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Living with a birthmark: Phenomenology of prematurity for mothers in Turkey

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ABSTRACT

Background: Mothers of premature infants are in the risk group for having psychological symptoms and attachment-interaction difficulties. Preventing these maternal risks is essential for providing optimal care and health opportunities for infants, consequently improving developmental outcomes.

Methods: In this study, we aimed to understand how mothers experienced prematurity within four processes retrospectively: (a) the mother's hospitalization after birth, (b) the infant's hospitalization in the Neonatal Intensive Care Unit (NICU), (c) after discharge, and (d) in early childhood. We adopted Max van Manen's phenomenology of practice and interviewed nine mothers whose children were born premature and reached early childhood.

Findings: The themes were as follows: (a) *incomplete mother*; (b) *facing prematurity, uncertainty, natural touch barrier, facing reductive social response*, and *NICU friendship;* (c) *being on the alert, a period of complete closure*, and *fighting with the reductive social response;* (d) *association to prematurity* and *(cannot) overcome the difficulties.* We expressed the mothers' overall experiences through the metaphor "*living with a birthmark.*" This metaphor represents the longitudinal effects of prematurity. As much as it is apparent and painful at first, it fades over time, and the pain lessens, but the effects of the birthmark remain in early childhood. The birthmark becomes a part of the mother-baby relationship.

Conclusions and practice implications: Our study contributes to premature infant care and health literature by highlighting the longitudinal experiences of mothers on prematurity.

Introduction

Although the survival rates of premature infants have increased by the progress made in Neonatal Intensive Care Units (NICU) in the last 30 years (Blencowe et al., 2012), premature birth is still one of the leading causes of perinatal and under-five mortality worldwide (World Health Organization, 2022a, 2022b). According to World Health Organization, premature birth has three sub-categories based on the gestational age: extreme (28 < weeks), very (between 28 and 32 weeks), and medium or late (between 32 and 37 weeks) (World Health Organization, 2018). Many long or short-term developmental and biological risk factors are associated with prematurity (Carvalho et al., 2019; Kobaş et al., 2022; Lean et al., 2018). Mothers of premature infants face several difficulties and stressors due to these risk factors (Arnold et al., 2013; Baia et al., 2016; Gonçalves et al., 2020). Therefore their parenting experiences differentiate from parents whose babies were born term (Gibbs et al., 2015; Gonçalves et al., 2020; Hall et al., 2013). Mothers of premature infants are in the risk group to exhibit more depression, anxiety, and attachment-interaction difficulties in the long term (Bozkurt et al., 2017; Butti et al., 2018; Dimitrova et al., 2018; Neri et al., 2017; Treyvaud et al., 2014). Paradoxically, due to these difficulties experienced by the mothers, the cognitive, neurological, behavioral, and social development of infants are negatively affected in the long and short term (Bozkurt et al., 2017; Dimitrova et al., 2018; Huhtala et al., 2014). Thus, determining and understanding mothers' detailed and extended experiences is essential to provide appropriate early intervention practices. Family-Centered Care (FCC), a healthcare standard and approach in nursing (Ahmann, 1994; Ahmann & Dokken, 2012), is an essential principle for early intervention practices concerning the negative experiences of premature infants' parents in NICUs (Blomqvist et al., 2022; Dien et al., 2022; Weber et al., 2022). When we consider the situation of the FCC in Turkey, there are no government-based or private/public hospital-based policies regarding FCC in NICUs (Feeg et al., 2016). Although there are some studies on kangaroo mother care (Erduran & Yaman Sözbir, 2022; Kurt et al., 2020), infant care training (Kadiroğlu & Güdücü Tüfekci, 2022) and FCC practices (Albayrak & Büyükgönenç, 2022; Zengin Akkus et al., 2020) in NICUs, these practices are limited and rare.

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In the existing phenomenological studies, mothers' experiences are mainly examined during the NICU (Abuidhail et al., 2017; Baum et al., 2012; Malakouti et al., 2013). Fewer studies were examined both during the NICU and a few months later after discharge (Hall et al., 2013) or only after-discharge experiences (Griffin & Pickler, 2011; Murdoch & Franck, 2012; Phillips-Pula et al., 2013). Only one study examined mothers' experiences at 18 months postpartum (Jackson et al., 2003). Therefore, the international literature is limited concerning mothers' experiences for a more extended period. In our study, we examined the mother's experiences after discharge and early childhood in addition to the mother's hospitalization after birth and NICU.

To our knowledge, no phenomenological research has been done with mothers of premature infants in Turkey regarding their experiences during the NICU or after discharge. Moreover, qualitative studies in Turkey examined mothers' needs during the NICU process (Balacan et al., 2020; Eryürük et al., 2021), not their detailed experiences of being a mother of a premature infant or the meaning they attributed to prematurity.

In this study, we aimed to understand how mothers in Turkey experienced prematurity within four processes retrospectively: (a) the mother's hospitalization after birth, (b) the infant's hospitalization in the NICU, (c) after discharge, and (d) in early childhood. Our study contributes to the national and international literature in terms of a retrospective and holistic approach regarding the experiences of preterm infants' mothers from their hospitalization after birth until their children reach early childhood. More insight into these experiences may give a deeper understanding of premature infants' mothers' lives longitudinally and provide directions for healthcare professionals to enhance early intervention services.

Method

Study design

We conducted our study in a phenomenological research design. Phenomenology is concerned with revealing the essential meaning or meanings of human experience (van Manen, 2007). We followed van Manen's phenomenology of practice in our study (van Manen, 2016), which could be classified under the hermeneutic tradition (Finlay, 2014). We shaped our study around the question, "how do mothers of premature infants experience prematurity through some experiential processes, and what does prematurity mean for them?" We obtained ethical approval for all the study procedures as a preliminary part of a future-dated early intervention project.

Data collection, interviewing, and participants

We reached mothers through various groups for parents of premature babies on Facebook. These groups are created for the parents of premature infants' to communicate and share their experiences. The numbers of group members vary between hundreds and thousands. The first author searched for the groups on Facebook at the beginning of 2020 and sent a request to join groups by introducing herself and stating her purpose. After the administrators' approval for five groups, she shared an announcement post in each group about the research and waited for mothers to volunteer to participate. Preliminary interviews were done with 12 mothers who volunteered, and detailed information about the research was given to the mothers. Three of the mothers stated that they were indecisive about joining the study and wanted to be optional participants. Consequently, we agreed that if the interviews we conducted did not provide enough data, we would contact them again. Then, appointments were made for the interviews to be held. We conducted interviews via telephone because of the shutdowns due to the COVID-19 pandemic. All participants provided written informed consent prior to enrolment in the study via Google forms.

We interviewed nine mothers, seven of whom had very and two had extremely premature births. All mothers were still married to fathers, had C-sections, and all fathers were working. The other detailed characteristics of mothers are shown in Table 1. The first author conducted interviews between 21 April and 2 May 2020. The duration of the interviews varied between 45 and 120 min. Semi-structured, non-directive, and open-ended questions (e.g., *"What do you remember about the birth?" and "What do you remember about your hospitalization after giving birth?"*) were used as a guide. In addition, some exploratory questions (e.g., *"What did you do when this happened?" and "What did you say or think when this happened?"*) were used to obtain detailed experience descriptions (see Annex-1 for the interview guide). Two assistant students transcribed the interview recordings.

In phenomenological research, gaining "examples" of experientially detailed descriptions is essential. Thus, the critical point is not the number of participants but data saturation. Data saturation does not depend on some logarithm, statistical criterion, or formula. To reach data saturation, the researcher keeps collecting data until the analysis reveals nothing new or different about the group (van Manen, 2016, p. 353). After the seventh interview, we realized that the data revealed nothing new or different. We conducted the remaining two scheduled interviews and were sure about data saturation.

Data analysis

Before we started the thematization in our study, we tried to became more familiar with the data by reading through all the transcripts and replaying the audio recordings. Then, we determined the lived experience descriptions and edited them into anecdotes. This kind of editing in phenomenological research is called *"the evocative method"* (van Manen, 2016, p. 250). After that, we read the anecdotes through wholistic, selective, and detailed reading, as van Manen (2016) suggests within the thematic analysis. In the *wholistic reading*, we considered the edited anecdotes as a whole and tried to capture the main significance. In the *selective reading*, we highlighted the statements that seemed essential or revealing about the phenomenon by reading the edited anecdotes several times. Then we wrote some descriptive/interpretive notes to capture the phenomenological meanings. In the *detailed reading*, we looked at every single sentence or cluster in the edited anecdotes and asked the question, " What does this sentence say about the experience of having a premature infant/child for a mother?" to be able to see the phenomenon which is revealed. In the end, we identified themes for each experiential process and a general theme that covers all of them. While doing the analysis, we used the qualitative research software MAXQDA (version 20.4.1).

Metaphor use in data analysis

The concept of metaphor can be defined as trying to understand or explain something by thinking of it as something else (Davidson, 1978; Gaut, 1997; Moran, 1989; Yoos, 1971). The use of metaphor, which is seen as an important element of poetry and narrative, has an important role in understanding scientific theories and concepts and in explaining scientists' ideas and theories to others (Kwesi, 2021). However, there are conflicting views on whether the metaphor is truth-evaluable or not. Therefore it is necessary to consider the use of metaphors carefully. According to Yoos (1971, p. 86), *"if we are not careful in distinguishing the meaning of the metaphor in the sense of what is signified from the meaning of the metaphor in the sense of what is intended by the use of metaphor, we may mistakenly identify the direct and indirect meaning as being connected or associated by a set of semiotic rules."* We adopt this view regarding the use of metaphors, and we believe that the use of metaphor in our study strengthens the expression of the meaning that emerges from the data.

Table 1
Detailed Characteristics of Mothers.

Mothers	Baseline characteristic																	
	Mother											Child						
	City	Current age	Working	Education level	Parity	Gravidity	Gestational week at birth	Complication before delivery (week)	Hospitalization before birth (day)	Hospitalization after birth (day)	Current nursing/counseling care	Gender	Birth order	Twin birth	Birth weight (gr)	NICU duration (day)	Current age (month)
M1	Ankara	41	✓	College	2	2	25	23rd	3	1	–	Boy	2nd	No	800	93	36
M2	Mersin	38	✓	Graduate School	1	1	25	–	2	1	–	Boy	1st	No	850	72	36
M3	İzmir	29	X	Junior College	1	1	32	–	–	1	Standard health follow-up	Girl	1st	No	1855	24	24 (adjusted)
M4	Ankara	31	✓	Graduate School	1	1	31	26th	30	3	Standard health follow-up	Boy	1st	No	800	26	18 (adjusted)
M5	Ankara	39	X	College	1	1	32	20th	21	1	–	Boy	1st	No	2130	20	42
M6	Zonguldak	36	X	High School	2	2	30	–	–	5	Standard health follow-up	Boy	2nd	No	1600	20	24 (adjusted)
M7*	İstanbul	31	✓	College	1	1	28	–	–	3	Standard health follow-up, private counseling	Boy	1st	Yes	1080	48	18 (adjusted)
M8	İstanbul	40	X	College	2	2	31 29	–	–	1 4	–	Girl Boy	1st 2nd	No	1680 1455	28 63	48 36
M9	Bursa	29	X	Junior College	1	3	29	21st	42	3	Standard health follow-up, private physiotherapy service	Girl Boy	1st	Yes	1050 1350	68 57	18 (adjusted)

Note. *Mother 7 had lost one of her twins in 28th gestational week and immediately had taken under operation for C-section.

Rigor

Although we adhere to reporting guidelines of Standards for Reporting Qualitative Research (O'Brien et al., 2014), van Manen (2016, p. 348) states about validity in phenomenology: "*The validity of a phenomenological study has to be sought in the appraisal of the originality of insights and the soundness of interpretive processes demonstrated in the study. No predetermined procedure such as 'members' check' or 'triangulation of multiple methods' can fulfill such demand for validating a phenomenological study.*" Thus, we did not use standard validity criteria (Creswell & Miller, 2000) defined for other qualitative studies. Instead, we made a list that includes our preliminary information from the literature, our existing theoretical and practical professional background (which is in infant and child development, parenting, parent-infant interaction, and early intervention fields), and our assumptions about this research. We kept this list in our mind throughout the research. Thus, we tried to set aside our prior knowledge or judgments and place ourselves open to experience (epoché) while trying to grasp the essence of the phenomenon and reflect it (reduction) phenomenologically (van Manen, 2016).

Results

All the themes in our study results are generated from the data we obtained. Mothers' lived experience descriptions are given in italic lines throughout the text.

Mother's hospitalization after birth

Incomplete mother

Mothers were deprived of their babies and of the experiences that can be seen as complementary to birth. "*They took me to the room. The sounds of babies were heard. They had put me in the unit where they hospitalized mothers. However, my side was empty, and my baby was not there with me. I cried a lot when I realized this.*" (M 5). The incomplete mother theme involved mothers' shock, disappointment, and self-blame reactions to premature birth.

Infant's hospitalization in the NICU

The traditional NICUs (Level III) in Turkey include a common ward with a maximum of twenty incubators. The visiting hours are restricted. While some hospitals allow one-day visits per week, some hospitals allow daily or once in two days visits. The visit time also may vary according to the hospital rules, but it can be a maximum of 15–20 min. During this period, the mothers cannot touch their babies most of the time. Rarely, and when the baby's condition is deemed appropriate by the staff, the mothers may touch or hold their babies for a short time. Hospitals with NICUs must have a mother-baby adjustment room with a maximum of three beds, which is subjected to the same standards as regular patient rooms. These rooms are used to provide information and education about baby care and breastfeeding to the mothers when the babies' discharge is approaching (on average, one week before). All mothers we interviewed had undergone the NICU process under these general circumstances.

Facing prematurity

When mothers first entered the NICU to see their babies, they were confronted for the first time with what prematurity means. This image represented a highly traumatic scene for them. "*They took me in a wheelchair to the NICU. After walking through its door, I felt weird seeing the tiny babies in incubators. There were wires everywhere on their body and hoses in their mouths. We passed such a hall, and they stopped me in front of an incubator and said to me, This is your baby.*" (M 1). Until that moment, mothers could not comprehend what a premature baby looked like. "*There were wires all over him, voices, the nurses. His hands and feet* *were purple, and all the veins on his face were visible. Under such thin skin, I could see his heart. His head looked like it was bent to one side." (M 8).* At the start of this process, the mothers were faced with the fact that they could not touch their babies whenever they wanted and could not take them home immediately. These confrontations were challenging for the mothers and represented a breaking point. "*I was shocked when I saw my baby in the incubator. The breaking of my resistance started that day. Because I was thinking, we will go and get her home the next day. It did not happen, and then I struggled more.*" (M 3). The NICU climate (e.g., sounds, devices, terminology, other babies) was also compelling for mothers. "*When I was in the NICU, I could see other babies in the same or worse condition than mine. This situation was pushing me too hard. There were constant device sounds; beep-beep, beep-beep.*" (M 2).

Uncertainty

The uncertainty of the process covered a large part of the mothers' anxiety in this process. It was unclear whether the baby would survive or, if the baby did survive would she/he be healthy. Because the mothers had difficulty due to this uncertainty, they found it challenging to focus on their interaction with their babies. "*I wonder if his development will delay, will he gain weight, will he catch up with his peers? Questions like these were always on my mind. So, I was very anxious when I spent time with my baby because of these questions.*" (M 4). Feeling intense anxiety due to those uncertainties, the mothers needed to know what the medical examinations of their babies meant. When they did not receive information about these examinations, self-search on the internet increased the possibility of the mothers being misguided. "*One day, it was written blood in stool on my baby's incubator's glass. I asked the doctor what it meant. He said general control but did not explain. Then I started doing research and learned that they searched for colon cancer. I said, Oh, no! I panicked even more. Is there any cancer? If so, what will happen? What kind of process awaits? I was left with such thoughts.*" (M 3).

Natural touch barrier

Mothers indicated that not having a baby at home while being a mother caused intense sadness. "*Whenever I saw my baby and came home, I would see that he was not at home again, and I would always cry.*" (M 1). The mothers who could not touch and hold their babies until a particular time still wanted to receive a signal that their babies felt their presence when they went to see her/him. "*His eyes were closed every time I went to see him. I constantly asked the nurses, Did he ever open his eyes? Then one day, when I went in front of the incubator, my baby was looking at me with his eyes open. It was such a big deal for me that he opened his eyes. I said, Yes! He opened his eyes; he heard me!*" (M 5).

The times when the mothers could touch or hold their babies were minimal and different from the usual mother-baby interaction. "*When I went to see my baby, I could touch him only if I washed and sterilized my hands and put on all my protective gear. I was putting my hands in the incubator and touching his face, body, hands, and feet.*" (M 2). For the mothers, this process meant not being able to interact with their babies as they wished. "*I could not smell my twin babies to the fullest during the NICU process. Instead of me, nurses washed, applied oil and cream, and dressed them. Those things made me very sad.*" (M 9). When the mothers could hold their baby for the first time, they felt very nervous because of the wires attached to the babies' body and were surprised by how tiny their baby was. "*A nurse made me sit on a chair next to the incubator and said we would make kangaroo care. My baby was so tiny that I was excited and scared at first. He had a catheter in his tummy, and many wires were passing through. I was terrified of damaging those wires. Hurting them meant harming my baby, too.*" (M 6). For these reasons, the mothers' interaction with their babies happened unnaturally. However, the first moment they held their babies was an extraordinary moment for them. "*A week later, they gave my baby into my arms. I was so happy at that moment, so grateful. I said, I am here my baby. I breathed in his scent and never wanted to let him go.*" (M 5). The mothers tried to capture special moments in this short time. They expected their babies to respond to their presence and touch. "*They gave my baby in my arms 20 days later after birth. She was petite. She raised her hand as if to say, I am here!*" (M 8). The mothers' interaction with their babies gradually increased after this first time. Involving the mothers in the baby-care process before discharge helped them to feel better. "*When I went to see him, they allowed me to participate in his care routines, such as feeding and changing diapers as much as possible. Even though he was fed through a hose, they let me pour milk and hold it in my hand. I felt like I was giving it. I was delighted when I was with him.*" (M 7).

Facing reductive social response

Mothers felt that close people around them, such as friends and relatives, did not understand what they were going through. Reductive responses from the close people around mothers included not knowing about prematurity and its risks, making insensitive comments, and being insensitive to mothers' experiences and feelings. The reductionist comments made by people who did not know what risks prematurity includes and what the mother and baby were going through upset the mothers. "*Some people said to me, So what? As if you can take care of her at home? about my baby's stay in the NICU. Even my mother said, Let her stay as long as she can. Let her exceed 3 kilos, and then you will get her. These comments bothered me a lot.*" (M 8). Therefore, mothers felt that no one understood them except their spouses and other mothers of premature babies. "*It seemed so simple to everyone. They said, Big deal, she is fine, she will come home! My husband and other mothers of premature babies were the only ones who understood me in this.*" (M 3).

NICU friendship

Mothers had the opportunity to meet and be friends during this process. "*While waiting outside, we met some other mothers of premature babies. We used to sit in the cafeteria while we were waiting. Everyone would talk about their story and their babies' situation.*" (M 6). They felt they could understand each other better because they had gone through similar processes and faced similar challenges. Their suggestions seemed more reliable than those from outsiders (that is, people who do not have premature babies). "*You know what they say 'only the wearer knows where the shoe pinches.' I felt better talking to mothers in a similar situation.*" (M 5). This friendship involved accompanying each other on this ongoing journey. "*I have a friend I met at the hospital, and I still keep in touch with her. Our babies' incubators were next to each other. She comforted me a lot when my baby was in distress. Then our friendship began. We call each other incubator friends now.*" (M 5).

After discharge

Being on the alert

With the transition to home, a state of alertness began for the mothers, and its subject changed over time. In the early days, the mothers were afraid that their babies might have unexpected health problems, and as mothers that they were unable to intervene appropriately on time. Therefore, they needed to check constantly whether there was a problem with their babies' vital functions, such as breathing. "*In the early days after coming home, I tried to follow my baby's breathing continuously because there were no medical tools in the house. I felt vulnerable in case I missed something important. This anxiety passed over time.*" (M 4).

Sometimes, when a serious incident happened, mothers had lost control because of fears regarding their vulnerabilities and their babies' lives. "*When he came out of the incubator, thoughts such as these crossed my mind: The incubator is safer than me. What if he doesn't come out? Should he stay a little longer? Afterward, we were discharged anyway. One day, while I was feeding him with the bottle, he suddenly started to be unable to breathe. I turned his face down and started hitting him on the back while my husband looked at him. I remember my husband saying, he is choking, drowning! When I looked up at his face, his lips were pitch black. The concept of time disappeared for me at that moment. I don't know if this event lasted a few minutes or seconds. My husband took me* *out to the balcony. I was pulling out my hair. Within seconds, the things that went through my mind were: How long has this child been in an incubator? You can't take care of this child! I said, He has gone! My husband was still intervening at that time. He was constantly hitting our baby's back. Suddenly, with a sound, his throat opened, and he began to breathe. I called the nurse in charge immediately. We took him to the hospital, and they said, Nothing to worry about; he is okay. It was one of the worst traumas I have ever experienced. I was crying and trembling when I thought of this incident back in those days. Afterward, I had a process of never leaving my baby's side, which lasted for months. Until my husband came home, I never left his side. It continued like this for months.*" (M 1).

The possibility of the baby being hospitalized again in case of any problem worried the mothers. They feared being separated from their babies again. "*After she was discharged, one day, she did not wake up so that I could breastfeed. I said, Omg! They will take her away from me again. This time this fear started in me, and I thought; I got her out of the hospital, but what if they get her back? I smelled her scent once. How am I going to leave her again?*" (M 3).

After the first months of discharge, mothers felt better because their babies were more stable than before, and they were less worried about losing their babies. However, they began to experience intense concerns about whether there would be any health issues and developmental problems due to prematurity during their babies' routine appointments. For the mothers, these appointments represented a reminder of the possibility of having a negative outcome because of prematurity. "*For the first six months, I always had these questions: I wonder if I hear something bad or something negative? This possibility made me worry a lot. One day we went to the doctor's check, tests were done, and the doctor explained the results. Some values were low. I left the room, and I could not walk. No matter how I tried, my foot was numb, and I could not walk.*" (M 5). In addition, mothers felt exhausted because of these routine appointments. "*When we went to developmental pediatrics for a general check-up when she was one year old, the doctor said very comforting things to me. However, when they arranged another appointment again, I said to them, Why? Isn't she okay? I told the doctor that I want to take her to the doctor only when she is sick. I am very bored; I am exhausted!*" (M 3).

As time progressed and they overcame many health issues, mothers thought more about whether their babies would be developmentally normal. "*I constantly waited until a specific month to see if he would do certain things. I was worried that he would fall behind his peers because he was premature. I had such concerns. That's why I always followed his behaviors.*" (M 2). The mothers stated that they began to compare their babies with other babies to see if they caught up with their peers. "*After age one, I created opportunities for my son to join in social activities with other children. If I must confess, I was trying to answer some questions in my head, such as whether my child catches up with them or not, how is my child in the social context, how does my child stand among them?*" (M 5).

A period of complete closure

After discharge, mothers were told to pay attention to isolation and hygiene. Within the scope of isolation, they learned that babies should be protected from external factors that would endanger their fragile health and life. Therefore, doctors told them they should not be in crowded environments. Doctors also informed them not to contact with anything that was not sterile and reminded them to wash their hands or use sanitizer before entering the baby's room. Therefore, they organized their whole life according to the necessary conditions for the baby. "*Since her immune system did not develop, we arranged the house accordingly. We did not accept guests. We isolated the baby when somebody came. We were constantly washing our hands. We would open the windows frequently and ventilate the house for fresh air. We were able to handle the current COVID-19 pandemic easily. We were already used to these isolation and hygiene procedures. We were already living like that.*" (M 8). They entered a period of complete closure for approximately six months after discharge. "*I closed myself to the outside world. I did not do much activity, and I stopped seeing almost everyone because my baby would get an infection. People wanted to see him, but we did not accept any visitors. We did not see anyone until his corrected age was six months. Of course, grandparents came and went, but other than that, other people did not.*" (M 7). Mothers gave much attention to hygiene conditions during and after this isolation period due to prematurity. "*I try to be very careful about hygiene. For example, I boil the bottles first, put them in the sterilization machine after boiling them, leave them for 2 hours after the sterilization machine and then feed my children. On shopping day, I leave the bags on the balcony for at least two or three hours so that nothing goes through the bags. I was already doing it before, but this situation has increased, especially during the pandemic.*" (M 9). Due to such restrictions, the social interactions of mothers were limited in this period. "*I never went out anywhere but the hospital. So, I was happy going to the hospital because I was going out.*" (M 7).

Fighting with the reductive social response

The first time the baby came home, other family members found her/him too small and refrained from touching her/him, making it difficult for the mothers to receive support in baby care. "*They have helped a lot in caring for me but not much in caring for the baby. They did not want to touch her because she was too little.*" (M 8). In the following times, mothers faced more reductive social responses. "*I fought a lot because she was not a normal kid. I said to them, I am the mother of this child, and you will not do it. I was very serious about these things. This time they started to say, It's like you're the only one with a child! I said, But she is premature. She needs protection more; she is less immune than other babies, do not do it! Sometimes they wanted to make her eat something, to have its taste. I said, she already has sensitive intestines. But I couldn't explain this to the people close to me. So they took it as normal and never understood she was not a normal kid.*" (M 3). The mothers felt that other people would not understand how necessary the isolation was for their baby, mainly because, in their culture, showing affection to a baby consisted of behaviors that require close contact (e.g., holding the baby, kissing, touching). "*We had difficulty explaining to people around us that premature babies are risky in many ways. We knew they would kiss and hold her if we went into that crowd. We were not going anywhere because preventing this would be very difficult.*" (M 8). When isolation was no longer required, mothers, who entered social environments with their babies, felt upset about the comments of people about their babies and needed to make an explanation. "*Until he turned one year old, when people asked how old he was or commented how tiny he was, I was immediately calculating and saying his corrected age.*" (M 7).

In early childhood

Association to prematurity

At the beginning of early childhood, mothers, who focused on whether their child was developmentally catching up with other children born at term or had a developmental delay, were afraid of having a problem because of prematurity. This situation continued as an extension of 'being on the alert' after discharge. "*Sometimes I think he cannot focus while playing or doing something, and I am scared.*" (M 4). Because of these fears, mothers attempted to prevent their children's development from falling behind. "*I bought activity books to catch up with his peers according to their age. However, I regret it because they pushed me harder. One book comes every month. It says what to do month by month. As I read, I started to say, He can't do this; he doesn't understand that! The more I said, the more I began to question. Why can't he? Why can't he play like that? I asked myself constantly. Then when he played with his peers, I saw that they communicated and played similarly. After that, I removed those book sets and never looked again.*" (M 7). Hence, when any situation directed their attention to their children's development, the mothers associated this with prematurity. "*For example, we could not get her to handclap at first. We tried to teach, but she never did. Then, unexpectedly, she started doing it. At first, this made me very nervous. I was thinking, Is she just not doing it because she does not want to, or is she* *not learning? I was so afraid that there would be a problem.*" (M 3). The mothers, who saw their children's improvement over time, developed strategies such as waiting for a specific time before taking action on developmental concerns. "*It was time to crawl, but he did not. I was worried and thought, Why didn't he crawl? Then, he was adjusted to 16 months old and was not walking. I thought he would not be able to walk. Then I set a time limit for myself to wait until he was adjusted to 18 months old. When I first encountered this kind of thing, I was worried that something would go wrong because of prematurity.*" (M 1).

(Cannot) overcome the difficulties

The mothers pointed out that they felt better as their babies continued to develop, and their interaction increased day after day gradually. "*The more my son interacts, the more he shares with me, and the better I feel. That is why every day is better than the last.*" (M 4). However, this did not prevent the effects of past difficulties on their present experiences. "*When I look at the time from her birth to this day, I say, Yes, she has physically improved and changed; it went faster than I expected. But when I see another 2-year-old, I can't help but compare. I say, Okay, your child had a difficult time, you were separated, but her development is good now. Now relax. Take a deep breath! But how much do I convince myself? I can't. I can't do it. My husband said, We can get professional support if you want. Cause no matter how much he talked to me, I said, Yeah, okay! Then we turned around, and I was in the same place again. I wish I could attend a psychological counseling session to erase the memories of the first year of this process from my mind.*" (M 3). Mothers had emotional difficulties when they remembered those days in daily life. "*Sometimes when I hold him in my arms, kiss him, and love him, I think of those days and want to cry. Then I say to myself, Do not cry; thank goodness you have come to these days.*" (M 6). Some things they encountered in their daily lives caused mothers to remember many challenging experiences. "*I was significantly affected when COVID-19 first appeared in Wuhan. For the first ten days, I watched TV until four at night and cried. It reminded me of those days we had to be apart during the NICU.*" (M 5). They felt those experiences as a continuous existence in themselves. "*I have experienced these things, and they left deep scars on me. I can feel it in myself. For example, I am still afraid. I still have the fear that my children will die. I wake up at night and check to see if they are breathing.*" (M 9). Therefore, they were challenged in early childhood to accept that their children's prematurity was not an issue anymore. "*We talked to the child development specialist and also to our pediatrician. They both said, You can treat them as normal kids. It was challenging to accept this because they asked their age when we went to a place, and I was still telling them their corrected age. Now I'm just starting to say their chronological age. The doctor said they are normal, but I can't say I don't see them premature anymore. Even though I don't think about it all the time anymore, I can't forget that they were premature.*" (M 8).

The experiential essence of prematurity for mothers: living with a birthmark

At the end of our analysis, we expressed mothers' overall experiences of prematurity through the metaphor "living with a birthmark." This birthmark represents a very different birth and the postpartum period than they imagined affects them deeply. After birth, when their babies were taken to the NICU, the mothers felt incomplete and struggled physically and emotionally. Different stressors due to prematurity entered their lives when mothers and their babies eventually came together after discharge. All these experiences that did not happen to every mother-baby dyad caused the mothers to have negative feelings. This difference became a part of the mothers, like a birthmark. As much as it is apparent and painful at first, the birthmark becomes a part of the mother-baby relationship. Even though it fades over time and the pain lessens, the effects of the birthmark remain in early childhood. The visual representation of the metaphor is shown in Fig. 1. The circles represent the metaphoric birthmark in Fig. 1. Therefore, they are more significant and bolder at the beginning due to the metaphoric meaning we explained throughout the results.

Discussion

Our study shows that prematurity persists for a long time in the daily lives of mothers and includes experiences specific to the process. However, these processes do not develop independently from each other. As a result of our phenomenological analysis, the experiential essence of prematurity is explained through the metaphor of *living with a birthmark*. This metaphor states that prematurity has a consistent place in mothers' lives. However, this consistent presence is not always felt with the same intensity as the child reaches early childhood. Prematurity, which is felt as a very intense and new condition during the first two processes in our study, continues to exist in the mother's life but becomes less visible and painful as time passes.

Shock, disappointment, and self-blame, which are involved in the '*incomplete mother*' theme in our study, have been described in previous studies (Baum et al., 2012; Gibbs et al., 2015; Hall et al., 2013). The mothers had certain expectations regarding their babies (e.g., birth on term, discharge from the hospital immediately after birth, socializing with their baby starting from early days) during their pregnancy. But, when they experience premature birth, they feel their postnatal processes are incomplete. The tendency of the human mind to complete any situation or event that left incomplete (Zeigarnik, 1927) through schemas that are already known in the literature (Piaget, 1999) may have a role in that. Our finding shows that mothers struggle to regulate their existing schemas and accommodate the prematurity situation. Due to this conflict, the metaphoric birthmark we used first appears in this process.

The findings of this study suggested that the most intense process for mothers was the *infant's hospitalization in the NICU*. During those days, *the birthmark* is felt as a painful existence. In the literature, previous studies (Arnold et al., 2013; Baum et al., 2012; Gibbs et al., 2015; Hall et al., 2013; Malakouti et al., 2013; Medina et al., 2018; Watson, 2011) indicated that this process includes too many compelling experiences for mothers. Similarly, our study showed that the process also includes compelling experiences for Turkish mothers. Our study revealed that during the NICU process, mothers face prematurity for the first time, understand the seriousness of the situation, and experience difficulty in providing their bonding needs (Ainsworth et al., 1975; Bowlby, 1969, p. 241) naturally due to prematurity and environmental conditions. Therefore, mothers have mental and emotional breaking points during this process. The absence of the FCC approach in the NICUs in Turkey was an important part of the mothers' negative experiences and meaning attributions to prematurity. Having a premature baby is a compelling and negative experience for mothers in any case. However, comprehensive FCC practices help to prevent the adverse effects of these challenging experiences (Beebe et al., 2018; Blomqvist et al., 2022; Dien et al., 2022; He et al., 2021; Weber et al., 2022). Recently, there are some promising early intervention studies acknowledged mother-infant interactions (Erduran & Yaman Sözbir, 2022; Kurt et al., 2020) and mother involvement (Albayrak & Büyükgönenç, 2022; Kadiroğlu & Güdücü Tüfekci, 2022; Zengin Akkus et al., 2020) in the NICUs in Turkey. Our results indicate a great need to increase future efforts in this area.

The experience of being objects in common alienation (Sartre, 2003) emerged from the experiences of *facing reductive social responses, NICU friendship*, and *fighting with the reductive social responses* in our study. This alienation starts in the NICU process and continues after discharge. During NICU, mothers' experiences make them come together with other mothers of premature infants and feel like a unique community. On the other hand, other people around mothers, except their spouses, do not understand them and give reductive responses to their experiences. These results are consistent with previous studies that indicated fathers and other mothers of premature infants function as essential

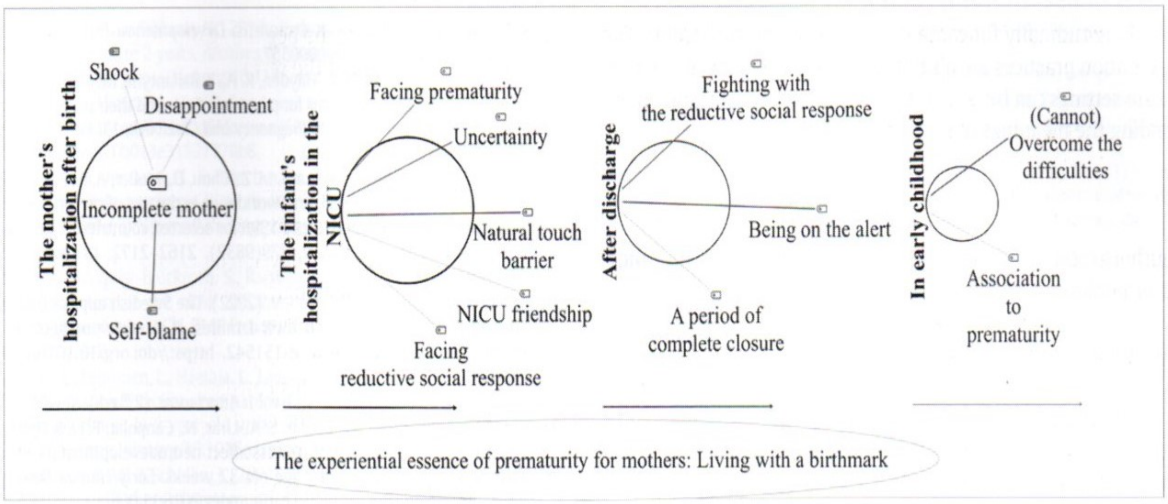

Fig. 1. The metaphor of the study.

support mechanisms for them (Amorim et al., 2019; Balacan et al., 2020; Gibbs et al., 2015). Our study concludes that Turkish mothers have to fight with reductive social responses after discharge because of the conflicts in baby care, the isolation period, and comments about their babies' appearance. A recent study by Emmanuel et al. (2022) emphasized that social and familial support networks influence premature infants' and caregivers' well-being longitudinally. It is also emphasized that the most effective intervention studies for both mother and infant include the psychological support dimension (Benzies et al., 2013). Within this knowledge, we suggest that fathers, other premature infants' mothers, and close family members should be considered inseparable actors while planning the psychological and social support longitudinally in early intervention settings. This knowledge can serve as an initiative to provide comprehensive psychological and social support to mothers of premature infants. Our findings also showed that increasing social awareness about prematurity and its risks might help to reduce the mothers' longitudinal alienation in the community.

In line with the previous studies (Adama et al., 2016; Granero-Molina et al., 2019; Hall et al., 2013; Murdoch & Franck, 2012; Phillips-Pula et al., 2013), our study revealed that the mothers were constantly on alert in the first months at home due to their baby's fragile health condition and social interactions with close family members. This finding showed that in addition to social and familial support, the support of healthcare professionals should also continue after discharge. It is acknowledged that home visits are essential in early intervention practices after discharge (Goyal et al., 2013). Although there is a standard hospital-based health follow-up for premature infants in Turkey, currently, there are no home visit procedures integrated into health follow-ups. Therefore, our results stressed the necessity to schedule home visits after discharge.

Focusing on development after the baby has survived is usual when we consider Maslow (1943) hierarchy of basic needs. Similar to Jackson et al. (2003), the mothers in our study started to worry more about the development of their babies after they got through these first months of discharge. However, our findings showed that the mothers did not receive appropriate counseling regarding these developmental concerns during the health follow-ups. Developmental counseling must be considered a key to mothers' well-being after discharge and following years. The optimal way to overcome this barrier would be to integrate child development specialists into the health follow-ups and home visits in Turkey since the child development specialists are healthcare professionals that serve families in developmental counseling from birth to 18 years of age (CoHE, 2016; Kaymaz & Demircioğlu, 2018).

Previous studies (Feeley et al., 2011; Gray et al., 2018; Pace et al., 2020) have shown that mothers of premature infants are at risk for experiencing post-traumatic stress disorder. Our study revealed that, after all these experiences, mothers could not get over the effects of the difficulties they experienced even when their children reached early childhood. Because the mothers came to this situation cumulatively and could not receive appropriate support and services starting from the NICU, prematurity might have taken its place in their lives as a traumatic experience like a birthmark belongs to them. Therefore, the combination of FCC practices provided in the NICU and family-centered early intervention practices after discharge until early childhood would be beneficial to prevent the negative effects of prematurity.

Practice implications

Our findings have implications for all professionals who work with premature infants and their mothers. Prematurity affects mothers deeply for a long time. Thus, premature infants' mothers should be supported longitudinally starting from the NICU process towards early childhood. Our study revealed that fathers, other premature infants' mothers, and close family members should be considered inseparable actors while planning the psychological and social support longitudinally in early intervention settings. Comprehensive and longitudinal early intervention practices that contain psychological, social, and developmental aspects are essential to benefit mothers' well-being and premature infants' care, health, and development.

Limitations

Our study should be considered under these limitations:

- We interviewed mothers a long time after the NICU process or discharge. Thus, recall bias is a limitation of this study.
- The telephone interview is a limitation because the subject is sensitive, and face-to-face interviews would be more appropriate, although we could not do so due to the COVID-19 pandemic.
- We did not have any participants who lived in eastern Turkey or belonged to other ethnicities than Turkish. The heterogeneity of mothers in this regard may help us comprehend the findings' cultural differentiations and similarities.
- Family-centered practices are required to obtain the best results in early intervention studies (Bruder, 2000). Therefore, understanding fathers' experiences in the context of prematurity would benefit the development of a comprehensive approach to early intervention practices.

Conclusion

Our study highlighted the longitudinal experiences of mothers of premature infants in Turkey. We aimed to understand those mothers' experiences and meaning attributions about prematurity. Our findings revealed that having a premature infant can be an extremely traumatic experience longitudinally for mothers when FCC and comprehensive early intervention practices are absent. The provision of these practices in healthcare settings can be initiated and improved by recognizing and understanding the meanings of parents' experiences.

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CRediT authorship contribution statement

Ezgi Taştekin: Conceptualization, Data curation, Investigation, Methodology, Software, Writing – original draft, Visualization, Validation. **Pınar Bayhan:** Visualization, Supervision, Writing – review & editing.

Declaration of Competing Interest

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Annex-1. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.pedn.2023.01.002.

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