)*

All the interviewed mothers expressed that it was easier to deal with the hospital stay due to the support they received from their partners and other family members. Also, sharing their feelings and experience with other parents and families in the same situation was comforting for the participants because they felt that they were not alone.

> *It was a feeling of relief, my husband did not separate from me, he was with me all the time. (07 – mother, one child, PT program)*

> *To be in contact with other families was very nice. Very nice. It is something that I appreciated because you can share your experience, they explain theirs ... you see that things that you feel and think are common, you don't feel alone when sharing your experience. (05 – mother, twins, NO PT program)*

Other problem-focused strategies used by the participants include searching for information on the internet or from health professionals. Most of the parents considered clear and honest communication about their child's condition and current status as a facilitator. When parents felt that they were appropriately informed and their questions were answered honestly, it was calming because they felt more secure and grateful.

> *At that moment (when they were informed that their children were going to born prematurely), I turned into a neurologist. I read and searched for a lot of information. (01 – mother, twins, PT program)*

> *As I ask everything, they (health professionals) informed me a lot. Even with pediatricians, with everyone (...)*

I asked absolutely everything. I mean, even if they thought "it's a nonsense", anyway, I did not care, I asked them just in case. (05 – mother, twins, NO PT program)

Subtheme 2: emotion-focused strategies

Participants also described some emotion-focused strategies as facilitators to deal with the situation. Wishful thinking, hope, and positivity were part of their daily strategies to cope with the days at the NICU. All the parents agreed that their greatest hope was to bring the infant home as soon as possible.

"One day less" was … what I repeated to myself, I consoled myself. (03 – mother, one child, PT program)

What I hoped … was to take them home, to have them at home with us. The first weeks that they were in the incubator, I came here (home) and I used to say, "I'm looking forward to having them here on the couch with me", or when I was at bed, I hoped to have them in bed with me. (06 – mother, twins, NO PT program)

Also, remaining near the preterm baby or focusing on daily progress were also positive emotion-focused approaches that parents adopted to struggle with the fact of being at the NICU.

I used to wake up at 7 in the morning, at 8 we left home and we used to arrive back home at 11 or 12 at night. I mean, I did not separate myself from her. (07 – mother, one child, PT program)

Having previous experiences (such as other children or having seen other babies with the invasive lines) were also helpful for some parents. These parents explained that having seen other babies at the NICU helped them to face what it means to have a preterm infant.

I supposed that, because of having seen another new-born intubated before (a friend of the family) … you are like more prepared, of course, it is different because she is not your daughter, but you can imagine how is it … at least … the feeling of seeing her intubated and with the cables. (09 – father, two children, PT program)

Discussion

The present study, based on qualitative methods of phenomenology, explored the early experiences of ten parents who had a preterm infant admitted at the NICU of the Sant Joan de Deu Barcelona Children's Hospital. Analysis of the data was summarized around three main themes: parental competence, difficulties related to infants' care, and parents' coping strategies.

The early PT intervention was focused on encouraging parental involvement (through the tactile and kinesthetic stimulation and education on preterm infants' care) and empowering parents (by providing information during NICU and at home). Participants that received this intervention felt more competent, secure, and empowered when caring for their baby and promoting their development. They found it to be beneficial and positive to alleviating some of the general stressors reported, such as feeling useless and insecure. Differently, interviewed parents that only received the usual physiotherapy at the hospital expressed their insecurity when managing the preterm infant during the NICU stay. They also experienced challenges when being in charge of the daily care of their preterm baby at home and promoting the child's development. Furthermore, the necessities described by these parents were related to handling and caring for their babies.

As shown in previous studies (Al Maghaireh et al., 2016; Dusing, Murray, and Stern, 2008; Fernández Medina et al., 2018; Håkstad, Obstfelder, and Øberg, 2016; Kynø et al., 2013; Lamontagne, Johnson, and Hepworth, 1995; Øberg et al., 2018; Russell et al., 2014; Toral-López et al., 2016), parents' involvement in early intervention programs both during NICU stay and after hospital discharge facilitates parents to develop coping strategies and to increase their parental competence, and also increases parent-infant attachment and bonding. Similarly, the early PT intervention described in the present study, based on parents' involvement and empowerment, was useful to help them to develop adequate coping strategies and mitigate some of the stressors experienced during the NICU stay and, consequently, to promote their parental role.

The results related to parents' difficulties when caring for their baby and coping strategies developed to deal with the prematurity were consistent with previous research (Baum, Weidberg, Osher, and Kohelet, 2012; Al Maghaireh et al., 2016; Cleveland, 2008; Premji et al., 2017; Russell et al., 2014; Stacey, Osborn, and Salkovskis, 2015; Toral-López et al., 2016). On the one hand, parents' difficulties were primarily related to personal situations that were translated to the disruption in healthy parenting, such as not being able to personally care for their baby. In previous research, this difficulty has been directly associated with the frustration related to not feeling like a mother during the NICU stay and the development of expected parental responsibilities

(Al Maghaireh et al., 2016; Miyagishima et al., 2017; Perricone et al., 2014; Provenzi et al., 2016; Provenzi and Santoro, 2015; Reid, 2000).

On the other hand, as described by the transactional theory of coping, parents of preterm infants usually focus on both problem- and emotion-based strategies to cope with the situation of prematurity (Lau and Morse, 2001). These responses depend on parents' cognitive appraisal (i.e. attitudes, attributions, beliefs, and thoughts) about the birth of their preterm infant, and help to manage the difficulties experienced regarding the interrupted parenting activities (Lau and Morse, 2001; Provenzi et al., 2016). Participants that received the early PT intervention highlighted that becoming involved in their child's care was helpful for them. As also described by the theory of coping (Lamontagne, Johnson, and Hepworth, 1995; Lau and Morse, 2001), this involvement helps them to increase their identity as parents, feeling helpful and connected to their baby (Håkstad, Obstfelder, and Øberg, 2016; Øberg et al., 2018; Provenzi and Santoro, 2015; Russell et al., 2014). Other strategies, such as seeking social support, asking for professional help, and sharing their experiences with other parents in a similar situation, were also helpful to feel accompanied and supported and deal with the difficulties during the NICU stay. Accordingly, Stacey, Osborn, and Salkovskis (2015) suggested that relationships with health professionals and other parents are important factors while determining parental coping, as well as promoting parental involvement in a child's care. Therefore, it is noteworthy that parents deal better with not being the principal caregivers for their babies when they are supported by the health professional for their infant's care and, also, when they share their experiences with other parents in the same situation.

In the case of the present study, as described above, the disruption of parents' function of caregiving during the early stage in the NICU could have challenged their competence, because they felt that they were not the major caregivers for their babies. Even though the hospital provides many involving opportunities for parents (e.g. opening 24 hours, the NIDCAP, encouraging parents' involvement during childcare, and offering information), participants experienced a high perception of incompetence. The sensation of helplessness among parents might be a result of their increased stress level and situation of prematurity. Also, when mothers were already involved in normal parenting activities, some of them were too focused on taking care of their children. As a result, they expressed having difficulties perceiving it as a moment to enjoy and develop their parenting role. These events could challenge parents in developing their parental role and coping responses. This is consistent with the literature, where it has been shown that stress from adverse life events, infant-related stress, and marital related stress are predictors of parent-infant relationship and attachment, as well as parental competence, which are components of the parenting role (Al Maghaireh et al., 2016; Mercer and Ferkehch, 1990).

Therefore, it is suggested that the health professionals should consider this knowledge to help parents to develop coping skills, bond with their preterm infant, and to encourage their parental competence. Other examples to help parents cope include encouraging them to express frustration and focusing on the daily progress of the child or accepting responsibilities (Lau and Morse, 2001; Lazarus, 1993). From the PT approach, touch and hands-on activities provided by parents might be a useful strategy to increase parents' competence to take care of their baby and to reinforce their parental role (Håkstad, Obstfelder, and Øberg, 2018; Øberg et al., 2018). Also, as stated by Toral-López et al. (2016), distancing is an emotion-focused strategy, and it is appropriate to recommend parents to leave the hospital for some time every day, to be able to disconnect and not to overthink. We add that this could also be a useful coping approach to endure the hospital routines.

Implications for practice

Based on the findings, we suggest that the physiotherapist should be involved in guiding and attending to the needs of the parents in the NICU and after hospital discharge. As recommended by other authors (Benzies, Magill-Evans, Hayden, and Ballantyne, 2013; Dusing, Murray, and Stern, 2008; Håkstad, Obstfelder, and Øberg, 2016; Kynø et al., 2013; Puthussery et al., 2018), we agree that interventions should be designed to enhance parents' involvement and based on parents' empowerment about infant management, education about infant development, and increasing parents' competence. Dusing, Murray, and Stern (2008) similarly suggested that physiotherapists should use a combination of formats to educate parents of preterm born infants about their infants' development, as well as methods to support motor development in the NICU and at home. Based on our findings, we also recommend that early PT intervention should ensure parental involvement by individualizing and adapting the intervention to each family's needs and context and considering their coping strategies.

Study limitations

The present study has several limitations. First, the data presented in this research were gathered from a small sample of parents recruited from a single site. As a consequence, it is difficult to know how representative their views might be regarding a broader population of preterm parents. Furthermore, the hospital from where participants were recruited is a third level hospital and implements NIDCAP-care. The results should be treated with caution when generalizing to other NICUs. Also, the groups of parents that received the early PT intervention and those that did not were not balanced. The parents that did receive the experimental intervention were more in touch with the hospital staff, so they were easier to contact and were more willing to meet the interviewer. However, the parents that did not receive the early PT intervention were more challenging to contact, and they reported being too busy to meet the interviewer because of the situation with the preterm infant at home. Therefore, we could not achieve more balanced groups. Further research within different, contrasting therapeutic approaches might increase the evidence and knowledge regarding the effect of early PT intervention on preterm infants' parents' competence and coping strategies.

Conclusion

Early PT intervention throughout parents' involvement in infants' care and education sessions was associated with parents' increased empowerment. The participants in the present study experienced difficulties when caring for their preterm babies during the NICU stay and after discharge. These difficulties were related to health services and personal situations, such as interruption of normal parenting activities. However, participants that received the early PT intervention developed coping strategies to deal with prematurity and challenges in the parenting role. Contrarily, the parents that did not receive the early PT intervention expressed difficulties when handling their baby and experienced more stressful events when caring for their infants.

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Appendix 1. Topics of interest for the research (open-interview questions)

Topic of interest	Open questions
Thoughts and feelings	What were your beliefs about premature children? What were your thoughts and feelings when your child was born prematurely? What were your beliefs about the care of premature infants? What were your expectations about premature infants' development? Can you tell me more about what it was like when you were told your baby was going to be preterm?
Barriers and facilitators	What do you remember about the initial days you were home after discharge? What support do you have to take care of your premature infant? Tell me about the challenges in caring for your baby. What would you like to had from the environment? What do you think is necessary so that families can better develop care for their premature infant?
Early PT intervention program	What do you think about early physical therapy intervention program that you received? * Do you think that the program brought you something? *

*Only for parents that received the early PT intervention program

Appendix 2. Semi-structured interview guide

AreasQuestionsBeliefs regarding prematurityWhat were your beliefs about premature children?What did it mean for you that your baby was born prematurely?What were your expectations and knowledge about the care of a premature child?What were your expectations about premature infants' development?Hospital stayHow was the first feeling of being a mother in the NICU?How was the experience during hospital admission?Tell me about the challenges in caring for your baby.Tell me about your experience and concerns at the hospital.How was the relationship with the other families? What would you say to a mother who just had a preterm infant?Is there anything that you missed during the hospital stay?Care at homeHow do you feel about taking care of your preterm baby?What support do you have to take care of your infant?Tell me about the challenges in caring for your baby. Tell me about the moments you feel confident about caring for your baby. Parental competencesWhat has contributed to you the early physical therapy intervention program you have done? *In what way do you feel able to favor your child's development after the early PT intervention program? *Do you think that something else should be done to favor the parenting skills?
*Only for parents that received the early PT intervention program.