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#### **DEVELOPMENTAL PSYCHOLOGY | RESEARCH ARTICLE**

# Parenthood after severely endangered pregnancy and delivery of a prematurely born child: An interview study with fathers and mothers

Fernanda Sampaio de Carvalho<sup>1\*</sup>, Monique van Dijk<sup>2</sup>, Irwin Reiss<sup>1</sup> and Nicole Vliegen<sup>3</sup>

**Abstract:** This study aims to gain insight into the development of parenthood six months after delivery of a preterm infant due to the mother's preeclampsia or HELLP syndrome. In this qualitative interview study, we conducted individual interviews with the Working Model of the Child Interview to tap into the subjective experiences of parents who went through preterm delivery due to preeclampsia or HELLP. The interview data were analyzed using thematic analysis. From February up to and including December 2017, parental couples were included of whom the mother had suffered from severe preeclampsia or HELLP, and whose child had been born at a gestational age of less than 32 weeks. Parents also filled out a depression, an anxiety and a bonding questionnaire. Five parental couples, five fathers and five mothers, were interviewed. Many statements made clear that these parents are undergoing a distinctive development. Fear of losing the baby was still central to all parents and they were afraid of being a parent or forming a loving bond. Importantly, both fathers and mothers described loss of control, recurring memories and catastrophic fears. Psychological support should help parents regulate the shock, process traumatic experiences and integrate the frightening life event into

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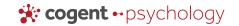
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parenthood development. Therefore, proper monitoring of parenthood development is necessary to detect problems, intervene and prevent adverse consequences.

Subjects: Infancy; Lifespan Development; Neonates; Parenting and Families; Attachment; Health Psychology; Psychology and Nursing; Midwifery; Nursing

Keywords: Family integrated care; parent support; parenthood; preeclampsia; preterm birth; pregnancy

#### 1. Introduction

#### 1.1. Background

Prevention of problems concerning parenthood and parent-infant relationship is pivotal, as it is well documented that these problems have a negative impact on the cognitive and socio-emotional development of children (Sroufe, 2021). Severe pregnancy problems and preterm delivery are associated with postpartum depression and posttraumatic stress in parents (McMahon et al., 2020; Mommersteeg et al., 2016; Srajer et al., 2021). The psychological and psychiatric problems come to the fore in an early phase of both the development of parenthood and that of the lifelong relationship with the infant, and can severely tax healthy developmental trajectories.

#### 1.2. Early family life after severe pregnancy problems

Severe pregnancy complications such as preeclampsia and the hemolysis, elevated liver enzymes, and low platelet count (HELLP) syndrome occur in two to four percent of all pregnancies (Magee et al., 2022) and in five of every thousand pregnancies respectively (HELLP Foundation, 2022). Both diseases are life-threatening to mother and infant and important causes of preterm delivery; i.e. under 32 weeks' pregnancy (Davies et al., 2016). Internationally, the rate of preterm birth ranges from 5% to 18% (World Health Organization, 2022). The associated psychological and psychiatric problems are extensive. Reported incidence rates of symptoms of depression are as high as 40% for mothers and 36% for fathers, the reported incidence rates for experiencing anxiety are respectively 48% and 47% (Leahy-Warren et al., 2020; Pace et al., 2016) and those for having posttraumatic stress disorder respectively 26% and 9% (Barthel et al., 2020). It is essential to monitor these parents' growth into parenthood as their mental health and their abilities to be responsive and sensitive parents are critical to early interaction with the child, and consequently to the child's socio-emotional and cognitive development (Tomlinson et al., 2022). The parents, the premature infant and any siblings face specific challenges related to family life. Often, delivery has to be induced on medical grounds because of an acute critical health situation of mother and child, even if the due date is still far away. Consequently, the newborn is in a fragile, critical medical situation and therefore in need of neonatal intensive care (Barton & Sibai, 2008; Steegers et al., 2010). Common consequences include separation of mother and baby immediately after birth, a postnatal period marked by anxiety, and sometimes an overburdened family life when there are any siblings to care for, while father goes to work (Roberts et al., 2017; Vaerland et al., 2017a, 2017b). At a psychological level, parents experience emotional disruption and shock, feelings of inadequacy, guilt, alienation and being unable to protect their child (Provenzi et al., 2016; Spinelli et al., 2016). Psychological support to scaffold the development of parenthood and that of the parent-child relationship can prevent current and later problems (Tomlinson et al., 2022). Various supportive interventions have been developed based on collaboration of the health care team with parents of a premature infant during the NICU stay. These support efforts range from peer support (Huenink & Porterfield, 2017), improving parental sensitivity and reducing parental stress and trauma symptoms (Kerr et al., 2017; R. J. Shaw et al., 2014; Tooten et al., 2012; van den Hoogen et al., 2020), to developmental care support (Als, 1998) and an intervention that promotes staff skills to collaborate with parents (Ahlqvist-Bjorkroth et al., 2022). Literature on psychological parent intervention after the infant's discharge home is scarce. More insight is needed into the



development of early parenthood after preeclampsia or HELLP and preterm delivery to fine-tune psychological support after NICU stay.

#### 1.3. Limitations of current knowledge

While research has provided insight in the effects of preterm delivery on early attachment relationships between parent and child and on the development of maternal sensitive interactions with the child (Korja et al., 2012; Shah et al., 2011), little is known about the development of parenthood in the early years after the induced preterm birth of the child because of mothers' preeclampsia and HELLP. Particularly the literature is inconsistent and scarce on the paternal role of the father after preeclampsia or HELLP and the birth of a premature baby (McMahon et al., 2020; Michalowska et al., 2022). While the vulnerable infant is being treated in the neonatal intensive care unit (NICU) and dependent on doctors and nurses for survival of the vulnerable infant, the parents have to grow into their parental roles and make a transition to parenthood.

#### 1.4. The present study

The objective of this study is to gain insight into the development of parenthood six months after delivery of a preterm infant due to the mother's preeclampsia or the HELLP syndrome. Notably we aimed to inventory any problems, setbacks and obstacles these parents encounter. Apart from the parenthood development of mothers, we were interested in the fathers' parenthood development. To our knowledge, this study is distinctive in that it focuses on the thoughts, expectations, fears and beliefs regarding parenthood and the parent-child relationship of both mothers and fathers, and is not limited to studying psychological and psychiatric problems.

#### 2. Methods

This study is part of a larger project to map experiences of parents confronted with preeclampsia and HELLP and preterm delivery, and ways to best support them psychologically (Sampaio de Carvalho, Vliegen et al. 2023, in press). This study was approved by the Erasmus MC Medical Ethics Review Board (MEC-2016-031).

#### 2.1. Research team and reflexivity

The research team consisted of the main researcher (FSC, MSc), who is a female psychotherapist, a clinical psychologist and clinical researcher, the co-authors and two master's psychology students. The main researcher conducted the interviews and thematic analysis (Braun & Clarke, 2006) with the two master's students separately. The reflexive dialogue to identify codes and patterns of meaning, group the codes, find and name themes took place within this research team. Notes were taken of the reflexive process.

#### 2.2. Study design

#### 2.2.1. Theoretical framework

To tap into the subjective experiences of parents who went through preterm delivery due to preeclampsia and HELLP, a qualitative interview study was designed for which we conducted the Working Model of the Child Interview (WMCI) (Benoit et al., 1997) with fathers and mothers separately. The WMCI invites parents to tell about pregnancy, the period in hospital due to the mother's illness and the infant's intensive care treatment, the current situation at home and the future, and provides detailed descriptions of parents' experiences and expectancies regarding the parenthood development and the relationship with their child. Interview data were analyzed on inductive and deductive levels. At the inductive level, thematic analysis was conducted according to the steps described by Braun and Clarke (2006). As theoretical framework for the deductive analysis we used Stern's theoretical concept "parenthood constellation" (Stern, 1995; Tyano et al., 2010). Stern describes life questions parents have in mind in relation to their child, which can be structured around four major themes, each theme including specific tasks. The "Life and growth" theme concerns the major question "Will I be able to keep my baby alive?". This theme concerns worries about being competent as a parent; e.g. producing enough breastmilk to feed the baby, or



being able to monitor the child's viable needs. Second, the 'Primary relatedness' theme concerns questions as 'Will I be able to love my baby and will the baby love me?'. Third, the 'Supporting matrix' theme is about 'Will I be helped raising my baby?'. A new parent longs for contact with people with whom he/she can exchange information and by whom he/she feels understood and supported. Fourth, the 'Reorganization of identity' theme refers to the question 'Will I be able to integrate these new challenges in my life?'. This theme concerns new balances with regard to family life, professional identity and partnerships. These four themes cannot be seen as mutually exclusive, but inevitably influence each other: feeling competent as a parent ('Life and growth' theme) can positively influence caring for the baby and feeling loved by the baby ('Primary relatedness' theme), can aid the sharing of experiences easier ('Supporting matrix' theme) and facilitate the process of going back to work ('Reorganization of identity' theme). Conversely, the four themes can be negatively influenced when parents have an infant who requires intensive care and is difficult to soothe. The infant's vulnerable condition can provoke parental feelings of failure and incompetency ('Life and growth' theme) and ambivalent feelings towards the care for the child ('Primary relatedness' theme). Then, it might be harder to organize childcare because of the specific nature of the care that is needed ('Supporting matrix' theme) and thus hinder the process of going back to work ('Reorganization of identity' theme).

Additionally, we sought information about the mindset from which parents spoke about themselves and about the parent-infant relationship. To this aim, parents filled out a depression, an anxiety and a bonding questionnaire.

#### 2.2.2. Participant selection

From February up to and including December 2017, participants were selected by purposive sampling. During a follow-up visit to the outpatient clinic, parents who met the following criteria were invited to participate: the mothers had been hospitalized during pregnancy because of severe preeclampsia or HELLP, remained monitored by a gynecologist and an endocrinologist, and the child had been born at a gestational age of less than 32 weeks. Parents without sufficient command of the Dutch or English language, with a cognitive impairment, or whose newborn had deceased, were excluded.

The main researcher (FSC) was present during the regular medical follow-up visits with a gynecologist and an endocrinologist. She met both mothers and fathers face-to-face, and asked permission to call them to invite them to participate in the study six months after delivery, emphasizing that declining participation would not affect medical treatment. In the telephone call, the research aims and design were explained. If the parent couples were interested, written information was sent to their home address. A week later, FSC called them to ask them if they were willing to participate. If so, consent was sought, and interviews were scheduled separately with the father and mother. If possible, interviewing was combined with other appointments of the parents in the hospital.

Thirteen women and their partners were invited to participate and received the research information. Four women declined participation, as well as the partners of four other women. These parents indicated they did not have time to participate. Five parent couples (n = 10) were included in the study.

#### 2.2.3. Setting

The study took place at the departments of Obstetrics and Neonatology of Erasmus University Medical Center Rotterdam, the Netherlands. The neonatal intensive care unit (NICU) where the babies were admitted immediately after birth pursues a policy of family-centered and developmental care. Parents could visit their baby 24 hours a day and were encouraged to participate in their baby's care and to have skin-to-skin contact. Nevertheless, they were not allowed to sleep with the baby on the ward at night, which means there was a daily moment of separation.



Psychosocial support was available to those families who requested it themselves or for whom nurses and doctors felt support was needed.

The interviews were administered in a quiet room at the outpatient clinic for patients with preeclampsia and HELLP. Only the parents and the researcher were present in the room.

#### 2.2.4. Description of sample

All participants had been born in the Netherlands, all mothers were first time mothers and all couples were living together. Two mothers (cases 3 and 4) had a history of miscarriages. One couple (case 5) had had prior problems with fertility. All mothers had given birth in the hospital and immediately after delivery had been separated from the child, who was admitted to the NICU. The delivery was induced for medical reasons of the mother (cases 1, 4 and 5) or of the child (cases 2 and 3). Four mothers (cases 2, 3, 4 and 5) had a caesarean section. Background features are given in Table 1. To ensure privacy protection, the table contains fictitious names of the parents and children, and the birth weights are listed in categories.

#### 2.2.5. Data collection

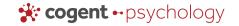
The parents were interviewed and filled in the questionnaires six months after the birth of their child. The interviews were conducted by FSC and lasted between one and a half and two hours. All interviews were audio-recorded and transcribed verbatim by the main researcher (FSC) and two master's students.

During the process of thematic analysis, the members of the research team discussed the data collection and decided not to include any more parents when it was felt that the extensive and rich data from the interviews provided sufficient information power about the parenthood development of this particular group of parents (Braun & Clarke, 2021; Malterud et al., 2016).

2.2.5.1. Working Model of the Child Interview (WMCI). A Dutch translation (Hall et al., 2015) of the Working Model of the Child Interview provides questions on parenthood and parent-child relationship (Benoit et al., 1997). The relevance of this semi-structured interview lies in the given that it makes ways to rich and extensive stories about the emotional and relational experiences of early parenthood (Vreeswijk et al., 2012). The WMCI addresses 16 main questions, each with multiple

Table 1. Background characteristics of mothers ( $N = 5$ ) and infants ( $N = 5$ )							
	Name and sex child	Age mother years	GA infant at birth	Birth weight Categories VLBW/ ELBW	LOS mother before delivery	LOS mother after delivery	LOS NICU Infant
Case 1* Jill & Peter	Stella, girl	34	32wks; 2d	VLBW	13 days	6 days	18 days
Case 2** Mary & Joe	Morris, boy	34	30wks; 6d	VLBW	8 days	2 days	9 days
Case 3** Rose & Mark	Jesse, boy	22	28wks; 6d	ELBW	3 days	4 days	23 days
Case 4* Esther & Carl	Nora, girl	31	31wks; 5d	VLBW	25 days	4 days	6 days
Case 5* Katie & Bob	Jacky, girl	31	28wks; 0d	VLBW	2 days	5 days	46 days

Note: GA= gestational age in weeks and days, NICU= Neonatal Intensive Care Unit, VLBW= very low birth weight (1000–1500 grams), ELBW= extremely low birth weight (less than 1000 grams), LOS= length of hospital stay, \*= delivery induced due to the mother's critical medical condition, \*\*= delivery induced due to the fetus' critical medical condition



sub-questions, which inquire after perceptions and subjective experiences concerning five episodes in becoming and being a parent: the phases of pregnancy, delivery, the period after birth, the current situation and the future as a family. The open-ended questions invite parents to provide comprehensive answers. If an answer remains too poor or superficial, questions such as "Could you tell me more about that?" are used to elaborate more into depth. The issue is not the accuracy of the memories, but the subjective experiences parents describe regarding parenthood.

To exemplify: concerning pregnancy, delivery and the period after birth, a question is "Can you talk about the pregnancy and birth? We would like to know how you felt emotionally and physically and how the first period was at home." A question concerning the first relational experiences with the child is "How would you describe your relationship with your baby (name). Choose five adjectives to describe your relationship and give examples." A question concerning the future is "What do you expect (name child) to be as a teenager? What gives you this feeling? In that period of your child's (name) life, what do you expect to be good and what not so good?" For an overview of all questions, see Appendix 1.

2.2.5.2. Parents' levels of distress and their bonding with the child. In addition to the interview, we obtained information about the mood of parents and the parent-infant relationship. Before the interview, parents separately completed at home three questionnaires: the Edinburgh Postnatal Depression Scale, the State-Trait Anxiety Inventory-State and the Postpartum Bonding Questionnaire.

The Edinburgh Postnatal Depression Scale (EPDS; Cox, Holden, & Sagovsky, 1987) is a self-report scale widely used for screening of pre- and postpartum depression during the transition to parenthood up to 30 months postpartum (Figueiredo et al., 2018). It consists of 10 items, each scored on a 4-point Likert Scale, leading to a score range of 0 (no symptoms of depression) to 30 (high symptoms of depression). Men as well as women scoring above a threshold of 12 are likely to be at risk for depression (Cox et al., 1996; Ramchandani et al., 2008). The EPDS has been validated for the Dutch population (Pop et al., 1992).

The State-Trait Anxiety Inventory-state (STAI-state) (Spielberger, 1983) is a widely used self-report questionnaire to measure one's state anxiety level. It consists of 20 items, and the total score ranges from 20 (below average anxiety level) to 80 (above average state anxiety level). The STAI has been validated for the Dutch population (van der Ploeg et al., 1980).

The Postpartum Bonding Questionnaire (PBQ) (Brockington et al., 2006) is a self-reporting questionnaire designed to detect disorders of the mother-infant and father-infant relationship and is used up to 24 months postpartum (de Cock et al., 2017). The questionnaire has 25 statements; the total score ranges from 0 (normal) to 125 (high). The PBQ consists of four scales, with a threshold each: impaired bonding (12 items); rejection and anger (7 items); anxiety about care (4 items); and risk of abuse (2 items).

#### 2.3. Qualitative data analysis

Caregiver's parenthood patterns across the interviews were identified through a data-driven latent thematic analysis (Braun & Clarke, 2006) of the narratives. Separately, the researcher (FSC) and two master's psychology students first familiarized themselves with the data by listening to, transcribing, reading and rereading the interviews. Anything interesting was noted and preliminary ideas about the data were generated. Next, every interview was coded separately by the three coders. Relevant parts in the interviews with regard to the research question were coded, grouped and discussed in the research team. This was an iterative process, and coders went back and forth between interviews as new codes were identified in later interviews. Then, codes describing comparable experiences were merged, and different codes were sorted in search for distinctive, overarching themes throughout the interviews. In this way, an attempt was made to generate coherent and meaningful themes. In the next step, the themes were reviewed and refined. To improve the coherence within themes and the distinction between themes, some codes had to be regrouped. To ensure trustworthiness, a thematic hierarchy of themes and subthemes was generated using extensive interview data; the created

# Table 2. Themes and subthemes identified in the interviews, organized according the "Parenthood Constellation" and the "Traumatic experiences" theme

"Parenthood Constellation" and the "Traumat	ic experiences" theme	
Life and Growth Theme: am I able to keep my baby alive?	<ul> <li>1.1 Troubled pregnancy and delivery: a dreadful adventure</li> <li>Experiences of pregnancy and delivery</li> <li>Medical situation of mother and child</li> </ul>	
	1.2 Troubles about viability: how will my child survive: • Fear of losing the child • Health of the child • Feeling guilty and helpless	
	Concerns about the child's future: will my child succeed and be happy in life?     Worries concerning development     Hope	
Primary Relatedness Theme: shall I love my child and will my child love me?	2.1 Caring and parenting: can I be a parent to my child and do the things parents do?     • Considering the particular needs of the child     • Feeling (in)adequate	
	<ul><li>2.2 Connectedness: is this my child?</li><li>• Separations in the hospital</li><li>• Alienation</li><li>• Developing relationship</li></ul>	
	Perceiving their preterm baby: who is my child?     First encounter with a prematurely born child     Comparing to full-term born children	
Supporting Matrix Theme:     can someone help me parenting my child?	3.1 Relationship with partner  • Being separated from partner  • Feeling supported by partner  •Medical situation and fear of losing the partner	
	3.2 Healthcare professionals	
	3.3 Grandparents: supportive but also burdened	
	3.4 Peers • Peers	
4. Identity Reorganization Theme: can I pick up my life and integrate parenthood in it?	4.1 Making room for the baby: preparing the arrival • Preparing for the arrival of child	
	4.2 Transition into parenthood  • Parenting role  • Professional activity  • Rehabilitation of medical situation	
	4.3 Family Planning: future children • Family planning of future children	
5. Traumatic experiences	Moments of loss of control     Recurring memories     Catastrophic fears about what might happen	

subthemes gave meaning to different and distinctive aspects of the large, overarching themes (see Table 2). The interviews were then reread to ensure that the themes accurately reflected the data set and that no relevant information had been overlooked. Themes and subthemes were then named, and lastly a report was produced containing verbatim interview quotes illustrating the themes. For the purpose of reflexivity and investigator triangulation (Patton, 1999), the entire analytic process was continuously discussed in the research team.

At the deductive level, FSC and the two master's students separately considered whether the different themes and subthemes could be theoretically understood and organized from the



"parenthood constellation". Finally, the arrangement of themes and subthemes into the theoretical framework of the "parenthood constellation" was compared, discussed and finalized. To support the data analyzing process, Atlas.ti (version 8.2.3) was used.

#### 3. Results

In this section, we first present the interview results. The themes and subthemes from the inductive thematic analysis are organized by the theoretical framework of the "parenthood constellation". Successively discussed are the themes and subthemes that were created inductively, categorized under the four parenthood constellation themes: the "Life and Growth Theme", the "Primary Relatedness Theme", the "Supporting Matrix Theme" and the "Identity Reorganization Theme". One important extra theme – "traumatic experiences" – that did not fit in the four "parenthood constellation" themes came up in several parental narratives. Table 2 lists the themes and subthemes identified inductively and organized deductively by "parenthood constellation" theme and the "traumatic experiences" theme. Lastly, we discuss the findings concerning levels of distress and bonding with the child.

#### 3.1. Findings of the interviews

The four parenthood constellation themes came to the fore in all the interviews. Issues concerning the "Life and Growth Theme" dominated the narratives and affected even the content of the other themes. For example, months after the baby had been discharged from the NICU, fear of losing the baby was still central to all parents and that made them frightened to be a parent (identity reorganization theme) or to form a loving bond (primary relatedness theme). Fathers told not only how afraid they still were of losing their baby, but also how afraid they had been of losing their partner. During the interviews, parents were sometimes overwhelmed by intense emotions.

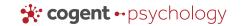
#### 3.1.1. Life and growth theme: am I able to keep my baby alive?

The Life and Growth Theme was present in every single interview. Fathers and mothers described "troubles concerning pregnancy and delivery", "troubles concerning the viability of the child" and "concerns regarding the future of the child".

3.1.1.1. Troubled pregnancy and delivery: a dreadful adventure. In the parents' narratives, the mental impact of the preeclampsia and preterm birth became clear. Shattered expectations concerning pregnancy and delivery as well as worries regarding the medical situation of mother and child came to the fore.

Experiences of pregnancy and delivery	Jill (case 1): "The gynecologist told me to push. "She needs to come out because her heartbeat is dropping!" I panicked and thought I have to do something to get her out."
Medical situation of mother and child	Rose (case 3): "I arrived at the hospital, and they put me on the monitor and then all was wrong. My blood pressure kept going higher and higher and I panicked."  Esther (case 4): "(crying) That was a very difficult moment. They (the doctors) told me that I was very ill and was about to have another seizure. At that moment, I was in so much pain and I felt so sick that I said: it does not matter what they do, but the baby really needs to come out, because I am not going to survive."

3.1.1.2. Troubles about viability: how will my child survive?. Parents mentioned fear of losing their child and worries concerning the baby's health during pregnancy and delivery, hospitalization, after discharge home and also 6 months after delivery. Important is the presence of feelings of quilt when a child's life is endangered.



Fear of losing the child	Bob (case 5): "The image of entering the church with a little coffin has often crossed my mind. The fear remains that something bad happens".  Carl (case 4) about when his daughter stopped breathing: "When Nora was finally home. the first evening, she stopped breathing. She was taken to the hospital by trauma helicopter since then I am even more worried."
Health of the child	Peter (case 1) mentioned worries about the fragile health of his daughter as she attends daycare, 6 months after birth: "If she has a cold for a week and loses a lot of weight so fast I just hope the cold goes away as soon as possible."
Feeling guilty and helpless	Esther (case 4): "A lot of guilt ran through me. Am I the reason she had to be born so prematurely?"  Mark (case 3) said: "You just feel helpless, there is nothing you can do except wait for him to grow and become stronger."

3.1.1.3. Concerns about the child's future: will my child succeed and be happy in life?. Parents' narratives voice worries concerning their child's future in terms of cognitive and psychosocial developmental problems, as well as feelings of hope.

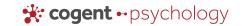
Worries concerning development	Carl (case 4): "I am very anxious that she will develop a conduct disorder and that she will have trouble adjusting to school or work situations."
• Hope	Katie (case 5): "I wish that she may at least be very happy and healthy, and if she ever wants to have children that she will not have to experience the same as I did when she was born."

3.1.2. Primary relatedness theme: shall I love my child and will my child love me? With regard to the Primary Relatedness Theme, referring to parents' concern "shall I be able to create a warm loving bond with my child and will my child love me", fathers and mothers mentioned situations regarding: "caring and parenting", "connectedness issues in the parent-child relationship, exposing possible bonding problems" and "aspects concerning the way they perceive the child". For both fathers and mothers, these three themes seem to be organized around the baby's vulnerability. The Primary Relatedness Theme came to the fore in every single interview.

3.1.2.1. Caring and parenting: can I be a parent to my child and do the things parents do?. In their narratives, parents voiced their endeavor to be a parent of a preterm infant with its particular needs and addressed situations in which they feel inadequate.

Considering the particular needs of the child	Esther (case 4): "When your baby is born very small, it needs breast milk because of all the substances it contains. So the choice was actually quite easy for me. It was the only logical option".
Feeling (in)adequate	Mark (case 3): "When I see that he is in pain and that he cannot be silenced, that is a kind of being powerless."

- 3.1.2.2. Connectedness: is this my child?. Parents talked about dealing with separation due to hospital logistics that did not enable parents to sleep with the baby during the night, about feelings of alienation during the first months, and about problems with staying connected to the child as a consequence. In addition, parents elaborated on how the parent-child relationship evolved and deepened.
- 3.1.2.3. Perceiving their preterm baby: who is my child?. In describing their baby when talking about the first encounter, parents often used detached words that emphasized the baby's vulnerability. In contrast, we noticed that when talking about their six months old baby, parents tended to compare their child to full-term born babies and emphasized their child's vitality.



Separations in the hospital	Rose (case 3): "When you are in hospital and you can only be once a day with him and then when you come home and your kid is not with you that was very difficult for me to endure."  Bob (case 5): "When I had to leave Jacky in the hospital, it felt like I abandoned my child who was in need it was as if I was not interested in her."		
• Alienation	Peter (case 1): "Your child is a patient and not yet 100% 'your child'. She was more of a kind of a patient than completely my baby I could take care of."		
Developing relationship	Esther (case 4), about discharge: "That was really the moment that I felt: now she is mine, ours. In the hospital I was just one of the caregivers. It was difficult for me to love her 100%. Officially you are the mother, but in practice you are one of the many that take care of her."		
First encounter with a prematurely born child		Jill (case 1): "Such a little bugger".  Mary (case 2): "Really a very small doll. I have always assumed that it would be a healthy child () I do not know if I want a disabled child".  Carl (case 4): "It was such a small and delicate creature."  Bob (case 5): "It looked sort of like a kid."	
Comparing to full-term born children		Carl (case 4): "She is a fighter, does everything quicker than other babies it is as if she wants to recover her setbacks."	

#### 3.1.3. Supporting matrix theme: can someone help me parenting my child?

In relation to the supporting matrix theme, parents mentioned support from the partner and the healthcare professionals such as doctors, nurses in hospital and maternity care at home and professional therapists, for instance the physiotherapist. They also mentioned that support from the child's grandparents and peers such as other parents at the obstetric ward and NICU had been comforting. The Supporting Matrix Theme was present in every single interview.

3.1.3.1. Relationship with partner. Mothers and fathers found it stressful to be separated from the partner during hospitalization, particularly during the night. Fathers mentioned the importance of being able to be present and support their partner, and also mentioned anxiety caused by being separated from her. Fathers also emphasized the fear of losing their wives because of their medical situation.

Being separated from partner	Katie (case 5): "After the delivery I hated it when Bob left. Even though he was actually next to the hospital in the Ronald McDonald house. I hated to be alone."  Peter (case 1): "One of those moments in your life that you won't forget: the moment we were taken to the ward room and someone entered the room and asked what she wanted to eat… I thought, shit, Jill has to stay here, and I cannot stay… that was really tough…"
Feeling supported by partner	Mark (case 3) about the importance of supporting each other: "One has to rely on the doctors and nurses but fortunately we were able to talk to each other and then we could handle it better."
Medical situation and fear of losing the partner	Joe (case 2): "I was really worried about her health failure of your organs, that is not to be taken lightly. I am glad that we live now, because 50 years ago, I wouldn't have had a wife or child anymore. This is the kind of thoughts that are going through your mind these are kind of nightmares to me."

3.1.3.2. Healthcare professionals. Both mothers and fathers emphasized the support received from healthcare professionals, but also brought up the consequences of a lack of support. Receiving clear information on medical issues and feeling heard and seen by the medical staff, helps to restore some feelings of safety and trust. Support from the healthcare professionals after discharge from the hospital was highly appreciated. Difficult communication with the healthcare professionals, e.g. when the treatment policy remains unclear, was mentioned as a cause of stress and mistrust and hence of feelings of unsafety.



Experiencing sup- port/trust	Peter (case 1): "I completely trusted the nurses and doctors that were helping my wife, even when they explained that it was a matter of choosing either in favor of the health of the mother or the baby. It was helpful that they were honest."  Bob (case 5): "When Jacky started playing with toys, we were unsure about how to react. We learned that – as a preterm born baby – she couldn't handle too many stimuli. So we were hesitant about giving her toys. It was helpful that the physiotherapist reassured us that she could play with the toys and this wouldn't harm her."
Experiencing stress/ mistrust	Katie (case 5): "The night that I had shortness of breath, a nurse came and just said: Oh, take it easy I didn't feel comfortable at that time. I doubted if she understood how serious it was, she didn't call a doctor. I was very short of breath that is a very anxious feeling."

3.1.3.3. Grandparents: supportive but also burdened. Most parents feel supported by their own parents, but also realize how the concerns about the health of their children and grandchildren are a burden for the grandparents.

Experiencing sup- port	Jill (case 1): "We were very lucky with my mother, that she was available for us. She managed our household while $I$ was in the hospital."
Felt burden of grandparents	Rose (case 3): "I noticed that my mother did not dare to get attached to Jesse when he was born. She was anxious that he would not survive. My father, on the other hand, had the attitude of giving Jesse as much love as he could give as long as Jesse was alive".

3.1.3.4. Peers. Furthermore, parents mentioned the support and comfort from other parents in the same situation at the obstetric ward and NICU.

<ul> <li>Peers</li> </ul>	Jill (case 1): "At the NICU, horrible things happened to other children. Talking to those parents helped
	us to keep our story in perspective, to exchange information and to compare situations."
	Mary (case 2): "It was a relief to hear the stories of other parents and have fun with them."

- 3.1.4. Identity reorganization theme: can I pick up my life and integrate parenthood in it? The Identity Reorganization Theme was present in every single interview. Parents talked about how the arrival of the baby was unprepared for, and how that rendered the transition from partners to parents complicated. Additionally, they were afraid that preeclampsia and preterm delivery would be repeated in a future pregnancy.
- 3.1.4.1. Making room for the baby: preparing the arrival. Fathers talked about having to prepare the baby room while mother and child were hospitalized, and mothers talked about not being able to prepare the arrival of the baby because of the short pregnancy.

Preparing for the arrival of child	Joe (case 2): "At the time my wife was hospitalized, we were moving. So that was a lot of stress for me: painting, preparing the baby room, doing jobs around the house and being with my wife in the hospital."  Rose (case 3): "It feels like I was pregnant for only 8 to 10 weeks, that is really weird."
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- 3.1.4.2. Transition into parenthood. The difficult start of family life with the preeclampsia and the preterm delivery had an effect on the transition into parenthood, in terms of taking up a parenting role, returning to professional activities and rehabilitating mother's health issues.
- 3.1.4.3. Family planning: future children. Parents mentioned hesitations concerning future pregnancies.



Parenting role	Esther (case 4): "It is beautiful to be a mother, but it is also negative, because you change as a person. It makes me emotional (cries). It frightens me to be a mother."
Professional activity	Katie (case 5): "I felt so relieved when I did not have to go back to work because the contract was not renewed. I could finally do what I had been supposed to do during maternity leave enjoy being with my baby."  Esther (case 4): "My work is very intensive, and I always have to perform at the top of my ability, and I cannot do that at all that just isn't possible When I think about the fact that I should do that again in the future, I really panic."
Rehabilitation of medi- cal situation	Rose (case 3): "You just do not trust your body anymore."
Family planning of future children	Rose (case 3): "I always said I wanted a few kids in a row. But now I feel completely different. I have been so ill and I lost so much strength I could have died. I feel responsible now I am a mother. I do not want to leave my husband and son behind, by dying of preeclampsia."

#### 3.1.5. Traumatic experiences

The identified theme "traumatic experiences" is about fathers and mothers being overwhelmed and not capable of reassuring themselves. During the interviews, parents tended to persevere in worries and often were unable to stop talking about the baby's medical situation. This theme differs from the other themes in that the predominant meaning in the narratives was not so much related to parenthood, but rather to panic, despair, loss of control and fear. Because of the overwhelming affects parents have experienced and the recurring catastrophic concerns, we termed these experiences "traumatic". First, parents mentioned moments when their lives seemed to slip out of their hands and they collapsed, afraid of what would happen next. We named these "moments of loss of control". Second, parents were struggling with intrusive memories that dysregulated and upset them. We named these "recurring memories". Third, parents mentioned being constantly alert to their child's well-being. We named these emotions "catastrophic fears about what might happen".

3.1.5.1. Parents' levels of distress and their bonding with the child. Six months after the child's birth, all parents except two reported doing psychologically well and not having problems with bonding, as reported on the questionnaires. One father (case 1) scored high on "impaired bonding" (score 12) of the PBQ. One mother (case 4) had a clinical score for depression as well as a heightened state anxiety (score 44). When asked, she told the interviewer she was seeking

Moments of loss of control	Bob (case 5): "The medical condition of my pregnant wife worsened. The two most important people in my life it was devastating I didn't know what to do with my feelings it was such a hard time".
Recurring memories	Carl (case 4): "My parents tell me that I've changed. I am brusque and irritable. Late at night I am often thinking about what happened. I haven't processed it all yet."  Rose (case 3): "I try to avoid thinking about the preeclampsia and preterm birth. My emotions are at the surface. If I admit the feelings, I will not be able to function properly; they will block me."
Catastrophic fears about what might happen	Jill (case 1): "She is not feeling well and pukes a lot the weight loss has to stop immediately, before it goes wrong!" (and Jill would lose her daughter). During the interview mother kept coming back to her daughter's puking and how disturbing that was.  Joe (case 2): When he sleeps, he cools down, and if I put my hand on his cheek and he is completely cold in a fraction of a second I wonder if he is still breathing."



psychological support. Two other parents (father in case 4 and mother in case 5) sought professional help, although they had psychological scores within the normal range.

#### 4. Discussion

The aim of this interview study was to gain insight into the development of parenthood of both fathers and mothers six months after the birth of a very premature baby due to the mother's preeclampsia or HELLP syndrome. This study is distinctive in that it focuses on the developing parenthood and the parent-infant relationship of mothers as well as fathers.

#### 4.1. Parenthood development

We found that although the narratives of the interviewed parents included common statements that all parents will make, the multitude of specific statements made clear that these parents were undergoing a distinctive development. Worryingly, the narratives spoke of difficulties in all domains of the parenthood constellation, such as fear of being a parent of a baby they might lose and difficulty of building a loving bond with their baby. In addition, they felt dependent on professionals for support and were hindered from moving on with their lives. Support was sought from the partner, professionals and other parents in similar circumstances, but friends and family members, such as brothers and sisters, were hardly mentioned as sources of support.

Other than the mothers, the fathers not only were afraid of losing the baby, but also of losing the partner. In addition, they felt responsible for taking care of the partner, organizing their family's return home by furnishing and painting the baby's room, and also taking care of the family's financial situation. More so, due to the mother's fragile health situation and sickness, the father was important in the communication with the nurses and doctors. In contrast to the worrisome narratives, the completed questionnaires on depression, anxiety and bonding revealed socioemotional problems only for two out of the ten parents.

#### 4.2. Trauma

As if still trapped in the terrifying situation of the obstetric ward or neonatal intensive care unit, parents cited moments when they panicked and felt overwhelmed with memories and emotions. Six months after delivery, these parents seem to suffer of posttraumatic stress symptoms with regard to the parent-infant relationship. This finding is very disconcerting in light of the known devastating effect of parental psychopathology, such as unresolved trauma upon the child's development and mental health (Chen et al., 2020; Narayan et al., 2021).

#### 4.3. Theoretical implications

The results are in accordance with the literature concerning struggles of parents shortly after preeclampsia and preterm delivery. It is known that parents of a prematurely born child suffer from anxiety, fear of loss and grief, among other things, and have difficulty feeling connected to the child (Lefkowitz et al., 2010; Spinelli et al., 2016; Vaerland, 2021). However, our study found that problems were still present after parents had experienced months of parenting the infant at home. Specifically for the mothers, the grief and mourning about the pregnancy and preterm birth (Shah et al., 2011) still persisted now they had to move on with their lives and thought about going back to work. The disrupted parenthood development seems to have an impact on family life as well as on mothers' social participation. Like the mothers, the fathers were still struggling to process what they had been through and were also facing a disrupted development. Without maternity leave, fathers face specific challenges in combining work and family responsibilities (Kuo et al., 2018; Petersen & Quinlivan, 2021; Vaerland et al., 2017a). During the mother's and infant's hospitalization, they served as liaisons between mother, caregivers and family members, and also between mother and infant when the mother's illness and the infant's stay in the NICU separated them. The fathers' presence was very much needed, and picking up caregiving tasks such as skinto-skin contact with the baby was encouraged. But reconciling family and work duties, being with the partner, being with the premature born infant, maintaining communication with nurses and doctors, getting the baby's room ready, and showing up at work, may have pressured them



(Deeney et al., 2012). In the case of preeclampsia of their partner and preterm birth of the child, fathers, both during hospitalization and after discharge home, needed more social recognition of their specific parental role and duties.

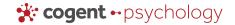
Of note, the questionnaire outcomes in this study hardly matched the worrying stories told by parents. If their well-being were to be monitored only through questionnaires, much hidden suffering and difficulties might go unnoticed.

#### 4.4. Clinical implications

Based upon the information gathered in this study, some important issues can be highlighted concerning parenthood development and need for specific parent support after complicated pregnancy and very preterm delivery. Early relational health, which implies warm, safe and stable parent-infant relationships, is known to be necessary for children's future wellbeing (Willis & Eddy, 2022). Besides the medical treatment, these parents seem in need of specific support from the nurses and doctors, family and friends—and even psychologists—to promote the parent-infant relationship. Parents are and feel responsible for the child's health and wellbeing (Pas, 2003; Weille, 2011); still, for parents of a premature baby, the baby's vulnerability and negative feelings such as quilt and helplessness have an extra burdening impact (Mew et al., 2003). From the point of view of prevention of later adverse developmental effects, it is important to support these parents and children in forming a healthy relationship early in life and create a context in which the child can healthily develop. Several domains of necessary support can be distinguished (Greenspan, 2008). These domains include helping meet basic needs such as housing and financial security, helping the continuous availability of, reliable and sensitive caregivers to meet the needs of the child, addressing specific developmental needs such as speech therapy or physical therapy, and providing psychological help to address complex emotional problems. In the case of these parents and children, psychological support should be provided during hospitalization and after discharge home to help parents regulate shock and fear, process traumatic experiences, and integrate the frightening life event into their lives and the development of parenthood. During hospitalization, periodic consultations with psychologists can offer parents a reflective context in which traumatizing events can be contained and processed. To this end, different tailored treatment approaches should be available for parents in the NICU. Infant mental health and parentinfant psychotherapy should be available to improve the parent-infant relationship, family therapy to support all family members, including siblings and, if desired, grandparents to process the lifethreatening events. Trauma-focused interventions are needed to help regulate the overwhelming effects of the traumatizing context and experiences (Grunberg et al., 2022; Hynan et al., 2015). Even after discharge to home, personalized treatment should be available if they are then struggling emotionally with their parenting (Purdy et al., 2015). To increase awareness and improve skills, psychologists and psychotherapists, even when not working in hospitals, should be educated during their professional training on the specific issues relating to parenthood after severe pregnancy complications and preterm delivery so that they can provide adequate help when parents are referred to them (Saxton et al., 2020).

Furthermore, specifically for fathers—and compliant with the family integrated care model (Waddington et al., 2021) –, it would be an improvement to enable fathers to stay with the pregnant mothers in the obstetric ward, and help them from pregnancy on to make the transition from partners to parents (Franck et al., 2020).

Furthermore, professionals and fellow sufferers seem to take over the roles of family and friends to reduce psychological distress (Hughes et al., 2020), but those are less available after discharge from the hospital. Psychoeducation to family members and friends during mother and child hospitalization may help raise their knowledge about severe pregnancy problems, preterm birth and NICU stay. Eventually, this can reinforce their commitment to support the parents after discharge home.



#### 4.5. Strength and limitations of the study

Although the narratives of the parents were very rich, clearly some limitations of the study need to be addressed. First, because we chose not to include parents with limited command of Dutch and who did not speak English, we included a restricted cultural-ethnic group. It remains unknown how parents with a background of migration or fleeing the home country develop after preeclampsia, HELLP and preterm delivery. These parents may have specific problems, such as war in the home country and concerns about family members left behind, unclear future prospects, housing and financial insecurities, a language barrier, and a limited support network. These are issues that put additional strain on the development of parenthood (Moro, 2014). It is important to investigate what these parents experience, how parenthood develops and what kind of support they need. Second, the study was conducted in a single hospital that had no visitation restrictions, except sleeping with the baby on the ward at night, and where closeness between parent and child was promoted. It is unclear how the results of this study relate to the parenthood development of parents in a NICU where closeness between parent and child is less ardently promoted. Conversely, it is not clear how the data relate to the situation where parents are allowed to be with their baby at all times and overnight via rooming-in.

#### 4.6. Recommendations for future research

The findings from the extensive narratives give reason for further qualitative research to monitor parenthood and the parent-infant relationship during the first years of the infant, and gain more knowledge about the specific difficulties and possible needs for psychological support of mothers as well as fathers. It is important to include cultural and migration aspects in such research. In addition, it seems important to conduct interviews in addition to questionnaires to gain insight into parents' well-being and the parent-infant relationship. It would be advisable to add a questionnaire that measures posttraumatic stress disorder.

Moreover, as parenthood usually decreases marital satisfaction (Hirschberger et al., 2009) and posttraumatic stress has a negative impact on couple functioning (Grunberg et al., 2022), it would be interesting to study how the partner-relation develops under the specific troubling circumstances of having experienced preeclampsia and preterm delivery and parenting a preterm born child.

#### 5. Conclusion

This study provides a clear insight in the burdened development of parenthood and the parent-infant relationship in the first half year after the mother's preeclampsia and the birth of the preterm infant. Good monitoring of this development might timely detect problems, intervene and prevent adverse consequences.

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#### Disclosure statement

No potential conflict of interest was reported by the authors.

#### Data availability statement

Privacy of the patients cannot be guaranteed when the qualitative data used in this study would be shared publicly.

#### Informed consent

For confidentiality reasons, we have used pseudonyms and categorized the infants' weights. We sought contact by email and invited them for an appointment to read the draft. The participants chose to conduct video



conferences or telephone calls in which the material referring to them was read aloud. The parents agreed with the publication of the material.

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## Appendix 1. Working Model of the Child Interview (Benoit, et al. 1997)

1. Can you tell about the pregnancy and birth? We would like to know how you felt emotionally and physically and how the first period was at home (feeding, sleeping, crying)?	9. Does your child often get upset? What do you do and how do you feel when this happens?
2. Can you describe the character of your baby (name) in five adjectives and give examples?	10. Tell one of your favorite stories about your baby (name)
3. Who does your baby (name) remind you of and in what way?	11. Are there any experiences your baby (name) has had that you think is a setback for her/him? Why do you think that? Knowing what you know now, if you could do everything over with your baby (name), what would you do differently?
4. What is unique, different or special about your baby (name) compared to what you know about other children?	12. Do you ever worry about your baby (name)? What are you worried about?
5. What about your baby's (name) behavior is the hardest to deal with right now. Give a typical example.	13. Some people would like their baby (name) to have a certain age. What age would you like for your child. Why?
6. How would you describe your relationship with your baby (name). Choose five adjectives to describe your relationship and give examples.	14. Looking ahead, what will be the most difficult time in your baby's (name) development? Why do you think this?
7. What do you like most about the relationship with your baby (name). How do you think that your relationship with your baby (name), influences the character of your baby (name). Did your relationship change over time?	15. What do you expect (name) to be as a teenager? What gives you this feeling? In this period of your baby's (name) life, what do you expect to be good and what not so good?
8. Which parent is your baby (name) closest to? How do you know that? How do you expect it to change?	16. For a moment think of your baby (name) as an adult. What kind of wishes and fears do you have for this period?