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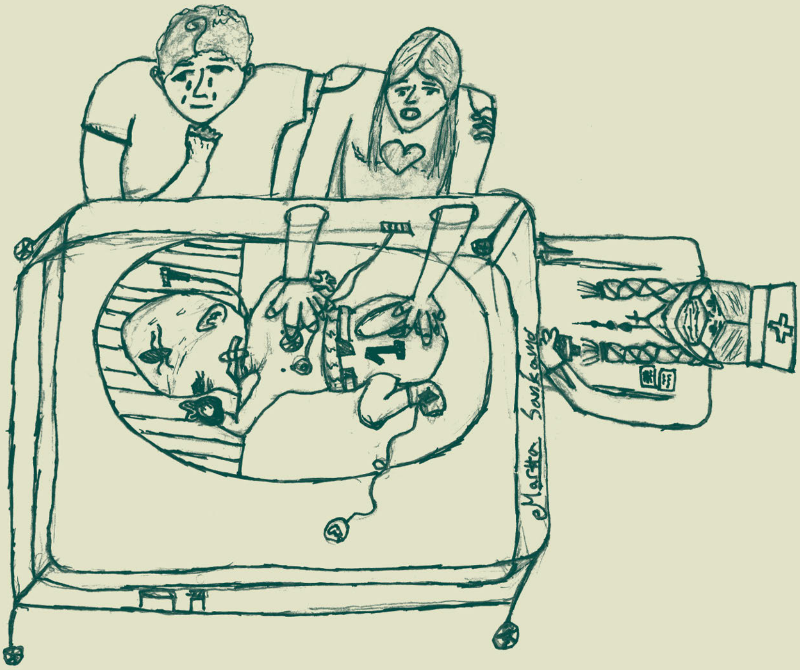

“MY MIRACLE CHILD” – EXPERIENCES OF FAMILIES WITH CHILDREN BORN AT 23–24 WEEKS OF GESTATION

A Qualitative Descriptive Study

Anniina Väliaho

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The originality of this publication has been checked in accordance with the University of Turku quality assurance system using the Turnitin OriginalityCheck service.

Cover Image: Martta Sankamo

ISBN 978-952-02-0340-5 (PRINT)
ISBN 978-952-02-0341-2 (PDF)
ISSN 0082-6987 (Print)
ISSN 2343-3191 (Online)
Painosalama, Turku, Finland 2025

To the four people without whom this thesis would not exist:
my research team, Riikka, Liisa, and Anna;
and my husband, Anssi

UNIVERSITY OF TURKU
Faculty of Social Sciences
Department of Psychology and Speech-Language Pathology
Psychology
ANNIINA VÄLIAHO: “My miracle child” – experiences of families with children born at 23–24 weeks of gestation. A Qualitative Descriptive Study.
Doctoral Dissertation, 131 pp.
Doctoral Programme of Social and Behavioural Sciences
September 2025

ABSTRACT

Preterm survivors born at 23 and 24 weeks are a growing population. However, the risks for health and developmental consequences increase the earlier a child is born. It is also known that the birth of a child extremely preterm, as well as the possible long-term morbidities of a preterm-born child, pose a challenge for the parents.

The aim of this qualitative thesis was to explore the experiences of families with children born at 23–24 weeks of gestation. Using a qualitative description approach and a semi-structured interview, 29 mothers and eight fathers of children born at 23–24 weeks of gestation were interviewed. In addition, 18 children and adolescents born at 23–24 weeks of gestation were interviewed. The children were born in between 2002-2014 and had received active neonatal care. The interviews were thematically analysed.

The results showed that the mothers’ accounts described the lives of their children born at 23 weeks of gestation as active and rich, even in the midst of the children’s long-term health and learning challenges. The mothers were dedicated to parenting and they also expressed feelings of gratitude. Parents of children born at 23–24 weeks, when describing retrospectively the bonding process between themselves and their infant, had often experienced the bonding as natural or even easy, despite the traumatic start to parenthood. Support from NICU staff, participation in infant care, parent-infant physical closeness and earlier parental experience were reported to enhance the bonding process. In the preterm survivors’ interviews, the children and adolescents exhibited different perspectives in terms of how they had experienced the effects of their extremely premature birth: from reporting no effects at all to identifying some small or moderate, mostly physical health-related challenges. One group of children did not connect their challenges to prematurity or overall reflected very little on their prematurity.

The results from this thesis highlight the need to include both parental perspectives as well as preterm survivors’ own experiences to assess neonatal care and its outcomes.

KEYWORDS: qualitative study, extremely preterm, parenting

TURUN YLIOPISTO
Yhteiskuntatieteellinen tiedekunta
Psykologian ja logopedian laitos
Psykologia
Anniina Väliaho: ”Ihmelapseni” – kokemuksia perheiltä, joissa on raskausviikoilla 23–24 syntynyt lapsi. Laadullinen kuvaileva tutkimus.
Väitöskirja, 131 s.
Yhteiskunta- ja käyttäytymistieteiden tohtoriohjelma
Syyskuu 2025

TIIVISTELMÄ

23–24 raskausviikoilla syntyvät keskoset ovat kasvava ryhmä. Keskosuuteen liittyvien terveys- ja kehityshaasteiden riski on sitä suurempi, mitä varhaisemmilla viikoilla lapsi on syntynyt. Tiedetään myös, että hyvin ennenaikaisen keskoslapsen syntymä haastaa vanhemmuutta, samoin kuin keskosuuteen liittyvät pitkäaikaiskehityksen ongelmat.

Tämän väitöskirjan tavoitteena oli kartoittaa 23–24 raskausviikoilla syntyneiden keskosten ja heidän perheidensä kokemuksia. Työ toteutettiin käyttäen laadullista tutkimusotetta (kvalitatiivinen deskriptio) ja menetelmänä oli puolistrukturoitu haastattelu. Tutkimuksessa haastateltiin 29 äitiä ja kahdeksan isää, jotka olivat 23–24 raskausviikoilla syntyneiden keskoslasten vanhempia. Lisäksi haastateltiin 18 lasta ja nuorta, jotka olivat syntyneet 23–24 raskausviikoilla, ja saaneet aktiivihoitoa Turun yliopistollisessa keskussairaalassa vuosina 2002-2014. Haastattelut analysoitiin temaattisesti.

Tulokset osoittivat, että äidit kuvasivat 23 raskausviikolla syntyneiden lasten elämää aktiivisena ja rikkaana, vaikkakin lapsilla oli pitkäaikaisia terveyden ja oppimisen ongelmia. Äidit kuvautuivat vanhemmuudelle omistautuneina, ja he myös ilmaisivat kiitollisuuden tunteita. 23–24 raskausviikoilla syntyneiden lasten vanhempien kuvauksissa varhaisen tunnesiteen muodostumisesta korostui suhteen rakentumisen luonnollisuus vanhemmuuden traumaattisista alkuvaiheista huolimatta. Keskolan henkilökunnan tuki, vauvan hoitoon osallistuminen, läheisyys vauvan kanssa sekä aiempi kokemus vanhemmuudesta olivat tukeneet suhteen rakentumista. Keskosina syntyneiden lasten ja nuorten kokemuksissa ilmeni erilaisia tapoja hahmottaa erittäin ennenaikaisen syntymän vaikutuksia: osa ei ilmaissut kokeneensa keskosuuden vaikuttavan lainkaan, osa kuvasi lieviä tai kohtalaisia, useimmiten fyysiseen terveyteen liittyviä haasteita. Yksi lapsiryhmä ei yhdistänyt haasteita keskosuuteen tai tuotti muuten hyvin vähän reflektiota.

Väitöskirjan tulokset korostavat niin vanhempien kuin keskosena syntyneiden omien kokemusten tärkeyttä keskoshoidon käytäntöjen ja tulosten tutkimuksen osa-alueena.

ASIASANAT: laadullinen tutkimus, erittäin ennenaikainen keskonen, vanhemmuus

Acknowledgements

The completion of my thesis marks the end of a long journey. I have had my share of moments when I thought this thesis would never be finished, but also moments of strengthened self-confidence and inspiration to continually challenge myself. At this point of crossing the finish line, I want to express my deepest gratitude to the people who have supported me along the way.

First, I owe my sincerest thanks to my supervisors, Professor Riikka Korja and Professor Liisa Lehtonen. I am deeply humbled to have had the privilege of working with you both. Riikka, I admire your confidence and open-mindedness as a researcher. You have taught me so much about psychological research, and your constructive criticism has consistently pushed me to improve my work. Liisa, you introduced me to the idea of studying the group of preterm children born at these earliest gestational weeks and encouraged me to use qualitative methodology. Your passion for high-quality research and your extensive knowledge continue to inspire me. Thank you for consistently making time from your busy schedule to help me. Most of all, Riikka and Liisa, I want to thank you for your encouragement and belief in me and in this project. Your support has truly made all the difference.

Another person that has been invaluable in this process is Professor Anna Axelin. Anna, I deeply admire your expertise in qualitative methodology and your generosity to share your knowledge. Thank you for patiently guiding me through the complexities of conducting thematic analysis. Your ability to see both the details and the bigger picture has taught me an enormous amount and shaped me as a researcher. Beyond methodology, your kind attitude, clear feedback, and willingness to devote your time have been of immense value.

I am honored that Professor Ragnhild Støen agreed to serve as the opponent in my doctoral defense. I also warmly thank the reviewers of this thesis, Docent Birgitta Lundberg and Professor Anna Rönkä, for their careful reading of the manuscript and for their constructive and insightful comments, which significantly improved the quality of this work. For financial support, I am sincerely grateful to the Signe & Ane Gyllenberg Foundation, the Foundation for Pediatric Research, the Turku University Foundation, and the Faculty of Social Sciences. The personnel at the

Department of Psychology and Speech-Language Pathology is acknowledged for their kind help in many practical matters, including providing me with a workstation.

Conducting research is always a collaborative effort. Most importantly, I wish to thank the families of premature children who so generously participated in this study and shared your experiences with me in interviews. This thesis exists because of your stories. Also, I am grateful to Minna Paaso, RN, for contacting the families about their willingness to participate. Professor Jaakko Seikkula, thank you for valuable advice during the development process of the interview. Language consultants Elizabeth Nyman and Henna Raudaskoski are acknowledged for help with English language revision.

During the time that I have been working with this thesis, I have also worked as a clinical psychologist at the child-welfare clinic system in Varha. I want to thank Tytti Lääperi, Annie Turunen, Anu Heikkilä, and Linda Ljungqvist, for supporting my research goals and making it possible for me to take study leaves. To all my dear colleagues over the years—you have cheered me on not only in research, but also in my clinical work and in life more broadly. I am grateful that I have gotten to work with so many amazing people. I especially want to acknowledge Kati Rinne, Jonna Salvi, and Eevi Korvensyrjä as colleagues who have become cherished friends.

I consider myself very fortunate to have a large circle of friends from all over the world, with different kinds of backgrounds and life situations. Thank you all for your support and care. In particular, I want to thank Marika Leppänen, for being a friend with whom to share the ups and downs of prematurity research and life in general. My heartfelt thanks also go to Tamara, Pasi, Katriina, Vesa, and Kirsti, for the joyful moments we have shared with our families over the years. If it is true that laughter prolongs life, I believe our get-togethers have already added many extra years to mine. Kaisa, Heidi, Carita, Petra, and Laura, thank you for your steadfast friendship, encouragement, and intercession.

It saddens me that my parents, Eija and Pasi, are not here to see this work completed. My parents modeled ambition and perseverance in a remarkable way for me. They also encouraged me to see the world open-mindedly and never to question my possibilities. If my parents were still here, I hope they would attend my defense with pride and joy. I am grateful to have my beloved grandparents, Katri and Esa, whom I want to thank for continued love and support over the years. Thank you also to other near and dear relatives in Finland, Estonia, and Germany, in particular to my mother-in-law, Marita, for caring for our children during the many times when I was working intensively on research. My goddaughter Martta is warmly acknowledged for the drawing in the cover of this thesis.

Being the mother of a large family is a privilege that I do not take for granted. Aida and Alvar, my two eldest, I am so proud of the competent and confident young people you are becoming. Oliver, my sweet middle child, you are the comedian of the family and such a source of joy. Eevi and Eino, my beautiful babies, what a gift it has been to experience once more the delight of small children through you.

Last but definitely not least, I want to thank my husband, Anssi. Thank you, Anssi, for wearing so many hats in the process of my thesis-writing: you have been my IT support, my proofreader, my problem-solver, and – quite often – my shoulder to cry on. You are my favorite person in the world, thank you for just being you.

Turku, August 2025

Anniina Väliaho

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Abbreviations

ADHD	attention deficit hyperactivity disorder
ASD	autism spectrum disorder
CP	cerebral palsy
FCC	family-centred care
GW	gestational week
NDI	neurodevelopmental impairment
NICU	neonatal intensive care unit
QoL	quality of life
RTA	reflexive thematic analysis
SSC	skin-to-skin contact
TA	thematic analysis
THL	Terveyden ja hyvinvoinnin laitos
VLBW	very low birth weight
WHO	World Health Organization
YIPTA	Yale Inventory of Parental Thoughts and Actions

List of Original Publications

This dissertation is based on the following original publications, which are referred to in the text by their Roman numerals:

I Väliaho A, Lehtonen L, Axelin A & Korja R. Mothers' experiences of parenting and everyday life of children born at 23 weeks of gestation – a qualitative descriptive study. *BMC Pediatrics 2021 (21), 48 (2021). https://doi.org/10.1186/s12887-020-02478-y*

II Väliaho A, Lehtonen L, Axelin A & Korja R. Parental Narratives of Bonding and Relational Experiences with Preterm Infants Born at 23 to 24 Weeks – A Qualitative Descriptive Study. *Children* 2023, 10, 793. *https:// doi.org/10.3390/children10050793.*

III Väliaho A, Lehtonen L, Axelin A & Korja R. Reflections about being born extremely preterm in children and adolescents: A qualitative descriptive study. *Early Human Development, Volume 194, 106048, ISSN 0378-3782, https://doi.org/10.1016/j.earlhumdev.2024.106048.*

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1 Introduction

The concept of "limit of viability", in neonatology, refers to the gestational age separating infants considered too immature for intensive care from infants who may benefit from active care (Rysavy et al., 2021). This limit has shifted dramatically with the advances of neonatal care, as 50 years ago “the lower limit of viability” was stated to be around 28 weeks of gestation (Rysavy et al., 2021), while today, the survival rate of infants born at 23 gestational weeks already exceed 50 % in many high-income countries and hospitals (Smith et al., 2018). As a result of the significantly improved survival, preterm survivors born before 25 weeks of gestation are a growing population.

However, the long-term outcome of infants born before 25 weeks of gestation has not improved in the same proportion as their survival. As they grow beyond infancy, the children born before 25 weeks of gestation face a high risk of multiple health and developmental challenges such as neurodevelopmental impairment, learning disabilities, and ADHD (Zayegh et al., 2022; Younge et al., 2021; Sucksdorff et al., 2015). The earlier the child is born, the higher the risk for long-term developmental problems (Söderström et al., 2021). Based on the poor long-term prognosis, there is substantial variation in the neonatal care practices for infants born before 25 weeks of gestation (Guillen et al., 2015). Especially the question about whether or not to offer active care infants born at 23 or 22 weeks remains controversial.

It has been proposed that it might not be ethical to save the life of an infant in case the child’s possibilities for a disability-free life are small (Lönnqvist, 2018). On the other hand, there may be a considerable difference between “disability-free living” and “not worth living” (Helgesson, 2018). This raises a question about how preterm survivors born at 23 or 24 weeks of gestation themselves experience the possible consequences of their extremely premature birth. Previously, some qualitative studies have explored the subjective experiences of adults born preterm (Saigal et al., 2014, 2016; D’Agata et al., 2022; Vederhus et al., 2025). However, there is a need to include even the voices of children and adolescents born preterm into the literature of prematurity.

Questionnaire studies on quality of life in preterm individuals (Vieira & Linhares, 2016) have faced criticism. While they give valuable data of the medical diagnoses and functional impairments, they capture very little about the subjective experience of the individual and the themes that they themselves find relevant to their everyday life (Saigal & Tyson, 2008). A more nuanced, in-depth, and holistic approach is clearly needed in exploring multi-faceted topics such as quality of life and the experience that being born prematurely means to the survivors.

In addition to the preterm children's own health and development, prematurity also poses a significant challenge for parenting and family functioning. The birth of an extremely premature infant is always a crisis for the parents. The stress and anxiety caused by the situation are even more evident in a situation when there is a high risk of death of the infant (Spinelli et al., 2016), such as in the case of an infant born under 25 weeks of gestation. An infant born at this age of gestation requires many weeks, even months, of neonatal intensive care – including a long duration of mechanical ventilation and many stressful medical interventions (Thernström Blomqvist et al, 2022). The uncertainty concerning the infant's survival and future, as well as the parent-infant separation caused by the neonatal care period, may distract the emotional bonding process between parent and infant (Feldman et al., 1999). Nonetheless, neonatal care has shifted towards a more family-centred care approach during recent decades (Gooding et al., 2011; Franck & O'Brien, 2019), providing parental support and aiming to maximise parent-infant closeness. Thus, neonatal units today may provide a more optimal setting for parent-infant bonding than in previous years.

Moreover, it is known that parents of preterm children are at risk for stress, anxiety, and depression even as the children grow (Treyvaud, 2014), and that both the preterm birth and the chronic illness of a child are risk factors for increased psychological parental distress (Cacciani et al., 2013). These parenting challenges in turn may negatively affect the child's well-being and development throughout childhood. Still, parents tend to express that neonatal care has been "worth it", regardless of the outcome of their child (Wraight et al., 2015). Janvier et al. (2016) stress that the negative effects are only one side of the story, and that caring for a vulnerable child may also make the parents realize their own strength and resilience and thus lead to a positive transformation.

This thesis aimed to address the knowledge gap about the experiences of families with a child or children born at 23–24 weeks, both from the parental and children's perspectives. As the goal was to complement the quantitative literature on the quality of life and parenting extremely premature children, this thesis used a qualitative descriptive approach with a semi-structured research interview. Mothers and fathers of preterm children born at 23–24 weeks were interviewed, as well as the children and adolescents themselves. Specifically, the research questions focused on the parental experiences of early parent-infant bonding as well as overall parenting and the everyday lives of the children from the mothers' perspective. Regarding the children and adolescents born at 23–24 weeks of gestation, the goal was to explore the experiences that having been born extremely preterm meant to the school-aged preterm survivors.

2 Review of the literature

2.1 Preterm children born before 25 weeks of gestation

Prematurity is often classified in subgroups such as very preterm infants (born before 32 weeks' gestational age) and extremely preterm infants (born before 28 weeks' gestational age). Premature children born before 25 weeks of gestation are a particularly vulnerable population, even amongst the extremely preterm infants (Arnolds & Laventhal, 2021). However, there is no well-established name to refer especially to this group of preterm infants. They are sometimes referred to as "infants born at the limit (or threshold) of viability" (Arnolds & Laventhal, 2021), but this definition can include preterm infants of varying gestational ages.

In this thesis, I prefer to define the patient population using the gestational weeks at birth as the "limits of viability" which have been shifting over time and continue to do so. Therefore, defining the patient population using gestational weeks is more precise than the term "at the limits of viability" which refers to different patient populations depending on time and geography.

2.1.1 Survival

The survival of children born at 23 and 24 gestational weeks, and even at 22 weeks, has improved dramatically during recent decades thanks to the advances in neonatal care. Still, these infants are a very small subgroup (1-2 %) of infants receiving care in the neonatal intensive units (Edwards et al., 2018). The variable approaches to active care have resulted in a wide range in the reported survival rates, from 1 % - 64 % for infants born at 23 weeks and 31 % - 78 % for infants born at 24 weeks (Patel et al. 2017). In a recent study of the survival of the most premature infants in the United States, 52.8 % born at 23 weeks and 71.1 % born at 24 weeks survived, while 24.9 % of infants born at 22 weeks survived, (Edwards et al., 2024). In Finland, the survival rates between 2021-2023 for 22, 23, and 24 weeks of gestational age were 26.3 %, 65 % and 75 %, respectively (THL, Pienet keskoset -rekisteri 2024).

It is noteworthy that the neonatal care extremely preterm infants, especially infants born before 25 weeks of gestation, requires a healthcare infrastructure that is able support the extensive and costly technology needed to provide the care (Arnolds & Laventhal, 2021). Therefore, their care is practically limited to high-income countries or hospital settings.

2.1.2 Variation in care practices

There is considerable variation internationally in the care practices of infants born before 25 weeks of gestation, ranging from comfort care and limited resuscitation to proactive resuscitation (Backes et al., 2021). Rysavy et al. (2021) refer to infants born at 22-23 weeks as comprising a “gray zone”, for whom the initiation of intensive care largely depends on the hospital or country in which the infant is born. In a review study of 47 developed countries (Guillen et al., 2015), there was wide variation in treatment recommendations at 23 and at 24 weeks’ gestational age, although in recent years, there has been a significant increase in the percentage of neonates that receive active care from 23 or even from 22 gestational weeks (Edwards et al., 2024).

For infants born before 25 gestational weeks, a so-called selective approach has often been recommended, where the treatment for the earliest-born infants is initiated or withheld based on physician or family preferences (Backes et al. 2019; Geurtzen et al. 2017). However, it has been debated whether a sceptical attitude towards providing active support for infants born at the lowest end of viability could result in a self-fulfilling prophecy (Janvier et al. 2017; Welty 2019). Noteworthily, a comparison of 22-week survival in a setting of universal resuscitation versus selective resuscitation based upon parental request showed that higher survival rates were achieved when 22 weeks infants were more commonly resuscitated (Söderström et al., 2021; Backes et al., 2019). In Japan and in certain neonatal units in Sweden, there is a longstanding tradition of active neonatal care for all infants born from 22 weeks of gestation, resulting in improving survival rates of the most immature infants (Ågren, 2022; Kono et al., 2020; Rysavy et al., 2021). In comparison, there are several countries, such as the Netherlands and Denmark, as well as individual hospital units, where intensive care at 22-23 weeks is not recommended (Wilkinson et al., 2018; Lantos, 2018).

In Finland, all neonatal intensive care units offer active care to infants born at 23 and 24 weeks of gestation, whereas for infants born at 22 gestational weeks, the decision between offering active care or palliative care is made together with parents (Ennenaikainen synnytys: Käypä hoito -suositus, 2018).

2.1.3 Long-term outcomes

Despite increases in survival, the long-term prognosis of the children born at the earliest gestational weeks has not improved in the same proportions. In many outcome studies, the term neurodevelopmental impairment (NDI) is used to define problems typical to extremely preterm infants. Although varying definitions are used to define NDI, it most often includes gross motor problems such as cerebral palsy (CP), sensory (visual or hearing) impairments, and cognitive/learning delays (Adams-Chapman et al., 2018; Doyle, 2018). The possibility of NDI increases the earlier the child is born, and for children born at the lowest spectrum of gestation, the impairment rates has exceeded 50 % in many studies (Hintz et al., 2011). Furthermore, in most studies, the rate of NDI among extremely preterm children has not changed substantially over time in spite of the survival rates rising (Kaempf et al., 2023; Zayegh et al., 2022; Doyle, 2018; Hintz et al., 2011). This has led to increasing absolute numbers of preterm survivors with NDI, which in turn causes concern about the means by which societies will be able to provide adequate care, interventions and education for this population (Twilhaar et al., 2017).

However, some studies have reported cautiously optimistic results long-term outcomes for children born before 25 weeks of gestation: in a Swedish study reporting the outcomes from a neonatal unit with a uniformly active approach to neonatal care, the rate of developmental delays at 2.5 years of corrected age were 50 % for children born at 22 weeks, 30 % for children born at 23 weeks, and 17 % for children born at 24 weeks (Söderström et al., 2021). Watkins et al. (2020) found similar rates of either moderate or severe neurological impairments among preterm survivors born at 22-23 weeks compared to 24-25 weeks. In a Japanese study, infants born at 22- and 23-weeks' gestation were at higher risk of death or NDI than infants at born at 24 weeks, but their outcomes were still improved compared with those in previous studies (Ishii et al., 2013). Furthermore, there is evidence that while the rate of moderate to severe NDI has not changed over time, the rates of severe CP has decreased, while mild CP has increased in extremely preterm infants (Adams-Chapman et al., 2018).

Regarding cognitive outcome, the prevalence of academic difficulties among preterm infants has remained high in spite of survival rates rising (Twilhaar et al., 2018). In a Swedish study, the outcomes at 6.5 years among children born extremely preterm, and the numbers of children born at 22, 23, or 24 weeks of gestation who had no, or mild cognitive disability were 3.9 %, 20 %, and 35.4 %, respectively (Serenius et al., 2016). Additionally, the study of Serenius et al. (2016) found that the percentage of children with moderate or severe cognitive disability increased from 2.5 to 6.5 years, which might reflect a better ability to diagnose developmental changes with advancing age (Serenius et al., 2016; Serenius et al., 2013).

Furthermore, the risks of both attention-abstract deficit/hyperactivity disorder (ADHD) have been shown to increase by each declining week of gestation (Sucksdorff et al., 2015). In a multinational cohort study comparing Finnish, Swedish, and Norwegian birth cohorts, the relative risk of autism spectrum disorder (ASD) increased by gestational age from 40 to 24 weeks, although the data on gestational age and ASD were sparse for the births before 24 gestational weeks (Persson et al., 2020).

2.1.4 Ethical perspectives of neonatal care for infants born before 25 weeks of gestation

The question of the care for the most vulnerable preterm infants is an ethically complex and controversial theme. The medical ethical framework is based on a view that doctors have a responsibility to decide whether treatment is clearly beneficial, futile, or somewhere in between (Lantos, 2018). However, Arnolds and Laventhal (2021) state that because of the uncertain prognosis, there is no singularly correct approach to the management of an infant born at less than 25 weeks. Some researchers have questioned the ethics of saving the life of an infant born at 22 or 23 weeks, if the infant's long-term prognosis is poor and the chances of a disability-free life are small (Lönnqvist, 2018; Helgesson, 2018). On the other hand, Helgesson (2018) notes that the distance between "not disability-free living" and "not worth living" may be considerable. Economic perspectives have also been considered in the discussion of care practices (Beam et al., 2020; Rysavy et al., 2021). While the initial treatment costs for infants born at the limit of viability are high, an even greater cost burden is the price of potential long-term disabilities, such as cerebral palsy (Korvenranta et al., 2010).

It has been suggested that decisions about the care for the infants born before 25 weeks of gestation should be made mutually with the parents based on the best available evidence, with a model known as shared decision-making (Edwards et al., 2024; Synnes et al., 2024; Arnolds & Laventhal, 2021). Still, Arnolds et al. (2018) stress that while physicians tend to rely on statistics as a way to ensure that parents of preterm infants have realistic expectations about their infant's prognosis, it should be noted that statistics may not have the same importance to families. Moreover, shared decision-making is challenging to evaluate, and the long-term impact of decisions concerning extremely premature birth, including decisions of regret, on parents remains unclear (Geurtzen et al., 2017; Belden et al., 2025).

Evidence suggests that parents typically find active neonatal care having been "worth it", regardless of the outcome for their child (Arnolds et al. 2018; Wraight et al. 2015). Similarly, in a study regarding guilt and regret experienced by parents of children born extremely preterm, no parents reported regret about life-and-death decisions made at birth or in the neonatal intensive care unit (Thivierge et al., 2023). In a recent study, Belden et al. (2025) assessed decision regret in women who delivered an extremely premature infant, comparing decision regret scores based on resuscitation decision. They found that decision regret was lower in 'active care' compared with 'comfort care', although regret was reported even after an active care decision. In addition, the women who identified as the primary decision-maker had lower regret scores (Belden et al., 2025). Geurtzen et al. (2017) found that for parents of preterm infants born at 24 weeks of gestation, there were very low rates of decision regret regarding the decision on initiating care in extreme prematurity, and the regret scores were influenced by the actual decision made and by the outcome. Interestingly, in a qualitative study exploring expert neonatologists' views on these decision-making processes and their own roles in counselling parents, it was found that neonatologists expressed more concern about parents' decisional regret should their child survive resuscitation, but have severe disability, than about decisional regret after foregoing resuscitation (Haward et al., 2017). Belden et al. (2025) suggest that the possibility of decision regret should always be discussed before birth.

Lantos (2018) has suggested that in situations of disagreement between parents and clinicians regarding the infants’ care at extremely early gestational ages, parents should have the ultimate decision. Nevertheless, even parental authority to advocate for continued intensive treatment for their infants is confined by futility and intentional or irreversible and unnecessary harm (Arnolds and Laventhal, 2021). The question about whether or not to initiate active care at the lowest spectrum of gestation remains controversial and unresolved and calls for updated quantitative and qualitative data on the long-term prognosis.

2.2 Parenting and prematurity

Preterm birth and raising a preterm born child have a significant impact on the parents and on the whole family. Before summarising what is known about parenting and prematurity, a brief account is given on psychological conceptualisations of parenting and the parent-infant bonding process.

2.2.1 Theoretical foundations of parenting, attachment, and parent-infant bonding

One of the most widely used theories to conceptualise early parenting in psychology is the attachment theory, originally formulated by child psychiatrist John Bowlby (Bowlby, 1969/1982), and later developed as a collaboration between Bowlby and psychologist Mary Ainsworth. Attachment theory addresses the establishment, maintenance, and consequences of affectionate bonds between parents and children (Holden, 2020). Taking cues on emerging ethological literature on parent–offspring bonds in birds and nonhuman primates, the theoretical aim of attachment theory was to provide an evolutionary explanation on human infant-mother attachment (Bretherton, 2010; Feldman et al., 1999). Bowlby's attachment theory states that the relationship between a parent and an infant reflects a behavioural system that has adapted to promote survival and competent functioning of the offspring, with two central parts of novelty seeking and proximity seeking – the developing infant seeks both novel experiences and safe proximity of the caregiver (Bowlby, 1969/1982; Holden 2020). According to the attachment theory, the parent, as the attachment figure, serves as a secure base from whom a child leaves to explore and to whom he or she returns as a haven of safety when alarmed or hurt (Bowlby 1969/1982; Holden 2020. While Bowlby´s theory initially focused on attachment between mothers and their infants, later research has shown that fathers, for their part, are also important attachment figures in their infant's life from very early on (de Wolff & van Ijzendoorn 1997; Lucassen et al. 2011).

A key factor in the attachment theory is **early parent-infant bonding**, i.e., the formation of an emotional bond between parent and infant during the infant's first weeks and months of life. Research has shown that the first months after birth are a highly sensitive period for the development of the bonding between parents and their infant (Moehler et al., 2006). Early parent-infant bonding has important influences on infant brain development, as well as the child's psychological well-being and social development (Winston & Chicot, 2016; Wittkowski et al., 2020). A positive bonding experience between parent and their baby promotes the development of parenting skills and parents' sensitivity to their infant's needs, and as such, the early bonding experiences are the basis on which the later parent-child relationship is built (Wittkowski et al., 2007; Winston & Chicot, 2016). As family relationships are impacted by multiple factors, the bonding experience alone does not dictate the quality of the later parent-child relationship. Other factors that have been found to contribute to the quality of parent-child relationship are, e.g., the elements of parenting such as parental sensitivity (Solomon & George. 2008), parental self-efficacy (Jones & Prinz, 2005), and reflective functioning (Zeegers et al., 2017), child characteristics such as child temperament (Belsky et al., 2007), and the interparental relationship (Belsky & Fearon 2004; Bretherton, 2010). However, the role of early bonding has been shown to be significant in a variety of factors considering child and parental well-being (Wittkowski et al., 2020; Le Bas et al., 2020).

Bowlby (1969/1982) focused on the infant's perspective, and emphasised the infant's need for proximity, physical closeness, with the mother as a basis for bonding. Continuous separation or distance from the mother would thus result in challenges in the bond formation (Feldman et al., 1999). Later theories have continued to build on the foundation of Bowlby's attachment theory, while highlighting the parental perspectives of bonding. The maternal representations theory by Daniel Stern (1991) emphasises the maternal prenatal mental preparation: mothers begin their bonding process already during pregnancy by forming mental representations of their future child, as well as representations of themselves as caregivers (Stern 1991; Ammaniti et al., 2013; Benoit et al., 1997). These prenatal representations include expectations, ideas, and experiences related to the expected child and the parent-child relationship, providing insight into the meaning of the child for the expectant parent (Benoit et al., 1997). For an expectant mother, a positive prenatal bond is associated with engaging in behaviours of affiliation and affection, such as talking to the unborn child, and positive health practices, such as abstaining from alcohol (LeBas et al., 2020). Later research has shown that the formation of prenatal representations even applies to fathers (Vreeswijk et al. 2014; Foley & Hughes, 2018): for prospective fathers, feeling foetal movements and seeing the foetus on the ultrasound can strengthen the paternal-foetal bond and offer feelings of becoming a family (Draper, 2002; Ekelin et al., 2004). As for the period after the birth of the child, Donald Winnicott's (1956) theory stresses the importance of primary maternal preoccupations. According to Winnicott, the new parent's preoccupation and anxiety, such as thoughts, worries, and distress about the infant, as well as the constant need to check the infant's well-being, are not only typical but rather are essential parts of parental behaviour during the bonding period, although this type of behaviour would be seen as problematic, or even a sign of psychiatric distress, at any other part of life (Winnicott, 1956; Leckman et al., 1999).

One important feature in Bowlby's theory was the link between human attachment and the empirical and theoretical framework of ethology (Feldman et al., 1999; Hess & Petrovich 2000). Discussing maternal bonding, Feldman et al. (1999) stresses that maternal bonding behaviour includes elements that are typical to the bonding of other mammals with new-born offspring, such as nursing, grooming, and touch. Still, theories of human attachment are not complete without the inclusion of cognitive structures, complex emotions, and cultural conducts, as those are part of the human adaptive heritage and have an evolutionary role (Feldman et al., 1999). Therefore, both the ethological focus on observed behaviour and the mental states – such as the parent's mental states, thoughts, feelings, worries, hopes, and representations of the infant – are necessary to take into account while studying maternal bonding formation. Both the mental set and the behavioural repertoire are directed to maintain the mother's physical and psychological proximity to the child (Feldman et al. 1999). Le Bas et al. (2020) define maternal bonding as "a function of the caregiving behavioural system, serving to protect and comfort the infant in times of distress or threat”. Both maternal and paternal bonding also have a strong neurobiological basis (Feldman, 2016; Feldman et al, 2019).

Noteworthily, the construct of bonding is often confused with the construct of attachment (Le Bas et al., 2020). While bonding refers to the formation of an emotional bond between parent and infant (LeBas et al., 2020), attachment, in turn, represents the patterning of the infant's behaviour and expectations of the parent's caregiving responses assessed observationally (Ainsworth, 1989). In observational studies of attachment patterns, the quality of attachment between parent and infant has been classified into secure, anxious-avoidant, and anxious-resistant (or ambivalent) types of attachment (Holden, 2020).

In this thesis, the term **parent-infant bonding** is used to refer to the formation of the early emotional bond between parents and their infant. Specifically, bonding is viewed as a parental self-reported experience of the formation of emotional connection between parent and infant (Le Bas et al., 2020). The categorisation of bonding in this thesis is modified from the YIPTA (The Yale Inventory of Parental Thoughts and Actions) by Leckman et al. (1999), a method theoretically based on Winnicott’s theory of primary maternal preoccupations (1956) described above. In addition to the early parental preoccupations, the YIPTA also addresses elements of typical early caregiving behaviour (Leckman et al., 1999). The categorisation of YIPTA, as well as modifications done to implement it in this study, are presented in more detail in the method section.

The term **relational experience**, in the context of this thesis, is used to refer to the later mutual experiences between parents and their growing children, reported by parents. As the early bonding experiences are the basis on which the later parent-child relationship is built (Wittkowski et al., 2007), these parental accounts of later relational experiences can be seen as reflective of the early bonding. A modified version of YIPTA serves as the categorization framework for the relational experiences.

2.2.2 Preterm birth and parent-infant bonding

The birth of an infant at early gestation inevitably affects parenting and early parent-infant bonding. In light of maternal representations theory of Daniel Stern (1991) described above, the formation of representations is interrupted in the parents of premature infants and so is the preparation process for parenthood. Premature birth – often a traumatic experience in its own right – includes considerable worry and stress for both parents (Janvier et al., 2016). The stress is even more evident when the infant’s risk of death and developmental problems are very high, such as in the case of the infants born at the lowest gestational weeks. Furthermore, vulnerable infants born at 23–24 weeks require many weeks of intensive care including a long duration of mechanical ventilation and numerous stressful medical interventions (Thernström Blomqvist et al., 2022). Parent-infant proximity is often limited, and separation time may be prolonged. These conditions are clearly different from the premises defined in Bowlby's (1969/1982) theory that emphasises physical parent-infant closeness as a prerequisite for bonding. Therefore, preterm birth, especially at the limit of viability, poses significant challenges to the healthy formation of parenthood and parent-infant bonding.

Several qualitative studies have identified obstacles preventing healthy bonding in parents of preterm infants, as summarized by Carton et al. (2020). It is noteworthy that mothers with infants in the neonatal intensive care unit (NICU) are studied on a much larger scale than NICU fathers (Provenzi & Santoro, 2015). Studies have shown that mothers tend to struggle with difficult emotions such as failure and guilt that further complicate the bonding process and maternal role formation (Fernandez Medina et al., 2018; Spinelli et al., 2016; Al-Maghaireh et al., 2016). In cases where mothers are afraid that their premature child might die, they tend to distance themselves emotionally and do not let themselves become attached to the child (Spinelli et al., 2016; Flacking et al., 2006).

The NICU fathers have been reported to struggle with feelings of helplessness and being out of control, which can act as a barrier to participating in the infant's care. The lack of physical contact with the infant may further enhance this feeling of detachment and challenge the bonding process (Provenzi & Santoro, 2015; Arockiasamy et al., 2009; Lindberg et al., 2008).

The quantitative study by Feldman et al. (1999) highlighted the challenges of the bonding process following a premature delivery. Feldman et al. (1999) interviewed three groups of mothers: mothers of full-term infants maintaining continuous proximity with the infant, mothers of healthy premature infants who were separated from the infant, and mothers of very low birthweight (VLBW) infants experiencing potential loss and prolonged separation. The authors found that maternal attachment behaviours and representations declined linearly with the duration of mother–infant separation. In addition, maternal preoccupations, such as anxiety about the infant's well-being, were significantly lower in mothers of VLBW infants. The authors concluded that the fear of losing the infant and the prolonged separation caused a distortion of the bonding process among the mothers of VLBW infants, which is in line with John Bowlby's attachment theory (Feldman et al., 1999).

2.2.3 Long-time perspectives of parenting preterm-born children

Despite preterm birth-related stress, preterm infants and their mothers are as likely to form secure attachments as full-term infants and their mothers (Bilgin & Wolke, 2015; Korja et al., 2012). Furthermore, the initial parental stress symptoms that are eminent during the preterm infant's hospital stay, tend to diminish after the infant's discharge (Al-Maghaireh et al., 2016). Nonetheless, parents of preterm children have an increased risk for stress, anxiety, and depression even as the children grow, and these parenting challenges in turn may negatively affect their child's well-being and development throughout childhood (Huhtala et al., 2011, 2014; Singer et al., 2007, 2010; Korja et al., 2008; Treyvaud, 2014). Indeed, psychosocial risks are known to accumulate in families with preterm infants and influence the outcomes of preterm-born children (Leppänen et al., 2024). For many parents of preterm children, there is an ongoing need to manage significant family stressors, such as greater care giving demands, higher financial burdens, and poorer child outcomes (Singer et al., 2007). Both preterm birth and the chronic disability of a child are associated with increased psychological parental, especially maternal, distress (Cacciani et al., 2013)

Huhtala et al. (2011) found an association between VLBW infants' 2-year-old cognitive outcomes and parental stress. Fathers experienced higher parental stress in cases where the child had cognitive delays, whereas mothers reported higher parental stress in relation to accepting the child (Huhtala et al., 2011). Singer et al. (2007) found that mothers of 8-year-old VLBW children reported more concern for their child's health compared to term mothers. Furthermore, the mothers of 14-year-old high-risk VLBW children had greater child-related stress than term mothers; however, they also expressed the highest levels of parenting satisfaction at 14 years (Singer et al., 2010). Similarly, Saigal et al. (2000) found that parents of 12- to 18-year-old, extremely low-birth-weight children acknowledged negative effects and higher mental stress compared with parents of term children but also felt greater self-esteem and family satisfaction. These findings suggest that parents of preterm children may have experienced posttraumatic growth, i.e., learned adaptive coping mechanisms in the adjustment to traumatic stress, after significant distress postpartum (Singer et al., 2010). Moreover, social support was found to buffer the effect of maternal psychological distress symptoms (Singer et al., 2010). In a Finnish study, parents of adolescent preterm-born children have been shown to be more protective and supportive compared to parents of full-term children (Pyhälä et al., 2011).

Studies of early interventions in families with preterm children have shown positive effects on parent-infant relations (Leppänen et al., 2024), which can significantly improve both parental and children's well-being. For example, a Norwegian study with families participating in an early mother infant transaction programme found that for the participating parents of preterm infants, parenting stress was reduced to a level comparable to their term peers (Kaaresen et al., 2006); and even resulted in better cognitive outcomes and fewer parental-reported behavioural problems for the children (Nordhov et al., 2010, 2012). However, several of the intervention studies had excluded the most preterm infants and almost all had excluded parents with high or multiple risk factors, even though for child development, multiple risk factor exposure is typically more harmful than singular risk exposure (Leppänen et al., 2024).

2.2.4 The evolving neonatal care and parent-infant bonding

A factor that has affected parenting in the NICU in a radical way is the change in neonatal care culture during recent decades. The previously *infant-centred* care has been replaced by family-centred, also known as family-integrated, care (FCC) (Franck & O'Brien, 2019; Gooding et al., 2011)). This approach emphasises the partnership and mutual trust between neonatal healthcare staff and parents, as well as the involvement of the family with the goal of improving quality, psychological well-being, clinical outcomes, and the overall patient and family experience (Franck & O'Brien, 2019).). An important principle in family-centred neonatal care is parent support, which includes unlimited parental access in the NICU, as well as providing emotional support to parents and even involving parents in decision-making regarding their infant's care (Ahlqvist-Björkroth et al., 2017; Thernström Blomqvist et al., 2022; Karlsson et al., 2022). Another cornerstone is involving parents in the overall caretaking of the infant in the NICU. Many elements that support parent-infant closeness are encouraged in FCC settings, such as parent-infant skin-to-skin contact (SSC), holding the baby, pain management by parents, and breastmilk feeding or direct breastfeeding (Franck & O'Brien, 2019; Lilliesköld et al., 2022; Holdren et al., 2019).

The components of FCC may provide a more optimal environment for parent-infant bonding than the previous infant-centred care. In a Canadian study, increased parental presence in the NICU, increased time involved in infant care, increased holding time of the infant, and greater time in SSC were all associated with greater parental emotional closeness (Lebel et al., 2022). In addition, immediate physical closeness and cuddles in the delivery room were meaningful and positive experiences for parents of very preterm infants (Lilliesköld et al., 2022, Kimkool et al., 2022). Kimkool et al. (2022) thematically analysed interviews with mothers of very preterm infants about their experience of physical closeness in the delivery room. The mothers in their study emphasised that they felt these moments of physical contact had been the only "normal" feature in their birth experience, and it remained a cherished memory. As for feeding practices, Holdren et al. (2019) found that in a

NICU care culture promoting parental autonomy and encouraging mothers not to stress about milk volumes, the mothers described that taking their infants to their breast was a means to build a relational bond. The privacy provided by single-family rooms was also described as beneficial for positive breastfeeding experiences (Holdren et al., 2019). Similarly, in a Swedish study with mothers of extremely preterm infants, the mothers referred to the feeding situations as moments when they formed a closer relationship with their infant (Mörelius et al., 2020).

With infants born before 25 weeks of gestation, the application of elements typical of FCC, such as SSC, has been more limited due to the vulnerability of the infants. However, SSC can be safely initiated even towards the end of the first week in infants born at 22-24 weeks of gestation (Thernström Blomqvist et al., 2022; Karlsson et al., 2022). Moreover, in NICUs with an established tradition of applying continuous SSC, staff tend to be more positive and confident about this model of care, also in unstable infants (Thernström Blomqvist et al., 2022).

Furthermore, the encouragement of the staff is critical in supporting parents in actively taking care of their extremely preterm infant; the goal being that the parents will become the primary caregivers, while staff act as supporting mentors (Thernström Blomqvist et al., 2022; Ahlqvist-Björkroth et al., 2025). Karlsson et al. (2022) stress the importance of the attitude of the NICU team in believing that even the tiniest infants can do well and thus even allowing the parents to hope and collaborate in the infant's care. The elements of FCC have also found to have a supporting effect to parental psychological well-being, such as a decrease in maternal depressive symptoms (Gooding et al. 2011; Ahlqvist-Björkroth et al., 2025). As a whole, the changes in the neonatal care culture toward family-centred care have significantly improved the premises more optimal parent-infant bonding, even with the most immature infants.

2.3 Preterm birth and quality of life

The quality of life (QoL) of preterm individuals has received much attention in research literature, as it is a more multidimensional and more holistic outcome than the specific motor skills, language, and behaviour outcomes (Vieira & Linhares, 2016). However, the concept of quality of life is complex define and to measure, and there is no universal consensus on what it actually means (Saigal & Tyson, 2008).

2.3.1 Definitions of QoL

Saigal & Tyson (2008) point out that the concepts of QoL, health status, and functional status are often used interchangeably. Of these, health status refers to the broad issues of physical and emotional well-being, while functional status refers to the level of ability to perform age-appropriate activities of daily living and socially allocated roles (Saigal & Tyson, 2008). As for QoL, World Health Organisation (WHO) defines QoL as “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHO, 1995, 2012). Another definition of QoL that has been viewed as more applicable to children (Saigal & Tyson, 2008) has been developed by Bradlyn et al. (1996) in studying children with cancer: “QoL includes, but is not limited to the social, physical and emotional functioning of the child and adolescent, and when indicated, his/her family, and it must be sensitive to the changes that occur throughout development.” Saigal & Tyson (2008) conclude that between the varying definitions, there is consensus about some of the characteristics of the QoL construct: QoL is multidimensional and subjective, it is based on the perception of the individual, and it includes both positive and negative facets of life.

2.3.2 Literature of QoL of preterm children

Previous studies about the QoL of preterm children have been mostly performed using questionnaires (Saigal & Tyson, 2008; Zwicker et al., 2008; Mottram & Holt, 2010; Vieira & Linhares, 2016). The majority of the QoL studies about preterm children have been based on parental perspectives, while there are a few studies with children’s self-reported QoL (Vieira & Linhares, 2016). A meta-analysis on the subject concludes that parents of preterm-born children at preschool or school age tend to report worse QoL in their children than the parents of the full-term control group, especially in the domains of physical health, behaviour, and functionality (Vieira & Linhares, 2016). A multinational European study found that parent-reported health-related quality of life was particularly impaired by extremely preterm birth (Kim et al., 2023). However, in a study that used both parental and self-reports, 8-year-old children who had been born preterm rated their QoL as better than their parents (Hack et al., 2011). Huhtala et al. (2016) also found the self-reported health-related quality of life of VLBW children, in the subgroup of very preterm infants without long-term morbidities, was very good, and similar to the control children.

When looking at adolescents, some studies report the QoL of preterm-born adolescents as satisfactory (Roberts et al., 2013; Hallin et al., 2011), however, Wolke et al. (2013) found that adolescents born very preterm had worse QoL than full-term adolescents. In a Finnish study, 11-year-old preterm-born children with a developmental coordination disorder reported lower health-related quality of life than children born very preterm without motor impairment (Uusitalo et al., 2020).

2.3.3 Limitations of the QoL questionnaires and the importance of subjective experiences

A criticism of QoL questionnaires has been that they tend to focus more on functioning in various domains and on "ill-being" rather than well-being and as such, are not consistent with the definitions of QoL that refer to well-being or positive facets of life (Saigal & Tyson, 2008; Waters et al., 2007). While questionnaire studies have provided valuable insight into the impact of medical diagnoses and functioning ability, they still only provide a narrow window into the personal, everyday lives of the individuals (Saigal, 2016). To gain a richer perspective on the QoL of an individual, it is important to take into account the person's subjective experience of the different dimensions of life and their connectedness to each other. An applicable approach here/to study this could be using qualitative research methods, especially open-ended interview questions, that can provide a rich, in-depth perspective on the research topic (DiCicocco-Bloom & Crabtree, 2006).

So far, there is very limited literature on the subjective experience of people born preterm, i.e., what the experience of being born premature means to the survivors (D'Agata et al., 2022; Vederhus et al., 2025; Saigal, 2014, 2016; Marlow et al., 2020). As the life course consequences of being born premature are not fully understood, including the perspectives of individuals being born preterm is critical to improve this understanding (Vederhus et al., 2025). The few studies on the subject have included preterm-born adults, and have all used qualitative methods. Saroj Saigal's book "Preemie Voices" (2014) presented autobiographical narratives of former premature adults. These narratives were later thematically analysed; the emerging themes ranged from living with disabilities and bullying to gratitude experiencing support (Saigal, 2016). D'Agata et al. (2022) used a qualitative interview to gain knowledge about how adult preterm-born survivors perceived the effects of prematurity on their lives. In their analysis, they identified three themes that represented a continuum of experience, from positive to neutral to negative, and meaning was linked to how typical or not participants perceive their health, learning and friends compared to peers (D'Agata et al., 2022). Another qualitative study found that while extremely preterm born adults reported various challenges of a physical, mental, social, and educational nature, they had learned to adapt and cope, and they even expressed gratitude for their life (Vederhus et al., 2025).

A limitation in the literature about subjective experience of prematurity is that no studies have included preterm survivors that are children or adolescents. In a study that reviewed the lived experience of a critically ill infant, Duffy et al. (2020) stated that the child is often seen only as an object of research, instead of an active participant. They stressed the importance in exploring the child's own perspective through a qualitative lens (Duffy et al., 2020).

In this thesis, the term **experience of prematurity** refers to the preterm-born children and adolescents' self-reported experience on how being born extremely premature has affected their life; specifically with regards to the domains of somatic health, functioning ability, learning and academic achievement, social and family relations, and emotional well-being, whilst also allowing the children and adolescents to add perspectives they find relevant.

Another focus in this thesis is to assess the experiences of extremely preterm children's everyday life from maternal perspective. Regarding prematurity, Jaworski et al. (2018) suggest that the lack of interest towards the parents' perception of their child's development could potentially lead to missing meaningful outcomes that are important to parents and families. Therefore, parental observations about the everyday life of their child are important in complementing the picture of children's QoL. In the context of this thesis, the concept of **experiences of everyday life** refers to the mothers' observations of their child's life in the domains of somatic health, functioning ability, learning and academic achievement, emotional well-being, and social and family relations, while also allowing the mothers to add perspectives that they find relevant in their child's everyday life.

Thus, aiming to complement the existing QoL literature of prematurity with a qualitative, more holistic approach, the concepts used in this thesis are based on Saigal & Tyson's (2008) definition of the consensus regarding the core characteristics of QoL: QoL is multidimensional and subjective, it is based on the perception of the individual, and it includes both positive and negative facets of life (Saigal & Tyson, 2008). Additionally, both parents' and preterm children's own thoughts and perspectives are respected and taken into account (Jaworski et al., 2018).

2.4 Gap in knowledge

There is a growing population of preterm survivors born before 25 weeks of gestation. The question of the limit from where to start offering active neonatal care has been an ongoing debate in neonatal care. Nowadays, the debate has shifted to the approach of care of infants born at 22 and 23 weeks. Regarding these infants, there is considerable variation in neonatal care practices internationally. The earlier the preterm survivors are born the greater the risks for long-term health challenges and learning disabilities. Even though there is a wide range of literature concerning the diagnoses and the high risk of long-term morbidities, the knowledge of preterm survivors' quality of life and subjective experience of prematurity are still limited. Furthermore, parenting a child born extremely preterm is known to be a challenging task, both as for the initial bonding process and with the risk of long-term morbidities posing burdens to families. Therefore, in order to gain detailed and specific knowledge of the lives of children born before 25 weeks of gestation, it is essential to include parental perspectives.

A qualitative research approach can serve as a way to gain a more holistic, in-depth understanding of the experiences of children born before 25 weeks of gestation and their families. In psychological research, there has been a strong quantitative emphasis during most of the 20th century, and this trend still continues to this day. However, qualitative methodologies have gained popularity in psychology during recent decades (Sullivan, 2018). Qualitative research stems from the social constructivist stance on knowledge, in which knowledge is considered as constructed and situated (Lincoln & Cuba, 1985), and this approach has traditionally been viewed as opposed to the positivist philosophy of science, according to which there exists a single tangible reality that can be understood, identified, and measured (Park et al., 2020). Nevertheless, recent decades in psychological research have seen a shift away from positivism in psychological research towards other approaches, such as social constructionism, critical realism, and post-positivism (Sullivan, 2018). It is increasingly acknowledged that qualitative methods can complement the measure-oriented psychological research in a more holistic way (Hoshmand, 1999). Rosenwald (1996) states that qualitative psychological research is important in that it is interested in the human wholeness, instead of separate psychological functions.

3 Aims

The aim of this thesis was to qualitatively explore the experiences of families of the tiniest preterm survivors, i.e., children before the age of 25 weeks of gestation. The goal was to obtain holistic, detailed insight by exploring both parental and children's perspectives. The participating families had a child or children who had been born at 22, 23, or 24 gestational weeks and received active neonatal care in Turku University Hospital between 2002-2014. As there was only one child born at 22 weeks' gestational age among the participating families, this thesis focuses on children born at 23–24 weeks of gestation and their families.

The thesis is based on a qualitative descriptive research approach using a semi-structured interview. In addition to interviewing the parents, I as the principal researcher also interviewed all the children and adolescents born at 23–24 weeks who were seven years or older at the time of the data collection. There were separate interview guides for adults, adolescents (11-15 years) and children (7-10 years). The transcripts of the interviews were analysed using thematic analysis to identify and interpret key content areas of the data.

In **Study I**, the aim was to explore, via inductive thematic analysis of interviews, the experiences of mothers ($n = 8$) of children born at 23 weeks of gestation. We were specifically interested in how the mothers had experienced their own parenting, and how they would describe the everyday life of their children.

In **Study II**, the aim was to explore the retrospective narratives of parents (29 mothers and eight fathers) about their experiences of the bonding process with their infant born at 23–24 weeks and of the relational experiences in later stages of childhood. Also, we aimed to explore the overall parental memories about the stay in the NICU. The study used a theoretical (deductive) thematic analysis of interviews, in which the analysis was driven by the theoretical framework of bonding by Feldman et al. (1999).

Study III focused on the extremely preterm children and adolescents ($n = 18$). The purpose was to explore the subjective experiences of children and adolescents born at 23–24 weeks of gestation, in order to understand their perspectives on how being born extremely early had affected their life. The children's interviews were analysed using inductive thematic analysis.

The specific research questions were:

1. How do mothers of children born at 23 weeks of gestation describe their experiences of parenting and the everyday life of their children? Study I.
2. How do parents, retrospectively, describe their bonding process with their preterm infants born at 23 to 24 weeks, and how do they describe the relational experiences in the later stages of childhood? Study II.
3. How do children and adolescents born at 23–24 weeks of gestation describe their subjective experiences of how being born extremely early has affected their life? Study III.

4 Materials and Methods

4.1 Study design and context

This thesis builds on a qualitative research approach, more accurately that of **qualitative description** (Sandelowski, 2000, 2010; Sullivan-Bolyai et al., 2005; Willis et al., 2016).

Qualitative description stems from the philosophical tenets of naturalistic inquiry (Lincoln & Cuba, 1985). This approach emphasises the recognition of varied shared experiences and the interactive-inseparable nature of human interaction (Willis et al., 2016). Sandelowski (2010) states that while researchers using qualitative description use various sampling, data collection, and data analysis strategies, the overarching goal, achieved by analysing the data with qualitative content analysis, is to describe at a surface or manifest level an individual's experiences in his or her own words. In qualitative description, the researcher must generate a rich descriptive database, commonly through qualitative interviewing (Willis et al., 2016). Sullivan-Bolyai et al. (2005) emphasise the importance of an underlying conceptual or theoretical framework, which will be used to guide and focus the initial interview questions. Depending on the specificity of the framework, it may provide a general direction about the topical areas to be addressed in the interview or it may provide more precise specification about the variables and relationships to be studied. Interviews are initially framed by open-ended questions that reflect concepts from an organizing framework (Willis et al., 2016).

As all qualitative research stemming from the social constructivist stance on knowledge, qualitative description emphasises the role of researcher's **self-reflexivity,** i.e., scrutinising one's personal and theoretical assumptions and values as a researcher, and of examining their impact throughout the research process (Burck, 2005; Braun & Clarke, 2006, 2020; Willis et al., 2016).

The study was carried out in Finland, a high-income country with public health care available at a low cost to all citizens. In Finland, neonatal care is guided by the family-centred care principle (Toivonen et al., 2020), reflecting the more general shift in neonatal care towards a more family-centred approach during recent decades (Gooding et al., 2011). Furthermore, the societal support in Finland includes a nine-month long parental leave during which a parent receives a maternity/

paternity/parental allowance. This is complemented by childcare leave, during which the parent staying at home receives a small allowance and has the right to keep her or his job, until the child turns three years.

4.2 Participants

Purposive sampling was used: all families with a surviving child or with children born at 22–24 gestational weeks in Turku University Hospital between 2001 and 2014 were asked to participate in the study (n = 39 families). All children had received neonatal intensive care in Turku University Hospital and multidisciplinary follow-up in the local paediatric unit until at least the age of two years of corrected age. No incentive was offered for participation. The NICU in Turku University Hospital (level III) has over 500 admissions per year. The NICU also places a strong emphasis on family-centred care. During the study period, between 2009-2012, the staff were trained using the Close Collaboration with Parents intervention, a systematic training model for neonatal intensive care unit staff to improve their skills in supporting parenting and improving the family-centred care culture of the unit (Ahlqvist-Björkroth et al., 2025).

The families were first contacted by a NICU nurse and if the parents expressed their interest, I, as the principal researcher, contacted them to provide more information about the study. The parents of seven families decided not to participate, either because of a busy life situation or lack of interest. One family could not be reached, and one family did not have a fluent enough capacity in Finnish for the interview to succeed. Of the remaining 30 families, parents were asked to participate in a semi-structured interview study concerning the everyday life of their child, the perceived effects of being born prematurely, and their parenting experiences during the neonatal care period. Both parents were given an opportunity to participate but were also informed that mothers and fathers would be interviewed separately. In 25 families, the parents were married or cohabiting; in five families, parents lived separately either as a single person or with a new partner. The premature child had been the parents' firstborn for 13 families; in 17 families, there were one or several siblings born before the index child. Twenty-nine mothers and eight fathers participated in the interview.

In addition to the parents, all the children who had turned seven years old were asked to participate in the interview. Age seven was used as the limit, as in Finland children start their school at the age of seven, and the interview guide for children and adolescents included questions about school and academic achievement. In the 30 participating families, there were 19 children that were seven years or older. One child attended boarding school and could therefore not be interviewed. The remaining 18 children (12 girls and 6 boys) were all interviewed. The children had been born at gestational weeks 23 (n = 4) and 24 (n = 14). The children were 7–15 years of age at the time of the interview. There were two sets of twins and two children that had lost a twin sibling at birth.

A total of 11 children were younger than seven years of age during data collection. They were, therefore, not personally interviewed. They included six girls and five boys, one set of twins and one child that had lost a twin sibling at birth. They were born at gestational weeks 22 (n = 1), 23 (n = 3), and 24 (n = 7).

4.3 Data collection

The interviews were conducted during a time period between March and August 2017. I conducted all the interviews myself, supervised by senior researchers RK and LL. The interviews took place either in the homes of the families or in a research facility provided by the university. The choice of location was left to the parents. If they chose to be interviewed at home, it was ensured that the interview setting was as quiet and peaceful as possible. Twenty-nine mothers, 8 fathers, and 18 children aged 7–15 were interviewed. There were three twin mothers, who were encouraged to recall their experience separately with each child. In cases where both parents of a family were interviewed, they were always interviewed separately. The length of one interview was approximately 1–1.5 hours for the adults, and between 20 to 45 minutes for children and adolescents. To ensure that no data would be lost due to possible technical problems, all interviews were both audiotaped and videotaped, and later transcribed verbatim.

The data collection method was a semi-structured interview that was developed for this study. The interview guide consisted of six categories with pre-determined topics (Table 1). There were separate versions for adults, for adolescents aged 11-15, and for children aged 7-10; each version included the same categories, but the questions were modified according the group to whom the interview was intended.

Five of the interview categories were developed based on a thorough review of the content of questionnaires that had been used in previous studies about quality of life in children (Apajasalo et al., 1996; Klassen et al., 2002; Raat et al., 2005; McHorney et al., 1993; Fekkes et al, 2000). The categories of somatic health and functioning were adjusted with a neonatologist to include topics that were relevant to extreme prematurity (e.g., breathing, infections). The sixth category in the parental version including questions about the parenting experiences and memories of the NICU stay was developed with the help of a psychologist specialized in the early mother-infant interaction. In the interview version for children and adolescents the sixth category included questions about how they felt that being born preterm had affected their life.

The interview started with warm-up questions about the child's age and schooling or day care situation, followed by an open question to give the interviewees a chance to freely describe their lives and situations. In the parental version, the open question was *"What would you like to tell me about the life of your child, if you think about it from the beginning until this moment?"* and in the children's and adolescent's version it was *"What would you like to tell me about your life, if you think about it from the beginning until this moment?"*. After that, the topics were introduced by open questions such as *"Has your child had / Have you had problems [in this area]? [If yes,] what kind of problems and how they affect the life of your child and your family / your life?"* or *"Could you please describe [this area]"*. As is usual for semi-structured interviews, it was possible to ask follow-up questions in response to the interviewee's answers to delve deeper into specific areas.

When developing the interview guide, I conducted a pilot interview with a mother who had a full-term born child aged four. Based on my observations from this experience and on the feedback from the pilot interviewee, the interview guide was modified and revised. Before the actual research interviews started, a second pilot interview was conducted with a mother of an extremely preterm-born child aged five. In addition, the adolescent version of the interview was piloted with a ten-year-old, and the children's version was piloted with a seven-year-old child. Minor changes were made to the interview guide after piloting by modifying questions that had been difficult for the children to understand in the pilot interviews.

During the process of interviewing the participating families (March – August 2017), the senior researchers and I met regularly to watch the interview tapes and assess the interviewing; however, to establish dependability, no changes were made to the interview procedure.

Table 1. The categories of the interview.[1]

Open question	*"What would you like to tell me about the life of your child?"*
Somatic health	Infections, growth, pain, breathing, vision, hearing, gross motor skills, fine motor skills, continence
Functioning	Eating, sleep & vitality, daily activities, hobbies & play
Learning and attention	Learning & memory, school achievement, possible special education arrangements, attention
Emotional well-being	Expression of emotions, self-regulation, anxiety, depression
Social relations	Family relations, peer relations, group skills, other important people
Parenting experience / experience of prematurity	Thoughts about how prematurity has affected child / self, for parents: NICU experiences, overall parenting experience, positive and negative feelings about parenting

[1] The interview was started with an open question before the semi-structured categories, to give the parents a chance to freely describe the life of the child and the family. In the other six categories, the topics were introduced by open questions such as "Have your child had / have you had problems [in this area]? [If yes,] what kind of problems and how have they affected the life of your child and your family / your life?".

4.4 Analysis and authors' positioning

The analysis of the interviews was conducted using thematic analysis (TA) (Braun & Clarke, 2006, 2019, 2020; Hsieh & Shannon, 2005). This type of analysis is sometimes also referred to as qualitative content analysis (Hsieh & Shannon, 2005). In a detailed and widely quoted account of the principles and strategies of TA, Braun & Clarke (2006) state that the purpose of TA is to identify key content areas of the data and integrate those into coherent results (Braun & Clarke, 2006). Furthermore, TA includes not only reporting but also interpreting (Braun & Clarke, 2006; Sandelowski, 2010). The goal is to move beyond reporting individual answers and cluster together common ideas from multiple individuals to form themes to represent the data. Themes are considered to be entities that capture something important about the data in relation to the research question, and that represent some level of patterned response or meaning within the data set (Braun & Clarke, 2006).

Braun & Clarke also stress (2006) the importance of clarity in the analysis: a researcher should be clear about what has been done and how and why the themes have been formed. The use of data extractions in the reporting of the analysis is needed to provide sufficient evidence of the themes within the data (Braun & Clarke, 2006). In their later accounts, Braun & Clarke (2019, 2020) differentiate between three different approaches of TA and emphasise that the researchers need to clearly demarcate which approach they are using. This study uses **reflexive TA (RTA)**, an approach stressing the researcher's active role in knowledge production. As opposed to other approaches such as coding reliability TA or codebook TA, RTA does not necessarily encourage the use of multiple coders of data, as it is not expected that two coders should reach the same conclusions (Braun & Clarke, 2020). The use of RTA analysis requires transparency from the part of the researcher, as (s)he should clearly position the underlying assumptions and ideas that may have influenced the interpretation of the data (Braun & Clarke, 2020).

As the principal researcher of this study, I was in charge of the analysis and coding process, while supervised by senior researcher AA. The interview transcripts were read several times to obtain a holistic understanding of the mothers' stories and the overall patterns in the data. The coding of the data was done by identifying meaning units in the text. A meaning unit in this context is considered to be words, sentences or paragraphs containing aspects related to each other through their content and context (Graneheim & Lundgren, 2004). The meaning units are then labelled with codes and clustered together to form subthemes and larger themes to represent the data (Braun & Clarke, 2006). Regarding coding, while I was principally responsible for the coding process, I had regular meetings with senior researchers to compare and discuss unclear cases.

As regards the authors' positioning, my long-term experience as a clinical psychologist working with families was probably beneficial in the process of approaching the interviewees sensitively and obtaining a good and confidential contact. This resulted in rich and detailed interview data. I also had experience in working with families of young preterm children through previous research projects, which I considered a good thing in that I had an initial understanding about prematurity and its impact on parenting. In my later reflection of the interviews, I noticed that I closely followed the interview guide in my interviewing technique, possibly missing opportunities for probing questions that could have deepened the understanding. This might reflect my background in quantitative research methodology. In addition, it is worth acknowledging that all the members in the research team were dedicated researchers of premature infants and families; LL also worked as a clinician in a neonatal intensive care unit.

4.4.1 Analysis in Study I

In Study I, an inductive (data-driven) thematic analysis was used. Eight interviews from mothers with children born at 23 weeks' gestation were analysed. The fathers were given a possibility to participate, but only two fathers of 23-weekers consented, and therefore paternal interviews were not included in Study I. The focus was on our research questions about parenting and the everyday life of the child.

The analysis started with the coding and meaning unit identification process described above. Then, meaning units were labelled with codes, and from the basis of these codes, twelve initial subthemes were produced. The subthemes were then further clustered into seven themes. The process of theme formation is exemplified in Table 2.

Table 2. Examples of meaning units, subthemes and a theme in Study I.

Meaning unit	Code	Subtheme	Theme
"I have been much more protective of her than of [the full-born sibling]. Of course, I protect [the sibling] as well, but it's different."	protecting the preterm child more than the full-term sibling	maternal protectiveness	Intensive mothering
"I haven't even trusted [husband] to stay home to take care of our son."	difficulty in trusting other caregivers		
"I have educated the coaches in her [sports team] about her special needs so that they would know how to cope with her."	actively participating in the child's free-time activities	maternal dedication	
"We were active to arrange her to start in special education. As the parent, you are the expert of your child, you know what's good for her and what's not."	advocating for the child in education decisions		

4.4.2 Analysis in Study II

In Study II, all parental interviews (29 mothers and eight fathers) were analysed in regard to the answers to the sixth theme, which included questions about overall parenting experience, e.g., parental bonding and the NICU period (Figure 1). These questions had been designed together with an experienced neonatologist (LL) and psychotherapist focused on early parent–child interaction (RK). In addition, some parents answered the first open question of the interview ("*Please tell me about the life of your child, from the beginning until today*") in a way that included experiences about both the hospital period and their child's life after discharge. These were also included in the analysis.

- *Your child was born extremely premature, and (s)he needed a long neonatal intensive care period at the hospital. Today, how do you think being born prematurely has affected the life of your child?*
- *I will now ask some questions about the neonatal intensive care period. Could you describe the neonatal intensive care period? How did you feel during that time?*
- *Are there any particular events that you still remember from the NICU?*
- *How would you describe the development of the bond between you and your child in the beginning? What was helpful to you in bonding with your child?*
- *At what phase did you start to have confidence that your child would survive?*
- *Could you please describe the memories you have about the first days and weeks of having your child at home?*
- *Now, I am asking you to think about the current situation again. Could you please describe the way you feel about being the mother / father of your child?*
- *What brings joy to you about parenting your child?*
- *What are the challenges or stressors you find in parenting your child?*

Figure 1. Interview questions analysed for Study II.

For the analysis in Study II, a theory-driven (deductive) approach was chosen. In this approach, the analysis is driven by a particular theoretical basis and thus it is a more explicitly analyst-driven approach than inductive thematic analysis (Braun & Clarke, 2006). The decision to use a deductive approach was based on the fact that parent-infant bonding is a well-studied area, and inductive analysis would not necessarily have provided relevant new theoretical information on parent-infant bonding. The theoretical basis for analysis in Study II was the categorization of bonding by Feldman et al. (1999): the YIPTA (The Yale Inventory of Parental Thoughts and Actions, Leckman et al., 1999). Feldman et al. (1999) used the YIPTA categorisation to compare the bonding processes between mothers of preterm infants and mothers of full-term infants. Because our qualitative approach was notably different from Feldman et al., the method YIPTA was assessed in detail for its appropriateness for this study, and some modifications to the categorisation were made as presented in detail in Appendix 3.

4.4.3 Analysis in Study III

In Study III, 18 interviews of children and adolescents aged 7–15 were analysed, using an inductive approach. Based on the meaning unit identification process, initial codes, sub-categories and main categories were generated. I drafted the initial categorisation, and it was discussed together with the research team for critical comparison and validation. Then I refined the categorisation accordingly. Finally, three main categories were formed concerning the classification of prematurity effects. The coding process is exemplified in Table 3. Furthermore, an overarching category was identified (prematurity as a part of the family story). The defining and naming of the final categories, as well as choosing the best suited quotes to credibly represent the interview data, were done collectively through mutual critical discussion.

Table 3. Examples of meaning units, codes, subcategories and a category (group) in Study III.

Meaning unit	**Code**	**Subcategory**	**Category / Group**
“When I’m running, I get out of breath faster [than my peers].	Problems with breathing	Identifying minor consequences related to prematurity	Ponderers
“I’m not really able to reach my toes because I have such stiff legs.”	Problems with mobility		
“Well it’s been quite nice, I don’t know … [I’ve had] quite a good life.”	General satisfaction with life	A positive outlook on life despite challenges	
“I don’t think it [prematurity] has [affected her life] terribly much.”	Experiencing the effects of prematurity as not significant		
“I still [at age 13] haven’t learned to swim… I’m a little bit afraid of water.”	Nervousness about learning new motor skills	“un-athleticism”	
“I dislike a lot of things related to sports and exercise, so I haven’t practiced them either”	Dislike of sports and exercise		

4.5 Ethical considerations

The study was ethically approved by the Ethical Committee of the Finnish South-West Hospital District in December 2016, and approved by the protocol of Turku University Hospital in February 2017. All participating parents, as well as all children that were interviewed, were first given oral and written information about the study, after which they all signed an informed written consent for participation.

Regarding the ethical perspectives of this study, during the design of the interview it was acknowledged that the interview topics involved personal and at times sensitive subject matter, and thus the interview might be an uncomfortable situation for the interviewees. As obtaining information about these topics was relevant to our research questions, covering these topics was deemed justifiable for the purpose of the study. Nevertheless, the nature of the interview emphasized the need for me, as the interviewer, to proceed with caution and sensitivity during the appointments. The interviewees were informed beforehand that they may find some questions difficult to answer and that they may answer those the best way they could. In addition, I had left the choice of the interview location to families – they could choose to conduct the interview either at their home, or at a research facility. This was done in order to enhance the safety and comfort of the situation for the interviewees.

During the interview process, most participants, either children, adolescents, or parents, did not find the interview disturbing or uncomfortable. One adolescent reacted to some questions by getting emotional and was given a chance to discontinue; however, she chose to continue the interview. On another occasion, one child spontaneously raised her experience about being bullied at school. I proceeded by asking the child's permission to share this experience with her father after the interview, which the child agreed to.

Regarding parental interviews, a further challenge was that there were questions about memories from the NICU, which could be sad or potentially even traumatic for the parents. Indeed, some of the parents did become emotional during the recollection of their memories of the NICU. On these occasions, they were asked if they still had the strength to proceed which they all expressed wanting to do. On the other hand, some parents also expressed eagerness and joy in being able to tell their child's story from the beginning. With some parents, a theme that arose in the interviews was the parent's tiredness. With these parents, I returned to the subject of tiredness after the official interview, and we discussed the possibilities of obtaining help for the family if needed.

5 Results

5.1 Overview of results

As described above in the research aims section, the aim of the thesis was to qualitatively explore the experiences of families of children born at 23–24 weeks of gestation, both from parental and children's perspectives. Thus, both parents (Studies I and II) and children and adolescents (Study III) were interviewed. The results from Studies I-III are described briefly in this overview chapter and in more detail below. Some data extractions are used in reporting the results to illustrate the themes within the data.

Study I analysed eight interviews from mothers of children born at 23 weeks of gestation. The mothers' narratives of their children's everyday lives, while openly describing the developmental challenges and their impact on the children and families as a whole, also emphasized the strengths of the children and their active everyday life. The parenting style of the mothers seemed dedicated and protective, and gratitude for the child was a common theme. The mothers' stories included numerous mentions about the amount of support they received from both their family and friends and from society.

Study II retrospectively explored the narratives of parents (29 mothers and eight fathers) with children born at 23–24 weeks about the early parent-infant bonding process and later relational experiences. The bonding process was generally described as natural, despite the traumatic start to parenthood. Support from NICU staff, opportunities for participation in infant care, and parent-infant physical closeness were reported to enhance the bonding process. Study II identified earlier parental experience as a new element supporting the formation of the parent-infant bond.

Study III focused on the perspectives of children and adolescents born at 23–24 weeks of gestation, about their experience of the effect of being born preterm. A common theme was that prematurity had become part of the family's story, from the memories that the parents had told their children. The narratives of the children exhibited different perspectives in terms of how they had experienced the effects of their extremely premature birth: from reporting no effects at all ("*Go-with-the-flow*"), to identifying some small or moderate, mostly physical health-related challenges ("*Ponderers*"). In addition, one group of children either did not connect their challenges to prematurity or reflected very little overall ("*Hesitants*").

5.2 Study I

This study focused on the experiences of mothers with children born at 23 weeks of gestation. Eight maternal interviews were thematically analysed regarding the mothers' experiences of parenting and of the children's everyday life.

Seven themes were formed on the basis of the mothers' interview data. The themes are presented in three dimensions below, as illustrated in Figure 2.

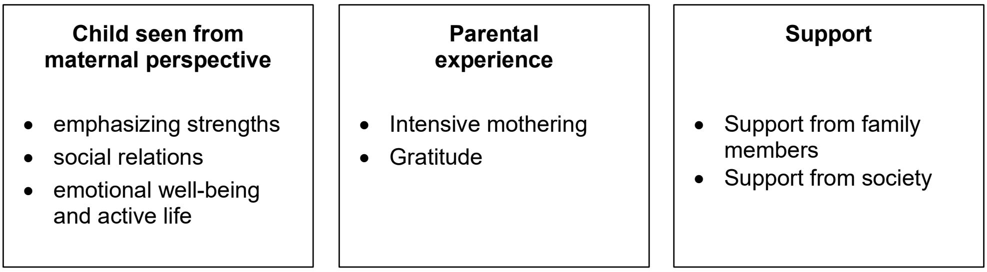

Figure 2. Illustration of results in Study I.

5.2.1 The child seen from maternal perspective

5.2.1.1 Emphasising strengths in the midst of challenges

Even though all of the mothers reported that their children had at least one of the long-term developmental challenges or disabilities (CP, epilepsy, ADHD, learning difficulties), the mothers tended to emphasise the strengths and skills of their children rather than the challenges. The mothers also mentioned milestones that the children had met age-appropriately. However, the mothers also openly described the challenges. Whereas learning-related problems were not necessarily evident in the stories of mothers of the youngest children, all school-aged children were, according to the mothers, in special education because of either learning-related or attentional problems.

> M6 (talking about her daughter who has severe learning disabilities): *Yet, her motor skills have developed [age-appropriately]. When she was very young, she learnt to ride her bicycle without training wheels. And if we [parents] didn't watch out, she would climb the ladder all the way up to the roof.* (laughs)

Mothers often described the children's personality traits, such as perseverance and resiliency, as being attributed to prematurity. According to the mothers, the children needed the will to fight for their lives as tiny premature babies, and later in life, will and perseverance were also needed to master developmental or learning-related challenges.

5.2.1.2 Relations with peers and siblings

All mothers, even mothers of the youngest children, felt that their child was interested in contact with other children. A common theme for the mothers of school-aged children was to describe the necessity of parental help in maintaining friendships. All of the school-aged children were reported to have had at least one good friend, but the number of friends they had was usually limited.

> M12: (talking about her child's friend who lived some way away from their house): *For [my child], it is too demanding to go there by foot, because she doesn't know how to be careful in traffic. But I am a friend with this child's mother, so we always try to make it work by driving the kids and arranging meetings.*

Several mothers mentioned siblings when describing their child's social relationships. As all siblings in the participating families had been born full-term and had no developmental disabilities, the sibling could be seen as an important supporting figure for the preterm-born child, as well as the best playmate. Some mothers even felt that their child would not be able to do all that he or she now did, without the help of siblings.

5.2.1.3 Emotional well-being and active life

The third theme in this dimension was the experience that the children were, in the mothers' opinion, doing emotionally well. The children were described with adjectives such as happy, joyful, or energetic. Mothers described some age-appropriate emotional problems, such as temper tantrums or teen-age related moodiness. However, when asked about anxiety and depression, none of them reported their children suffering from these conditions.

> M36: *He is a happy child. He comes to hug and kiss us a lot. He doesn't yet know how to say I love you, but he shows that he cares in his own way.*

From the mothers' descriptions, the life of the children seemed active and rich. Besides school or day care, many children had free-time activities, such as playing an instrument, singing in a choir, scouting, or doing sports. Time spent together with the extended family was described by many mothers.

5.2.2 The parental experience

5.2.2.1 "Intensive mothering" – dedication and protectiveness

The mothers seemed to have a dedication and commitment to parenting, investing considerable time and effort into helping their children to thrive. For many mothers, this included an active role in school issues or the children's therapies and rehabilitation. This mothering style could be described as "intensive mothering".

> M36: *We did those exercises [recommended by the physical therapist] every week, and we obtained good results. I think it has really benefitted [my son's] development, that all possible challenges have been tackled early on.*

One element in this intensive mothering style was some mothers' descriptions of being protective of their children – perhaps resulting from the child's background as an extremely small premature baby whose care had required much precision. Some mothers described having problems in trusting other people to take care of their child, even long after the baby period.

5.2.2.2 Gratitude

One of the motivating factors behind the mothers' dedication and protectiveness could be the feelings of gratitude that they felt about the child having survived the difficult beginning of their life, as the mothers expressed their gratefulness for the high-quality neonatal care the child had received. In general, the mothers spoke highly of the staff in the NICU. Moreover, the NICU period, although exhausting and challenging, was seen by some mothers as an experience that had resulted in tying the family more closely together. Some mothers felt that the child had a closer relationship with either the mother or the father, and that this closeness might be attributed to the way the parent had cared for the child in the NICU.

> M25: *Her father is probably the most important thing in the world to [the child]. [...] They have a very special bond. I don't know if it might be because of that [the father] had her so much in kangaroo care in the NICU.*

The expressions of gratitude emphasised the fact that the mothers were grateful for the child just as he or she was, even with the child's developmental delays or challenges.

5.2.3 Support

5.2.3.1 Support from social network

With regards to the intensive and dedicated parenting style that the mothers described, there was surprisingly little content about tiredness in the maternal interviews. Often the mothers reported having a good social network that helped them cope. The mothers' narratives included examples of fathers having an active role in childcare, marital satisfaction supporting the mothers, or getting help from grandparents or other relatives.

The mothers who did express feelings of tiredness usually had a quite young child with sleeping problems, and the feelings of tiredness were tolerated as the mothers believed that sleeping problems would resolve in time. Tiredness or exhaustion could also be related to a difficult life situation, not connected to the child. However, one single mother with little support described prolonged tiredness and attributed it to the child's demanding needs.

5.2.3.2 Support from society

Aside from the family and social networks, the mothers had received support from both health care and education systems. This support played a significant role in their narratives. Many mothers expressed satisfaction with the frequent follow-up visits the children had received after the NICU period, and the developmental challenges had been discovered early. The children had also had good access to therapies. The mothers described therapies and special school arrangements as an integral part of their life, and mostly, in a positive tone. Special education arrangements, such as an individualized learning plan or a smaller class, were seen as beneficial for the child and family.

> M14: *He's a slow learner, he needs more time and tuition [than the other kids]. And he can easily engage in his own thoughts during his classes. So the decision [about special education] has been good.*

A few mothers talked about rehabilitation or education arrangements that had, despite good intentions, not benefited the well-being of the child or family. In cases when therapy appointments were too frequent or the distance to rehabilitation was too long, the burden of these support services exceeded the benefits. However, the overall experience the mothers reported about the support from both health care and educational system seemed positive and might have been a significant factor in helping the mothers navigate in their parental role in the demanding situation.

5.3 Study II

Study II focused on retrospectively exploring the narratives of parents with children born at 23–24 weeks about their bonding formation and relational experiences. Twenty-nine maternal and eight paternal interviews were analysed regarding the parents' experiences about bonding with their infant during the period in the neonatal intensive care unit, as well as experiences of later relational experiences with their growing child. Parents' narratives were deductively analysed according to the YIPTA - a framework previously developed for studying parental bonding (Leckman et al. 1999).

In the analysis, I derived five categories of elements of parent-infant bonding and relational experiences, based on the categories of Feldman et al. (1999). Additionally, a new category was identified from our analysis. The categorization is presented below.

5.3.1 Thoughts, Worries, and Distress

Parents' feelings and thoughts of distress regarding their baby during the NICU period included descriptions about fears for their child's safety, well-being, and survival, as well as grief about their baby having to endure pain and discomfort. Traumatic memories related to surgeries or sudden deteriorations in their child's condition were recalled. Some parents had vivid memories of specific aspects of a typical NICU environment, such as the sound of the ventilator, causing them anxiety.

Another common experience was that parents could not recall details, which they explained by the neonatal intensive care period feeling "unreal" or "like being in a bubble". Fathers had experienced "double worry" for their baby, as well as for their spouse who was recovering both physically from the birth and mentally from the realisation that their child needed intensive care.

Some mothers had felt a need to keep an emotional distance to their child in the beginning because of the uncertainty of the baby's survival. Nevertheless, most recalled having had strong emotional feelings even in the beginning.

> *"[The attachment] didn't form at once, of course not, it couldn't have, when it wasn't possible to hold him . . . though I could touch him, he was my son, the emotional bond was strong even then."* M19

When the preterm-born child was older, parental worry and distress were related to the challenges and difficulties that prematurity had caused to the child and the whole family. Some parents reported that the traumatic memories from the NICU period had influenced both family life and the parent–child relationship even years later in a way that the parents experienced normal, everyday life challenges to be extra burdensome.

5.3.2 Distress Management

A majority of mothers and fathers described that support and encouragement from NICU staff had a significant role in reducing their stress and anxiety. Parents praised the staff's professional knowledge and the quality of care their babies received, as well as the kindness and helpfulness of the staff. They also emphasised the importance of the staff encouraging them into becoming active caregivers of their babies, instead of bystanders.

> *"I am really grateful to the NICU staff. They were very capable in taking care of premature babies, but they also took care of us parents."* M4

Other elements that were mentioned as distress-relieving were discussions with other NICU parents (especially mothers), work arrangements that had made it possible to be present in the NICU (especially fathers), a strong confidence that their baby would make it, and personality traits that helped the parents cope – positivity, sense of humor, the ability to take one day at a time.

> *"In general, I am a positive person. I will always believe in the good."* F25

When the preterm born child was older, some parents viewed their children's journey as an example of "per aspera ad astra", "through hardships to the stars", and express thankfulness over their child having survived the rough start and presently doing so well. The parents whose children had developmental challenges had the approach that those were not very significant from a broader perspective. This attitude supported the parents through challenging times even later in the life of their child.

5.3.3 Compulsive Checking

Compulsive checking did not emerge as a common theme in the parents' descriptions of the neonatal intensive care period in the participating parents, although some mothers described discomfort when they had to be away from the hospital.

Anxiousness about the discharge was also mentioned, as the parents doubted their ability to take care of their fragile baby's needs.

Most of the content that could be classified into the compulsive checking category was found in parents' stories regarding the first weeks and months after discharge. This was a time of anxiety and uncertainty for many parents. The parents described feeling the need to frequently check that their sleeping baby was breathing, while some mothers recalled even being scared to fall asleep themselves because of this. Parents' desire to do "all they could" for the baby, including both caretaking and rehabilitation, was also classified as compulsive checking.

> *"Perhaps the most difficult time period was just after discharge from the NICU, at least for me. Because she still had times when her breathing was bad, and [...] it was supposed to be our job to assess when it might be [more serious]."* F29

5.3.4 Affiliative behaviour and caretaking

During the babies' intensive neonatal care period, the parents' possibilities for affiliative behaviour and caretaking were first limited because of the infants' vulnerable state. Nevertheless, the parents reported expressing their affiliation with things such as stroking the baby's hand, singing a familiar song, or reading children's books to the baby. Later during the neonatal period, the ability to take responsibility for caretaking activities such as changing diapers or bathing the baby, felt very relevant for the bonding process between parents and their child. These activities increased the parents' confidence. Additionally, both mothers and fathers strongly emphasised the importance of physical closeness, especially kangaroo care, in the bonding process with their child.

> *"Thinking back, I feel it was the most important thing, that I got to be with him and do some of those [caretaking] things and to hold him."* M13

> *"Kangaroo care was really important. It made me feel at once that [my daughter] was my child."* F24

When the child was older, the parents still described elements of physical and/or emotional closeness in the relationship between them and the child. Some even felt a connection between kangaroo care in infancy and having lots of physical closeness with the child later.

5.3.5 Parental Representations

Both mothers and fathers tended to attribute tenacity to their child as a very premature baby, and it could be considered a personality trait that the child had needed to overcome the rough beginning of life. Describing the neonatal intensive care period, parents used expressions such as the baby having been *"a fighter", "a survivor", "resilient", "the miracle child".* The opposite kind of representation was to describe the baby with expressions of fragility and smallness: *"the little weakling", "little bird", "poor thing",* mostly by mothers. However, tenacity and fragility did not necessarily rule out one another, as in the mothers' stories, the child could first be described as "a weakling" and a few sentences later as a "a fighter".

Surprisingly, a common representation - which the mothers and fathers shared - was that they had experienced the baby "being theirs" from early on or having a strong bond at once. Even the mothers who initially had trouble becoming attached, described that the bond between themselves and their baby had started to develop quite quickly after the most uncertain first days. Only one mother in the study expressed having had the feeling that the baby belonged to the hospital.

Parents tended to describe even older children as tenacious or resilient. Stubbornness or other demanding personality traits could also be seen through the lens of resiliency or perseverance. Furthermore, parents emphasised the role of the NICU experience in that it had made their relationship with their child more "special" because of the unusual start.

> *"She's a very positive, an amazingly tenacious girl.[. . .] And that's what she's always been. She'll never give up trying."* M17

5.3.6 Earlier Parental Experience

Our study identified earlier parental experience as a new element supporting the formation of the parent-child relationship. Parents with older children often expressed their opinion that having had a child or children before the premature baby was beneficial for bonding. For these parents, the bonding process had felt natural, amidst all the uncertainty.

> *"I didn't find [bonding with my son] difficult. I have wondered if that might be because he was my second child."* M13

In comparison, mothers, for whom the premature child had been their first, described their initial emotional confusion with added meaning because it had been such a new situation for them. As one mother (M27) put it, *"Growing into motherhood with [my firstborn daughter] hasn't been an easy task."*

Furthermore, this category had an interesting feature with the several twin families in our sample. During the neonatal period, parents of twins had struggled when the progress of the twins had not been similar, and one of them could be doing better while the other was having problems. For other parents, the situation had been even more challenging as they had lost one twin at birth while the other had survived, leading to an emotional struggle between grieving for the baby they had lost and forming bond with the other baby who was in an unstable condition in the NICU.

5.4 Study III

This study analysed interviews of the preterm-born children and adolescents, born at 23 or 24 weeks of gestation. At the time of the interview, the children were aged between 7 and 15 years. The focus was on the children's reflections about how being born extremely preterm had affected their life. In the analysis, a common theme emerging was prematurity becoming a part of the family's shared story. Furthermore, the children's narratives were classified into three groups according to their experience of prematurity and its effect.

5.4.1 Prematurity as a family story

Most children reported that their parents had told them about their premature birth and early life. The child's early life had been shared, for example, by looking at the photographs from the NICU period together or visiting the NICU staff as a family. While the children mostly did not report that their premature birth had affected the parent-child relationship, they did recognise examples of how the preterm birth and the NICU stay had become a part of their family's mutually shared story. The children had heard stories of the challenges of the neonatal period, such as the pain they had had to endure, or about specific physical complications, such as cerebral haemorrhage. Many children also reflected on their extremely small size as preterm infants, comparing it to things such as a carton of milk or a barbie doll.

"I was really tiny… and I was poked with many needles." Boy, 11

Prematurity as a part of the family story also appeared in situations in which the child had lost a twin sibling in the premature birth. One of the children who had lost her twin during birth told her story as the surviving twin and how she felt their lives were intertwined. Another child with a similar background talked about the X-ray images that had been taken during the time her mother had been pregnant with her and her twin sister. These stories signalled that the memory of the deceased twin sibling still lived on in the family story, first told by parents and later by the children themselves.

5.4.2 Categorization of the children's narratives about the effects of prematurity

When analysing the stories of the children about the effects of prematurity on their personal lives, the narratives were classified into three categories. The categories were named *the go-with-the-flow*, *the ponderers*, and *the hesitants*, and they are presented below.

5.4.2.1 The go-with-the-flow children (n = 7)

These children typically responded that they did not feel that being born prematurely had affected their life in any way, or that the effect had been minimal. When probed, they could not state particular examples of ways it had affected them. The go-with-the-flow children often felt that everything in their lives had gone “pretty well”, and they often reported being content with their lives.

> *“Well, it [being born prematurely] hasn't affected me terribly much. I think it actually hasn't affected me at all. Everything's gone well.”* Girl, 9

Most of the go-with-the-flow children had extra-curricular activities, often sports such as soccer, ice hockey, parkour, or cheerleading. They did not describe experiencing physical challenges, such as problems in gross motor skills, in a way that would affect athletic hobbies. A few children mentioned that they felt they needed to work harder at school than their peers in order to keep up with learning, often in one or two specific subjects, and they disliked those subjects which required more effort. Nevertheless, when asked further, the children did not report experiencing actual learning difficulties, and one boy reported performing really well academically.

5.4.2.2 The ponderers (n = 5)

These children identified some consequences of having been born prematurely. The consequences they mentioned were small or moderate health challenges, or health issues that had been the result of prematurity or neonatal care in the beginning. However, the ponderers also emphasised that they saw the challenges as minor things and that overall, they did not feel that prematurity had played a big role in their lives. It is worth noting that the pondering children were all 12 years or older.

> *"Perhaps the fact that my breathing is like... when I'm running, I get out of breath faster. Or when I'm climbing the stairs, like at school or somewhere. [...] Otherwise, there's really nothing special. All other things are quite similar [to everyone else]."* Boy, 12, who had needed medication for asthma until the age of eleven.

An interesting feature about these children was that they tended to describe themselves as "not very athletic", or "not liking sports", and this was also evident in the fact that all except one had no sports as hobbies and even disliked physical education at school. In terms of this feature, this group differed from the go-with-the-flow children.

5.4.2.3 The hesitants (n = 6)

The children in this group mostly answered, "I don't know" or "I'm not sure", when asked about the effect that prematurity had had in their lives. In the hesitant group, all except one of the children had cognitive development issues and attended special education. This group also included two children with cerebral palsy, one with autism spectrum disorder, and one with epilepsy. Some of the hesitant children had described challenges in the areas of health or functioning, such as asthma, gross motor challenges, or mobility issues caused by cerebral palsy – all of which are possible consequences of premature birth. However, when asked directly about the effects of prematurity, the hesitant children could not connect prematurity and the challenges they had described. Instead, they were more likely to answer either that they were not affected by prematurity at all, or that they did not know about the effects.

> *"Because of my cerebral palsy, my left arm hurts almost all of the time."* Girl, 8

> *"My little sister is a faster runner than I am... for me, it's quite slow because of my legs are so rigid. My legs are like ... if I try to stand and catch my toes, I can't reach them. Because I'm tense."* Boy, 11

The hobbies that the hesitant children mentioned were athletics, music, and boy scouts, but there was little reflection on the joys or the challenges resulting from the activities. While in the two other groups there was a clear tendency to either feel "unathletic" (the ponderers) or to enjoy an athletic free-time activity (the go-with-the-flow), there was more variation regarding athletics in the hesitant group.

Two of the hesitant children gave very short answers throughout the interview, often shrugging or responding they did not know what to say. This tendency persisted even when they were prompted and encouraged. Even when asked to elaborate and offered support through further or more detailed questions, these children still maintained elusive and short answers.

6 Discussion

6.1 Overview of the theoretical and methodological contributions of the study

The thesis focused on a very small preterm population that is only able to survive in the most advanced medical settings (Rysavy et al., 2021), the children born at gestational weeks 23–24. Even though the population is tiny and represents only a small fraction of all children born prematurely (Edwards et al., 2018), children born before 25 weeks represent a distinct subgroup within the extremely preterm population, as they are at the highest risk for long-term morbidities and learning disabilities of all preterm children and their care practices are constantly under debate (Arnolds & Laventhal, 2021). Moreover, the parents of the infants born at these earliest gestational weeks face a high risk of losing their baby in the early days, which naturally poses challenges to the parent-infant bonding process. Due to this, the children born at 23–24 gestational weeks, as well as their families, require unique attention and research of their own, and the results of this thesis address this gap of knowledge.

The results of the thesis contributed to the literature of prematurity by providing subjective perspectives of preterm families, including both the preterm-born children and their parents. Using a qualitative approach and semi-structured interview as the primary method, personal, in-depth information was obtained. Previous studies about the subjective experience of premature birth and its consequences had included only adult participants (Vederhus et al., 2025; D'Agata et al., 2022; Saigal et al., 2016), so adding the voices of children and adolescents into the literature, which was done in Study III, provided relevant new information. Furthermore, results from parental interviews deepened the understanding of parenting extremely preterm-born children. These results even emphasised the importance of parental perspectives in assessing neonatal care and its outcomes (Jaworski et al., 2018). The inclusion of paternal interviews in Study II was a significant contribution, as fathers' perspective is often missing from studies of NICU parents (Provenzi & Santoro, 2015).

Furthermore, the parental accounts of the everyday life of children born at 23–24 weeks of gestation, as well as preterm children and adolescents' own experiences, added a more holistic, in-depth perspective into the picture of QoL in extremely preterm population.

6.2 Perspectives on parenting children born at 23–24 weeks of gestation

A lot of the earlier literature about parenting extremely preterm children has focused on the burden that extreme prematurity and its byproducts may cause to parenting and family life (Huhtala et al., 2011, 2014; Singer et al., 2007, 2010; Korja et al., 2008; Treyvaud, 2014). Less attention has been given to the more positive consequences. The results in this study provided new and deeper, more holistic insights to parenting extremely preterm children. The findings also underlined the importance of viewing parenthood in preterm families not solely through a deficit-based lens, but also as an opportunity for growth and strengthened family cohesion.

6.2.1 The parenting experience

As is known from previous studies, children born at 23–24 weeks of gestation have a high risk of long-term health- and learning-related challenges (Hintz et al., 2011; Twilhaar et al., 2018). In Study I, with mothers describing the everyday lives of their children born at 23 weeks of gestation, descriptions of children's health- and learning-related problems were frequent. Still, although mothers openly described the challenges, they still emphasised their joy of the child's skills and strength. Gratitude for the child was a prominent theme in both Studies I and II. The findings seem to be in line with Wraight et al. (2015), as they stated that mothers of preterm children, even when their child's prognosis was not good, still expressed the opinion that active neonatal care had been 'worth it'. Jaworski et al. (2018), studying parental perspectives about young children born preterm, found that even in circumstances where the child had a neurological impairment, parents emphasised the child's personality and happiness.

The mothers in Study I gave a picture of an intensive, dedicated, and emotionally involved parenting style. They seemed to put considerable effort into helping their children thrive, and this dedicated mothering may have benefitted the children's development. On the other hand, Study I included some mothers' expressions about tiredness. These findings bear similarities to previous quantitative studies about risk factors for longitudinal parental stress. In Singer et al. (2010), mothers of high-risk VLBW children at 14 years expressed more child-related stress than term mothers, but they also expressed the highest levels of parenting satisfaction. Singer et al. (2010) suggests that these positive feelings might be the result of post-traumatic growth, which is seconded by Janvier et al. (2016). It is worth keeping in mind that there might be some selection bias, as parents who agree to interviews might be more likely to have had a positive parenting experience and more energy. Parents' emotional bonding to their child might make them emphasise the positive aspects of a child with disabilities.

Geurtzen et al. (2017), in their study about whether parents involved in the process of deciding between active or comfort care for their extremely premature infants, found that parental decision regret scores were low. The authors suggested that coping style might also have an influence in the absence of regret: it might be easier to live with the decision when there is no regret. While the parents in our study were not involved in the decision-making of active or non-active treatment for their infants, their attitudes bear similarities to the coping style described by Geurtzen et al. (2017).

Parental support was an overarching theme in the parental interviews. Mothers in Study I emphasised the significance of support both from immediate and extended family members, and from a more societal level. Satisfaction was expressed about the NICU care itself and the dedication of the personnel, and the close follow-up the children received after NICU. Also, the parents expressed gratitude over the low threshold to starting rehabilitation, and the possibility for close collaboration with hospital staff and therapists. A well-working follow-up system might be relevant to the overall well-being of preterm-born children and their families. A noteworthy factor in interpreting the results is the context where the study is conducted. Finland is a high-income country where considerable societal support is directed to families. Besides the generous family leave policy (Työ- ja elinkeinoministeriö: Perhevapaat, 2025), most of the therapies and rehabilitation activities for children with special needs are free of charge for families. Primary education is also free, and day care costs are low compared to many other countries.

6.2.2 Early bonding and relational experiences

Preterm birth has in many previous studies been connected as a challenge for healthy bonding between parents and their infant (Carlton et al., 2020). This has been especially evident in the cases of extreme birth, which includes considerable worry about the infant's survival (Spinelli et al., 2016; Flacking et al., 2006). In Study II, most of the parents described having experienced the bonding process with their infants as natural or even easy despite the circumstances. Still, some parents reported difficulties in their bonding process, such as a fear of becoming attached to their child, and almost all parents expressed traumatic memories, worries, and emotions concerning the NICU period. A common theme was the re-activisation of traumatic elements from the NICU period, which is in line with the literature about later PTSD (post-traumatic stress disorder) symptoms in parents of premature children (Malouf et al., 2021).

The results of Study III emphasised how the more agreeable memories of the NICU period had become a part of the families' mutually shared story, as the children themselves reported that their parents had told them memories from the NICU period or shown pictures. This finding was evident also in the interview study of adults born preterm by D'Agata et al. (2022). Another finding was that parents' experience of emotional closeness with an older preterm-born child – the NICU period was often described as a challenging but rewarding experience that has ended up strengthening the family emotionally. Similarly, Janvier et al. (2018) emphasise that the experience of having a child in the NICU had resulted in a deepening understanding of the importance of family and connectedness.

Parents in Study II described NICU staff as significant supporters of the bonding process, as the staff had encouraged parents to become active caregivers to their infants. The role of NICU staff has been acknowledged as important even in earlier studies. Spinelli et al. (2016) suggest the medical staff in the NICU should be aware of their role in shaping the maternal experience; beyond caring for the infant, the staff are indirectly caring for the mothers (Spinelli et al., 2016). The results of Study II also highlighted other elements that parents had experienced as beneficial for the bonding process, such as the possibility to actively participate in the infant's care, parent-infant physical closeness, and earlier parental experience.

One possible contributing factor to the positive parental experiences regarding early bonding may be the family-centred care culture in the NICU where the study was conducted. During the period which the children received active neonatal care in Turku University Hospital, the NICU staff were trained using the Close Collaboration with Parents intervention, a systematic training model for neonatal intensive care unit staff to improve their skills in supporting parenting and improving the family-centred care culture of the unit (Ahlqvist-Björkroth et al., 2025). Even before the intervention, the NICU had a strong family-centred care culture, reflecting the overall change in neonatal care in recent decades (Franck & O´Brien, 2019; Gooding et al., 2011).

6.3 Perspectives on the QoL of children born at 23–24 weeks of gestation

The results of this thesis complemented the existing literature about QoL in the preterm population by adding qualitative perspectives with nuance and detail. As described earlier, the previous studies of QoL in the preterm population have mainly used questionnaires or other quantitative methodology (Vieira & Linhares, 2016). These studies have been criticised for focusing too much on the problems and limitations caused by developmental disabilities or functional restrictions (Saigal & Tyson, 2008; Waters et al., 2007). In Study I, the mothers' accounts about the everyday lives of their children born at 23 weeks of gestation emphasised the emotional well-being and active living, even in the midst of health and developmental challenges. Study III produced first-hand accounts of school-aged preterm survivors themselves regarding their experience of prematurity, and these insights deepen the understanding of QoL in the extremely preterm population and their families.

QoL is an important perspective in the ethical discussion regarding neonatal care, as many countries and units have opted to withdraw from active neonatal care for infants born at 22 or 23 weeks because of the poor long-term prognosis and low possibility of disability-free living (Rysavy et al., 2021). The results in this study provided new perspectives into the ethical discussion, highlighting that there can be a wide variation between "disability-free living" and "not worth living" (Helgesson, 2017).

In Study III, the children and adolescents themselves described their experiences about how being born preterm had affected their lives. The children's reflections were divided into three categories, the go-with-the-flow, the ponderers, and the hesitants. The diversity of their experiences illustrated that the significance of prematurity is neither uniform nor static across individuals. The go-with-the-flow children reported little or no effect of prematurity and overall good functioning in different areas of their lives, while the ponderers reported some effects, mostly small physical challenges. The hesitants, for their part – the group in which most of the children had mild or more significant cognitive delays – either gave very short answers or described health-related challenges without connecting them with prematurity. As delayed intellectual development has been connected with challenges in mentalisation development (Derks et al., 2019) and problems in more abstract thinking processes, cognitive deficits might partially explain why the hesitant children had difficulty connecting their challenges with being born prematurely, or even understanding the interview questions. The children categorized in the group of hesitants seemed, from the perspective of an outsider, to be "the most affected" of the preterm birth, and therefore other complimentary perspectives are needed to obtain a better understanding of this population.

Nevertheless, Study III was a valuable contribution to the literature on the quality of life of preterm infants, in that it provided the first account of information in the subjective experiences of school-aged children and adolescents born preterm. To my knowledge, no other studies have interviewed school-aged preterm survivors themselves about their experience of prematurity.

The findings in Study III also highlight the fact that even amongst the children born at the limit of viability, many preterm survivors grow up without suffering from significant morbidities or delays. One contributing factor to this is the role of gestational age and long-term outcome, as the majority of our participants were born at 24 weeks of gestation: children born at 24 weeks have a smaller risk for developmental delays than children born at 23 weeks (Serenius et al., 2016; Söderström et al., 2021), and thus more preterm survivors born at 24 weeks grow up without major morbidities compared to the ones born at 23 weeks. The morbidities were more evident in Study I, where the mothers of only the children born at 23 gestational weeks were included.

6.4 Limitations of the study

6.4.1 Participants

One possible limitation regarding the participants of the study may be the range of socio-economical contexts in the data. Quantitative research shows that Finnish families of very preterm infants are usually coping reasonably well psychosocially and socio-economically (Korja et al., 2008). Therefore, this sample may not represent a wide range of socioeconomical or psychosocial contexts typical to some other countries with lower incomes or wider social class differences.

In Study I, mothers were interviewed about their children's everyday life, and not the children themselves. Therefore, the findings in Study I may reflect more the quality of life among mothers than among the children. Also, only maternal, and not paternal, interviews were included in Study I. Despite the possibility to participate, only two fathers of the children born at 23 weeks' gestation agreed to be interviewed, and as a result the fathers' interview data were not saturated enough.

Study III was limited by the small number of participants ($n = 18$) and the variation caused by the wide age range (7–15 years). Similarly, Study I, featuring the mothers of children born at 23 weeks of gestation, had only eight participants. However, as explained earlier, the children born at 23 and 24 weeks of gestation are a special group of premature children due to the high risk of long-term consequences. As there are few survivors born on these gestational weeks, it was necessary to include a wider age perspective.

6.4.2 Methodological considerations

As for the methodological limitations, it is worth noting that the study was not methodologically innovative or multifaceted, as thematic analysis was used as the only analysis method. Additionally, there are some limitations concerning the interview guide used in the study. The interview guide, which was developed based on QoL questionnaires used on earlier quantitative studies, consisted of several themes and subthemes, including a large number of questions. In retrospect, it might have been a wise option to limit the number of questions and perhaps use a questionnaire to complement the health-related information gathering. This would have allowed more time and possibility to deepen the themes that each participant raised. In retrospect I acknowledge that my role of being the principal researcher and the interviewer may have challenged my interviewing technique; I may have been at times too cautious in asking follow-up questions. This structured approach was due to my background in quantitative methodology and the need to prioritise the comparability of the interviews.

Another consideration is the applicability of the interview guide for children with cognitive challenges. In Study III, the interview guide may not have been the most applicable method to gain information of the cognitively challenged children. While the interview guide was piloted beforehand, both pilot interviewees were healthy full-term children. In retrospect, it would have been advisable to pilot the interview guide with children who have cognitive challenges in order to ensure its applicability. Furthermore, a lack of motivation or willingness to concentrate might also have influenced some children's willingness to elaborate on their stories.

In Study II, a methodological limitation was the framework used for the analysis, the YIPTA. While it had originally been used to interview parents soon after the birth, in Study II it was used retrospectively. However, the framework was modified accordingly (see appendix III), and it served as a good basis for categorization of parental bonding and relational experiences.

6.5 Clinical implications and future prospects

Preterm survivors born at 23–24 weeks of gestation form a growing population. Extremely preterm birth poses significant challenges for families, spanning the NICU and the years after discharge and affecting bonding, parental mental health, and everyday family life. Therefore, support interventions for preterm families are needed across the care pathway. Studies of early interventions in families with preterm children have shown positive effects on parent-infant relations (Leppänen et al., 2024). The results of this study regarding the early bonding process may be useful in designing interventions to support parent-infant bonding in neonatal care settings, especially as this study identified several factors that supported bonding in the NICU.

As the risk for neurodevelopmental challenges and other health problems is significant for extremely preterm children (Hintz et al., 2011), it should be noted that both preterm birth and the chronic disability of a child are associated with increased psychological parental, especially maternal, distress (Cacciani et al., 2013). Therefore, supporting parental well-being should be an important consideration in the long-term follow-up and interventions for families with children born extremely preterm. This study highlighted preterm mothers' highly dedicated parenting style and the importance of support from both relatives and wider society. These findings may help inform future intervention guidelines.

In the clinical setting, the well-being of parents in preterm families should therefore be addressed systematically. Support should be provided both during neonatal follow-up and later on, in particular if the child has long-term delays or disabilities. Furthermore, support interventions may serve families best when they can be tailored to the unique needs of each family.

In future studies, it is important to further improve the understanding of preterm individuals' own experiences, which is best achieved through qualitative methods such as interviews. In this study, interviews with children and adolescents born at 23–24 weeks were sometimes challenged by a lack of motivation, limited ability to concentrate, and the suitability of the interview guide. A more loosely structured guide might encourage participants to speak more spontaneously and provide new and unexpected information. Future studies should also consider carefully how best to motivate and support participating children. A multifaceted approach, including children, parents, teachers, and therapists, may provide a broader and more reliable view of the lives of preterm survivors.

Follow-up interview studies could also deepen understanding of the themes raised in the parental interviews. For example, sibling relationships in families with preterm children, especially in the case of twins born prematurely, would be an interesting topic to explore. The role of grandparents in preterm families could also be examined in more detail, given how strongly parents in this study valued the support they received from their relatives.

In research of children born extremely preterm, quantitative longitudinal studies remain essential for establishing long-term outcomes and guiding neonatal care. Equally, qualitative approaches are needed to capture the lived experiences of survivors and families. By integrating these perspectives, a more comprehensive understanding of extremely preterm birth and its consequences can be achieved.

7 Summary / Conclusions

The focus of this thesis was on the experiences of families with surviving children born at 23 to 24 weeks of gestation. These children, although a small subgroup of all preterm-born children, are a special, particularly vulnerable preterm population, and they therefore require unique attention. Due to the small possibility of survival without long-term morbidities, the active neonatal care of infants born at especially 23–24 weeks of gestation has often been questioned. Furthermore, the families of the smallest preterm survivors are at risk due to the children's health and developmental challenges. The aim of this study was to complement the current literature of parenting and quality of life of preterm-born children, with a complementary, more in-depth perspective, using a qualitative approach.

Regarding the bonding period with parents and their extremely preterm-born child, while even challenges concerning NICU time and relational experiences were reported, the parents had generally experienced bonding with their extremely preterm infant mostly as natural or even easy. Support from NICU staff, participation in infant care, parent-infant physical closeness, and earlier parental experience were reported to enhance the bonding process. Maternal experiences about older preterm children's everyday lives showed that while the parents were open about the challenges that their preterm-born children faced, they also emphasised the skills and strengths of the child, as well as gratitude of the child. A dedicative and intensive attitude to parenting was evident, as well as the perceived importance of support both from society and family members. Interviewing the preterm survivors themselves (7–15 years at the time of the interview) showed a wide range of perceived consequences about being born extremely preterm: from experiencing no effects at all to experiencing small to moderate, mostly health-related challenges.

The results from this thesis highlighted the importance of adding the preterm survivors' own voices and experiences into the literature, as well as the importance of parental perspectives in assessing neonatal care and its outcomes. Regarding the discussion of QoL and the ethical considerations of neonatal care for infants born at the threshold of viability, our results added a needed, more holistic, and nuanced perspective about the experience of QoL in the extremely preterm-born population.

Because of the challenges that extremely preterm birth and its consequences may pose to families, support interventions for preterm families are needed across the care pathway. The results of this study can be used in designing support interventions, both during the NICU period and in longer-term follow-up of extremely preterm children.

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Appendices

Appendix 1. Research interview for adults.

Most of the interview questions were presented to all participants. The questions separated by a margin are defining questions, which were presented to participants in need of help to elaborate the theme in question. If the interviewee spontaneously gave an elaborate answer that included the same information, the defining question wasn't presented.

Warm-up questions.
(Welcoming the parent, telling about the video and audio recording.)
How old is your child at the moment?

(For the parents of school-aged children): What class does your child attend at the moment? What kind of a school does (s)he attend?

(For the parents of children under school age): Does your child currently attend day care or kindergarten, or are you taking care of him/her at home?

> (If the child is in day care): When did your child start attending day care?

This interview will be started off with an open question. What would you like to tell me about the life of your child and his / her life, when you think about it from the very beginning until this moment?

(The parent is let to freely describe the life of his / her child, and the researcher doesn't ask defining questions during this part of the interview.)

> (If the parent has trouble getting started, a prompting question will be asked): You can start, for example, by describing the first years of your child.

Introduction to theme questions.
I will now ask you questions about different themes that have to do with quality of life. As this is a research interview, all participants will be asked the same questions.

All questions might not feel very well suited to the situation of your particular family. In spite of this, please answer to each question as well as you are able.

Theme 1. Somatic health.

General health
Could you please describe your child's health in general?

How often does your child approximately get sick, for example, with flu or with fever?
Do you find your child is sick more often than his peers or siblings?

Growth, body image
Does your child grow according to the growth expectations?
(If not): Could you describe the problems with growth?

Does it seem to you that your child is content with the way he looks, with his length and his weight?

Pain
Does your child suffer from some kind of physical pain or ache – e.g. stomach ache or headache?
(If yes): Can you describe these pains and their regularity?
Do you find your child suffers more of these pains than his peers or siblings?
How do these pains affect the life of your child and your family?

Breathing
Is your child able to breathe easily, or does he have asthma or asthmatic symptoms?
(If the child suffers from asthmatic symptoms):
How do you find these symptoms affect the life of your child and your family?
Does your child have medication for asthma?
If yes: Is the medication used regularly? How often?

Vision
The next question is about vision. Does your child have normal vision, or does he have to wear glasses in order to be able to see clearly?
(If the child wears glasses or has problems with vision):
How do you find that using glasses has affected the life of your child?
Does it affect the place (s)he has in the classroom?
Does it affect his/her choice of hobbies?

Hearing

Does your child have normal hearing, or does (s)he have to use some kind of a device to be able to hear clearly?

(If the child has a hearing device):

How do you find that wearing the device has affected the life of your child?

Gross motor skills

The next question is about motor skills. When you think of your child with regard to his peers, do you find that your child's basic motor skills, such as walking, running and jumping, are equal to those of his/her peers?

(If the child has problems with motor skills):

How do you find these problems have affected the life of your child and your family?

Has your child already learned / at what age did your child learn to

a) walk,

b) drive a bicycle without training wheels,

c) swim?

If there has been some trouble learning these skills, could you please describe these problems?

Fine motor skills

Again, please think of your child with regard to his peers. How do you find your child does with activities that require fine motor skills or prestidigitation? For example, to tie his shoelaces, cut with scissors, eat with a knife and a fork?

(If the child has problems in this area):

How do you find these problems have affected the life or your child and your family?

Continence

Next, some questions about your child's continence.

Is your child able to use the bathroom on his own?

Does (s)he need to be reminded of bathroom visits?

Has your child had trouble with bedwetting and/or daily wetting himself?

(If the child has problems in this area): Does the child use diapers?

How do you find these problems have affected the life of your child and your family?

Theme 2. Functioning

Eating

How would you describe your child's eating behaviour?

Does (s)he eat independently?

> (If the child does not eat independently): Could you please describe the type of help your child needs?

Does your child have a good appetite?

Some kids tend to be picky with what they want to eat and what they don't. Is your child picky in this way?

> (If yes): Could you elaborate on this?
>
> What do you think this pickiness originates from?
>
> How do you think eating problems affect the everyday life of your child and family?

Sleep, vitality

How would you describe your child's sleeping behaviour?

(If the following hasn't come up already): Does (s)he have trouble falling asleep?

What about sleeping through the night?

All children have varying days when it comes to feeling energetic throughout the day. How do you think your child is most of the time – does it seem to you that (s)he is energetic and has enough energy to cope with the activities of the day?

> (If not): Do you find your child struggles with a lack of energy?
>
> Do you find that your child would seem more tired or lacking energy than his siblings/peers?
>
> How do you find the problems with sleep and/or vitality affect the life of your child and family?

Daily activities

Again, please think of your child with regard to his/her peers. How do you find your child does with daily activities such as getting dressed, taking a shower, brushing his teeth, etc.?

> (If your child has problems in this area): Could you please describe these problems?

How do you find these problems affect the life of your child and family?

To parents with kids under 13: Play

Could you describe the way your child likes to play?

Is there something in your child's play skills that either you or your child's teacher have worried about?

(If yes): How do you find these problems affect the life of your child and your family?

Hobbies and free-time activities

What kind of hobbies or free-time activities does your child have?

(If the child has some kind of a hobby or a free-time activity):
How often does your child go to [this activity]?

Is there something with your child's hobbies that you or the instructor would have been worried about?

(If yes): Please describe those worries.
(If the child doesn't have any free-time activities): Could you describe why not?

Screen time

How much time screen time does your child have, e.g. watching television, using a tablet, a cell phone or a computer?

Do you know what your child does with a computer or a tablet?

Do you think your child has too much screen time?

(If yes): Do you find this is notable in your child's behaviour? In what way?

Is there some kind of application or a digital program that helps your child in some area of his development?

Theme 3. Learning and attention

Learning & memory

Could you please describe how you find your child as a learner of new things?

What about his memory, how well do you think your child remembers the things (s)he's already learned?

Is there anything about the learning skills of your child that you or the child's teacher have been worried about?

(If yes): Could you please describe these problems?
How do you find these problems have affected the life of your child and your family?

Academic achievement

Could you please describe your child's achievement at school / kindergarten / day care?

Does your child like school / kindergarten / day care?

Why do you think (s)he likes it / Why do you think (s)he doesn't like it?

What school subjects / day care activities does he like?

Is there any subject or activity your child has had problems learning?

(If yes): Could you please describe these problems?
Why do you think this has been difficult for your child?
Does your child have specific learning arrangements due to learning challenges?
(If yes): Could you describe these arrangements and the way affect the life of your child and your family?

Attention / concentration

How would you describe your child's ability to be attentive and to concentrate on different kinds of activities?

(If the child has trouble concentrating): Could you please describe what kind of situations do these troubles arise?
How do you find these troubles affect the life of your child and family?

Are there activities in which your child seems to be able to concentrate for a longer time period?

Theme 4. Emotional well-being.

Emotions and self-regulation

Could you please describe how you find that your child feels and shows different emotions, such as sadness, happiness, anger?

How do you find your child is able to regulate his/her feelings?

How does your child calm himself when (s)he's upset?

What does he do when (s)he feels sad?

Is there anything with your child's emotional well-being or self-regulation skills that either you or the child's teacher have worried about?
    (If yes): Could you please describe these problems?
    How and in what kind of situations do the problems arise?

Distress, anxiety, depression

Do you think your child often seems distressed or anxious?
    (If yes): What do you think these feelings originate from?
    Have you discussed it with your child?
    How do you find this affects the everyday life of your child and your family?

Has your child ever been diagnosed with depression or anxiety?
    (If yes): How does this affect the everyday life of your child and family?

Theme 5. Social relations.

Family relations

Could you please describe the type of relations that your child has with family members, parents, and siblings?

Is there anything about your child's relations with family members that have caused you worries?
    (If yes): Could you please describe this further?

Relationships with friends

(Only to parents of children younger than the age of five): Do you find your child is interested in other people?

Does your child have friends?
    (If yes): Could you please describe the relationships that your child has with his/her friends?

Could you please describe how you find your child functions in a group?

Is there anything about your child's social relations that you or the child's teacher have been worried about?

(If yes): Could you please describe these problems?

Other relationships

Are there other important people in your child's life than parents, siblings, and friends?

(If yes): Could you tell me about your child's relationships with these people?

Theme six. Parenting experience.

Your child was born extremely premature, and (s)he needed a long neonatal intensive care period at the hospital. Today, how do you think being born prematurely has affected the life of your child?

I will now ask some questions about the neonatal intensive care period. Could you describe the neonatal intensive care period? How did you feel during that time?

Are there any particular events that you still remember from the NICU?

How would you describe the development of the bond between you and your child in the beginning? What was helpful to you in bonding with your child?

At what phase did you start to have confidence that your child would survive?

Could you please describe the memories you have about the first days and weeks of having your child at home?

Now, I am asking you to think about the current situation again. Could you please describe the way you feel about being the mother / father of your child?

What brings joy to you about parenting your child?
What are the challenges or stressors you find in parenting your child?

Final

I have now asked all the questions that are presented to each participant. You are now able to again openly describe the life of your child in your own words.
If you find something important was left out in any of the themes we discussed, feel free to elaborate that theme now.

(Turning off the video and audio recording, thanking the parent.)

Appendix 2. Research interview for children and adolescents.

Most of the interview questions were presented to all participants. The questions separated by a margin were defining questions, which were presented to participants who had answered positively to the question before but hadn't elaborated their answer. If the interviewee spontaneously gave an elaborate answer that included the same information, the defining question wasn't presented.

Some questions included time definitions (every day, a couple of times a week, more seldom). These were presented as examples if the child / adolescent needed help with defining the frequency of some activity.

Warm-up questions

What is your age at the moment?

What grade are you on? What kind of a school do you go to?

Open question

I will start with an open question. What kinds of things would you like to tell me about your life, if you think about it from the very beginning until this moment? There is no right or wrong answer to this.

Introduction to the more structured questions

Next, I will ask you questions about different topics regarding life. The way this interview is planned is that everyone is asked all the same questions. You might think that some of the questions sound funny or strange. Still, please answer in the best way you are able to.

Theme 1. Physical health.

General health

Do you generally feel that you are healthy and you feel well?

How often do you approximately get sick, for example with flu or with fever?

Do you find that you are sick more often than your peers or siblings?

Growth, body image

Please think of yourself and other children/adolescent your age. Do you find you have grown approximately as fast as other children your age?

Do you feel content with the way you look, your weight and your height?

Why are you content / not content?

Pain

Some people often have stomach pains, or headache, or other bodily pains such as the aching of a hand of a foot. Do you have pains like these?

- How often? (every day, a few times a week, more seldom)?
- How do you find these pains affect your life?
- Do you sometimes miss school because of these pains?
- Are you at times unable to sleep because of the pains?

Breathing

I will now ask you about breathing. Are you able to breathe easily, or do you often feel breathless or have to cough, even though you haven't had to exercise?

- How often does this happen? (every day, a few times a week, more seldom)?
- Do you have a medication for asthma?
  - How often is the medication used?

Vision

Do you have normal vision or do you have to wear glasses in order to be able to see clearly?

- How do you find that using glasses has affected your life of your child?
  - Does it affect the place you have in the classroom?
  - Does it affect the free-time activities you can have?

Hearing

What about your hearing? Are you able to hear clearly what is spoken to you, or do you use some kind of a device to be able to hear clearly?

- How do you find the wearing of the device?
- Has it been to you a positive or a negative thing?
- Can you describe why?

Gross motor skills
The next questions are about motor skills. Please, think of yourself and other children/adolescents your age. Do you think you are able to walk and to run approximately as well as other children/adolescents your age?

Is there some kind of exercise you feel is difficult to you even though it seems easy to other children/adolescents your age?

The next things you perhaps won't remember, but perhaps you have discussed it with your parents. At what age have you learned, or are you now able to
walk
drive bicycle without training wheels
swim?

If you are not able [to some of the above], what kind of help do you need?
Sometimes motor problems can affect, for example, the choice of free-time activities. They can also affect the amount of help one needs moving outside the house. How do you think motor problems have affected your life?

Fine motor skills
Some people find that activities that require prestidigitation are difficult. These activities can include tying of one's shoe laces, cutting with scissors, or constructing a set of Legos. Again, when you think about yourself and other children / adolescents your age, how do you think you are able to do these kinds of activities?

Sometimes problems with prestidigitation can affect slowness in the activities that require them. How do you think problems with prestidigitation have affected your life?

Continence
Next is a question about using the bathroom. You may find it difficult or strange, but just answer the best way you can. Do you need help from others in going to the bathroom?

Does it ever happen that you don't make it to the bathroom in time?
How often? (every day – a few times a week – more seldom)

Theme 2. Functionality

Eating
Now let's talk about eating. Are you able to eat independently, or do you need help from others? Such as somebody feeding you, or cutting the food in pieces for you?

Are there any types of food that you don't want to eat at all?

Do you like eating situations or is there something in them that you find difficult? Some people feel that their eating is too slow or that they don't want to eat in public place as that makes them feel uncomfortable. Do you have similar feelings or other difficulties regarding to eating?

Sleep, vitality
How do you sleep?

Do you find it difficult to fall asleep at night?

Do you often wake up during the night?

Sleeping issues can affect life in multiple ways. How is your life affected because of the sleeping problems?

Everyone can feel energetic on some days, and then tired on other days. Do you mostly feel energetic and able to do the activities of the day, or do you feel tired during the day?

> Why do you think you feel tiredness?
> Do you find you are generally more tired than other children/adolescents your age?

Daily activities
Again, when you think about yourself and children/adolescents your age, how do you think you are able to cope with daily activities such as getting dressed, taking a shower, or brushing your teeth?

> Are you able to do them by yourself or do you need help? What kind of help?

[To kids under 13]: **Play**
Do you like to play?

Tell me about to things you like to play.

Free-time activities

Tell me about your free-time activities.

How did you come up with this activity / these activities?

For how long have you had this activity? How often do you do it? How do you experience doing this activity?

Screen time

Some children like to use tablets, computer and cell phones. How much time of the day do you spend on the computer, on the tablet or by your phone?

What do you do at those times – do you play games, do you watch TV programs, or surf the internet?

Do you think the amount of screen time you have is an appropriate amount?
Is there some kind of an application or a digital program that helps you in something, such as learning?

Theme 3. Cognition

Learning & memory

I will now ask you about learning. How do you think you learn new things?

And how do you remember things you've already learned?
    How do think that problems with learning / memory affect your life?

Academic achievement

Do you like school? What subject or activity at school do you like? Why this one?

What about subjects that you don't like? Why not?

Is there any subject or activity at school you find difficult to learn?
    Can you tell me why you find it difficult?

Attention / concentration

Some people find it difficult to concentrate on something for a long time. What do you think, do you find it easy or difficult to concentrate?
    Is there some activity that you find is particularly hard to concentrate on?
        Can you tell me why?
Is there some activity in which you can concentrate on for a longer time period?

Theme 4. Emotional well-being

Emotions

I will now ask you about emotions. Can you tell me what kinds of emotions you feel.

Self-regulation

All people sometimes get upset, and all people at times experience sadness. Different people do different things to calm themselves down whenever they are upset. What do you do to calm yourself down when you feel upset?

What do you do when you feel sad?

Distress, anxiety, depression

Do you sometimes feel sad, or anxious and frightened?
 How often do you feel this way?
 Can you tell me why you feel this way?

Some people feel that when they are sad or anxious, they don't want to meet friends or leave home at all. How do you think feeling sad / anxious has affected your life?

To kids > 12 years: Have you ever been diagnosed with anxiety or depression? How do you think this has affected your life?

Theme 5. Social skills

Family relations

I will now ask about your relationships with other people. Can you tell me about your family. What family members do you have?

Who are your most important people?

Do you feel that in your family, everyone listens to one another?

Is there someone in your family with whom you often get into arguments?
 What about?

Relationships with friends

Can you tell me about your friends. Who is / who are your closest friends?

Is there anything about your relationship with friends that you have been worried about?

Please describe these.

Other relationships

Are there other important people in your life than family members or these friends that we already talked about? Could you tell me about them.

Theme 6. Thoughts regarding prematurity, parent-child relationship and quality of life

Your life has had a start that is different from many others. You were really tiny when you were born, and in the beginning, you spent at long time in the hospital. Have your mom or dad talked with you about the time in the NICU? What kind of things have they told about it?

How do you think it has affected you and your life that you have been born a small preemie?

Do you think the fact that you have been born a small preemie has affected the relationship between you and your mom, or you and your dad? Can you describe how?

What kinds of things in life bring you joy?

What kind of things in life do you find sad or distressing?

Is there something in your life you wish to be different? Could you tell me why?

Final

These were the questions I had for you. Is there something else about your life you would like to tell me about?

Is there something you would like to add to the themes we have discussed? Or is there something that you would like to ask me?

Turning off the video and audio recording, thanking the child.

Appendix 3. Modifications from YIPTA

Name of category in YIPTA	**Content of category in YIPTA (according to Feldman et al., 1999)**	**Name of category in our study**	**Content of category in our study**	**Example**
A: Frequency of Thoughts and Worries	Typical thoughts and worries mothers experience in the immediate post-partum period	Combined category AB: Thoughts, worries and distress	Thoughts, worries, emotions, and frightening situations parents described during the neonatal intensive care period and after discharge. Parental worries about an older child and the effects that prematurity had had on the child	“The constant fear of death. And the worry. You are living with that fear 24/7, and you sleep holding your phone, in case you get a call from the NICU, and you are afraid of that call.” M12
B: Distress Caused by Thoughts and Worries[1]	Level of distress caused by thoughts and worries in the immediate postpartum period			
C: Distress Management	Strategies for managing the distress caused by thoughts and worries	Distress Management	Strategies parents had to deal with their distress during the neonatal care period, after discharge, and later in the child’s life	“I am really grateful to the NICU staff. They were very capable in taking care of premature babies, but they also took care of us parents.” M4 “In general, I am a positive person. I will always believe in the good.” F25
D: Compulsive Checking	Frequency of the mother checking her infant. Maternal anxiety in cases when checking was prevented	Compulsive checking	Situations of frequently checking the infant during neonatal care period and after discharge. Checking and overprotective parental behaviour later in the child’s life. Parental anxiety in cases when checking was prevented	“The few times I was at home, taking a break from the NICU, felt really hard. I was pressurized to go by the hospital staff … but it didn’t do me good. I felt I should be there with the baby, all the time.” M31 “[After the discharge…] For almost two years, I felt a need to check her during the night, to see if she was breathing.” M32 “I’m still anxious. Now I worry about her starting daycare, although I realise I am overprotective.” M37

Name of category in YIPTA	**Content of category in YIPTA (according to Feldman et al., 1999)**	**Name of category in our study**	**Content of category in our study**	**Example**
E: Affiliative Behaviour	Repetitive behaviours typical of maternal caretaking and interactions with newborn infants in mammals that appear to promote the selectivity of the mother-infant bond	Affiliate Behaviour and Caretaking	Affiliative and caretaking behaviours that were possible in the NICU environment, such as changing diapers, feeding, and kangaroo care Affiliative behaviour, caretaking, and closeness with an older child.	“Thinking back, I feel it was the most important thing that I got to be with him and do some of those [caretaking] things and to hold him.” M13 “The kangaroo care was really important. It made me feel at once that [my daughter] was my child.” F24
F: Attachment Representations	Mother's emerging internal model of her child. Mental indicators of bonding that point to the uniqueness of the bond in the mother's mental life	Parental representations	Descriptions, mental images, or explanations that parents used to describe their child and his or her uniqueness or personality.	“Sometimes I call her my miracle child.” M31 “He was a little, poor thing there”. M36 “She’s a very positive, an amazingly tenacious girl.[…] And that’s what she’s always been. She’ll never give up trying.” M17
H: Frequency of Caretaking behaviour	Mothers were asked to estimate the cumulative time per day devoted to various caretaking activities	-	[not applicable retrospectively]	
-	-	Z Earlier parental experience	Parental narratives about having had a child(ren) before the index child affected the bonding experience. Content that could not be classified into the categories of the YIPTA.	“My first child, and a preemie. I didn’t know what I should do.” M30 “Growing into motherhood with [daughter, her firstborn] hasn’t been an easy task.” M27 “I didn’t experience any difficulties [in bonding with her son]. I have wondered if that might be because he was my second child.” M13

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[1] Category B in the YIPTA assessed levels of distress, which we had not explored quantitatively in our study; however, in our interviews the parents described their feelings of distress qualitatively. Thus, we combined categories A and B to one category AB.

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YLIOPISTO
UNIVERSITY
OF TURKU

Painosalama, Turku, Finland 2025

ISBN 978-952-02-0340-5 (PRINT)
ISBN 978-952-02-0341-2 (PDF)
ISSN 0082-6987 (Print)
ISSN 2343-3191 (Online)