



Being parents of extremely preterm children, from a long-term perspective: A qualitative study of parents' experiences

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ABSTRACT

Background: In recent decades, modern neonatal intensive care has improved, increasing the survival of extremely preterm children. Few studies have examined the experiences of parents of extremely preterm children from a long-term perspective.

Aim: To describe parents' experiences of parenting extremely preterm children during their childhood and transition to adulthood.

Study design: A qualitative interview study with a descriptive design.

Subjects: Thirteen parents of eleven children born at 24 gestational weeks in Sweden, 1990–1992, participated in individual semi-structured interviews.

Outcome measures: Data were analyzed using qualitative reflexive thematic analysis.

Result: Five themes forming a timeline were created in the analytic process: *parenthood, at the NICU, young childhood, adolescence, and adulthood*. Various aspects affecting parenthood were described throughout the timeline, and occasionally the parents experienced difficulties dealing with their children's special physical and/or mental needs. Today, some families have established a functioning situation despite their children's physical and/or mental difficulties, while some still struggle with their children's everyday life.

Conclusion: Having an extremely preterm family member profoundly affects the whole family for various lengths of time. Parents expressed a need for support from both healthcare and school throughout their children's childhood and in their transition to adulthood, although the need varies between parent–child pairs. By studying the parents' experiences, their need for support can be further recognized and understood, and developed and improved accordingly.

1. Introduction

Improved neonatal intensive care has increased the survival of extremely preterm (EPT) children (born <28 gestational weeks) in recent decades [1]. In Sweden, a proactive perinatal strategy has increased the survival rate of children born at <25 gestational weeks and improved these children's postnatal wellbeing at 2.5-year follow-up [2]. Thirty-eight percent of children born EPT from 2014 to 2016 survived at one year of age, without any major neonatal morbidities [3]. Children born EPT have still an increased risk of neurodevelopmental impairments such as cerebral palsy, visual and hearing impairments, lower cognitive ability [1], dyslexia and dyscalculia [4], attention deficit hyperactivity disorder, autism spectrum disorder, and anxiety and/or depression [5], and fewer of them complete higher education [6]. Adults born preterm have increased rates of shyness, cautiousness,

behavioral inhibition, decreased sociability, and sensation seeking [7].

Having children in a neonatal intensive care unit (NICU) is stressful for parents and the whole family [8]. Even long after the NICU stay, the family is affected; studies have found higher levels of distress, depression, and anxiety among parents of very preterm (VPT) children (born 28–32 gestational weeks) than among parents of term children [9]. Preterm children have fewer younger siblings than do term children, and the more preterm the child, the greater the likelihood of their being the family's last child [10]. In recent decades, many NICUs worldwide have shifted their focus from caring solely for children to family care, and now use approaches that enable parents to become primary caregivers in the NICU, with very positive results [11]. Parents' experiences of having a child in an NICU are well studied. Studies have explored, from a long-term perspective, EPT children's health disabilities [12] and the stress parents experience during their child's NICU stay [13]. However, we

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lack information on the long-term experience of being a parent during the EPT child's childhood and transition to adulthood; the aim of this study was accordingly to explore this experience.

2. Method

2.1. Design

A qualitative descriptive study based on semi-structured individual interviews with parents of EPT children born at <25 gestational weeks in the early 1990s in Sweden.

2.2. Recruitment and participants

Thirteen parents of 11 EPT children who are now adults were recruited from a Swedish cohort of 633 children each with a birth weight <1000 g, with 28 children born at 23–24 gestational weeks. The children were born from April 1990 through March 1992. Of these children, 370 (58 %) survived to the age of one year [14]. A sub-cohort, born at 23–25 gestational weeks, was followed up at age 11 years [15–18], and one ongoing study is investigating the psychosocial and physical health of the now-adult EPT children. The parents were identified via Swedish public records using the children's social security numbers. A purposeful sample was collected to acquire varied baseline data [19] regarding birth weight, sex of the children, multiple versus single pregnancy, residential area in Sweden, and whether the parents were living together, and both mothers and fathers.

2.3. Data collection

The first contact with the parents was made by sending an invitation letter to 25 parents; the letter contained information about the study, a study invitation, a consent form, the researchers' contact details, and a prepaid envelope. Thirteen parents, all with children born in gestational week 24, agreed to participate (Table 1). None of the parents ($n = 3$) of children born at 23 gestational weeks agreed to participate. The participating parents were called by the first author and asked when and where they wanted to be interviewed. The interview was conducted by telephone ($n = 8$), through a secure online link (Zoom Video Communications Inc., CA, USA) ($n = 4$), or face to face ($n = 1$). Parents who did not reply to the first invitation were contacted by telephone; if no answer, a second invitation letter was sent.

The interviews with the parents were individual and semi-structured, based on an interview guide designed by the authors according to clinical experience and the literature. The interview guide was tested in a pilot interview. During the interviews, the parents were asked to talk about their EPT child and about their experiences when their child was born, entered adolescence, and transitioned to adulthood. Questions were asked about whether their own life had been affected in any way by having a child born EPT and whether they had experienced differences in how they treated their EPT child compared with their term children (if

Table 1
Background data on the included parents ($n = 13$) and their children ($n = 11$).

Variables	<i>n</i>	<i>m</i> (min–max)
Parents		
Mother's age, years	9	58.6 (46–68)
Father's age, years	4	61.5 (57–67)
Parents of twins	3	
Children		
Current age, years	11	30.2 (29–31)
Sex, girls/boys	7/4	
Gestational age at birth, weeks+days	11	24 + 3 (24 + 0–24 + 6)
Birth weight, g	11	676.5 (588–795)
Born as a twin	3	

any) and with children other than their own. Probing questions were consistently asked to gain a deeper understanding of the parents' experiences.

Interviews were conducted until they no longer provided any new information and the author experienced redundancy [20], i.e., the same content was repeated in interviews with different parents. The first author conducted the interviews from November 2021 until March 2022. The interviews were digitally recorded and lasted, on average, 78 min (range 42–138 min). The interviews were transcribed verbatim by the first author and saved in encrypted digital storage.

2.4. Data analysis

Reflexive thematic analysis [21] as described by Braun and Clark [22] was used in an analytical process comprising the following six phases. 1) Familiarization with the data started during transcription and an initial understanding appeared through identifying items of potential interest. The first and last authors actively read the transcripts several times and wrote comments. 2) The initial coding started systematically, first individually and then jointly, followed by another read-through of the text. 3) The initial codes were clustered to generate potential themes. These themes were compared, and a thematic map was drafted to reveal relationships and patterns in the data. The first and last authors read the transcripts to confirm that the themes were indeed represented in the original text and that they were unified. 4) To identify whether the themes worked in relation to the codes and to the entire dataset, the codes and themes were discussed and then reviewed. 5) The themes and subthemes were defined and named, and some subthemes were clustered to ensure that they made sense in relation to the overall analysis. All authors jointly discussed the themes and the patterns that they formed. 6) The thematic map was redesigned and finalized, as shown in Fig. 1. All authors participated in the writing process. The quotations included in the “Results” section to give the reader a deeper understanding of the interview material were chosen to capture the parents' experiences and reflections. All authors work in neonatal care in a clinical setting and have clinical experience of meeting parents during their time at the NICU. None of the authors was working during the period when these parents' children were admitted to NICU care. Throughout the interviews and analysis, the authors paid careful attention to their pre-understandings, which would inevitably have influenced their interpretations of the parents' stories.

3. Results

In the analytical process, five themes and subthemes were created and are presented as forming a timeline: *parenthood, at the NICU, young childhood, adolescence, and adulthood*. Different aspects affecting parenthood were described throughout the thematic timeline, so the theme of *parenthood* runs throughout the results (see Fig. 1).

3.1. Parenthood: the downside

The parents described how being parents of an EPT child was occasionally very difficult. They needed to deal with many issues when their EPT child was growing up, making the experience different from raising a term, healthy child.

3.1.1. Social relations and networks

The parents described how the preterm birth of and life with an EPT child had affected their social life. They described experiencing difficulties in their partner relations, and divorce was a fact in almost every family: “It also affected the marriage so ... it got a bit strained, you might say” (Parent 2). For some, the divorce was because of the challenges with the EPT child, while others attributed it to other reasons. However, parents also said that their social network was important for support and help: “Without them [i.e., parents and siblings] I wouldn't have made it”

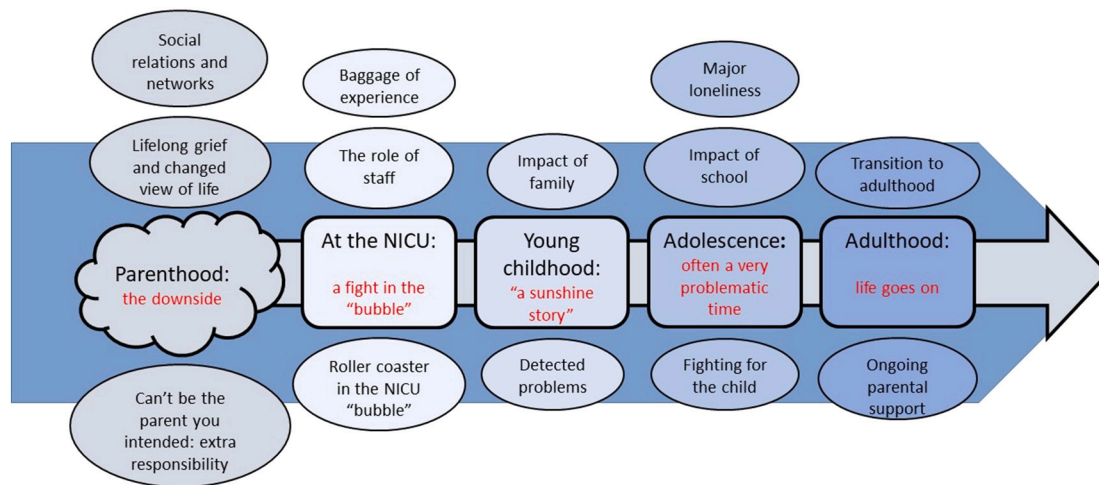


Fig. 1. A timeline starting from the time at the NICU and extending to adulthood. The parenthood cloud (left-hand side) gives rise to an arrow that follows the parents' stories throughout their children's childhood and adulthood.

(Parent 3); “My close friends have been told a lot ... They've been amazing” (Parent 10). Still, some felt that no one could really understand what they had been through.

3.1.2. Lifelong grief and changed view of life

The parents said that having an EPT child gave them a different view of life: “It's nothing I'd wish on anyone else, but at the same time you also learn a lot, I think ... and become grateful for what you have, yes” (Parent 5). Their lives had been affected in various ways, starting from the moment the child was born up to the present. They experienced grief: at the incomplete pregnancy, unexpected birth, and time at the NICU; at the child's delayed development, time in school and experience of bullying and isolation, and failure to enter adulthood independently. They were sometimes tired of other parents' whining about what they perceived as less important problems. Several of the parents thought it was rewarding to talk about these experiences, and were grateful for the opportunity to participate in the study.

3.1.3. Can't be the parent you intended: extra responsibility

The parents described a sense of being divided in their parenting, behaving one way with their healthy child and another with their EPT child: “She sits inside one's heart, all children do, but that's the way it is ... so I also think about how it has shaped my parenting, and it has done that very, very much, I think” (Parent 3). Some have become a type of parent they had not intended to be, which feels problematic for them. Many of the parents felt that they had been watching over their child for a long time, “like a hawk” and had struggled for their child throughout their childhood. They felt an extra responsibility because their child was born EPT: “Of course it has left its mark, and it is probably what has made me perhaps significantly more sensitive today than I was perhaps before” (Parent 11).

3.2. At the NICU: a fight in the “bubble”

The parents described the time at the NICU as living in a “bubble” with ups and downs that one could not control. Even after 30 years, they retained very clear memories of the NICU.

3.2.1. Baggage of experience

The parents described the baggage of various experiences they took with them when they entered the NICU. Some had a long struggle before getting pregnant and had to cope with infertility; for others, the pregnancy was an IVF pregnancy. Some had experienced miscarriages: “So we had tried to have children earlier and it had gone wrong—there were

miscarriages” (Parent 7). Some parents had experiences of having lost a child before or during the time at the NICU. Some mothers were cared for at the hospital before the delivery.

3.2.2. The role of staff

Some parents knew that a child born this early, at 24 gestational weeks, was at the limit of survival and new to healthcare. They described feeling that some staff were inexperienced in caring for such children and new medications were tested. However, the parents said that having professionals around them in the NICU made them feel safe: “The time at the hospital, at the children's intensive care unit there, was absolutely fantastic; there were absolutely wonderful people and there was nothing to complain about” (Parent 1). They had very specific memories of the staff they liked and disliked, trusted or distrusted: “So I had to fight, I fought like an animal. They were going to chase me to bed, but I said you can forget it—I don't need to sleep. I never need to sleep again. I'll be here. I'm going to sit here. I want to know how it's going. But sometimes I slept when it was safe, and so on” (Parent 13). The parents described feeling dependent on the staff, and they liked that the staff did not euphemize anything: “They told us as it was” (Parent 6).

3.2.3. Roller coaster in the NICU “bubble”

Parents described ups and downs, struggles and beautiful experiences. Many explained that they could not be present at the NICU around the clock because of the NICU's restrictions: “We didn't have a parents' room, so we travelled ... back and forth every day. Going home in the evening and not bringing your child with you, it was really hard” (Parent 10). Siblings were often not allowed at the NICU, or if they were, for only short periods. Some mentioned their room in the maternity ward: they remembered all the other big babies and all the happy families, and being exposed to them made them very sad.

The family's financial situation was affected, as in Sweden at that time, only one parent had leave to be with the child at the NICU. The parents described the NICU environment as horrible for them and their child, with many sounds, bright lights, and medical devices: “They flashed and beeped, and then there were monitors on the walls” (Parent 11). Many of the parents mentioned having the opportunity to hold their child skin to skin, and expressed how grateful they were for that experience: “Then I got to hold her kangaroo ... and that was an incredibly special moment ... I remember that too, very strongly, this first moment and her little hands ... scratched me” (Parent 10). They also expressed gratitude to healthcare for investing in their child's life and working hard for the child's survival.

Many strong feelings were associated with the time at the NICU:

anxiety, fear, sorrow, joy, powerlessness, not daring to believe, and fragility. Life outside the NICU went on as usual, while the parents had to live with uncertainty about the future and try to gain control over the situation, which was very hard to do. Everything could change so quickly, from good to bad, and the experience was described as riding a roller coaster: “All the time awake, riding the roller coaster with all the emotions and stuff, there was a lot of that happening at that time ... a terrible time that you wouldn't wish on your worst enemy, I usually say. But at the same time, those feelings, it was like you didn't want to forget them either” (Parent 4).

3.3. Young childhood: “a sunshine story”

The parents described great gratitude for being able to bring their child home despite everything, and the inconceivability that their child had survived against all odds. However, not everything was peace and joy once they got home, and “a sunshine story” was meant ironically.

3.3.1. Impact of family

When the EPT child was discharged from hospital, some parents felt a sudden lack of support. Some longed for follow-up visits to the doctor to feel secure. Many described watching over their child and having medical care at home. This led to a lot of anxiety for the parents about their child: “It was incredibly nerve wracking [going home] ... trusting your own abilities, because you were so used to having a professional around you ... so it was very scary” (Parent 10). The family's finances were affected because of their child's great sensitivity to infections.

The parents discussed siblings in different ways: “It was only positive ... that she got a sibling, and I think for the whole family it was like that, and from time to time we were perhaps more normal” (Parent 9). Other parents felt that they did not have the opportunity to have another child: “She was terribly ill when she was little, we didn't even know if she would survive, and it wasn't until she was several years old, so there was ... no energy or any time to think at all about having more children” (Parent 13). Parents also described how older siblings provided support for the EPT child.

3.3.2. Detected problems

The parents described the multiple diseases, health conditions, and other physical and mental problems experienced by their EPT child. Some described their child's development as early in terms of walking and talking, while others described their child as late developing, for example, in smiling, making contact, walking, and learning gross and fine motor skills. Many said that they needed to seek medical care frequently, and it was often complicated to get the right kind of care. Several found that they were not taken seriously: “Yes, but sometimes you could feel as though they didn't believe what you were saying ... didn't take it in. Because in that department, before she was discharged and sent home, you learned that ‘you know your child best’ ... but then when you went to the emergency, you didn't know best ... Well, then you definitely had to fight a lot more” (Parent 6).

The parents said that early in childhood they noted that their child was different in mental condition and/or social capacity: “Perhaps I noticed that she didn't really keep up with her age, and so on, but, ah, you were forbearing about that because you thought that, yes, she will eventually catch up” (Parent 1). Some described the child's personality as precocious or as odd, while others noted that their child had poor self-confidence or difficulty with social interactions. Some of the children were very lonely and had few or no friends. Some parents also reported that their child had later told them about having suicidal thoughts at a very early age.

3.4. Adolescence: often a very problematic time

The parents described their child's adolescence as problematic in many ways, and many of the teenaged children were lonely and had a

tough time in school.

3.4.1. Major loneliness

The parents described the EPT teenager as having difficulties handling emotions and reactions to life experiences. Some had suicidal thoughts, were bullied, or isolated themselves and became very lonely: “The older she got, the fewer her friends ... she had this hope that things would get so much better when she started high school, but it didn't happen ... She became lonely” (Parent 6). The EPT teenager could become “nerdy” in specific areas, and some took neurological tests with or without getting a diagnosis. Those who did not get a specific diagnosis were said not to have met enough criteria, but had “a little of everything.”

3.4.2. Impact of school

Primary school and middle school were often all right, according to the parents, but high school presented a lot of trouble. When higher demands were made of the EPT teenager, it became difficult to keep up: “Elementary school was good ... I don't really know what happened, but then [the child] never liked school ... So no, it wasn't fun at school. Then she has this thing [difficulty] with reading techniques, and studying isn't her thing either, so it was difficult at school ... when she entered higher classes, yes” (Parent 6).

Some parents had concerns about their child's ability in school and for the future. For some, school was a positive place, especially when it was adapted to the child's special needs, for example, having smaller classes or being tailored to the teenager's disability: “She learned an incredible amount—the school was fantastic” (Parent 11). Some parents described math as difficult, but language as easy for their child; some children had an easy time in school without any problems.

3.4.3. Fighting for the child

The parents noted that the whole family was affected when the EPT child became a teenager, and family resources and finances were, once again, affected. Siblings were described as supporting the EPT teenager, but parents also thought that the siblings sometimes felt neglected when the EPT child took so much of their parents' attention. Parents said that they had to fight for their child in many ways, waging “war against the authorities” (Parent 9). This fight was against the school, city council, insurance funds, politicians, and healthcare, to explain their child's needs. On the other hand, one parent expressed remorse: “I have such an extremely guilty conscience because I wish I could have given him more time and attention” (Parent 3).

3.5. Adulthood: life goes on

The now-adult EPT children's current needs were described in various ways by the parents, in relation to where life had taken these children. Life went on but in different directions for different families. Some parents said that their child's especially problematic period was now history, while others explained that there were still everyday problems.

3.5.1. Transition to adulthood

The EPT children often obtained an education, most of them having at least completed high school, but not all of them had employment or were able to work. The parents commonly described their children as having difficulty finding a place in society. Some felt excluded and lonely or had difficulties in social contexts and seeing other's perspectives. Some wanted a partner but found it difficult to meet someone: “She's not completely happy—she wants to meet someone, she wants a partner, and that's the hardest part of all” (Parent 12). Some EPT born adults were married or living with a partner and had children. Some had sought professional support for their mental health. Several of the parents said that animals were a big part of their child's life.

3.5.2. Ongoing parental support

Many described still having a lot of responsibility for their now-adult EPT child who had difficulties coping as an adult, for example, regarding finances, household management, social contexts, and raising their own children. Some thought their child's situation was good enough: "Because as it is now, he can, even though he never will be able to work ... paid work, like 100 percent and so on, but he can have a dignified life ... it is very good" (Parent 8). Some parents experienced frustration with society: they felt that they still needed to speak for their EPT children, even though they were now over 18 years old and were now expected to take care of themselves. Some described feeling frustrated with their own child due to this unsustainable situation.

The now-adult EPT child with a disability might require an adapted living environment, and one EPT born adult had medical assistance at home around the clock. The children's relationship with their siblings was also affected: some had good relations in which the EPT born adult and the siblings supported one another, while other siblings have no contact at all with the EPT born adult because it is too draining for them, the parents reported. Sometimes the EPT born adult surprised the parents by displaying new or unexpected abilities, managing better than the parent expected: "But in a way, I've probably let go ... she's not like us, but she copes in her own way" (Parent 7).

Summarizing the EPT child's journey from the parents' perspective, and how it affected the parents in their parenthood, one parent said: "I also want to say that it's going well anyway, no matter what. That crooked path—you may not walk on a highway like everyone else, but you get on a fantastic side road where perhaps, as a parent, you need to be ... It goes well, it goes well, anyway, in the end" (Parent 12).

4. Discussion

When reading about the parents' experiences in this study, it is important to recall that a lot has happened in Swedish neonatal healthcare over the last 30 years, although there is still much to learn. We found that being a parent of an EPT child was occasionally very difficult. At the NICU, these parents experienced separation from their children. How this separation negatively affects the parents, the EPT children, and these children's development has now been well described [23]. This separation can interrupt the development of the parent-child relationship [24]. The parents also described the NICU environment as bad for both them and their child. Today, we know that being in this environment is not good for the EPT child's growing brain [25], and that what was supposed to have developed in utero instead must develop in the NICU environment [26]. However, the parents expressed trust in the staff of the NICU and felt that their children were safe there [24]. Thivierge et al. [27] asked parents to EPT children about the presence of regret or guilt related to the child's neonatal period. They showed that 54 % of the parents to EPT children reported no regrets. Of those who had regrets; 35 % experienced guilt about the preterm birth, 28 % experienced regret about self-care decisions during NICU time, and 20 % regret that they were not enough involved in the care early in their child's life. No parents mentioned that they regret that their child survived despite difficulties. Janvier et al. [28] found that the majority of parents of EPT born children thought there were both positive and negative aspects of having a preterm born child, when the child was between 18 and 36 months. The parents stated, similar to what parents in this study also expressed, a gratitude to life and that this experiences has given them new ways of looking at things happening in life [28].

What is fascinating in the parents' stories is that, even after 30 years, they had very clear memories of the time at the NICU and could still describe their experiences in detail. This is something all NICU staff should take into account when working with these families. What you say and do today—just another workday for you—could be something a family will remember for a very long time.

What has happened in NICU care over the last 30 years is not only technical improvement in the medical care but also a shift in focus. The

focus has shifted, or expanded, from just ensuring the preterm child's survival to also including the wellbeing of the whole family and involving the parents in caring for their child at the NICU, through different care emphases and programs [29]. Furthermore, bundled care improvements have been implemented, and "small baby units" have been formed in NICUs worldwide [30,31]. The purpose of these units is to create an optimal environment for EPT children, to expose their extremely fragile brains as little as possible to unwanted stimuli and to ensure that their families can care for their children from the outset at the NICU [32]. Various details of the nursing care have also been improved [33]. Axelin et al. [34] demonstrated that in families with EPT children cared for in a NICU that has implemented family-centered care, both mothers and fathers experience fewer depressive symptoms at discharge and after four months.

The parents in our study described how their experiences affected their social relationships. Research [34] has identified the positive effects of involving significant others at the NICU, and significant others should perhaps still be involved even after discharge. The parents also described how siblings were affected by the EPT child, and studies [6] have suggested that, since we do know how EPT children affect the entire family, a wraparound service is needed to provide comprehensive support for the whole family.

The "sunshine story" of the EPT child who has survived against all odds could feel like an empty cliché to parents returning home from hospital with their EPT child. They could feel that the difficult time was just starting at home, when they had to assume total responsibility on their own. Today we know that such experiences expose parents to a higher risk of developing postpartum depression up to one year after birth [35]. Even today, it is common for EPT parents to experience feelings such as emptiness, isolation, and loneliness when their child is discharged from hospital [36].

Survival without impairment is substantially lower for children born before 25 gestational weeks [37]. One study of adults born with very low birth weight show that they have more mental health difficulties [38] and/or physical difficulties [39]. Complications such as asthma, pulmonary conditions, diabetes, thyroid disorders, hypertension, venous thromboembolism, infections, epilepsy, metabolic syndrome, and neurocognitive and psychiatric disorders have been described [39]. The parents we interviewed had many unanswered questions about whether their EPT children's physical and/or mental conditions were caused by the EPT birth. The parents said that healthcare had not been willing to take the child's full medical history. Studies [40] have argued that preterm birth should be recognized as a chronic condition that requires long-term follow-up to prevent, early detect, and treat health sequelae of the preterm birth. Previous studies [39] have also suggested that medical records should routinely include gestational age at birth to gain a complete picture of the health context and to help healthcare reduce the risks of cardiac, metabolic, and other chronic disorders that preterm birth could cause. Preterm born individuals and their families have the right to know what kinds of health issues and diseases they have increased risks of acquiring in the future.

Adults born EPT rated their own health as an eight out of a ten-pointed scale, even though 78 % of the group had at least one adverse health outcome [41]. The authors concluded that how the "story" of being born EPT was told by the parents is often how the EPT adult internalizes it. Interview studies [42] of adults born preterm have recognized the ongoing need for support and encouragement, above all, from the education and healthcare communities. Families with EPT born children are especially vulnerable and need additional long-term follow-up and family support. Parents, as well as educators, healthcare professionals, and policymakers, need to consider both the emotional and behavioral needs of EPT children, as well as their need for additional academic support [40]. This emphasizes the importance of following up EPT children using screening tools to ensure early detection of difficulties and, later in life, in school, the transition to adulthood, working life, and social settings, to help EPT born adults have the structure they

need in life [38].

Treyvaud et al. [43] showed that a VPT birth negatively influences parental and family functioning seven years after the birth, relative to at-term peer births. The parents have more moderate to severe anxiety symptoms, higher levels of depressive symptoms, and increased parenting stress [43]. For some parents, the child's needs may feel under control and to be manageable in the early years of life but become more apparent when the child is exposed to greater challenges, being compared with and exposed to other children, at older ages and in school. This argues for a need for a broader view of the services available to the EPT child's family after discharge, including for parental mental health. Almost thirty years after birth, the parents of VPT children have a quality of life similar to that of the parents of term children. Their quality of life is mainly affected by their child's peer relationships and mental health, rather than by their prematurity or disability [44]. The parents in our study said that some of the EPT born adults had families and children of their own. Adults born VPT commonly have fewer children and suffer from more pregnancy complications, such as hypertension, but have no higher risk of preterm birth than do their term peers [45].

A Norwegian study [46] found that adults with very low birth weight have a higher risk of school difficulties, have a lower educational level, are less financially independent, and are more likely to live alone. Parents in the present study described how their adult EPT children were lonely and longed for a partner, as also described by researchers in a systematic review [47]. The review showed that adults born preterm were less likely to experience sexual intercourse, have a romantic partner, or become parents than were their peers born at term. Despite this, when adults born preterm were in a romantic partnership or had friends, these relationships were not poorer in quality than those of their peers [47].

The last 30 years in Sweden have seen the development of a national follow-up program for EPT children up to the age of 5.5 years [48]. If we have learned anything from the parents' stories reported here, we should expect more difficulties after 5.5 years. The neurodevelopmental deficits of children born preterm persist beyond primary school [40]. There is a need to disseminate knowledge of what EPT birth can mean to individual children and their families to school, healthcare, and society.

4.1. Methodological discussion

Trustworthiness in qualitative research is defined by credibility, transferability, dependability, and confirmability [49]. In this study, *credibility* was strengthened by the prolonged engagement of the researcher, who asked probing questions to follow up the parents' statements. In the analytical phase, there was investigator triangulation between the two authors doing the coding, all four authors participated in the analysis, and the interpretation was discussed several times. Several quotations were included in the results to allow the reader to judge the authenticity and credibility of the analysis. *Transferability* was ensured by giving the reader detailed descriptions of the context of the parents' experiences and of the participant selection, data collection, analytical process, and data interpretation. These details allow the reader to assess the relevance of the study. *Dependability* concerns consistency over time, and is supported by the detailed information about the six phases described in the method section of the thematic analysis [22]. *Confirmability* means that the results agree well with those of previous studies, so that the study can be confirmed by others. During the analytical process, the researchers were aware of their pre-understandings and used Braun and Clark's [22] 15-point thematic analysis checklist to reinforce the confirmability of the study. The researchers' pre-understandings may nevertheless have affected the parents' sense of unconditional participation. They may have been influenced by the care they had received or felt in debt to the author during the interviews, potentially leading to bias in their responses [20]. Based on the depth and openness of the parents' responses in the

interviews, however, it is unlikely that their answers were affected in this way.

A limitation of this study is that 30 years had passed since the births of these parents' EPT children, and they could have forgotten a lot of information that would have been of interest. Given the results and the in-depth information shared, however, these parents apparently remembered a great deal about their children's experience in the NICU and when growing up. Another limitation is that it is impossible to distinguish the characteristics of the parents who agreed to participate from those of the parents who declined. Perhaps only those who had the most traumatic experiences wanted to participate or, on the contrary, only those who thought that everything had worked out well. Nevertheless, considering these factors, the parents' experiences were diverse and there was variation in their children's outcomes and well-being. This can be perceived as considerable breadth in the collected interview material. However, it remains a fact that we cannot know the experiences of the parents who did not participate.

A strength of the study is that all participating parents themselves chose how they wanted to be interviewed [50], i.e., via telephone, online (Zoom), or face to face, and where. The analyses of the interviews were based solely on the parents' experiences and no background information was collected about the children's current conditions or diagnoses. This meant that the authors gave their full attention to the parents' expressed experiences instead of evaluating them relative to the diagnoses their children had received.

5. Conclusion

A lot has happened in neonatal healthcare over the last 30 years, and much remains to be learned. It is crucial that there should be awareness in schools, society, and the healthcare system of the long-term outcomes of EPT children and their families. The parents said that they wanted to be heard and trusted, and to receive needed help from healthcare, schools, and society. Being born EPT is not something that disappears later in life; rather, it can be something that continues to affect EPT children and their families in very different ways. This being so, these families need help along the way, although the help needed can differ from case to case. By highlighting the parents' stories, the future of present-day children who are born EPT can be improved as new standards of follow-up programs are developed and knowledge is disseminated to the relevant authorities. The need for improved parental support during and after the NICU stay is obvious.

Ethics approval

The study was conducted in accordance with the Declaration of Helsinki and was approved by the Swedish Ethical Review Authority (protocol no: 2019-05484; date of decision: 2019-11-06).

Advice from the parents to families with preterm children

During the interviews, the parents gave some advice to parents of EPT children. They advised such parents to strengthen their relationship to be able to cope as a couple, and to contact a counselor for help when life gets difficult. They advised parents to trust their own abilities, to follow their "gut feelings" about what is right for their children, but also to listen to their children when they express what they want from life. The last piece of advice from these parents was to seek others with similar experiences.

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CRedit authorship contribution statement

Veronica Starke: Methodology, Validation, Formal analysis, Investigation, Writing – original draft, Visualization, Project administration, Funding acquisition. **Barbro Diderholm:** Conceptualization, Validation, Resources, Writing – review & editing, Funding acquisition. **Maria Heyman:** Conceptualization, Validation, Writing – review & editing. **Ylva Thernström Blomqvist:** Conceptualization, Methodology, Validation, Formal analysis, Writing – original draft, Supervision.

Declaration of competing interest

The authors declare no conflict of interest.

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