Turun yliopisto
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PSYCHOLOGICAL WELL-BEING OF THE PARENTS AND CHILD DEVELOPMENT, BEHAVIOR, AND QUALITY OF LIFE IN VERY LOW BIRTH WEIGHT INFANTS

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TURUN YLIOPISTON JULKAISUJA – ANNALES UNIVERSITATIS TURKUENSIS
Sarja - ser. D osa - tom. 1197 | Medica - Odontologica | Turku 2015

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Cover photo: Veera Ruohomäki

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

ISBN 978-951-29-6273-0 (PRINT)
ISBN 978-951-29-6274-7 (PDF)
ISSN 0355-9483
Painosalama Oy - Turku, Finland 2015

To my family

It always seems impossible
until it's done.

– Nelson Mandela –

ABSTRACT

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Psychological well-being of the parents and child development, behavior, and quality of life in very low birth weight infants

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Annales Universitatis Turkuensis, Medica-Odontologica, Turku, Finland 2015

The parents of premature infants, especially the mothers, are at increased risk for distress. Infants born prematurely are at risk for developmental problems. The aim of this study was to investigate whether the psychological well-being of both parents is associated with child development in very low birth weight (VLBW, ≤1500g) children. The burden of prematurity-related morbidity to the children and to the family was also assessed.

A cohort of 201 VLBW infants born during 2001–2006 in the Turku University Hospital, Finland, and their parents were studied (I–IV). One study included a control group (n=166) of full-term infants (IV). The psychological well-being of the parents was evaluated by assessments of depressive symptoms, parenting stress, the sense of coherence and general family functioning. Cognitive, behavioral, and socio-emotional development, and the health-related quality of life (HRQoL) of the children were determined when the children were 2 to 8 years old.

The psychological well-being of the parents was associated with the cognitive, behavioral and social development of the VLBW children. The VLBW infants with prematurity-related morbidities had a poorer HRQoL and the general functioning of the family was inferior compared to the control children and their families. 64.5% of the VLBW children survived without morbidities. Most of the VLBW children did not have significant behavior problems (93%), had normal social skills (63%), had no emotional problems (64%), and had no problems in executive functioning (62%). Only 3% of the surviving VLBW infants had significant cognitive delay.

In conclusion, the depressive symptoms and stress of the parents can be risk factors for disadvantageous child development, while a strong sense of coherence can be protective. Parents of the premature children with developmental delays might also experience more depressive symptoms and stress than other parents. Prematurity-related morbidities were a burden to the VLBW child as well as to the family.

Key words: cognitive development, behavioral development, depression, family functioning, follow-up, health-related quality of life, morbidity, parenting stress, parents of premature infants, prematurity, preterm infant, sense of coherence, socio-emotional development, very low birth weight

TIIVISTELMÄ

Mira Huhtala

Vanhempien psyykkinen hyvinvointi ja hyvin pienipainoisena syntyneiden lasten kehitys, käyttäytyminen ja elämänlaatu
Kansanterveystieteen laitos sekä lasten ja nuorten klinikka, Turun yliopisto ja Turun yliopistollinen keskussairaala
Annales Universitatis Turkuensis, Medica-Odontologica, Turku, Suomi 2015

Keskosten vanhemmilla, varsinkin äideillä, on riski ahdistua ja masentua. Keskosten elämää voivat varjostaa kehitykselliset ongelmat. Tämän tutkimuksen tarkoituksena oli selvittää molempien vanhempien psyykkisen hyvinvoinnin yhteyttä pienipainoisena syntyneen keskoslapsen (syntymäpaino ≤1500 g) kehitykseen. Lisäksi tutkittiin keskosilla yliedustetuiksi todettujen sairauksien vaikutusta lapsen elämänlaatuun ja perheen yleiseen toimivuuteen.

Tutkimukseen otettiin 201 vuosina 2001–2006 Turun yliopistollisessa keskussairaalassa hyvin pienipainoisena syntynyttä keskosta vanhempineen (I–IV). Yhdessä tutkimuksessa (IV) oli mukana verrokkiryhmä (n=166). Vanhempien psyykkistä hyvinvointia arvioitiin heidän kokemiensa masennusoireiden, vanhemmuuden stressin ja elämänhallinnan tunteen kautta. Myös perheen yleinen toimivuus kartoitettiin. Keskosilta arvioitiin kognitiivinen kehitys, käyttäytymisvaikeudet, sosio-emotionaalinen kehitys ja terveyteen liittyvä elämänlaatu eri ikäpisteissä 2–8 vuotiaina.

Vanhempien psyykkinen hyvinvointi oli yhteydessä keskoslasten kehitykseen. Niillä keskosilla, joilla oli pitkäaikaissairauksia, oli myös huonompi terveyteen liittyvä elämänlaatu ja heidän perheissään oli huonompi toimintakyky. Suurin osa keskosista selviytyi ilman keskosuuteen liittyviä pitkäaikaissairauksia (64.5%), ilman merkittäviä käytösongelmia (93%), ilman tunne-elämän ongelmia (64%) ja ilman toiminnanohjauksen ongelmia (62%). 63%:lla oli normaalit sosiaaliset taidot ja vain 3%:lla oli merkittävä kognitiivisen kehityksen viive.

Yhteenvetona todettiin, että keskoslasten vanhempien kokemat masennusoireet ja vanhemmuuden stressi voivat olla uhka keskoslasten normaalille kehitykselle, kun taas vanhempien hyvä elämänhallinnan tunne voi olla suojaava tekijä. On myös mahdollista, että kehityksessään viiveisten lasten vanhemmat voivat kokea muita vanhempia enemmän masennusta ja stressiä. Keskoslasten pitkäaikaissairaudet ovat taakka lapselle itselleen mutta myös koko perheelle.

Avainsanat: hyvin pienipainoinen, keskonen, keskoslapsen vanhemmat, keskosuus, kognitiivinen kehitys, koherenssin tunne, käytösongelmat, masennus, perheen toimivuus, sairastavuus, seurantatutkimus, sosio-emotionaalinen kehitys, terveyteen liittyvä elämänlaatu, vanhemmuuden stressi

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ABBREVIATIONS

ADHD	Attention-deficit hyperactivity disorder
BDI	Beck depression inventory
BSID-II	Bayley scales of infant development
BW	Birth weight
CBCL	Child behavior check list
CP	Cerebral palsy
EF	Executive function
ELBW	Extremely low birth weight
FAD	Family assessment device
FSIQ	Full-scale intelligence quotient
FT	Full-term
FTF	Five to fifteen questionnaire
GF	General functioning
HRQoL	Health-related quality of life
IQ	Intelligence quotient
LBW	Low birth weight
MDI	Mental development index
NDI	Neurodevelopmental impairment
NICU	Neonatal intensive care unit
SGA	Small for gestational age
SoC	Sense of coherence
SoC-13	Sense of coherence scale
VLBW	Very low birth weight
VLGA	Very low gestational age

LIST OF ORIGINAL PUBLICATIONS

This thesis is based on the following original publications, which are referred to in the text by the Roman numerals I–IV. The original publications have been reproduced with the kind permission of the copyright holders.

I Huhtala M, Korja R, Lehtonen L, Haataja L, Lapinleimu H, Munck P, Rautava P; the PIPARI Study Group. Parental psychological well-being and cognitive development of very low birth weight infants at 2 years. *Acta Paediatr.* 2011 Dec;100(12):1555-1560.

II Huhtala M, Korja R, Lehtonen L, Haataja L, Lapinleimu H, Rautava P, on behalf of the PIPARI Study Group. Parental psychological well-being and behavioral outcome of very low birth weight infants at 3 years. *Pediatrics.* 2012 Apr;129(4):e937-44. Epub 2012 Mar 12.

III Huhtala M, Korja R, Lehtonen L, Haataja L, Lapinleimu H, Rautava P; the PIPARI Study Group. Associations between parental psychological well-being and socio-emotional development in 5-year-old preterm children. *Early Hum Dev*. 2014 Mar;90(3):119-24. Epub 2014 Jan 10.

IV Huhtala M, Korja R, Rautava L, Lehtonen L, Haataja L, Lapinleimu H, Rautava P; on behalf of the PIPARI Study Group. Health-related quality of life in very low birth weight children at nearly eight years of age. *Acta Paediatr.* 2015 In Press.

Some previously unpublished data are also included in the thesis.

1 INTRODUCTION

The delivery of a premature infant is a crisis for the parents. The parents have to cope with many issues that may rise unexpectedly, since their transition to parenthood is interrupted, and the worries about the survival and future development of the child take over (Miles et al. 2007, Davis et al. 2003). The degree of symptoms of the parent varies in relation to the time since the preterm delivery. Some parents of the preterm children continue expressing depressive symptoms, anxiety, parenting stress and poor family functioning even years after the preterm delivery (Treyvaud et al. 2014). On the other hand, some parents seem to cope rather well later as the former preterm infant reaches school-age, adolescence and finally adulthood (Saigal et al. 2010, Singer et al. 2007, Singer et al. 1999).

Despite improvements in survival rates, premature children still have a substantial risk for persisting effects on different organ systems, neurocognitive and behavioral problems, and functional disabilities (Stahlmann et al. 2009, Anderson and Doyle 2003, Bhutta et al. 2002, Ong et al. 2001). The risks are higher for low birth weight (Saigal and Doyle 2008, Tommiska et al. 2007) and very preterm infants (Potharst et al. 2011). The underlying cognitive or neuropsychological deficiencies may worsen the academic performance and functional outcomes of premature infants when they come of school age and mild and moderate disabilities become evident (Aylward 2005). Both preterm birth and the chronic disability of a child are associated with increased psychological distress for the parents, particularly for mothers (Cacciani et al. 2013).

The psychological well-being of the parents, parenting styles and home environment are important modulators of the neuropsychological and cognitive development of preterm children (Treyvaud et al. 2009, Ong et al. 2001). Studies on parental resilience in preterm populations have thus far mainly focused on the mothers. However, also the fathers have an important role in the development of their vulnerable children (Yogman et al. 1995). More information on the relationship between the psychological well-being of both parents and the development of their preterm child is needed.

Since all chronic morbidities and developmental impairments cannot be avoided, only recognizing them may not be sufficient if one wants to understand the significance of these impairments for the children and their families. Subjective information on the burden of the disabilities and diseases on the everyday life of premature children can be obtained by assessing their health-related quality of life.

The focus of this study was on evaluating the psychological well-being of both of the parents of the very low birth weight infants and to study the association between the psychological well-being of the parents and some aspects of child development. In addition, the burden of premature-related morbidity on the children themselves and on the family was assessed.

2 REVIEW OF THE LITERATURE

2.1 Preterm birth

Preterm infants are born before 37 completed weeks of gestation, according to the World Health Organization (WHO). The WHO classifies infants born before gestational week 32 as very preterm or as of very low gestational age (VLGA) infants. The infants born before gestational week 28 are called extremely preterm or extremely low gestational age infants. Other classifications can be made by birth weight. Low birth weight (LBW) infants are born with a birth weight of less than 2500 grams (g). Newborn infants who weigh less than 1500 g are defined as being born with very low birth weight (VLBW), and those who weigh less than 1000 g with extremely low birth weight (ELBW). Infants who weigh less than 2 SD below the mean birth weight for each gestational week, are called small for gestational age (SGA) infants.

The major risk factors for LBW and VLBW include preterm delivery, multiple pregnancies, maternal smoking, inadequate maternal nutrition, maternal age extremes and short inter-pregnancy interval. Worldwide, the average rate of preterm birth is 11.1% (Blencowe et al. 2012). From 2001 to 2006, there were 341634 live births in Finland of which 22076 (6.5%) in the Turku University Hospital (National Institute for Health and Welfare 2007). The preterm live births in Finland and in the Turku University Hospital during 2001–2006 are presented in Figure 1. In 2013, there were 58525 live births in Finland. Of these infants, 5.7% (n=3355) were born prematurely and 0.7% (n=425) had a birth weight of ≤1500 g (National Institute for Health and Welfare 2014). For comparison, in 2013, 11.4% of the live births in the United States were preterm and 1.4% infants were born with VLBW (March of Dimes: PeriStats web site, retrieved on September 2nd, 2015).

Premature infants are at increased risk for early complications related to prematurity: intraventricular hemorrhage, respiratory distress syndrome, necrotizing enterocolitis, sepsis, and retinopathy of prematurity (Baron et al. 2011). In addition to higher mortality and prolonged hospitalization, early complications of prematurity are often precursors of later morbidity (Roze et al. 2009, Dahl et al. 2006, Foulder-Hughes and Cooke 2003, Powls et al. 1997).

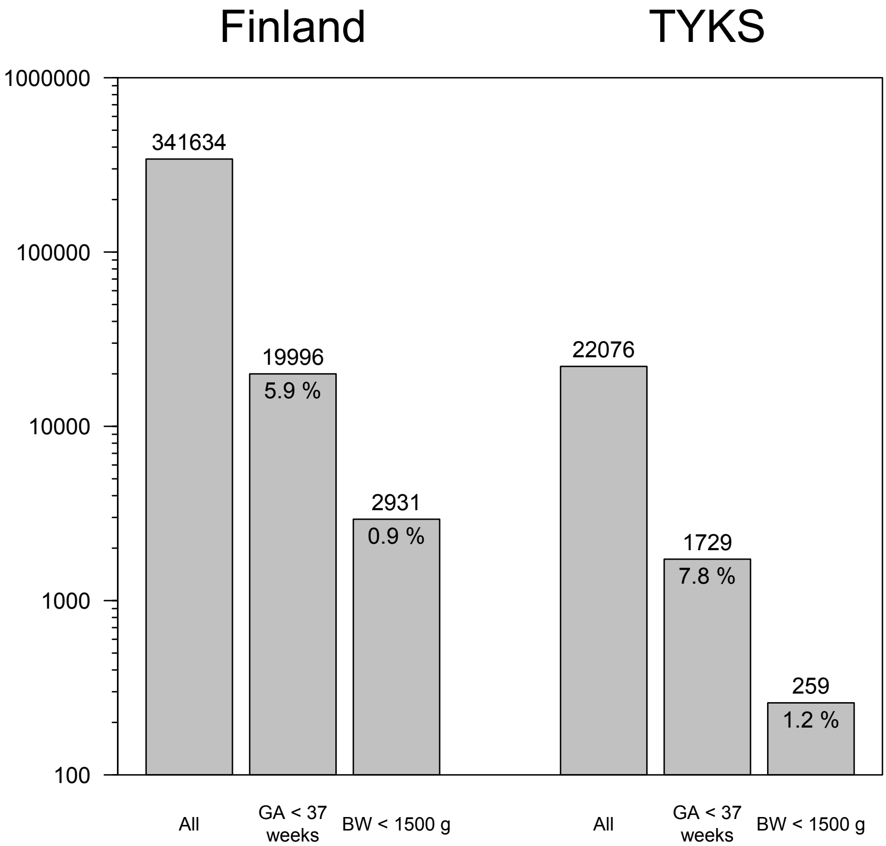

Figure 1 Live births in Finland and in the Turku University Hospital (TYKS) between 2001 and 2006. GA:Gestational age; BW: Birth weight.

2.2 Impact of preterm birth on the parents

2.2.1 Acute psychological responses of the parents

The birth of a child is the most momentous event for the parents-to-be. It has straight effects on the emotions and attention of the parents, and alters or modifies almost all the aspects of their life: emotions, eating, sleeping, working, and the roles of being a woman or a man, a wife or a husband. The transition to parenthood requires substantial reorganization of the family system (Spielman and Taubman 2009). The process of becoming a parent is interrupted when the infant is born prematurely (Miles et al. 1992). Most parents are not prepared for a premature birth and they lack the psychological and emotional readiness (Jackson et al. 2003). The interrupted pregnancy and neonatal intensive care are very stressful situations for the parents and pose threats to parental psychological well-being (Dudek-Shriber 2004, Miles et al. 1992). The presence of uncertainty about the child's survival, future health and development will introduce additional stress on the family (Miles et al. 2007, Davis et al. 2003). Mothers have to recover from the high-risk pregnancy and the interrupted antenatal bonding to the infant. Parents have to adjust to role changes and to the uncertainty of the child's survival and developmental prognosis (Miles et al. 1992). The physical contact between parent and child may be reduced because of the medical condition of the infant. The hospital stay of the preterm infant will be prolonged and it will always separate the parents from the infant to some extent. Prematurity, VLBW and disability of the child have a negative impact on the psychosocial well-being of the parents (Cacciani et al. 2013, Cronin et al. 1995).

Mothers and fathers interact differently with their infant in the neonatal intensive care unit (NICU) (Johnson 2008) and the stress experienced by the mothers and the fathers may manifest itself differently in the NICU (Sloan et al. 2008). While both of the parents report high levels of stress, the mothers express more anxiety than the fathers (Shields-Poë 1997). In the NICU, the mothers want to have responsibility and take control over the care of their infant, while the fathers have more confidence in the nurses and physicians as they are rebalancing their family responsibilities and their obligation to provide financially for their family (Jackson et al. 2003). Still, the fathers may feel marginalized by the NICU staff, although they want to be more informed of the care of their infant and involved in the care and decisions in the NICU. Fathers also want to share their experiences with someone who can understand them (Lindberg et al. 2007, Jackson et al. 2003). In the NICU, the fathers often feel responsibility for the mother and the baby, and they tend to worry about the injured infant. The fathers may be more concerned for the mother than for their infant during the NICU stay (Lindberg et al. 2007). It may be difficult for the fathers to balance between the work and the hospital (Pohlman 2005). The fathers of the VLBW infants visit less and shorter times the NICU than the mothers, suggesting that the mothers may be more engaged in the caregiving to their infants compared to the fathers (Garten et al. 2011). Later, after hospitalization and during the toddler-years of the prematurely-born child, the father-child interaction will involve more stimulation and playing than other forms of caretaking compared to the mothers (Yogman et al.1995, Levy-Shiff and Mogilner 1989).

Maternal depression may interfere with the mother-infant relationship (Korja et al. 2008) which weakens the support the child needs for early emotional development. The development of a preterm child can be influenced by improving the quality of the mother-preterm infant relationship already in the NICU (Forcada-Guex et al. 2006). A Finnish study has reported that the infants whose mothers visited the NICU daily had less behavioral and emotional problems when the child was school-aged (Latva et al. 2004). A planful coping style, problem solving and positive reappraisal (i.e., finding positive meaning in the situation) of the mothers has been found to be associated with a better development of the infant by age 1 year, as well as with an improved mother-infant relationship (Veddovi et al. 2004). Positive parenting (i.e., positive affect and sensitivity) plays also an important role in the early development of very preterm infants who are exposed to biological and environmental risks (Treyvaud et al. 2009). If the birth experience is traumatic to the parents, this may affect the behavioral outcomes of the preterm child irrespective of the biological risk factors (Pierrehumbert et al. 2003). Similarly, a good caregiving environment may compensate for the deleterious effects of early medical complications of preterm birth on child development (Veddovi et al. 2004, Levy-Shiff et al. 1994).

2.2.2 Long term psychological well-being of the parents

2.2.2.1 Depression

Postpartum depression is a significant public health problem for both mothers and fathers (Paulson et al. 2006). The prevalence of postpartum depression in general and community populations has been reported to vary from 6.5% to 13% within the first year after the childbirth for mothers (Gavin et al. 2005, O'Hara and Swain 1996) and around 10% for fathers (Paulson and Bazemore 2010). In Finland, these rates of postpartum depression are around 13% for the mothers (Tammentie et al. 2004) and around 5% for the fathers of healthy infants (Luoma et al. 2013). The rates of depression of parents of preterm infants may be higher than the rates of parents of healthy or full-term infants (Vigod et al. 2010). However, the rates of depression among Finnish mothers of preterm infants seem to be lower than the corresponding rates in other countries (Garfield et al. 2015, Veddovi et al. 2004, Davis et al. 2003).

The amount of depressive symptoms varies according to the time that has passed after the preterm delivery. From 63% to 65% of the mothers (Pinelli et al. 2008, Miles et al. 2007) and 45% of the fathers have depressive symptoms during the time their infant is hospitalized in the NICU (Pinelli et al. 2008). After discharge, the prevalence of depressive symptoms of the parents tends to decrease (Vigod et al. 2010, Pinelli et al. 2008, Mew et al. 2003). One month after very preterm delivery approximately 40% of mothers have depressive symptoms (Garfield et al. 2015, Davis et al. 2003) and one year after the discharge, approximately 20% of the parents still experience depressive symptoms (Veddovi et al. 2004). A Finnish study reported rates of around 13% for maternal depressive symptoms at 6 months of the preterm infants' corrected age (Korja et al. 2008). Later, the mothers of young adults born with ELBW have not reported more depressive symptoms than the mothers of control persons, even in the presence of neurosensory impairment of the offspring (Saigal et al. 2010). In summary, although depressive symptoms of the mothers tend to decrease over time after preterm delivery, some mothers remain depressed (Poehlmann et al. 2009, Miles et al. 2007).

The mothers and the fathers may experience different amount of depressive symptoms after a preterm delivery. While their infant is in the NICU, both the mothers and the fathers experience more depressive symptoms than the parents of term infants, and the mothers may be more depressed than the fathers (Shaw et al. 2014, Rimmerman and Sheran 2001). However, after discharge, the level of depression becomes similar for both parents (Pinelli et al. 2008). The covariation of maternal and paternal postnatal depression has been demonstrated in population-based samples (Luoma et al. 2013, Paulson and Bazemore 2010).

Current research suggests that the strongest predictors of maternal postpartum depression are a previous history of depression and depression or anxiety during the pregnancy (Robertson et al. 2004). A recent stressful life event and experience of a low level of social support also expose mothers to postpartum depression. Other potential risk factors for postpartum depression include certain maternal personality characteristics, infant temperament, marital problems, single marital status, low socioeconomic status, parental role alteration, worry about the child's health, the child's re-hospitalization and pregnancy- or delivery-related complications, including premature delivery (Miles et al. 2007, Robertson et al. 2004, Beck 2001, O'Hara and Swain 1996).

Premature delivery seems to be an independent maternal risk factor for postpartum depression. The risk for postpartum depression is higher among mothers of preterm infants compared to mothers of full-term infants, even after controlling for depression during pregnancy and for a range of social variables (Drewett et al. 2004). The risk factors for maternal postpartum depression at the time of discharge of the preterm infant are experienced role alteration and prolonged ventilation support of the baby. The latter risk factor is related to a more serious medical condition of the neonate and requires prolonged separation of the mother from the baby (Rogers et al. 2013). Contrariwise, a Finnish study showed that maternal postnatal depression was not associated with the medical condition of the preterm child nor with some family characteristics (parents' age, education, or family structure) (Korja et al. 2008). A lack of an association between maternal depressive symptoms and the medical condition of the preterm child has also been reported elsewhere (Miles et al. 2007).

2.2.2.2 Parenting stress, distress, and anxiety

Apart from acute distress, premature birth itself causes chronic distress for the parents (Lou et al. 2009, Kaaresen et al. 2008, Indredavik et al. 2005, Ong et al. 2001, Singer et al. 1999). Previous research has found that mothers of VLBW and very prematurely born children have higher levels and a longer duration of parenting stress and anxiety compared to mothers of full-term children (Landsem et al. 2014, Treyvaud et al. 2014, Grunau et al. 2009, Singer et al. 1999). A high level of parenting stress is associated with low birth weight, low gestational age (Schappin et al. 2013), and with medical risks and complications (Halpern et al. 2001) of the premature child. The stress of the mothers is particularly caused by child-related factors, e.g., low intelligence quotient (IQ) and behavioral problems (Baker et al. 2003, Ong et al. 2001). On the other hand, a high level of maternal education may be a protective against psychological distress and parenting stress (Cacciani et al. 2013, Singer et al. 2007).

After hospital discharge, the daily care of a preterm infant is more time consuming and demanding (Cherian et al. 2014), and sometimes special requirements for feeding

(Meerlo-Habing et al. 2009), nourishment (Nzegwu and Ehrenkranz 2014), and medication (Damgaard et al. 2015) need to be fulfilled. Parents have long-standing concerns about the well-being and development of the child which puts additional demands on the parents (Pyhälä et al. 2011, Korja et al. 2008, Chapieski and Evankovich 1997, Miles and Holditch-Davis 1995). Health problems, behavioral impairment and poor cognitive development of the child may further contribute to the chronic stress of the parents (Witt et al. 2012, Singer et al. 2007, Halpern et al. 2001, Singer et al. 1999, Cronin et al. 1995).

The risk for distress is high particularly for mothers of high-risk VLBW infants (Halpern et al. 2001, Singer et al. 1999). Three years after preterm delivery, the mothers of low-risk, as well as high-risk VLBW infants do not differ from the mothers of full-term infants in terms of psychological distress symptoms (Singer et al. 1999). This suggests that these mothers may have found coping strategies to manage the stressors and uncertainty of the neonatal period (Singer et al. 1999). The results were similar when the VLBW children were 8 years old (Singer et al. 2007). In a recent study, parents of very preterm children reported more parenting stress, both parent- and child-related, compared with control parents, even after adjustment for child neurodevelopmental disability and social risks 7 years after birth (Treyvaud et al. 2014). The fathers of preterm infants experience greater stress than the fathers of term infants (Rimmerman and Sheran 2001). During the acute neonatal period, the level of stress and anxiety of the fathers is lower (Rowe and Jones 2010, Franck et al. 2005) or similar (Franck et al. 2005, Miles et al. 1992) to the mothers. Still two years after hospital discharge, the parenting stress of the fathers is lower than of the mothers of premature infants and remains lower until the child is 7 years old (Landsem et al. 2014). However, another study showed that the paternal stress 2 years after the birth of an ELBW infant was significantly lower than the maternal stress (Tommiska et al. 2002). Maternal stress is reduced and buffered by an unstressed father of a preterm child (Feldman 2007) and the father's involvement in household and childcare responsibilities (Simpson et al. 2003).

2.3 Family adjustment after preterm birth

The current literature focuses on family burden and distress of the parents associated with the preterm birth while the positive experiences are rarely reported. In the NICU, the coping mechanisms of the parents include holding and touching the baby, giving basic care, learning the behavioral and physical cues of the baby, participating in decision making, and communicating with staff, partner or other parents (Arockiasamy et al. 2008, Johnson 2008). Many of these factors can be modified or moderated by the NICU staff.

Later, parenting a child with disabilities may provide parents with opportunities to deal successfully with challenges. Parents of children with intellectual disabilities have found parenting both rewarding and empowering (Willingham-Storr 2014). Studies on extremely prematurely born children have found that parents feel that their child has brought the family together despite the negative effect on the emotional health of the parents (Saigal et al. 2010, Saigal et al. 2000). Another study found that the child contributes positively to the family life, to the love and joy of childrearing, despite any physical or developmental impairments the child may have (Lou et al. 2009). Also, the parents of adults born VLBW describe their parenting as more supportive than those of controls (Pyhälä et al. 2011). Adolescents and adults born VLBW have described their parents to be more protective and authoritarian than control parents (Pyhälä et al. 2011, Indredavik et al. 2005). Sometimes, again, the parents have been described as overprotective, controlling and intrusive (Feldman 2007, Wightman et al. 2007). Among the underlying factors leading to intrusive parenting might be the unclear emotional expressions and limited social interactions of preterm infants (Feldman 2007).

Sufficient support and care from the parents, as well as positive, warm and sensitive parenting may be protective factors for the child's behavioral, emotional and cognitive development (Verkerk et al. 2012, Treyvaud et al. 2009). The quality of the early mother-infant relationship may exacerbate or soften the potentially adverse impact of preterm birth and be important for the later neurocognitive development of the preterm child (Rahkonen et al. 2014, Forcada-Guex et al. 2006). A warm and sensitive mother-infant relationship is associated with improved behavioral development of the preterm infant (Forcada-Guex et al. 2006). In summary, balancing between protecting the child by recognizing the child's vulnerabilities, but also by facilitating a normal social and physical life of the preterm child, may be key concepts to the well-being of the parents and the child (Eiser et al. 2005).

2.3.1 Sense of coherence

People have an individual capacity to respond and adapt to stressful situations. One tries to find meaning in threatening situations and to understand how the threat fits in with the perception of the order and purpose of the world (Thompson and Janigian 1988). An Israeli American sociologist, Aaron Antonovsky, has developed the theory and concept of *sense of coherence* (SoC) (Antonovsky 1983) which is a key concept of salutogenesis (Antonovsky 1987). According to this theory, people have individual psychological resources (general resistance resources) that contribute to the development of a strong SoC and help people to cope with adverse events. The SoC can be seen as an ability to deal with stress and as a resource of an active approach to one's own life. The core concepts of SoC are 1) the ability to understand what happens around oneself (comprehensibility), 2) the ability to find meaning in the situation (meaningfulness), and 3) the ability to manage the situation by oneself or through one's social network (manageability) (Antonovsky 1987). The SoC is more like a dispositional orientation rather than as a coping strategy, and it is more stable than depression. Still, it is possible that particularly negative life events may challenge and alter the SoC of a person. (Antonovsky 1993)

The SoC of a person can be strong or weak. Compared with people with a weak SoC, people with a strong SoC are more apt at finding major life events as less dangerous or as non-stressors, and to find purpose and meaning in negative experiences. People with a weak SoC tend to experience major life events as threats (Antonovsky 1987). A weak SoC is associated with depressive symptoms in parents raising a child with intellectual disability (Olsson and Hwang 2002) and in parents of children with chronic health condition (Grøholt et al. 2003).

2.3.2 Family functioning

Each and every family has its unique way to adjust to stressful events. If the family adjustment is good, the family is capable of making changes in the family system in order to maintain balance and function after a stressful event. Family functioning may relate rather to transactional and systemic properties of the family system than to individual psychiatric characteristics of family members (Epstein et al. 1983). Family functioning in the families with a child needing neonatal intensive care, including premature infants, is affected negatively during the first months after the child's birth (Pinelli et al. 2008). After that, family functioning seems to remain stable at least for the first year following the birth of an infant who required NICU-treatment (Pinelli et al. 2008). By two years after hospital discharge, family functioning tends to improve among the mothers and to deteriorate among the fathers, especially if the child has persisting health problems (Doucette and Pinelli 2004). The mothers of VLBW infants have reported better family functioning and less symptoms of depression if they had received high levels of support from their spouses after the hospital discharge (O'Brien et al. 1999). Family functioning is compromised in families where the medical health of the preterm child is still poor when the child is 5 years old (Taylor et al. 2001). However, the mothers of the high-risk VLBW children may adapt positively over time and by the time the child reaches school-age (Singer et al. 2007). According to a recent study, families with a very prematurely born child reported poorer family functioning compared to the families with a full-term child still 7 years after the birth (Treyvaud et al. 2014). However, 20 years after the birth of an ELBW infant, the mothers usually find the family function as being as good as in the full-term control families. Interestingly, family functioning became even better if the ELBW infant had had neurosensory impairment. This suggests that the compromised development of the child may, in fact, enhance the coping of the family and bring the family closer together (Saigal et al. 2010).

2.4 Impact of preterm birth on the child

2.4.1 Neurodevelopmental and psychological development of preterm children

It is a well-established fact that preterm infants have an increased risk for neurocognitive and behavioral problems later in life (Anderson and Doyle 2003, Foulder-Hughes and Cooke 2003, Bhutta et al. 2002), even in the absence of severe complications of prematurity (Smith et al. 2006). Some 10% to 20% of very preterm infant survivors have moderate or severe problems in their cognitive, neurosensory or neuromotor functioning at different ages (Brévaut-Malaty et al. 2010, Spinillo et al. 2009, Woodward et al. 2009, Hille et al. 2007). Preterm birth remains a risk factor for impaired neurocognitive performance into adulthood (Heinonen et al. 2015, Pyhälä et al. 2011). Young adults born prematurely have a lower IQ, poorer executive functions (Pyhälä et al. 2011) and, in late adulthood, poorer episodic memory compared to peers born at term (Heinonen et al. 2015).

Neurodevelopmental comorbidity is also common (Cacciani et al. 2013, Woodward et al. 2009) and is even more prevalent in very preterm (Potharst et al. 2011) and extremely preterm infants (Brévaut-Malaty et al. 2010, Woodward et al. 2009). Of the very preterm children, 75% have at least one disability and 50% more than one disability, compared with 27% and 8%, respectively, of term control children (Potharst et al. 2011). During the last decades, the rates of delayed cognitive development have not changed for children born prematurely (Wilson-Costello et al. 2007) and they continue to have more deficits in their academic skills, attention, behavior and executive functions (Dahl et al. 2006, Aarnoudse-Moens et al. 2009a). In addition, even a larger proportion of less severe disabilities may be hard to detect or they may become evident later (Potharst et al. 2011, Foulder-Hughes and Cooke 2003, Elgen et al. 2002) even in children without obvious neurologic deficits (Sommerfelt et al. 1993). However, the rates of cerebral palsy (CP) have decreased since 1990 from 7.3% to 5.1% in VLBW infants (Platt et al. 2007)

Some previous studies have found that the increased risk for developmental problems in preterm children is associated with prematurity-related medical and biological risk factors. Previous studies also suggest that the biological effects of prematurity on psychoneurologic development gradually decrease, while the role of the social environment grows (Ong et al. 2001, Miceli et al. 2000, McCormick et al. 1996). It is likely that the neurologic and motor development of children born premature is mostly influenced by the biologic risk of the child, while the social risks contribute to cognitive and behavioral outcomes (Potharst et al. 2011).

As many of the biological risk factors of the preterm infants cannot be reduced, focus has turned to the environmental risk factors affecting neurodevelopment. There are several social and environmental factors which mediate developmental outcomes, e.g., parent-child interaction (Rahkonen et al. 2014, Forcada-Guex et al. 2006), parenting behaviors (Treyvaud et al. 2009, Koldewijn et al. 2010, Koldewijn et al. 2009, Newnham et al. 2009), child temperament (Sajaniemi, Salokorpi & von Wendt 1998), socioeconomic status of the family (Potharst et al. 2011, Mikkola et al. 2005), and parenting stress and depression (Kaaresen et al. 2008, Melnyk et al. 2006). Responsiveness and sensitive parenting enhance and protect the cognitive development of the preterm child (Nordhov et al. 2010, Treyvaud et al. 2009, Landry et al. 2008, Smith et al. 2006). This association is particularly strong for VLBW children who do not have severe neonatal complications (Smith et al. 2006).

2.4.1.1 Cognitive development

Children born premature have a high occurrence of cognitive impairment. In one study, 28% of 5-year-old preterm children had mean intelligence quotient of <-1 SD, and 12% of <- 2 SD (Potharst et al. 2011). In other studies the rates of severe cognitive delays have ranged from 9% to 16 % (Luu et al. 2009, Larroque et al. 2008, Mikkola et al. 2005). The mean IQ for VLBW children without major handicaps are generally from 8 to 11 points lower than for full-term control children (Grunau et al. 2009, Bhutta et al. 2002). In a Finnish population of VLBW children, the mean intelligence level corresponded to the normative mean but was around 9 points lower at age 2 years and around 12 points lower at age 5 years compared to the group mean of a low-risk control group (Munck et al. 2012a). Of the biological risk factors, low gestational age (Foulder-Hughes and Cooke 2003, Bhutta et al. 2002), low birth weight (Mikkola et al. 2005, Foulder-Hughes and Cooke 2003, Hack and Fanaroff 2000), and male gender (Hintz et al. 2006, Mikkola et al. 2005) are associated with impaired cognitive development. Also, perinatal medical complications are associated with suboptimal cognitive development (Levy-Shiff et al. 1994); here, severe neonatal brain injury is as the strongest predictor (Luu et al. 2009, Mikkola et al. 2005).

Preterm birth puts normal brain development at risk. Previous studies have shown associations between cerebral white-matter abnormalities and adverse neurodevelopmental outcomes in 2-year-olds who were born very preterm (Woodward et al. 2006). The presence of CP is predictive of later delayed cognitive development (Pleacher et al. 2004). The cognitive outcome of VLBW and very preterm children may be delayed despite normal brain sonography (Luu et al. 2009) and magnetic resonance imaging findings (Setänen et al. 2013, Woodward et al. 2006), suggesting that there are other modulating factors, in addition to neonatal brain injury, associated with neurodevelopmental sequelae of prematurely born children.

Executive function (EF) is a concept covering a set of higher-order neurocognitive functions important for goal-directed behavior and planning, conceptual reasoning and strategy use, spatial conceptualization, working memory, cognitive flexibility and inhibitory control, and it important for the integration and organization of information. EF develops throughout childhood and adolescence, and plays an important role in the cognitive and social development of the child and for school performance. A total of 7.8% of 5-year-old VLBW children had considerable difficulties in their executive functions and significantly higher scores related to problems in EF compared to control children (Rautava et al. 2010). Deficits in EF are associated with behavioral problems and learning difficulties (Mazzocco and Kover 2007) and with deficits in attention (Aylward 2005), social competence, and adaptive behavior skills (Luu et al. 2011). A growing body of literature shows that there are EF deficits among children born prematurely (Aylward 2005), even after controlling for cognitive development (Ni et al. 2011, Aarnoudse-Moens et al. 2009b, Böhm et al. 2004).

2.4.1.2 Behavioral and emotional development

A number of studies have shown that VLBW or very preterm infants are at increased risk for later behavioral and emotional problems (Arpi and Ferrari 2013, Bhutta et al. 2002, Ong et al. 2001). The behavioral problems can be divided into internalizing and externalizing problems. The internalizing behavioral problems include anxiety and depressed mood, emotional reactivity, somatic complaints without medical causes, and withdrawal from social contacts. The internalized behavior problems may not be easily identified in young children, and they tend to increase across the childhood years (Gilliom and Shaw 2004). A higher occurrence, compared to full-term peers, of behavioral problems, particularly internalizing problems, may be observed in very preterm infants as early as at age 2 years (Spittle et al. 2009). Externalizing problems of early childhood typically take the form of obvious disruptive behaviors, e.g., aggressive behavior, defiance, attention problems, and hyperactivity. One must, however, keep in mind that, for most preschoolers, mild externalizing problems represent normal developmental struggles with self-regulation which diminishes after early childhood (Gilliom and Shaw 2004, Campbell et al. 2000).

Very preterm children have more difficulties with internalizing behavior and dysregulation at age 2 compared to their peers born at term (Spittle et al. 2009). At age 3, these children have more difficulties on every behavioral scale: a prevalence of problems of 20% versus 9% in the comparison children has been reported (Delobel-Ayoub et al. 2006). At age 5, the prevalence of hyperactivity, inattention, emotional symptoms, and peer problems of very preterm children is reportedly two-fold higher compared to controls (Delobel-Ayoub et al. 2009). In another study on 5-year-old very preterm children the prevalence of behavior difficulties was 39% versus 8% in the comparison group (Potharst et al. 2011). A higher occurrence of behavior problems has also been reported among 5-year-old children born with VLBW compared to full-term controls, particularly problems of internalizing and externalizing, obsessive-compulsive behavior and poor social skills (Rautava et al. 2010). From age 7 to 16 years, the parents of ELBW (Hille et al. 2001) and VLBW children (Conrad et al. 2010) report more behavioral problems compared to controls. Parents to adolescents aged 13 to 18 years report that their offspring with VLBW express more externalizing and internalizing behavior problems and less competence than parents to adolescents born full-term (Dahl et al. 2006). Paradoxically, the VLBW adolescents themselves self-report less behavioral problems than their peers born full-term (Dahl et al. 2006).

The behavioral problems have shown moderate stability over time in preterm populations regardless of birth weight (Bohnert and Breslau 2008, Baker et al. 2003). A total of 46% of the very preterm children with a high score for behavioral problems at age 3 years continue to have a high score at least until age 5 years (Delobel-Ayoub et al. 2009). The prevalence of behavior problems persists in about 20% in LBW children from age 3 to 8 years (Gray et al. 2004). Low birth weight, being born with SGA, delayed motor performance and neurologic abnormalities are risk factors for behavioral problems (Conrad et al. 2010, Janssen et al. 2008). Interestingly, though, studies have failed to report excessive behavioral problems in the most preterm children (Delobel-Ayoub et al. 2009, Gray et al. 2004). The risk for persistent behavioral problems is higher in the preterm children with major neonatal cerebral abnormalities and lower cognitive development than controls (Potharst et al. 2011, Delobel-Ayoub et al. 2009, Clark et al. 2008). One study, however, found that a lower intelligence quotient was not associated with behavioral problems in 11-year-old children born with a low birth weight (Elgen et al. 2002). The following environmental risk factors relate to the amount of behavioral problems of preterm children: early mother-infant relationship (Forcada-Guex et al. 2006), parenting behaviors (Treyvaud et al. 2009), maternal psychological well-being (Delobel-Ayoub et al. 2009, Gray et al. 2004) and disadvantaged social conditions (Spittle et al. 2009, Delobel-Ayoub et al. 2009, Stoelhorst et al. 2003).

Johnson and Marlow (Johnson and Marlow 2011) have characterized a “preterm behavioral phenotype” with an increased risk for symptoms and disorders associated with inattention, anxiety and social difficulties. Prematurity and low birth weight are risk factors for specific psychiatric disorders, e.g., anxiety and depression (Räikkönen et al. 2008, Indredavik et al. 2004), childhood autism (Lampi et al. 2012) and attention-deficit hyperactivity disorder (ADHD) (Bhutta et al. 2002, Hayes and Sharif 2009). ADHD is the most studied and prevalent psychiatric disorder in preterm populations and carries a prevalence of 16% to 47% in childhood and adolescence (Aylward 2005). Low birth weight (Taylor et al. 2000), but not SGA (Indredavik et al. 2004), is associated with a higher prevalence of ADHD. Boys seem to have a higher prevalence of ADHD than girls according to some (Elgen et al. 2002) but not all (Botting et al. 1997) studies. Very preterm or VLBW children with ADHD are less likely to have comorbid conduct disorders than their full-term peers (Elgen et al. 2002, Botting et al. 1997).

The social and attentional skills of children develop as they grow older. At preschool-age, children start to have a range of gestural, affective and verbal behaviors that direct the attention of other persons. Preterm children may have impairments in these skills (Assel et al. 2002, Breslau and Chilcoat 2000) and such impairments may be associated with behavioral problems (Elgen et al. 2002, Baker et al. 2007). A total of 4.3% of 5-year-old VLBW children have reportedly considerable difficulties in social skills and significantly higher scores for problems in social skills compared to control children (Rautava et al. 2010). Poorer social skills associate with a poorer cognitive development of premature children by 5 years of age (Hoff et al. 2004) and by school-age (Ross G et al. 1990). Poor social skills are also associated with the SGA status of the child (Schothorst and van Engeland 1996). The risk for attention problems is increased particularly among VLBW children and the prevalence of attention problems and of problems in externalizing and internalizing behavior is rather stable through the years of school attendance (Bohnert and Breslau 2008).

2.4.1.3 Quality of life in preterm populations

The quality of life of a premature child can is more important to the child and the family than the child’s level of disability (Dinesen and Greisen 2001). Subjective information on the burden caused by disabilities and diseases can be obtained by assessment of the health-related quality of life (HRQoL). Preterm birth comes with co-morbidities and problems in everyday life and these are associated with HRQoL, albeit in a complex fashion (Stahlmann et al. 2009, Dinesen and Greisen 2001). The HRQoL combines the health status (including physical, mental and psychological well-being) with the degree to which an individual experiences positive or negative emotions in matters of health (Theunissen et al. 2001, Theunissen et al. 1998). For self-perceived health, some studies have reported that infants born VLBW do not significantly differ from their peers (Gäddlin et al. 2009, Hack et al. 2007). These results may partly be explained by exclusion of the most disabled individuals (Wolke et al. 2013). Still, even more optimistic findings exist: Adults born preterm have reported better general health perception compared with adults born term, despite impaired physical health and neurocognitive and behavioral development (Dalziel et al. 2007). Therefore, recognizing chronic morbidities and developmental impairments of preterm children may not be sufficient if one wants to understand the significance of these impairments for the children themselvesduring their childhood, adolescence, and adulthood. Increasingly, the HRQoL of children born preterm has been taken into account when planning and evaluating the impact of intervention studies.

The HRQoL of children born very prematurely has been lower compared with full-term peers, as recorded by their parents when the children are pre-school aged (Theunissen et al. 2001), at adolescence (Verrips et al. 2012, Verrips et al. 2008, Rickards et al. 2001), and at adult age (Baumgardt et al. 2012, Gäddlin et al. 2009, Cooke 2004, Dinesen and Greisen 2001). These results are, however, not consistent, and infants born VLBW have subsequently as adults self-reported that their health profiles are similar to the ones of the control group (Hack et al. 2007). According to WHO's definition (WHO 1995), the quality of life is subjective and thus should be self-reported.

The majority of studies have examined the HRQoL of preterm children born in the 1970's or 1980's as reported by the parents. Neonatal intensive care practices have been changed since those years as the nutritional support and the control of infections have improved and the care of the premature infants has become less invasive and more family-centered. There are some controlled studies on HRQoL in VLBW children born in the 2000's but there is a need to update the information. Compared to parents of full-term peers, parents of VLBW children report lower HRQoL in their children at age 3 to 4 years (Chien et al. 2006) and at age 5 years (Rautava et al. 2009). A study of Berbis et al. (Berbis et al. 2012) found that the HRQoL of prematurely born children at age 6 to 10 years was lower than that of the reference population. Also, a low HRQoL of the preterm children was related to the presence of neurocognitive disorders, e.g., CP, blindness, deafness, cognitive impairment and epilepsy (Berbis et al. 2012).

2.4.2 Prematurity-related morbidities

Preterm birth is a significant health problem and carries a risk for persisting adverse effects on many organ systems (Stahlmann et al. 2009). VLBW children have a significantly higher incidence of physical handicap than control children born with a normal weight (Ong et al. 2001). Children with VLBW and VLGA are at risk for later prematurity-related morbidities, e.g., CP (Platt et al. 2007, Vohr 2007), visual impairment (Bodeau-Livinec et al. 2007, Schalij-Delfos et al. 2000), hearing impairment (Cristobal and Oghalai 2008, Ari-Even Roth et al. 2006), epilepsy (Pisani et al. 2004), obstructive airway disease (Gough et al. 2014, Vrijlandt et al. 2005), ADHD (Sucksdorff et al. 2015, Bhutta et al. 2002), cognitive impairment (Woodward et al. 2009), and growth failure (Hack et al. 2003). The prevalence of severe impairments of hearing and vision has remained rather low in preterm populations, while less severe problems have been more common (Marlow 2004). Neurosensory impairments are present in around 10% of adolescents born prematurely, even in the absence of severe brain injury, as assessed by cranial sonography during the neonatal period (Luu et al. 2009). The chronic morbidities of preterm children are associated with low gestational age (Korvenranta et al. 2009, Bodeau-Livinec et al. 2007), low birth weight (Platt et al. 2007), early complications (perinatal brain damage) (Roze et al. 2009) and neonatal intensive care (Silverman 2004, Bancalari et al. 2003). No less than 66.2% of VLBW infants in Finland survive the first three years of their life without major medical diagnoses (Korvenranta et al. 2009) and 68% of very preterm infants survive up to age 10 years without neurodevelopmental disorders (Brévaut-Malaty et al. 2010).

2.5 Associations between the psychological well-being of the parents and child development

Population-based studies have shown that maternal anxiety and depression postnatally affects the early mother-child relationship negatively (Nicol-Harper et al. 2007) which, in turn, may affect the outcomes of the child (Glasheen et al. 2010, Brand and Brennan 2009). In families with children born prematurely, depressive symptoms and parental distress may indeed affect parent-child relationship (Korja et al. 2008), attachment (Poehlmann and Fiese 2001), caregiving/parenting behavior (Nordhov et al. 2010, Treyvaud et al. 2009, Landry et al. 2008, Smith et al. 2006) and child development (Treyvaud et al. 2009, Sarkadi et al. 2008, Smith et al. 2006). Later, depressive parents may have negative perceptions of their children and thus difficulties interacting with them and further fulfill the social and emotional needs of their children (Goodman and Gotlib 1999).

The cognitive skills of VLBW children with less severe neonatal complications are better than of VLBW children with more severe complications (Smith et al. 2006). However, maternal distress may even be a more important risk factor to a preterm infant's cognitive development than the neurobiological risk factors of the child (Thompson et al. 1994). The severity of maternal depression and parenting stress is related to delayed cognitive development of a child born prematurely (Singer et al. 1999, Cronin et al. 1995). In a more recent study (Grunau et al. 2009), there was no correlation between parenting stress and level of cognitive development of preterm children by 8 months or 18 months of corrected age. Instead, parental low level of education and low social class were associated with a poor cognitive and motor development of the preterm children (Grunau et al. 2009). Irrespective of the risk status of the child, consistent maternal responsive parenting improves the cognitive development of VLBW children across early childhood until 10 years of age (Smith et al. 2006). Also daily paternal involvement with the care of their preterm child improves the cognitive outcome of the child by the time the child is 3 years old (Yogman et al. 1995).

Less sensitive parenting (Clark et al. 2008), maternal psychological distress (Gray et al. 2004), depression (Avan et al. 2010, Beck 1999, Boyle and Pickles 1997) and social disadvantage (Breslau and Chilcoat 2000) have also been presented as risk factors for a disadvantageous behavioral development of the child. The risk for behavioral problems, both externalizing and internalizing problems, is higher if the depression of the mother is persistent rather than intermittent (Giles et al. 2011). Maternal emotional stress influences the social and attentional problems of the child still at the age of 4 years (Assel et al. 2002). On the other hand, VLBV children at the age of 9 months have more behavioral problems than their full-term peers, and this may cause excessive parenting stress to their mothers (Halpern et al. 2001). For children with intellectual disability, the behavioral problems generate maternal child-related parenting stress (McConkey et al. 2008) and impaired family function (McConkey et al. 2008, Baker et al. 2003).

The associations between mental health and depression of the fathers with later child behavior problems have been widely studied in a population-based cohort by the Norwegian ALSPAC study group. These studies have concluded that at 3 years of age, prenatal distress (Kvalevaag et al. 2013) and early postnatal depression (Ramchandani et al. 2005) of the father are associated with behavioral difficulties of the child and that the postnatal depression of the fathers is associated with psychiatric disorders (Ramchandani et al. 2008) and behavioral problems (Gutierrez-Galve et al. 2015) of their children 7 years later. The association is strongly moderated by depression of the mother and conflicts between the parents (Gutierrez-Galve et al. 2015). In preterm populations, the involvement of the father, including daily playing with their premature child, has not been a significant predictor of the behavioral development of the child (Yogman et al. 1995) by 3 years of age. It is possible that the paternal involvement has a greater influence on the behavior of the preterm children when they grow older.

The negative family burden and parental psychological distress have been more frequent if the child has neurodevelopmental or behavioral problems (Singer et al. 2007, Drotar et al. 2006, Taylor et al. 2001, Singer et al. 1999). There is also an association between maternal postnatal depression and the behavioral problems of the child at 2 years of age, if the child grows suboptimally (Avan et al. 2010). Mothers, in particular, provide most of the support to their children with intellectual disability, and the mothers are more likely to experience parenting stress and impaired family functioning than the fathers (McConkey et al. 2008).The importance of fathers in the lives and development of children has been discovered only many years later than the role of mothers. A recent review study concluded that the father's positive involvement with his child seems to affect positively the social, behavioral, psychological and cognitive development of the child (Sarkadi et al. 2008). Accordingly, an early adverse father-infant relationship is associated with more behavioral problems during the first year of the life of the infant, even after accounting for the influence of several chracteristics related to the child, father and mother (Ramchandani et al. 2013); this effects persists and is present when the child is of school-age (Trautmann-Villalba et al. 2006). Fathers of preterm infants are more involved with their children compared to full-term and normal birth weight children. Paternal involvement is associated with the cognitive and behavioral development of the children at least until adolescence (Yogman et al.1995, Levy-Shiff et al. 1994).

Accumulation of the risk factors (child factors, parental factors and family factors) during the early years may predict poor maternal and paternal adjustment and impaired child development (Poehlmann et al. 2009, Miles et al. 2007). Early identification of risk factors may allow interventions focused on supporting child development. After discharge and later, the family-centered intervention programs have been able to reduce child-related parenting stress (Holditch-Davis et al. 2014) and the mothers of the intervention group have experienced their children happier and less distractible than the mothers of the control group (Meijssen et al. 2011). Some of the interventions have led to a reduction of the maternal distress and improved parent-infant interactions (Newnham et al. 2009, Kaaresen et al. 2006, Melnyk et al. 2006). Interestingly, some of these interventions have also been associated with better cognitive development (Nordhov et al. 2010) and less behavioral problems (Melnyk et al. 2007) of the child. However, all intervention programs have not been that successful or beneficial. An early individualized parenting intervention study did not improve the mother-infant interaction, parenting stress nor the short-term infant neurobehavioral function (Glazebrook et al. 2007). To improve outcomes, it is important that the timing of an intervention is right, since the levels of parenting stress tend to increase as the difficulties and disabilities of the premature child become more apparent (Glazebrook et al. 2007). Interventions just before (Landsem et al. 2014) or after discharge (Koldewijn et al. 2005) have been successful in reducing maternal stress and depression and increasing maternal self-esteem; the positive early parent-preterm infant interactions have improved.

There are many problems in evaluating the relationship between psychological well-being of the parents and the developmental problems of the children. During the recent decades, less invasive and more family-centered care of premature infants has been rapidly introduced. Studies on the developmental problems of premature children and the distress of their parents have mainly focused on the experiences of the mothers. The developmental problems of the child are often assessed through what the parents report. It is thus quite feasible that distressed parents may perceive and report the behavior of their children more negatively than mentally healthier parents or the children themselves would do (Najman et al. 2000). The causal relations between child development and parental psychological well-being are often impossible to establish and the confounding factors are numerous. It is impossible to determine the direction of the associations among what may be protective environmental factors and the factors that may put the development of the child at risk. A child with neurocognitive or behavioral impairments may have challenged the parent-child relationship and the parental psychological well-being from the beginning and vice versa: poor parental psychological well-being may affect the development of the premature child.

3 AIMS OF THE STUDY

The aims of the study were:

1) To study the psychological well-being (depressive symptoms, parenting stress, and sense of coherence) of the parents and general family functioning in the families of VLBW children (Studies I–IV, and new data).

2) To describe the cognitive, behavioral, and functional development of very low birth weight (VLBW) children (Studies I–III).

3) To evaluate the associations between parental psychological well-being and some developmental aspects of VLBW children.

   More specifically, to study

   a) the associations between parental psychological well-being and cognitive development of VLBW children at 2 years of corrected age (Study I).

   b) the associations between parental psychological well-being and behavioral development of VLBW children at 3 years of age (Study II).

   c) the associations between parental psychological well-being and socio-emotional and functional development of VLBW children at 5 years of age (Study III).

4) To evaluate the self-reported health-related quality of life in VLBW children at 7 to 8 years of age (Study IV).

4 MATERIALS AND METHODS

4.1 Participants

4.1.1 Very low birth weight infants

This study is part of a prospective longitudinal cohort study examining the development and functioning of very low birth weight (VLBW) preterm infants from infancy to school age (the PIPARI Study, "Development and Functioning of Very Low Birth Weight Infants from Infancy to School Age", "PIeniPAinoisten RIskilasten käyttäytyminen ja toimintakyky imeväisiästä kouluikään"). The PIPARI Study included all premature infants born in the Turku University Hospital between January 2001 and December 2006 and whose birth weight was ≤1500 grams.

A total of 261 VLBW children met the inclusion criteria. Forty-one of the infants died during the neonatal period (15.7%). The exclusion criteria were the same for all the individual studies: 1) domicile outside the hospital catchment area, 2) congenital genetic syndrome and 3) parents speaking some other language than Finnish or Swedish (the official languages of Finland). The families of 11 infants declined participation after having received oral and written information of the PIPARI Study.

The age of the VLBW children was corrected for prematurity (later: "corrected age") until the age of 2 years. After that, the chronological age was used to determine the age of the child.

The infant and family characteristics of the VLBW children are presented in Table 1.

4.1.2 Full-term controls

The PIPARI Study collected the data of the 199 healthy full-term (FT, ≥37 gestational weeks) infants who were born in the Turku University Hospital, Finland, between November 2001 and March 2004. The research psychologist recruited the control group in the delivery ward by asking the parents of the first boy and the first girl born each week to participate. If they declined participation, the parents of the next boy or girl of the week were approached. The exclusion criteria for the control group were 1) congenital anomalies or syndromes, 2) mother's self-reported use of illicit drugs or alcohol during pregnancy, 3) birth weight <-2.0 SD (small for gestational age [SGA]) according to age and gender-specific Finnish growth charts and 4) admission to the neonatal intensive care unit for any reason during their first week of life.

The infant and family characteristics of the FT children are presented in Table 1.

4.2 Study populations

The study populations of VLBW infants for Studies I–IV are shown in Figure 2.

Study I consisted of 182 VLBW and preterm infant survivors whose cognitive development was assessed within the time limits and who did not meet the exclusion criteria. The score of cognitive test was not applicable for one infant since the test was assessed too late. The cognitive test results of 18 infants were not used in the analyses, since Finnish and/or Swedish were not the only language(s) in their families. The cognitive test values of the infants were used in the analyses also when the questionnaire measuring the psychological well-being of the parent was returned (number varies by questionnaire).

Study II consisted of 189 VLBW and preterm infants who were born between May 2001 and December 2006. The 12 children born during the first four months of the year 2001 were not included, since the questionnaires measuring the behavioral problems of the children were not sent to their homes. The scores for the behavioral problems were used in the analyses also when the questionnaire measuring the psychological well-being of the parent was returned (number varies by questionnaire).

Study III consisted of 201 VLBW and preterm children who were born between January 2001 and December 2006. The scores for child development measures were used in the analyses also when the questionnaire measuring the psychological well-being of the parent was returned (number varies by questionnaire).

Study IV consisted of VLBW preterm children, FT control children and their parents. Before sending any questionnaires, the families were contacted and asked if they wanted to continue participating the PIPARI Study. A total of 27 of the VLBW children and 33 of the FT children declined the invitation to continue or were not reached by phone or by mail. Thus, the size of the study cohort was 174 VLBW children and 166 FT children and their families.

4.3 Study design

The study design of Studies I-IV is shown in Figure 2.

Study I

At 2 years corrected age, as part of the PIPARI Study follow-up, the children were invited for an outpatient visit for medical and neurologic examinations conducted by a pediatrician, and for standardized developmental testing conducted by a psychologist. The psychological well-being (depressive symptoms, parenting stress and the level of sense of coherence) of both parents was evaluated at the corrected age of 2 years of the infant by using the results of individually completed parental questionnaires. The

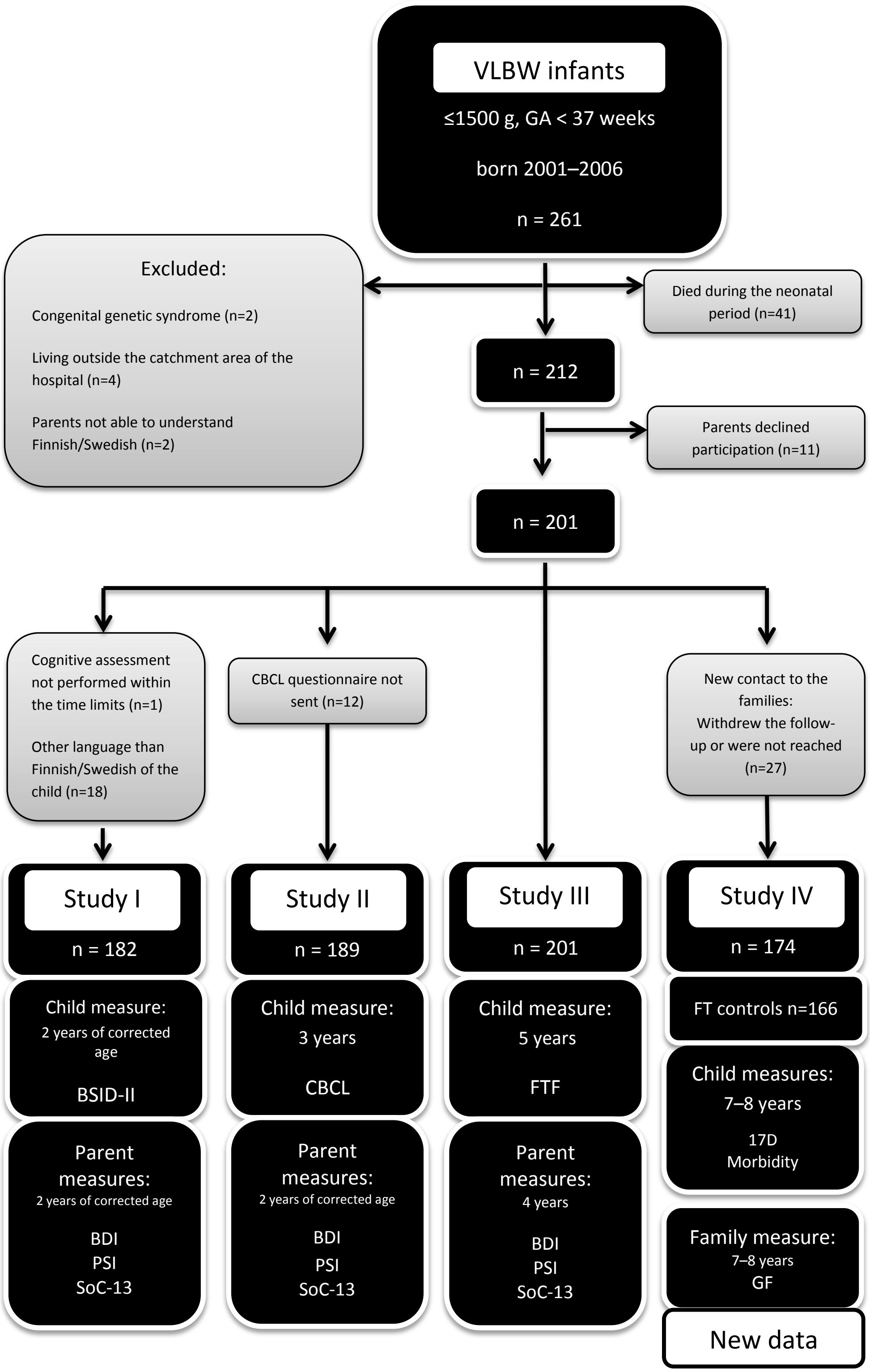

Figure 2 Study populations and study design. Abbreviations are explained in the text.

standardized questionnaires for the parents were mailed home. The associations between the psychological well-being of parents and the cognitive development of the child were analyzed. The associations were adjusted for multiple births and neurosensory impairment of the child as covariates.

Study II

At 3 years of chronological age, the behavioral and emotional problems (internalizing, externalizing and total problems) of the children were reported by the parents. The standardized parental questionnaires collected at 2 years corrected age of the child was used to analyze the associations between the psychological well-being of the parents (depressive symptoms, parenting stress, and the level of sense of coherence) and the behavioral problems of the child. The associations were controlled for the mental development index of the child and maternal education, since these variables were associated with the child behavioral problems score.

Study III

At 5 years of chronological age, parents and day-care providers evaluated the development of the child (social skills, emotional and behavioral problems and executive function). The psychological well-being of both parents (depressive symptoms, parenting stress and the level of sense of coherence) was evaluated with standardized questionnaires mailed home, when the child was 4 years old. The associations between the psychological well-being of the parents and child development were adjusted for the neonatal and parental background variables which had a significant association with the selected developmental domains of the child. These were gestational age, birth weight, length, and mental development index for social skills, maternal education for behavioral problems, and birth weight, length of hospitalization, and maternal education for executive function.

Study IV

At the end of their first school year, the VLBW and FT children self-reported their health and functioning. The health-related quality of life (HRQoL) was determined according to the answers. The following prematurity-related morbidities known to be over-represented in preterm populations were chosen: CP, hearing impairments (sensorineural hearing loss, conductive hearing deficits, or hearing impairment requiring amplification), visual impairments (strabismus, amblyopia, refractive errors, or blindness), epilepsy, obstructive airway disease, ADHD, significant cognitive delay, and short stature. The diagnoses were retrieved by inquiring from the school nurses and the parents of the VLBW children, and by cross-checking them with the medical records of the children. The diagnosis of CP was confirmed by a pediatric neurologist based on a systematic follow-up to 2 years of corrected age. Cognitive development was evaluated by a psychologist when the children were 5 years. The VLBW children were divided into two groups: 1) children without morbidities (healthy VLBW children) and 2) children with one or more prematurity-related morbidities. The HRQoL scores were compared between the VLBW children (healthy and those with morbidity) and the control group.

New data

Beyond the data provided in the original publications, I wanted to examine further family resilience, a variable that may impact on the well-being of preterm infants during early childhood. For that, the associations between depression, parenting stress and sense of coherence in the parents of the VLBW children were studied at two time points: 1) when the children were at 2 years of corrected age, and 2) when they were 4 years of chronological age. The general functioning of the family was evaluated by the parents when the VLBW children started school. The impact of prematurity-related morbidities on family functioning was described and compared with the family functioning of the families of the control children.

4.4 Collection of background data

Parental background data were obtained from the parents when the child was born, and complementary questions were asked of the parents when the child was 2 years of corrected age.

Neonatal background data were prospectively collected from the medical records. Gestational age was based on ultrasound examination before the end of the 20th week of gestation, or on the last menstrual period. Neurodevelopmental impairment (NDI) of the child was considered to be present if the child exhibited one or more of the following factors: severe visual impairment, severe hearing deficit, CP or cognitive disability (Mental Development Index [MDI] <70). Severe visual impairment was categorized as a visual acuity <0.3 or blindness. Hearing was systematically screened in early infancy (at 1 month of corrected age) by using brain stem auditory evoked potentials. Severe hearing impairment was defined as hearing loss requiring amplification in at least one ear or hearing impairment with a cut-off of 40 dB. A diagnosis of CP was confirmed by a pediatrician during a systematic clinical follow-up by 2 years of corrected age using the classification of Himmelmann et al. (Himmelmann et al. 2010, Bax et al. 2005).

The chronic morbidities which were known to be over-represented in preterm populations included CP, hearing impairments (sensorineural hearing loss, conductive hearing deficits, or hearing impairment requiring amplification), visual impairments (strabismus, amblyopia, refractive errors, or blindness), epilepsy, obstructive airway disease, attention-deficit hyperactivity disorder (ADHD), significant cognitive delay, and short stature (a length <-2 SD according to the WHO growth curves). In an effort to achieve the most accurate and comprehensive data, information on the child's morbidity was collected by scrutiny of the reports by the parents and school nurses when the children started school (age 7 to 8 years) as well as the hospital records. At 5 years of age (from 0 to +2 months), the cognitive development of the VLBW children was evaluated by a psychologist using a short form of the Wechsler Preschool and Primary Scale of Intelligence-Revised (WPPSI-R) (Wechsler 1995). The Full-Scale Intelligence Quotient (FSIQ) was estimated (normal M=100, SD 15.0) and FSIQ <70 was used as indication of significant cognitive delay. The amount of prematurity-related morbidities was calculated by using the data provided by the 155 VLBW children who returned the 17D questionnaire.

4.5 Measures of psychological well-being of the parents and family functioning

4.5.1 Beck Depression Inventory (I–III)

The modified 13-item (Beck and Beamesderfer 1974) Finnish version (Salmela-Aro et al. 2001) of the original 21-item Beck Depression Inventory (BDI) (Beck et al. 1961) was used to measure depressive symptoms of the parents. The parents were asked to rate symptoms or attitudes usual among patients with depression (e.g., negative self-concept, sadness and loss of appetite). The items were rated on a 5-point Likert scale ranging from "not at all true of me" (1) to "very true of me" (5) according to how they felt at the moment. Scores of individual items were summed and rescaled to range from 0 to 39.

The BDI scores were used as continuous and categorized variables. In the analyses assessing the associations between parental psychological well-being and child development, the scores were used as continuous variables because we did not want to lose any information or establish any diagnoses. However, when determining the level of depression in the parents, a cut-off of ≥16 points was used as indicator for significant amount of depressive symptoms (Beck and Beamesderfer 1974).

The BDI questionnaire was sent home by mail when the VLBW children reached 2 years of corrected age and at 4 years of chronological age. The parents were asked to fill in the questionnaire independently of each other and to return it by mail.

4.5.2 Parenting Stress Index (I–III)

The Finnish translation of the Parenting Stress Index (PSI) (Abidin 1995) was used to measure the stress related to parenting of VLBW children. The instrument is widely used by clinicians and researchers for screening, diagnostic assessments and measurements of intervention, including preterm infants (Thomas et al. 2004). The questionnaire includes a total of 120 items of which 101 items are rated on a 5-point

Likert scale and 19 are categorical questions about the stressful life situations (life stress) the respondent has experienced over the past 12 months. The first 101 items comprises a child domain (six subscales) and a parent domain (seven subscales). These domains include stress related to a) individual child characteristics that makes it difficult for parents to fulfill their roles as parents (subscales of distractibility/hyperactivity, adaptability, reinforces parent, demandingness, mood and acceptability), and b) the parent's own vulnerability and personality, parent-child relationship, and relation to the spouse (subscales of competence, isolation, attachment, health, role restriction, depression and spouse). The combined score for the child and parent domains yields a total stress score. The higher the score, the higher the degree of parenting stress. In this study, the first 101 items were used and the scoring of the PSI was performed according to the instructions in the PSI manual (Abidin 1995). Scores for Life stress were recorded but not analyzed.

The scores of the questionnaire were used as continuous and as categorized measures. In the analyses assessing the associations between parental psychological well-being and child development, the scores were used as continuous and categorized measures. The categorization was done by dichotomizing the PSI scores; the upper quartile of our own data was used as a cut-off point. When describing and comparing the PSI scores of the parents, the scores ≥85th percentile according to the norms was the indication of significant amount of parenting stress, as suggested in the manual (Abidin 1995).

The PSI questionnaire was sent home by mail when the VLBW children reached 2 years of corrected age and at 4 years of chronological age. The parents were asked to fill in the questionnaire independently of each other and to return it by mail.

4.5.3 Sense of Coherence Scale (I–III)

The Finnish translation of the short Sense of Coherence Scale (SoC-13) (Antonovsky 1987) was used to measure the parents' resilience and personal strength to respond to stressful life events. The 13 items of the scale were rated on a 7-point Likert scale (1–7). The score includes the three main concepts of SoC: comprehensibility, meaningfulness, and manageability. The theoretical range of the score is from 13 to 91 points, lower scores representing weaker SoC.

We used the inventory as a continuous variable since the concept of SoC renders cut-off points inappropriate (Antonovsky 1987). For describing and comparing the SoC scores of the mothers to the scores of the fathers, the scores of less than the median of our own data were used as indication of weak SoC.

The SoC-13 questionnaire was sent home by mail when the VLBW children reached 2 years of corrected age and at 4 years of chronological age. The parents were asked to fill in the questionnaire independently of each other and to return it by mail.

4.5.4 General Functioning subscale of the Family Assessment Device (new data)

The General Functioning subscale (GF) of the McMaster Family Assessment Device (FAD) (Epstein et al. 1983) was used to evaluate the general functioning and dynamics of the family. The FAD is a valid, reliable and one of the most profoundly scrutinized family assessment tools available. It is based on the McMaster Model of Family Functioning, a clinical conceptualization of families. The assessment is a self-report measure of six subscales measuring perceptions of family members of family functioning. The seventh scale is the GF which incorporates items from each of the other scales and is recommended as a summary score for six other dimensions of FAD especially for surveys (Byles et al. 1988). The GF scale has good reliability and validity (Byles et al. 1988). The dimension of GF is made up of 12 statements; six items reflect healthy family functioning and six items reflect unhealthy family functioning, rated from 1 (strongly agree) to 4 (strongly disagree). The scale for the negatively worded items is reversed. The total score is based on the mean of the items ranging from 1 (best functioning) to 4 (worst functioning). The total score can be used as a continuous or as dichotomous measure. If it is used dichotomously, the sample is divided into functional and dysfunctional families according to the cut-off points published by Miller et al. (Miller et al. 1985).

In this study, the mean GF scores were calculated for families of both VLBW and FT children. The scores were used as continuous variables for the analyses.

The assessment was sent to the homes of the participants at the end of the first school year. The parents were asked to answer and to return the questionnaire. One reminder was sent and, if needed, the family was contacted by phone in order to get the questionnaire mailed back.

4.6 Measures of child development and health-related quality of life

4.6.1 Bayley Scales of Infant Development (I–III)

The cognitive development of the children was assessed at the corrected age of 2 years (from - 1 week to + 1 month) using the Mental Development Index (MDI) of the Bayley Scales of Infant Development, II (BSID-II) (Bayley 1993). For categorizing the MDI scores, the BSID-II scores of the FT healthy control group of the PIPARI Study born in the same hospital between November 2001 and March 2004 were used (Munck et al. 2010). This FT group performed approximately 10 points higher than the normative sample of BSID-II (Munck et al. 2010). The MDI scores were used as categorized and continuous variables. In Study I, the MDI scores of the VLBW children were categorized into three groups (normal, mild delay significant delay) according to the distribution of the FT group as follows: Development was considered normal if the MDI score was over 98.1 (above -1 SD), mildly delayed if the score was between 98.1 and 86.4 (-1 SD – -2 SD) and significantly delayed if the score was below 86.4 (below -2 SD). In Studies II and III, MDI <70 (below -2 SD according to the norms) was used as one of the factors defining NDI, indicating a significant delay in cognitive development. The MDI was used as continuous variable in the drop-out analyses.

4.6.2 Child Behavior Check List (II)

The Child Behavior Checklist for Ages 1.5–5 (CBCL/1.5–5) (Achenbach 2001) was used to evaluate the behavioral development of the VLBW children at 3 years of chronological age. The CBCL is a comprehensive measure of parental perception of behavioral and emotional problems and social competencies of children aged 1.5 to 5 years. It reflects similar patterns of psychiatric problems of children in 23 countries, including Finland (Ivanova et al. 2010). The 100 items of the questionnaire comprise the total problem score, which ranges from 0 to 200. For detailed information, 36 items are scored on *internalizing problems* (depression/anxiety, emotional reactivity, somatic complaints with no medical cause and withdrawal from social contacts) and 24 items on *externalizing problems* (attention problems and aggressive behavior). In this study, the parents completed the questionnaire with 100 problem items: 99 closed and 1 open-ended problem. The items were scored as (0) not true, (1) somewhat or sometimes true, and (2) very true or often true. Missing items were scored as 0. Questionnaires missing more than 8 items were excluded. The CBCL scores were used as continuous and categorized measures.

4.6.3 Five to Fifteen Questionnaire (III)

The Five to Fifteen (FTF) questionnaire was used to assess the socio-emotional development and functional development of the VLBW children. The FTF questionnaire has been developed by a multidisciplinary group of Scandinavian clinical researchers for detecting developmental deficits in 5 to 15-year-old children (Kadesjö et al. 2004, Thomas et al. 2004). The FTF is a suitable instrument for screening developmental and behavioral problems (Bohlin and Janols 2004, Kadesjö et al. 2004, Korkman et al. 2004, Trillingsgaard et al. 2004). The questionnaire was originally created in Swedish, but Korkman et al. (Korkman et al. 2004) conducted a pilot study on the Finnish translation (called VIIVI). The FTF is now validated (Bohlin and Janols 2004, Korkman et al. 2004) and the norms for 5-year-old children have been obtained from the Finnish study population, which included 769 children (Korkman et al. 2004). FTF comprises 181 questions grouped into eight problem domains (*motor skills*, *executive function*, *perception*, *memory*, *language*, *learning*, *social skills*, *emotion/behavior*) of child development and behavior. Rather than providing diagnoses, the FTF questionnaire was developed to gain information about the relevant problem areas of the child as perceived by the parents (Kadesjö et al. 2004). The items were scored (0) “does not apply”, (1) “applies sometimes or to some extent” or (2) “definitely applies”. The sum of the scores of each domain was divided by the number of items which yields a mean value. The higher the score, the more numerous the problems.

For the present study (III), the evaluation was limited to three domains of FTF: *social skills*, *emotional/behavioral problems* (including the subdomains *internalizing symptoms*, *externalizing symptoms* and *obsessive-compulsive behavior*) and *executive function* (EF) (including the subdomains *attention*, *hyperactivity/impulsivity*, *hypoactivity* and *planning/organizing*); these domains cover the aspects of everyday functioning. The children whose domain score was below the 75th percentile limit of the normative children were considered to be within the normal range of that domain area. The children, whose domain score exceeded the 90th percentile limit of the normative children, were regarded as being at risk for problems in that domain area. The children whose domain score exceeded the 98th percentile limit of the normative children, were regarded as having considerable difficulties in that domain area. (Korkman et al. 2005)

The FTF questionnaire was mailed one month before the child's fifth birthday. The parents completed and returned the questionnaire by mail. No reminders were sent. In order to explore whether the parents' own psychological well-being influenced the way they perceived their child's development and behavior, we also asked the day-care providers to complete the FTF questionnaire. The FTF scores were used as continuous variables in the analyses.

4.6.4 17D questionnaire (IV)

The 17D (Apajasalo et al. 1996) is an illustrated, generic questionnaire, which can be used for assessment of healthy as well as sick children. It measures the health-related quality of life (HRQoL) and reflects the ability of a person to function in daily life. It has been developed for children aged 8 to11 years and it consists of 17 multiple choice questions on 17 health-related dimensions (*mobility*, *vision*, *hearing*, *breathing*, *sleeping*, *eating*, *speech*, *excretion*, *school & hobbies*, *learning & memory*, *discomfort & symptoms*, *depression*, *distress*, *vitality*, *appearance*, *friends* and *concentration*). Each dimension of the questionnaire has five levels of functioning varying from perfect to severe dysfunction. The dimension importance weights were calculated according to the instrument's home page http://www.15d-instrument.net/rmd. The total HRQoL score is calculated from the health state descriptive system by using a set of populationbased preference or utility weights, which have been elicited from a sample of parents of 8-to-11-year-old healthy elementary school children (Apajasalo et al. 1996). The total HRQoL score ranges from 0 (worst possible, equals death) to 1 (best possible, equals perfect health).

The questionnaires were sent to the participants' homes at the end of the first school year. If the children were not able to read, or had some other limiting problem in completing the questionnaire, the parents were allowed to help the children. One reminder was sent and, if needed, the family was contacted by phone in order to get the questionnaire returned for analysis.

4.7 Statistical analysis

The statistical analyses were performed with the SAS for Windows software (version 9.2 for studies I, III, and III, and version 9.3 for study IV and for the new data; SAS Institute, Cary, NC). P-values <0.05 were considered statistically significant.

4.7.1 Analyses of parents' psychological well-being

Differences in the BDI scores between the mothers and the fathers were compared using Wilcoxon's signed rank tests. Differences in the PSI and SoC-13 scores between the mothers and the fathers were compared using paired samples *t*-tests. Correlations between continuous variables of BDI and SoC-13 were analyzed using Pearson's correlation coefficient.

4.7.2 Analyses of child development and health-related quality of life

One-way analysis of variance was used for examining univariate associations between CBCL scores of the child as a continuous outcome variable and the categorical independent variables of the background characteristics (e.g., parental education and neurodevelopmental impairment of the child). The CBCL scores of singletons and multiples were compared using a mixed model with family as the random effect. The association between the CBCL total score and the continuous background variables (e.g. child MDI and gestational age) were studied using the Pearson correlation coefficient. The significant variables were further included in the analyses as covariates.

Proportions of FTF scores given by the parents above the 90th percentile were compared with the Finnish norm population using the χ^2-test. The FTF scores given by the parents and the day-care providers were compared using a paired samples *t*-test.

Since the scores for the dimensions of the HRQoL were ordinal, the comparisons of the 17 dimensions and the total HRQoL scores (univariate associations) between the VLBW children with a different number of prematurity-related morbidities and the control group were studied using cumulative logit models. If three dimensions, at most, were missing from the 17D, multiple imputation was used to replace missing values with one value as suggested by the instrument's home page http://www.15d-instrument.net/rmd. The imputation model includes all the dimensions of the 17D and complementary neonatal background variables.

4.7.3 Analyses of associations between parental psychological well-being and child outcomes

At 2 years of the child's corrected age, the univariate associations between the parents' depressive symptoms, parenting stress and SoC and MDI classification of the child were studied using cumulative logit models. The cumulative logit models were also used when the associations were adjusted for neurosensory impairment of the child and multiplicity. These covariates were chosen, since birth weight and SGA status were not associated with the MDI of the child (if controlled for other background variables), as shown in a previous study of the PIPARI Study (Munck et al. 2010).

At 3 years of the child's age, the association between continuous predictors and the CBCL total score was studied using Pearson's correlation coefficient. Multiple regression analysis was used to study associations between parental psychological well-being and child CBCL scores controlling for child MDI and maternal education, since these were significant predictors for CBCL total score.

At 5 years of the child's age, the associations between scores defining parents' psychological well-being (continuous predictor variables) and child development, i.e. social skills, behavioral problems, and executive function (continuous outcome variables) were studied using a generalized linear model with a negative binominal distribution and log-link. The logarithm of the number of answered questions was used as the offset variable. Negative binomial regression was used to study if any of the background characteristics were a predictive variable for FTF domains. The associations between parental measures and child development measures were controlled for the background variables, which had a significant univariate association with the FTF score (gestational age, birth weight, length of hospitalization and MDI of the child for social skills; maternal education for behavioral problems; birth weight, gender, length of hospitalization, and maternal education for executive function).

At 7 to 8 years of the child's age, the relationship between family functioning (GF score) and morbidity was studied using Spearman's correlation. Continuous background variables between the VLBW and the FT group were compared using the independent samples *t*-test. Differences in nominal background variables between the VLBW and the FT group were tested using the χ^2-test. The χ^2-test for trend was used for ordinal background variables.

4.8 Drop-out analyses

Drop-out analyses between two nominal variables were performed using the χ^2-test or Fisher's exact test, as appropriate. If the other variable was nominal and the other ordinal, the χ^2-test for trend was used. The *t*-test for independent samples was used for comparison of continuous background variables between responders and non-responders.

The parents who did not return any of the questionnaires on the psychological well-being of the parents when the children were at 2 years of corrected age (n=59, 29%) were more often unemployed than the parents who returned the questionnaires (mothers 59% vs. 43%, $p<0.05$; fathers 15% vs. 2%, $p<0.01$). The children of the non-responding parents did not differ significantly from the children of the responding parents in terms of any of the neonatal background characteristic or the MDI.

At 4 years of the child's age, 25 parents did not return any of the parental questionnaires. The fathers who did not answer any of the parental questionnaires, smoked more often than the responding fathers (17% vs. 6%, $p<0.05$), and the non-responding mothers had been more often unemployed when the children were at 2 years of age (home with the children) (20% vs. 4%, $p<0.01$) and had fewer educational years ($p<0.01$) compared to the responding mothers. Of the neonatal background characteristics, the duration of hospitalization had been longer in the group of children of responding parents than in the non-responding parents (mean 75 days vs. 60 days, $p<0.05$). The MDI of the children did not differ significantly between the non-responding and the responding parents.

A total of 49 (26%) parents did not return the CBCL questionnaire for their 3year-old child. The non-participating children did not differ from the participating children in terms of any of the neonatal background characteristics or the cognitive level of the child. The parents of the non-participating children were more often divorced (16% vs. 4%, $p<0.05$) and smokers (mothers 34% vs. 16%, $p<0.05$; fathers 45% vs. 28%, $p<0.05$) than the parents of participating children.

At 5 years of age of the child, 40 (20%) parents did not return the FTF questionnaire for their VLBW child. The MDI of the VLBW children (mean 93.1 vs. 103.2, $p<0.001$) and the educational level of the mother ($p<0.001$) were lower in non-participating children compared to the participating children. The day-care providers did not return the FTF questionnaire for 77 (38%) children. We did not have any background characteristics of the day-care providers for the drop-out analysis.

At 7 to 8 years of age, 174 VLBW children and 166 FT children with their families continued in the PIPARI Study. A total of 19 VLBW children and 37 FT children did not return the self-report-17D questionnaire. The non-participating VLBW children did not differ significantly from the participating VLBW children in any of the neonatal background characteristics. The mothers and the fathers of the non-participating VLBW children were less educated (mothers $p<0.01$, fathers $p<0.05$) and smoked more often (mothers 37% vs. 16%, $p<0.001$; fathers 49% vs. 28%, $p<0.05$). The fathers of the non-participating VLBW children had been more often unemployed when the children were 2 years old compared to the participating fathers (16% vs. 3%, $p<0.01$). The mothers of the non-participating VLBW children had been also more often unemployed (on parental leave) (mothers 64% vs. 44%, $p<0.05$) compared to the mothers of the participating VLBW children. The non-participating FT children did not differ significantly from the participating FT children in any of the neonatal background characteristics. The mothers and the fathers of the non-participating FT children were less educated (mothers $p<0.05$, fathers $p<0.001$) and smoked more often (mothers 24% vs. 8%, $p<0.05$; fathers 48% vs. 16%, $p<0.001$).

4.9 Ethics

The PIPARI Study protocol was approved by the Ethics Committee of the Hospital District of Southwest Finland in December 2000. The principles of the Declaration of Helsinki were followed. The parents gave informed consent after receiving written and oral information.

5 RESULTS

5.1 Background characteristics

The infant and family characteristics for very low birth weight (VLBW) (n=201) and full-term (FT) infants (n=199) are presented in Table 1. More detailed information on each study population of Studies I–IV is presented in the original publications. The distribution of the prematurity-related morbidities is shown in Table 2 and in Figure 3. A total of 64.5% of the VLBW children did not have any prematurity-related morbidity at the age of 7 to 8 years (number calculated from the population of 155 VLBW children who answered the 17D questionnaire).

Table 1 Infant and family characteristics of very low birth weight (VLBW) and full-term (FT) control children.

Characteristics
Birth weight (grams), mean ± SD [min,max]
Gestational age (weeks), mean ± SD [min,max]
Small for gestational age (SGA[a]), n (%)
Days in neonatal intensive care, mean ± SD [min,max]
Multiple birth, n (%)
Male, n (%)
Neurodevelopmental impairment[b], n (%)
Mental development index[c] <70
Cerebral palsy
Severe visual impairment
Severe hearing deficit
Mother, n (%)
Age* (years), mean ± SD [min,max]
Education*
≤9 years
over 9–12 years
>12 years
Smoker*
Employed**
Father, n (%)
Age* (years), mean ± SD [min,max]
Education*
≤9 years
over 9–12 years
>12 years
Smoker*
Employed**
Parents married / living together*, n (%)
Parents divorced / separated after child birth,** n (%)

[a] SGA is defined as a birth weight of <-2.0 SD according to age- and gender-specific Finnish growth charts.

[b] Assessed at 2 years of corrected age

[c] Bayley N. *Bayley scales of infant development-II.* 2nd ed. San Antonio, TX: Psychological Corporation; 1993.

*Asked when the child was born. **Complementary question, asked when the child was at 2 years of corrected age.

VLBW infants, n=201 born 1/2001–12/2006	**FT control infants,** n=199 born 11/2001–3/2004	**Difference** **p**
1076 ± 283 [400, 1500]	3665 ± 449 [2570, 4980]	<0.001
28.8 ± 2.8 [23.0, 35.9]	40.1 ± 1.2 [37.1, 42.3]	<0.001
79 (39)	0	<0.001
61 ± 32 [3,183], missing data n=7	0	<0.001
59 (29)	1 (0.5)	<0.001
107 (53)	94 (49)	0.6
23 (12), missing data n =6	N/A	N/A
6 (3), missing data n=6	1 (0.5), missing data=7	0.1
12 (6), missing data n=2		
0		
10 (5), missing data n=2		
31.4 ± 5.6 [16, 44]	29.5 ± 5.2 [18, 43]	<0.001
missing data n=5	missing data n=34	<0.05
24 (12)	9 (5)	
53 (27)	59 (36)	
119 (61)	97 (59)	
37 (20), missing data n=15	22 (13), missing data n=34	0.1
99 (52), missing data n=11	N/A	N/A
33.6 ± 6.7 [17, 50], missing data n=18	32.4 ± 6.3[23, 63], missing data n=42	0.09
missing data n=6	missing data n=41	<0.05
18 (9)	15 (9)	
114 (59)	69 (44)	
63 (32)	74 (47)	
59 (32), missing data n=16	38 (24), missing data n=43	0.1
177 (94), missing data n=13	N/A	N/A
183 (98), missing data n=14	162 (98), missing data n=33	0.9
12 (7), missing data n=20	N/A	N/A

Table 2 Prematurity-related morbidities in VLBW children (n=155) at 7 to 8 years.

Prematurity-related morbidities	n (%)
Cerebral palsy	8 (5.2)
Hearing impairment	5 (3.2)
Visual impairment	20 (12.9)
Epilepsy	3 (1.9)
Obstructive airway disease	29 (18.7)
Attention-deficit hyperactivity disorder	7 (4.5)
Significant cognitive delay (FSIQ<70)	5 (3.2)
Short stature [a]	3 (1.9)

FSIQ: Full Scale Intelligence Quotient (Wechsler 1995)
[a] Length < -2SD according to the World Health Organization growth curves.

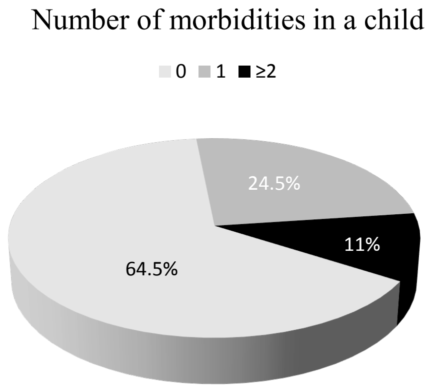

Figure 3 Percentages of VLBW children aged 7 to 8 years of age by number of prematurity-related morbidities.

5.2 Psychological well-being of the parents

The psychological well-being of the parents (depressive symptoms, parenting stress and SoC) was evaluated twice: when the child was 2 years of corrected age and again at 4 years of chronological age. The mean scores for the inventories are presented in Table 3 and in Table 4. The data were collected directly from the parents of the VLBW children. Also the number of questionnaires returned is presented in the tables. Higher scores in the questionnaire represent a higher level of depressive symptoms, parenting stress or a better sense of coherence, and the significance of differences between the scores of the mothers and the fathers are indicated.

The analyses evaluating the associations between parental psychological well-being and child outcomes included the questionnaires of the parents if the questionnaire or assessment for the child was also available. This explains the different numbers or scores reported in the original publications (I, II, and III).

5.2.1 Depression among parents of VLBW children (I–III)

Of the 201 eligible children of the PIPARI Study, 134 (67%) mothers and 118 (59%) fathers returned the BDI questionnaire when the children were 2 years of corrected age. The mean BDI scores for the mothers and the fathers are presented and compared in Table 3. A total of 16% (n=22) of the mothers and 11% (n=14) of the fathers reported significant depressive symptoms (BDI score ≥16) as their child reached 2 years of corrected age. The mothers with significant depressive symptoms had a lower level of education compared to the other mothers ($p<0.05$).

When the child was 4 years of age, 144 (72%) of the mothers and 118 (59%) of the fathers returned the BDI questionnaire. The mean BDI scores for the mothers and fathers are presented and compared in Table 4. A total of 16% (n=23) of the mothers and 8% (n=9) of the fathers reported significant depressive symptoms (BDI score ≥16) when their child was at 4 years of age.

At both age points, the mothers of the VLBW children experienced significantly more depressive symptoms than the fathers. The mean BDI score of the mothers was 2.4 points higher than the mean score of the fathers ($p<0.01$) at 2 years of child's corrected age and 2.7 points higher ($p<0.001$) at 4 years of child's age.

Table 3 Mean scores (SD) of inventories defining parental psychological well-being when the child was 2 years of corrected age.

Inventory	Mothers		Fathers		Difference
At child's 2 years of corrected age	n	mean (SD)	n	mean (SD)	p
Beck Depression Inventory	134	**9.2** (5.6)	118	6.8 (6.4)	**<0.01**
Parenting Stress Index					
Child domain	137	92.9 (20.0)	126	**93.2** (17.1)	0.9
Distractibility/hyperactivity	138	22.8 (5.5)	127	**22.9** (4.8)	0.9
Adaptability	137	22.2 (5.3)	127	**23.3**(5.0)	**<0.05**
Reinforces parent	139	9.1 (2.7)	128	**9.2** (2.5)	0.7
Demandingness	138	**18.1** (5.3)	127	16.9 (4.5)	**<0.01**
Mood	139	9.2 (2.8)	128	**9.5** (2.4)	0.2
Acceptability	139	11.2 (3.5)	128	**11.4** (3.4)	0.7
Parent domain	136	**120.2** (25.8)	126	109.9 (22.3)	**<0.001**
Competence	137	**28.1** (6.9)	128	25.5 (5.5)	**<0.001**
Isolation	139	**13.6** (4.6)	128	12.4 (4.0)	**<0.01**
Attachment	139	12.0 (3.0)	128	**12.9** (2.9)	**<0.01**
Health	137	**12.3** (3.4)	128	11.0 (3.1)	**<0.001**
Role restriction	137	**18.0** (4.9)	128	16.3 (4.4)	**<0.001**
Depression	138	**19.3** (5.5)	127	16.7 (4.8)	**<0.001**
Spouse	138	**16.9** (5.0)	127	15.5 (4.7)	**<0.001**
Total Score	136	**213.3** (41.9)	126	203.1 (35.9)	**<0.01**
Life stress	139	**1.9** (1.6)	128	1.4 (1.5)	**<0.01**
Sense of Coherence Scale	124	**67.3** (12.0)	107	70.4 (11.5)	**<0.05**

p-value defines the significance between the maternal and paternal mean scores. Scores representing more symptoms and p-values of significant differences are bolded.

Table 4 Mean scores (SD) of inventories defining parental psychological well-being when the child was 4 years of age.

Inventory	Mothers		Fathers		Difference
At child's 4 years of age	n	mean (SD)	n	mean (SD)	p
Beck Depression Inventory	144	**8.4** (6.9)	118	5.7 (5.8)	**<0.001**
Parenting Stress Index					
Child domain	149	91.7 (24.2)	124	**92.0** (22.8)	0.9
Distractibility/hyperactivity	150	21.0 (6.1)	124	**21.6** (5.1)	0.18
Adaptability	149	22.5 (6.5)	124	**22.8** (6.5)	0.7
Reinforces parent	150	9.2 (3.2)	124	**9.3** (3.3)	0.7
Demandingness	149	**18.3** (5.8)	124	17.3 (5.9)	**<0.01**
Mood	150	**9.5** (3.1)	124	9.5 (2.6)	0.8
Acceptability	151	11.3 (4.4)	124	**11.5** (4.1)	0.9
Parent domain	147	**117.8** (29.2)	123	108.2 (25.1)	**<0.001**
Competence	148	**27.4** (7.6)	123	25.8 (6.2)	**<0.01**
Isolation	148	**12.9** (4.4)	124	12.0 (3.6)	**<0.05**
Attachment	149	12.1 (3.2)	123	**12.6** (3.7)	**<0.01**
Health	150	**12.1** (3.6)	124	10.4 (2.9)	**<0.001**
Role restriction	148	**17.0** (5.2)	123	15.7 (4.9)	**<0.01**
Depression	148	**19.3** (6.4)	124	16.4 (5.1)	**<0.001**
Spouse	149	**17.1** (5.5)	124	15.3 (4.9)	**<0.001**
Total Score	147	**209.6** (50.5)	123	200.3 (45.6)	**<0.01**
Life stress	150	**1.8** (1.5)	124	1.3 (1.6)	**<0.01**
Sense of Coherence Scale	140	**67.9** (11.7)	112	71.4 (10.1)	**<0.001**

p-value defines the significance between the maternal and paternal mean scores. Scores representing more symptoms and p-values of significant differences are bolded.

5.2.2 Parenting stress among parents of VLBW children (I–III)

At 2 years of child's corrected age, 137 (68%) mothers and 126 (63%) fathers out of the eligible 201 parents returned the PSI questionnaire. The mean PSI scores of the mothers and the fathers are presented and compared in Table 3. The fathers reported higher scores in the child domain of the PSI than the mothers, although the differences were generally not significant. The significantly higher stress of the fathers compared to the mothers was related to child *adaptability* ($p<0.05$). However, the mothers reported significantly higher scores for the parent domain ($p<0.001$) compared to the fathers, except for *attachment* to the child, which was more stressfull to the fathers ($p<0.01$).

At 4 years of child's age, a total of 150 (75%) mothers and 124 (62%) fathers returned the PSI. The mean PSI scores for the mothers and the fathers are presented and compared in Table 4. Again, the mothers reported significantly higher scores for parenting stress mainly in the parent domain ($p<0.001$) compared to the fathers. Similarly, the fathers reported higher stress than the mothers in *attachment* to the child ($p<0.01$).

The distribution of significant parenting stress, i.e. ≥85th percentiles of the norms (Abidin 1995), experienced by the mothers and fathers of VLBW children at 2 years of corrected age and at 4 years of age is presented in Figure 4. It shows that in the mothers, the significant amount of parenting stress was mainly related to circumstances pertaining to the parent domain, e.g., the parent's own vulnerability, personality or relation with the spouse, when the child was 2 years of corrected age. However 2 years later, the parenting stress of the mothers was mostly related to child characteristics. In contrast to the mothers, the significant amount parenting stress experienced by the fathers when the child was 2 years of corrected age and at 4 years of chronological age was related to child characteristics. The parenting stress of the mothers and fathers related to child characteristics increased over time, while the parenting stress related to the parent's own vulnerability, personality or relation with the spouse decreased.

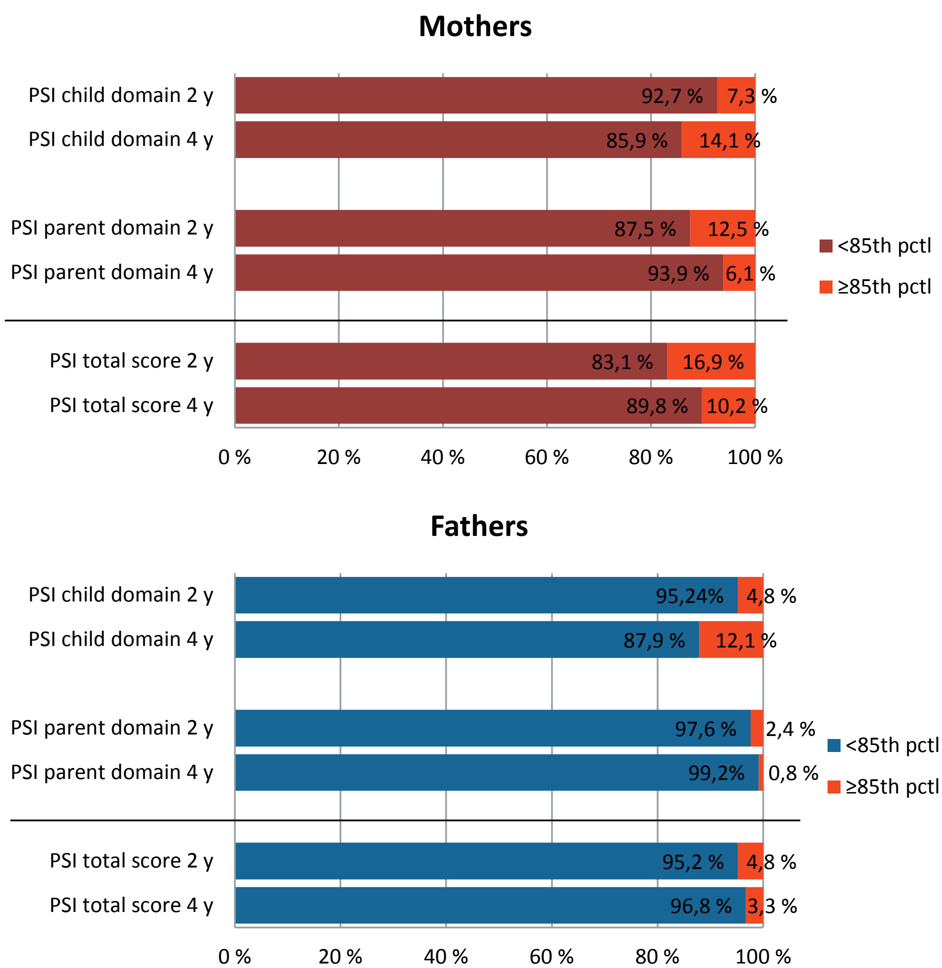

Figure 4 Distribution of significant parenting stress (≥85th percentiles relative to norms [Abidin 1995]) in mothers and fathers of VLBW children at 2 years of corrected age and at 4 years of chronological age.

5.2.3 Sense of coherence of parents of VLBW children (I–III)

At 2 years of corrected age of the VLBW child, a total of 124 (62%) mothers and 107 (53%) fathers returned the SoC-13 questionnaire. The mean SoC-13 scores for mothers and fathers are presented and compared in Table 3. The mothers reported weaker SoC compared to the fathers (estimate 2.6 points, 95% CI -5.1 to -0.1, $p<0.05$). The weaker SoC of the mother was related to a lower level of education of the mother ($p<0.05$).

At 4 years of age of the child, 140 (67%) mothers and 112 (56%) fathers returned the SoC-13 questionnaire. The mean SoC-13 scores for the mothers and fathers are presented and compared in Table 4. Again, the mothers of the VLBW children reported weaker SoC compared to the fathers (estimate 4.1 points, 95% CI -6.1 to -2.0, $p<0.001$). A weaker SoC was related to older age of the parent (mothers $p<0.05$, fathers $p<0.01$), as well as being a first-time parent (mothers $p<0.001$, fathers $p<0.05$).

5.2.4 Associations between depression, parenting stress, and sense of coherence (new data)

At 2 years of child's corrected age, weaker SoC of mothers and fathers was predicted by higher scores for depressive symptoms (mothers 58% of variance, $p<0.001$; fathers 44% of variance, $p<0.001$) and total parenting stress (mothers 42% of variance, $p<0.001$; fathers 20% of variance, $p<0.001$). The results hold true also when the children were 4 years of age: Weaker SoC of both parents was predicted by higher scores for depressive symptoms (mothers 38% of variance, $p<0.001$; fathers 53% of variance, $p<0.001$) and total parenting stress (mothers 43% of variance, $p<0.001$; fathers 40% of variance, $p<0.001$).

5.2.5 Family functioning in the families of the preterm children and of control children (new data)

A total of 148 (85%) families of the VLBW children and 119 (72%) families of the FT children who attended the PIPARI Study when the child was 7 years (n=174 and n=166, respectively) completed the general functioning (GF) scale of the FAD questionnaire. The mean score describing the general functioning was 1.49 (SD 0.48, range 1.00–3.33) in the families of the preterm children and 1.42 (SD 0.47, range 1.00–2.92) in the families of the control children.The difference between the mean scores of the study groups was not significant ($p=0.24$). The level of family functioning in the families of the healthy VLBW children did not differ significantly from the control families (difference 0.003 points, 95% CI -0.13–0.13, $p=0.97$). However, if the VLBW child had one or more prematurity-related morbidities at age 7 to 8, the mean GF score (1.61 SD 0.56, ranging from 1.00 to 3.33) was significantly lower compared to the mean score of the control group (difference 0.18 points, 95% CI 0.03–0.34, $p<0.05$), as shown in Figure 5.

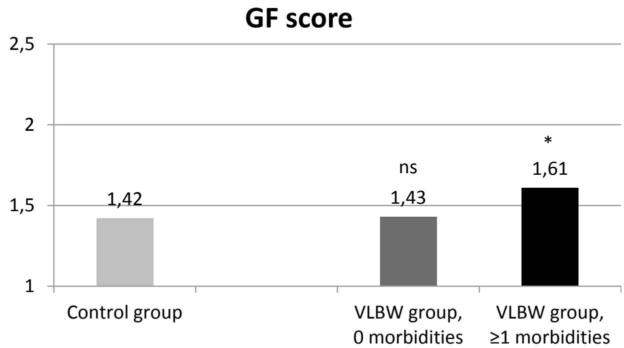

Figure 5 General functioning (GF) scores of VLBW children with or without prematurity-related morbidity compared to the scores of the control group. The significances of the differences between the mean scores of the controls and 2 groups of VLBW children are non-significant (ns) for children with no morbidity and significant ($p<0.05$, *) for children with ≥1 morbidity. GF score 1= best functioning, 4=worst functioning.

5.3 Child outcomes

5.3.1 Cognitive development of VLBW children at 2 years of corrected age (I)

Out of 201 VLBW children, 18 (9%) could not perform the cognitive test (Bayley 1993) at 2 years of corrected age because they spoke some other language than Finnish or Swedish. One test result was withdrawn because the test was not performed within the given time limits. Seven (4%) families out of 199 FT control children declined participation in the cognitive testing. The mental development indexes (MDI) attained have been published previously (Munck et al. 2010). The mean MDI of the VLBW cohort tested (n=182) was 101.7 (SD 15.4) which was 7.7 points lower than the score of the FT group (n=192) and high compared with the BSID-II American normative data (mean 100, SD 15). Since only 6 (3.3%) of the VLBW infants had a significant cognitive delay (MDI<70) according to the BSID-II norms, we re-grouped the children according to the MDI scores of our own FT group. The MDI scores of the VLBW infants were categorized into three groups (normal, mild delay, significant delay) according to the MDI distribution of the FT control group

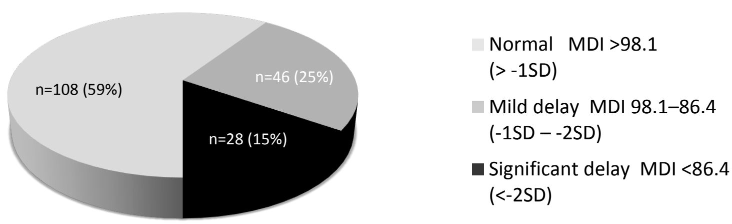

Figure 6 Level of cognitive development of VLBW children (n=182) by FT norms. MDI: mental development index (Bayley 1993).

5.3.2 Behavioral development of VLBW children at 3 years of age (II)

A total of 140 (74%) parents completed the CBCL questionnaire when the VLBW children were 3 years old. No questionnaires had to be rejected because of missing items. 63% of the questionnaires were completed by the mother, 6% by the father, and 30% by the parents together. The responder was not mentioned in 1% of the questionnaires.

The CBCL scores of the children are presented and compared to the norms (Achenbach 2001) in Table 5. The mean scores for girls and boys did not differ significantly from each other (total problems p=0.47; internalizing problems p=0.10; externalizing problems p=0.47). In addition, the mean scores did not differ significantly between the groups of multiples and singletons (total problems p=0.67; internalizing problems p=0.97; externalizing problems p=0.73). Because of that, the genders were considered as one group for the subsequent analyses, as were multiples and singletons. The mean CBCL total score was significantly higher in VLBW children with lower MDI (r=-0.22, p=0.01) or who had a less educated mother (difference 12.8 points, p=0.02, 95% CI 2.7 to 22.9).

Table 5 Scores of Child Behavior Checklist 1½-5 (CBCL/1½-5) in very low birth weight infants at age 3 years. (Huhtala et al. 2012)

CBCL Scores	Mean (SD)	Score ≥90th percentile according to norms[a]
All (n=140)		
Total problems	28.5 (17.9)	10 (7.1)
Internalizing problems	5.8 (5.7)	7 (5.0)
Externalizing problems	12.5 (7.5)	10 (7.1)
Boys (n=78)		
Total problems	27.5 (17.0)	3 (3.9)
Internalizing problems	5.1 (4.9)	2 (2.6)
Externalizing problems	12.4 (7.5)	6 (7.7)
Girls (n=62)		
Total problems	29.7 (19.1)	7 (11.3)
Internalizing problems	6.7 (6.5)	5 (8.1)
Externalizing problems	12.6 (7.6)	4 (6.5)

[a] The Achenbach System of Empirically Based Assessment (Achenbach 2001)

5.3.3 Socio-emotional and functional development of VLBW children at 5 years of age (III)

A total of 161 questionnaires for assessment of the socio-emotional and functional development (social skills, emotional and behavioral problems and executive function) of the VLBW children were returned by the families whose child had turned 5 years of age. The responder had been the mother (83%), the father (3%) or the parents together (12%). The responder was not indicated in 2% of the questionnaires. The day-care providers completed the questionnaire for 124 (62%) children. Fifteen children were not attending day-care services. The day-care providers had been acquainted with the children for an average of 17 months.

The VLBW children were reported to have significantly more problems in all of the selected domains compared to the Finnish norms (Korkman et al. 2005). According to the Finnish normative values, 2.5% of the VLBW children had considerable difficulties in social skills, 2.5% in emotional and behavioral problems and 2.5% in executive function. A total of 21% of the VLBW children were at risk for problems in social skills, 15 % in emotion and behavior and 21% in executive function. However, 63.4% of the VLBW children were considered to be within the normal range in social skills, 64.0% in emotional and behavioral problems and 61.5% in the executive function.

The day-care providers reported more problems in social skills compared to the reports of the parents ($p<0.001$, 95% CI -0.17 to -0.05) and in the subdomain level of attention ($p<0.05$, 95% CI -0.20 to -0.02) and hypoactivity ($p<0.001$, 95% CI 0.30 to -0.11). The mean FTF scores for VLBW children reported by the parents and the day-care providers are shown and compared in Table 6.

Table 6 The Five to Fifteen (FTF) questionnaire for the 5-year-old VLBW children: scores reported by parents and day-care providers, means (SD) and differences. (Huhtala et al. 2014)

FTF domains	**Parental scores** Mean (SD) n=161	**Day-care providers' scores** Mean (SD) n=124	**Difference** Estimate (95% CI)
Social skills	0.20 (0.24)	0.34 (0.42)	-0.11 (-0.17 to -0.05)***
Emotional/ behavioral problems	0.17 (0.18)	0.17 (0.21)	0.02 (-0.02 to 0.06)
Internalizing symptoms	0.14 (0.16)	0.15 (0.20)	-0.007 (-0.04 to 0.03)
Externalizing symptoms	0.25 (0.29)	0.22 (0.31)	0.06 (-0.002 to 0.12)
Obsessive-compulsive	0.09 (0.15)	0.13 (0.28)	-0.03 (-0.07 to 0.02)
Executive functions	0.43 (0.33)	0.53 (0.51)	-0.07 (-0.15 to 0.005)
Attention	0.44 (0.39)	0.58 (0.58)	-0.11 (-0.20 to -0.02)*
Hyperactivity/impulsivity	0.52 (0.43)	0.53 (0.58)	0.02 (-0.08 to 0.13)
Hypoactivity	0.21 (0.30)	0.44 (0.54)	-0.20 (-0.30 to -0.11)***
Planning and organizing	0.42 (0.47)	0.53 (0.60)	-0.09 (-0.19 to 0.02)

* p=0.05; ** p<0.01; *** p<0.001

5.3.4 Self-reported HRQoL of VLBW children at 7 to 8 years of age (IV)

A total of 155 (89 %) VLBW children and 129 (78%) FT children returned the HRQoL evaluation at the end of the first school year. The VLBW children were on average 7.8 years (SD 0.3, range 7.2 to 8.6 years) and the FT children 7.9 years (SD 0.3, range 7.2 to 8.6 years). The mean scores for 17 dimensions of the HRQoL as well as the total HRQoL score are presented and compared in Table 7 for the three groups: VLBW children without morbidities ("healthy"), VLBW children with one or more morbidities, and control children. The mean total HRQoL score of the healthy VLBW children (0.960) did not differ significantly from the mean total score of the control children

Table 7 Mean scores for the 17 dimensions and the total health related quality of life (HRQoL), and the differences between the scores. (Huhtala et al. 2015, in press)

Health-related quality of life dimensions	**Healthy VLBW children** n=100 Mean (SD)	Healthy VLBW children vs. Control children OR (95% CI)	**Control children** n=129 Mean (SD)
Mobility	1.000 (0.00)	ns	1.000 (0.00)
Vision	0.999 (0.01)	ns	0.992 (0.05)
Hearing	0.990 (0.05)	ns	0.991 (0.05)
Breathing	0.972 (0.10)	ns	0.970 (0.10)
Sleeping	0.882 (0.15)	ns	0.889 (0.14)
Eating	0.992 (0.05)	ns	0.997 (0.03)
Speech	0.997 (0.03)	ns	0.998 (0.02)
Excretion	0.946 (0.15)	17.2 (2.2-134.6)**	0.996 (0.05)
Learning & memory	0.942 (0.10)	ns	0.956 (0.10)
Discomfort & symptoms	0.901 (0.13)	ns	0.872 (0.16)
Depression	0.971 (0.09)	ns	0.953 (0.13)
Distress	0.899 (0.14)	ns	0.919 (0.14)
Vitality	0.987 (0.06)	ns	0.988 (0.06)
Appearance	0.983 (0.05)	ns	0.973 (0.08)
Friends	0.992 (0.05)	ns	0.981 (0.08)
School & hobbies	0.994 (0.04)	ns	0.993 (0.04)
Concentration	0.876 (0.15)	ns	0.898 (0.16)
Total HRQoL score	0.960 (0.03)	ns	0.964 (0.03)

VLBW: very low birth weight, ≤ 1500 grams
OR describes the risk of having lower score in one of the health state dimensions or in the total HRQoL measure.
ns: non significant
* $p<0.05$, ** $p<0.01$, *** $p<0.001$

(0.964). However, the mean total HRQoL score of the VLBW children with at least one morbidity (0.931) was significantly lower compared with the control children (0.964, $p<0.001$) and with the healthy VLBW children (0.960, $p<0.01$). The healthy VLBW children had significantly lower scores compared with the control children only in one dimension, *excretion*. However, the VLBW children with morbidities had significantly lower scores in nine dimensions of HRQoL compared with the control children: *vision*, *hearing*, *breathing*, *eating*, *speech,* *excretion*, *learning & memory*, *appearance*, and *concentration*. The mean scores of six dimensions of HRQoL were significantly lower in the VLBW children with prematurity-related morbidities compared with the healthy VLBW children: *vision*, *breathing*, *eating*, *speech*, *learning & memory*, and *appearance*.

VLBW children with morbidities vs. Control children OR (95% CI)	**VLBW children with morbidities** n=55 Mean (SD)	VLBW children with morbidities vs. Healthy VLBW children OR (95% CI)
ns	0.986 (0.10)	ns
11.5 (3.6-36.5)***	0.953 (0.09)	36.6 (4.7-286.8)***
4.6 (1.3-16.4)*	0.962 (0.10)	ns
4.0 (1.7-9.5)**	0.901 (0.17)	4.3 (1.6-11.1)**
ns	0.884 (0.16)	ns
15.8 (1.9-134.5)*	0.954 (0.13)	6.1 (1.2-31.1)*
18.7 (2.2-156.2)**	0.949 (0.15)	14.4 (1.7-120.9)**
37.8 (4.8-297.4)***	0.880 (0.24)	ns
3.6 (1.8-7.3)***	0.876 (0.18)	2.4 (1.2-4.8)*
ns	0.879 (0.16)	ns
ns	0.958 (0.10)	ns
ns	0.926 (0.14)	ns
ns	0.983 (0.07)	ns
2.8 (1.3-6.0)**	0.931 (0.13)	3.8 (1.6-8.9)**
ns	0.956 (0.14)	ns
ns	0.974 (0.10)	ns
2.5 (1.4-4.7)**	0.824 (0.19)	ns
3.0 (1.7-5.2)***	0.931 (0.06)	2.6 (1.4-4.7)**

5.3.5 Associations between parental psychological well-being and cognitive development of VLBW children at 2 years of age (I)

Table 8 shows the unadjusted and adjusted associations between parental measures and scores for cognitive development of VLBW children at 2 years of corrected age. The study included parental questionnaires of 182 VLBW children who underwent cognitive testing (Bayley 1993) at 2 years of corrected age. A total of 126 (69%) mothers and 112 (62%) fathers returned the BDI questionnaire. Twenty-two (17%) mothers and 14 (13%) fathers of the assessed children reported significant depressive symptoms (BDI score ≥16 points). Of the depressive mothers, 4 (18%) had a child with significantly delayed cognitive development (see Figure 7). The association between the mothers' depressive symptoms and the cognitive development of the child was not significant (OR 1.13, 95% CI 0.37–3.41, p=0.85). Of the depressive fathers, 6 (43%) had a child with significantly

Table 8 Unadjusted and adjusted associations between scores defining the psychological well-being of the parents and cognitive development of very low birth weight infants. (Huhtala et al. 2011)

	Mothers			
	Unadjusted		Adjusted*	
	OR (95% CI)	p	OR (95% CI)	p
BDI	1.13 (0.37 to 3.41)	0.85	1.26 (0.41 to 3.87)	0.70
PSI				
Child domain	1.01 (1.00 to 1.03)	0.14	1.01 (1.00 to 1.03)	0.15
Distractibility/hyperactivity	1.06 (1.00 to 1.14)	0.06	1.06 (0.99 to 1.13)	0.08
Adaptability	1.02 (0.96 to 1.09)	0.51	1.03 (0.96 to 1.09)	0.44
Reinforces parent	1.06 (0.94 to 1.21)	0.39	1.07 (0.94 to 1.22)	0.33
Demandingness	0.99 (0.93 to 1.06)	0.78	0.99 (0.93 to 1.05)	0.70
Mood	1.05 (0.94 to 1.19)	0.39	1.05 (0.94 to 1.19)	0.39
Acceptability	**1.18 (1.07 to 1.29)**	**0.001**	**1.17 (1.06 to 1.29)**	**0.002**
Parent domain	1.01 (0.99 to 1.02)	0.39	1.01 (0.99 to 1.02)	0.34
Competence	1.01 (0.96 to 1.06)	0.71	1.01 (0.96 to 1.06)	0.61
Isolation	1.03 (0.92 to 1.15)	0.37	1.04 (0.96 to 1.12)	0.32
Attachment	1.03 (0.96 to 1.11)	0.62	1.03 (0.91 to 1.15)	0.68
Health	0.99 (0.90 to 1.10)	0.87	1.00 (0.91 to 1.11)	0.97
Role restriction	1.02 (0.95 to 1.09)	0.60	1.02 (0.96 to 1.10)	0.51
Depression	1.04 (0.97 to 1.11)	0.69	1.01 (0.95 to 1.07)	0.80
Spouse	1.01 (0.95 to 1.08)	0.27	1.05 (0.98 to 1.12)	0.18
Total score	1.01 (1.00 to 1.01)	0.21	1.01 (1.00 to 1.01)	0.20
Life stress	1.05 (0.86 to 1.28)	0.66	1.05 (0.86 to 1.30)	0.61
SoC-13	1.00 (0.97 to 1.03)	0.95	1.00 (0.97 to1.03)	0.92

MDI: Mental Development Index of the Bayley Scales; BDI: Beck Depression Inventory; PSI: Parenting Stress Index; SoC-13: Sense of Coherence Scale
OR describes the risk of having a VLBW infant with poorer cognitive development when PSI score increases by 1 or SoC-13 score decreases by 1, or the risk of having a VLBW infant with poorer cognitive development when expressing significant amount of depressive symptoms (on BDI).
* Adjusted for multiple birth and neurosensory impairment.
Significant (p<0.05) associations are bolded.

delayed cognitive development (see Figure 7). The association between the fathers' depressive symptoms and the cognitive development of the child was significant (OR 4.09, 95% CI 1.31–12.77, p=0.01). The association remained significant after adjustment for selected background variables (OR 4.77, 95% CI 1.49–15.32, p=0.007).

A total of 132 (73%) mothers and 123 (68%) fathers returned the PSI questionnaire. Only one association between the parenting stress of the mothers and the cognitive development of the child was identified, namely between the subdomain of child *acceptability* and the MDI of the child (OR 1.18, 95% CI 1.07–1.29, p=0.001). However among the fathers, 4 out of 6 subdomains of the child domain were significantly associated with the MDI of the child (see Table 8). All of these associations remained significant after appropriate adjustments. The parent domain of the PSI in either of the parents, or any of its subdomains, was not associated with child MDI.

Fathers			
Unadjusted OR (95% CI)	p	Adjusted* OR (95% CI)	p
4.09 (1.31 to 12.77)	**0.01**	**4.77 (1.49 to 15.32)**	**0.007**
1.04 (0.97 to 1.10)	**0.002**	**1.04 (0.98 to 1.11)**	**0.002**
1.10 (1.03 to 1.19)	**0.009**	**1.09 (1.01 to 1.18)**	**0.02**
1.09 (1.01 to 1.18)	**0.03**	**1.10 (1.02 to 1.18)**	**0.02**
1.09 (0.95 to 1.26)	**0.22**	1.09 (0.94 to 1.25)	0.25
1.07 (0.99 to 1.16)	**0.08**	1.07 (0.99 to 1.16)	0.10
1.16 (1.00 to 1.34)	**0.05**	**1.19 (1.02 to 1.38)**	**0.02**
1.24 (1.11 to1.39)	**<0.001**	**1.26 (1.12 to 1.41)**	**<0.001**
1.01 (0.99 to 1.02)	0.27	1.01 (1.00 to 1.03)	0.17
1.04 (0.97 to 1.10)	0.28	1.04 (0.98 to 1.11)	0.20
1.07 (0.98 to 1.17)	0.13	1.08 (0.99 to 1.18)	0.09
1.14 (1.01 to 1.29)	**0.04**	**1.15 (1.01 to 1.31)**	**0.03**
0.98 (0.88 to 1.09)	0.07	0.99 (0.89 to 1.11)	0.92
1.00 (0.93 to 1.08)	0.96	1.02 (0.94 to 1.11)	0.59
1.05 (0.97 to 1.13)	0.22	1.05 (0.98 to 1.14)	0.19
1.04 (0.97 to 1.13)	0.25	1.05 (0.98 to 1.13)	0.19
1.01 (1.00 to 1.02)	**0.04**	**1.01 (1.00 to 1.02)**	**0.03**
0.88 (0.69 to 1.12)	0.29	0.89 (0.70 to 1.13)	0.32
1.07 (1.01 to 1.12)	**0.04**	1.03 (1.00 to 1.07)	0.06

Of 182 parents, 113 (62%) mothers and 102 (56%) fathers returned the SoC-13 questionnaire. There were no significant associations between the SoC of the mother and child MDI (see Table 8). Also the significance of the association between fathers' SoC and child MDI (p=0.04, OR 1.07, 95% CI 1.01–1.12) vanished after adjustments.

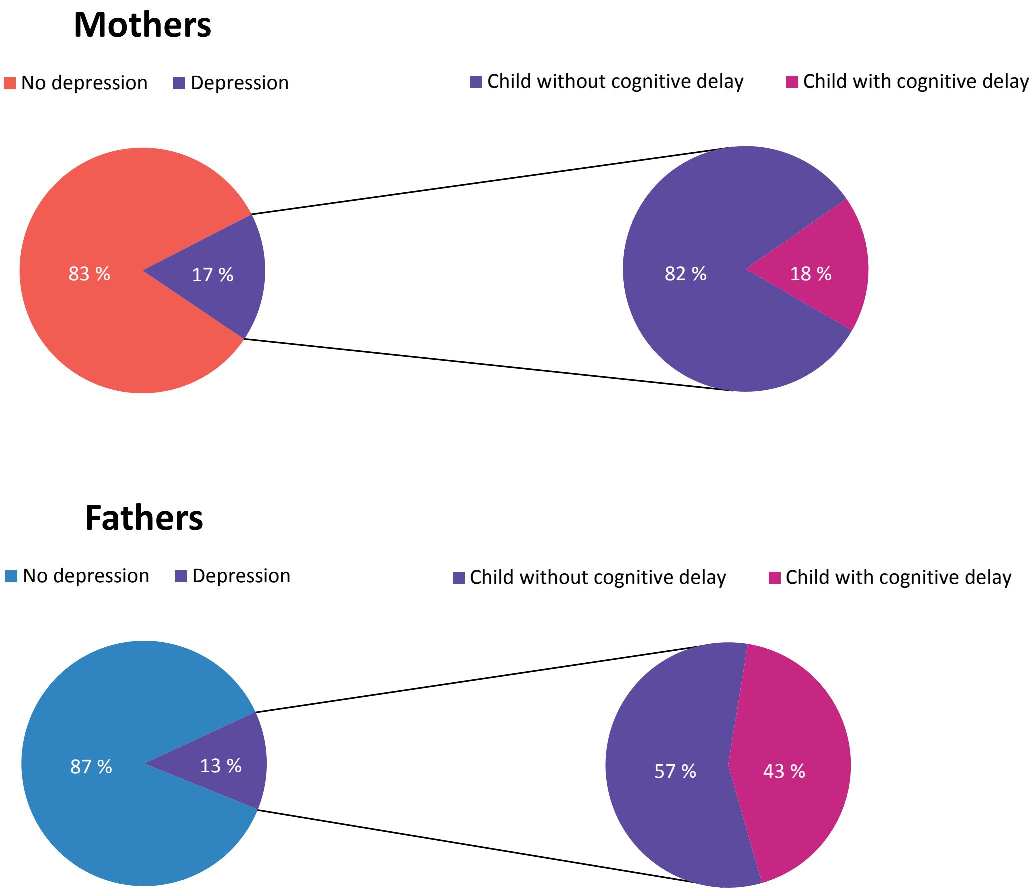

Figure 7 Depressive symptoms of the parents and cognitive development of the child.

5.3.6 Associations between parental psychological well-being and behavioral development of VLBW children age 3 years (II)

Table 9 shows the adjusted associations between parental measures and scores for behavioral problems in VLBW children aged 3 years. The associations were adjusted for child MDI and educational level of the mother, since these factors out of all neonatal and background factors were significantly associated with the CBCL scores of the child (see 5.2.2). All associations were significant even after adjustment, except the associations between the father's depressive symptoms or SoC, and externalizing behavior problems of the child.

Table 9 Adjusted associations between scores defining psychological well-being of the parents and child behavioral problem scores. (Huhtala et al. 2012)

	CBCL total score Regression coefficient (95% CI)	**CBCL Internalizing problem score** Regression coefficient (95% CI)	**CBCL Externalizing problem score** Regression coefficient (95% CI)
BDI			
Mothers n=110	**0.92 (0.45 to 1.39)**	**0.22 (0.06 to 0.39)**	**0.42 (0.23 to 0.62)**
Fathers n=102	**0.56 (0.02 to 1.11)**	**0.24 (0.07 to 0.41)**	0.08 (-0.16 to 0.31)
PSI			
Mothers n=111			
Total score	**0.24 (0.17 to 0.32)**	**0.07 (0.04 to 0.09)**	**0.11 (0.08 to 0.14)**
Child domain	**0.33 (0.20 to 0.45)**	**0.14 (0.09 to 0.19)**	**0.24 (0.18 to 0.29)**
Parent domain	**0.50 (0.35 to 0.65)**	**0.09 (0.04 to 0.13)**	**0.13 (0.08 to 0.19)**
Fathers n=108			
Total score	**0.21 (0.11 to 0.31)**	**0.05 (0.02 to 0.08)**	**0.08 (0.04 to 0.13)**
Child domain	**0.37 (0.16 to 0.59)**	**0.09 (0.03 to 0.15)**	**0.17 (0.08 to 0.26)**
Parent domain	**0.33 (0.19 to 0.48)**	**0.09 (0.05 to 0.14)**	**0.11 (0.04 to 0.17)**
SoC-13			
Mothers n=99	**0.57 (0.27 to 0.86)**	**0.15 (0.05 to 0.26)**	**0.27 (0.15 to 0.39)**
Fathers n=91	**0.43 (0.08 to 0.77)**	**0.15 (0.03 to 0.26)**	0.10 (-0.05 to 0.24)

Associations are adjusted for mental development index of the child and maternal education. Associations are significant when 95% confidential interval (CI) does not include value 0 (e.g. one point increase in mother's BDI score was associated with 0.92 point increase in CBCL total score).
Significant associations are bolded.

5.3.7 Associations between parental psychological well-being and socio-emotional and functional development of VLBW children at age 5 years (III)

Table 10 shows the adjusted associations between parental measures and scores describing the socio-emotional and functional development of VLBW children by age 5 years. The depressive symptoms of the mothers measured with the BDI (at the child's age of 4 years) were significantly associated with all of the child developmental areas at age 5 years (social skills, behavioral problems and executive function). However, the depressive symptoms of the fathers were not associated with any of the domains measuring child development. All maternal measures of parenting stress (total score and scores for child and parent domain) were associated with all of the child development measures. The measures of parenting stress were also associated with the child development measures, except the association between parent domain PSI and executive function of the child. The mothers' SoC was associated with all the child development measures, but the paternal SoC was not associated with any of them.

Table 10 Adjusted associations between scores defining psychological well-being of the parents and socio-emotional development of the VLBW children. (Huhtala et al. 2014)

FTF at 5 years	**Social skills**[a] RR (95% CI)	**Emotional/ behavioral problems**[b] RR (95% CI)	**Executive function**[c] RR (95% CI)
BDI			
Mothers	**1.06 (1.02 to 1.09)*** **	**1.06 (1.03 to 1.09)*** **	**1.05 (1.03 to 1.07)*** **
Fathers	1.02 (0.97 to 1.06)	1.01 (0.98 to 1.05)	0.99 (0.96 to 1.02)
PSI			
Mothers			
Total	**1.01 (1.01 to 1.02)*** **	**1.01 (1.01 to 1.01)*** **	**1.01 (1.00 to 1.01)*** **
Child domain	**1.02 (1.02 to 1.03)*** **	**1.02 (1.01 to 1.03)*** **	**1.02 (1.01 to 1.02)*** **
Parent domain	**1.02 (1.01 to 1.02)*** **	**1.01 (1.01 to 1.02)*** **	**1.01 (1.00 to 1.01)*** **
Fathers	**1.01 (1.01 to 1.02)*** **	**1.01 (1.00 to 1.01)** **	**1.00 (1.00 to 1.01)* **
Total			
Child domain	**1.03 (1.02 to 1.04)*** **	**1.02 (1.01 to 1.02)*** **	**1.01 (1.00 to 1.02)** **
Parent domain	**1.02 (1.01 to 1.03)*** **	**1.01 (1.00 to 1.02)* **	1.01 (1.00 to 1.01)
SoC-13			
Mothers	**0.95 (0.94 to 0.97)*** **	**0.96 (0.95 to 0.98)*** **	**0.97 (0.96 to 0.98)*** **
Fathers	0.99 (0.96 to 1.01)	0.99 (0.97 to 1.01)	1.00 (0.98 to 1.01)

RR: rate ratio; E.g. one point increase in mother's BDI score was associated with 1.06-fold increase in FTF social skills score.

Associations are significant when 95% confidence interval does not include value 1. Significant associations are bolded.

*p<0.05; **p<0.01; ***p<0.001

FTF: Five to Fifteen parent questionnaire; BDI: Beck Depression Inventory; PSI: Parenting Stress Index; SOC-13: Antonovsky's Sense of Coherence Scale

Higher scores on BDI and PSI indicate more depressive symptoms and stress, respectively. Higher scores on SOC-13 indicate better sense of coherence.

a Adjusted for gestational age, birth weight, days of hospitalization in a level III hospital, and mental development index.

b Adjusted for maternal education.

c Adjusted for birth weight, gender, days of hospitalization in a level III hospital, and maternal education.

6 DISCUSSION

This prospective longitudinal follow-up study gives insight into the psychological well-being of both of the parents, and into the development, morbidity and health-related quality of life (HRQoL) of a cohort of preterm infants born with a very low birth weight (VLBW, ≤1500 g) in the beginning of the 2000's and followed for 6 years. The associations between the factors were studied as the children developed from toddlers to schoolchildren. The burden of the prematurity-related morbidity to the children themselves and to the family was addressed.

6.1 Psychological well-being of the parents and family resilience in the families of premature children

6.1.1 Depression

A total of 16% of the mothers reported significant depressive symptoms both when the VLBW child was 2 years of corrected age and at 4 years of age. Previous studies have reported varying prevalence figures for depressive symptoms experienced by mothers of prematurely born children, depending on the definition of depressive symptoms and on the time since delivery (Garfield et al. 2015, Vigod et al. 2010, Davis et al. 2003, Mew et al. 2003). Usually, the depressive symptoms of the mothers diminish over time, also in preterm populations (Silverstein et al. 2010). The high percentages shortly after the birth of a premature infant have been thought to reflect the unexpected and unusual nature of the premature birth, medical complications and procedures, and the natural worry about the child's survival and future (Davis et al. 2003, Mew et al. 2003). However, the correlates for depressive symptoms change over time (Mew et al. 2003), as the mothers experience the stressors differently than the father (Gutierrez-Galve et al. 2015, Lindberg et al. 2007, Jackson et al. 2003). The prevalences of maternal depression in the present study are comparable to the prevalences reported in previous studies; rates of maternal depression of 12% in families with 2-year-old low birth weight children (Poehlmann et al. 2009) and of 19% among mothers of VLBW preschoolers (Silverstein et al. 2010) have been published.

Some 11% of the fathers reported significant depressive symptoms when the VLBW child was at 2 years of corrected age and 8% when the child was 4 years. The mean scores of the fathers were approximately 2.5 points lower than the scores of the mothers. Previously, the mean BDI score of men has been approximately two points lower than of women in large studies (Beck et al. 1988), which supports the present finding. There is a paucity of studies reporting rates of depressive symptoms in the fathers of prematurely born children, and the existing ones report rates no later than during the postpartum period (approximately 6 to12 weeks after the birth) (Cano Giménez and Sánchez Luna

2015, Mehler et al. 2014, Mackley et al. 2010). The present study adds valuable data to the existing knowledge on later depressive symptoms experienced by fathers of the prematurely born children.

6.1.2 Parenting stress

When the VLBW children were 2 years of corrected age, the mothers experienced more parenting stress than the fathers, as also reported by a recent Norwegian intervention study (Landsem et al. 2014). The parenting stress of the mothers was more parent-related than child-related. On the other hand, the parenting stress of the fathers was more child-related than parent-related. This means that parenting stress to the mothers of premature children arose from the mother's own personality, vulnerability, attachment to the child and relationship to her spouse. The main causes of parenting stress experienced by the fathers are based on the characteristics of the child which made it difficult for the fathers to fulfill their roles as parents. Still two years later, when the VLBW children were 4 years old, the mothers reported more parenting stress than the fathers. At this age, the parenting stress experienced by the mothers was primarily caused by child-related factors rather than parent-related factors. The parenting stress of the fathers was, again, caused by child-related factors. Also according to a previous Finnish general population-based study (Saisto et al. 2008), the fathers of the 2 to 3 year-old children reported parenting stress to be mainly child-related. The current study found that the amount of total parenting stress of both of the parents diminished over time, which is in parallel with previous studies (Landsem et al. 2014, Singer et al. 2007). However, the parenting stress for both parents caused by child characteristics increased over time. As the preterm child grows, the less severe impairments (Potharst et al. 2011, Roberts et al. 2011, Elgen et al. 2002) of the child might become more evident and the sources of parenting stress are modulated.

6.1.3 Sense of coherence

At 2 years of corrected age and at 4 years of chronological age the SoC scores of both parents were good. The scores of the fathers were slightly but significantly higher than the scores of the mothers implying a better SoC of the fathers than the mothers. This finding agrees with a previous finding that men usually have a slightly better SoC than women (Eriksson and Lindström 2005). Interestingly, our study showed even better SoC for both parents than a previous study on the average population in Finland (Honkinen et al. 2006) and a study on developmental disabilities in Sweden (Olsson and Hwang 2002). According to Antonovsky, who developed the theory of SoC (Antonovsky 1987), individuals with a strong SoC are capable of taking an active role in life and taking advantage of available resources. Consequently, in the current study, strong SoC seemed to protect both of the parents from depression and parenting stress. Thus, SoC may serve as a source of resilience in the families of premature children. This finding supports earlier research according to which low SoC subjects parents to depression (Olsson and

Hwang 2002). To my knowledge, the SoC of parents of preterm children has not been studied before.

6.1.4 Family functioning

Family functioning was good both in families of VLBW and of FT children. However, it was not as good in the families of VLBW children with prematurity-related morbidity compared to control families or to families of healthy VLBW children. This result agrees with a previous study showing that in 8-year-old extremely low birth weight children, the functional impact of chronic conditions predicted a negative impact on the family (Drotar et al. 2006). We might expect that, if the child has disabilities, the parents may experience maladjustment and distress, which is then reported in the form of poorer family functioning. This assumption is supported in a recent study, which also found an association between parenting stress and family functioning among the parents of 7-year-old very prematurely born children (Treyvaud et al. 2014). The same study found that the general functioning of the families of very prematurely born children is poorer than of control families, and even poorer if the child has neurodevelopmental or other disabilities (Treyvaud et al. 2014). Based on the current study and previous knowledge, we suggest that parenting stress and problems in family functioning are likely to continue throughout childhood in families of prematurely born children, especially if the child has disabilities.

6.2 Development, morbidity, and health-related quality of life of VLBW children

6.2.1 Cognitive development

The cognitive development of VLBW children of the PIPARI Study at the corrected age of 2 has been published and discussed previously (Munck et al. 2010). The mean mental development index (MDI) of the VLBW children (101.7) was compared with the American normative data of the BSID-II (mean 100, SD 15) (Bayley 1993). Only 3% of the VLBW infants in our study had MDI <70. In addition, the MDI of the VLBW infants was at or above the average of the current research results on premature children of same age born in the 2000's (Bode et al. 2009, Maguire et al. 2009, Treyvaud et al. 2009, Johnson et al. 2008, Wilson-Costello et al. 2007). However, the inclusion criteria for the previous studies were not identical to ours. When comparing the cognitive level of the VLBW infants to the full-term control group of the present study, 59% of the VLBW children had normal cognitive development (MDI score above -1 SD), 25% a mild delay (MDI score -1 SD – 2 SD) and 15% a significant delay (MDI score below -2 SD) in their cognitive development. The more positive cognitive development in our unselected study population may be due to different treatment strategies, and the rather small variation in the socio-economic background characteristics in Finland compared to other countries. Other factors protecting the cognitive development of premature infants in Finland may be free antenatal clinics enabling close monitoring of pregnancies, maternity leave of nine months and paternity leave of about nine weeks (from term age in premature infants). The protective influence of maternity and child care clinics on early child development would be impossible to study in a controlled, clinical setting because these free services reach almost 100% of the families residing in Finland (National Institute for Health and Welfare/Birth register, unpublished statistics).

6.2.2 Behavioral and emotional development

At child age 3 years, most of the parents did not report behavior problems in their VLBW children. Only 7% of the VLBW children had clinically significant behavior problems according to the American norm data ($\geq 90^{th}$ percentile) (Achenbach 2001). The rate reported here is also smaller than in a previous study on the behavioral problems in low birth weight children (Gray et al. 2004). Our numbers were 5% for internalizing and 7% for externalizing problems. Compared to our results, more behavior problems in the clinical range (total problem score) have previously been reported in 3-year-old children born with low birth weight the 1980's (21%) (Gray et al. 2004) and in 5-year VLBW children born in the early 1990's (13%) (Reijneveld et al. 2006). However, similar scores implying behavior problems have been reported in a Norwegian study on 2-year-old (age corrected for prematurity) low birth weight children born between the late 1990's and the early 2000's (Kaaresen et al. 2008). There was no significant difference in behavioral problems between the genders, which corroborates a previous study on premature children (Kaaresen et al. 2008). The VLBW children in the current study had the more behavioral problems the lower their level of cognitive development. This finding was not fully comparable with a previous study which did not find any association between cognitive deficits and behavioral problems in prematures (Conrad et al. 2010). The encouraging finding of our results for parents of premature children was that the mean scores for behavioral problems were similar to the ones reported for a non-selected Finnish population sample of 3-year-olds (Sourander 2001). The rather low rate of behavior problems may be due to the same factors as the good level of cognitive development of VLBW infants: the variation in the socio-economic background is rather small, which is typical for the Finnish society, and the well-child clinics are free of charge, which generates an attendance rate of almost 100% (National Institute for Health and Welfare/Birth register, unpublished statistics).

At 5 years of age, the VLBW children had more developmental problems compared to the Finnish normative children of same age (Korkman et al. 2004, Korkman et al. 2005). A total of 2.5% of our VLBW children had considerable difficulties ($>98^{th}$ percentile of the norms) in their social skills, in emotion and behavior, as well as in their executive functioning. A total of 21% were at risk for social problems ($>90^{th}$ percentile of the norms), 15% were at risk for emotional and behavioral problems and 21% were at risk for problems related to executive function. However, the percentages of VLBW children within the normal range were high: 63.4% for social skills, 64.0% for emotional and behavioral problems and 61.5% for executive functioning. The results of the behavioral and social development of the 5-year-old VLBW children were comparable to the population covering the VLBW infants of the whole Finland born during 2001–2002 (Rautava et al. 2010). That study also demonstrated that VLBW children had more developmental problems compared with the control children of similar age (Rautava et al. 2010). Also, 5-year-old extremely premature children have more problems of attention, behavior and social skills compared with control children, but the difference is not significant in preterm children with normal intellectual development (Hoff et al. 2004). Comparing the results of the behavioral problems reported for VLBW children at age 3 and at age 5, it seems that VLBW children exhibit an increase in the occurrence of problems of emotion and behavior as they grow from infants to preschoolers. The emotional and behavioral problems of prematurely born children may become more evident as the children get older and socially more active. Another explanation is that the FTF questionnaire used at age 5 is more comprehensive than previous assessments which may bring forth more subtle aberrations.

6.2.3 Prematurity-related morbidities and health-related quality of life

The majority of the VLBW children survived without prematurity-related morbidities up to nearly 8 years of age. A percentage of 64.5% for healthy VLBW children is in line with previous studies which have reported that 66.2 % of the VLBW children survive without chronic conditions up to 3 years of age in Finland (Korvenranta et al. 2009), 62.5% of very preterm children survive up to 5 years without severe disabilities (Potharst et al. 2011) and 68% up to 10 years without neurodevelopmental disorders (Brévaut-Malaty et al. 2010). A total of 5.2% of the VLBW children had cerebral palsy, 3.2% hearing impairment (sensorineural hearing loss, conductive hearing deficits, or hearing impairment requiring amplification), 12.9% visual impairment (strabismus, amblyopia, refractive errors, or blindness), 1.9% epilepsy, 18.7% obstructive airway disease, 4.5% ADHD, 3.2% significant cognitive delay (FSIQ <70), and 1.9% short stature. Previous studies have reported a prevalence of 1 to 12% of cerebral palsy (Abily-Donval 2015, Doyle et al. 2010, Larroque et al. 2008, Platt et al. 2007, Wilson-Costello et al. 2007), 1 to 5% of hearing impairment (Doyle et al. 2010, Larroque et al. 2008, Vohr et al. 2005), 0 to 4% of visual impairments (usually reported as unilateral or bilateral blindness) (Doyle et al. 2010, Vohr et al. 2005, Larroque et al. 2008), 1 to 2% of epilepsy (Abily-Donval 2015), 9 to 13% of obstructive airway disease (Vrijlandt et al. 2005), 6 % of ADHD (Taylor et al. 2000), 4 to 15% of severe cognitive impairment (Doyle et al. 2010, Taylor et al. 2000), and 8% of subnormal weight and height (Hack et al 1996). However, the cohorts of the previous studies are not fully comparable to ours, since they have included, e.g., only the most severe impairments, younger or older children, only very preterm infants or ELBW infants, or infants born in the 1980's or 1990's.

The current study shows that the health-related quality of life (HRQoL) of VLBW children at 7 to 8 years of age is associated with prematurity-related morbidities. The VLBW children with one or more morbidities have a lower total score and a lower score in 9 of the 17 dimensions of the HRQoL measure (*vision*, *hearing*, *breathing*, *eating*, *speech*, *excretion*, *learning & memory*, *appearance*, and *concentration*) than control children. This finding is in line with a previous study on HRQoL of premature children, which reported that the HRQoL of the preterm children at 6 to10 years of age was lower compared to the reference population, and that the presence of major neurocognitive disorder (cerebral palsy, blindness, deafness, comprehensive retardation or epilepsy) is associated with a lower HRQoL (Berbis et al. 2012). Importantly, however, the health and function of the healthy VLBW children do not differ from the FT children. This is an important finding since it impacts counselling of parents of preterm children. There was only one variable that had a poorer score among healthy VLBW children compared to the FT children, *excretion*. The difference in *excretion* might be by chance (α risk), since multiple comparisons were made on the same data set and since it turned out to be the only significant difference. The problems in urine and bowel functions are not over-represented in premature infants (Rautava et al. 2010).

6.3 Associations between psychological well-being of the parents and outcomes of prematurely born children

At 2 years of corrected age, depression was more common among the mothers than the fathers of the VLBW children. However, the depressive symptoms of the mothers were not associated with the level of cognitive development of the child, as were the depressive symptoms of the fathers. This finding is parallel to a previous study which also found no correlation between the depression of the mothers and the cognitive level of the child at either 11 months or 4 years of age (Silverstein et al. 2010). This is a most relieving result for the mothers with postpartum depression after delivery of a premature infant. Parenting stress experienced by the mothers was not, for the most part, associated with the cognitive level of the child at 2 years of corrected age. These findings may indicate that the mothers of the premature infants have good coping mechanisms and, therefore, may deal successfully with the many challenges of delayed cognitive development of the child (Singer et al. 2007). Parents with a high level of SoC had also less depressive symptoms. Therefore, the stronger SoC might explain the fewer depressive symptoms in the parents of cognitively delayed children. This suggestion is supported by a previous study which concluded that having a strong SoC will probably help the parents of the children with intellectual disability to view parenting as an enjoyable challenge (Olsson and Hwang 2002).

It is noteworthy that in the 2-year-old VLBW children it is the father who may not find ways to interact with the infant with a developmental delay or who may have a poor ability to handle stressful situations. When the child was 2 years old, the fathers expressed more depressive symptoms and higher levels of parenting stress (particularly related to child characteristics) if their VLBW child had delayed cognitive development, compared to the fathers of non-cognitively impaired children, i.e., paternal depression may be a reaction to the child's poor cognitive development. On the other hand, poor psychological well-being of the fathers might not support the cognitive development of the child, and this may lead to depressive symptoms. These interpretations are supported by the finding that the parenting stress of the father was for the most part caused by child characteristics and also related to depressive symptoms. However, the associations most probably are bi-directional and thus it is impossible to determine the causes and the consequences.

At 3 years of age, the behavioral problems of the VLBW children were associated with depressive symptoms, parenting stress and a low SoC of both parents. Findings presented here support previous works on 3-year-old prematurely born children that significant behavior problems are predicted by maternal psychological distress (Gray et al. 2004), and that depressive symptoms and parenting stress of the mothers are related to internalizing and externalizing behavior problems of the children (Miceli et al. 2000). The current study adds to these observations: also the psychological well-being of the fathers contribute to the behavioral development of the prematurely born child. However, externalizing behavioral problems were more strongly associated with the psychological well-being of the mothers than of the fathers. As the father-infant interaction involves more playing and stimulation than other forms of care-taking (Yogman et al.1995, Levy-Shiff and Mogilner 1989), fathers might find it easier than mothers to tolerate externalizing behaviors of the preterm child.

By the time the premature child was 5 years old, the depressive symptoms and low SoC of the mothers, but not of the fathers, correlated with problems in social skills, emotion and behavior and executive functioning in the VLBW children. Our findings concerning the mothers corroborate previous studies (Giles et al. 2011, Silverstein et al. 2010) which conclude that depressive symptoms of the mothers is associated with behavioral problems and impaired social skills and abilities of their preschool-aged VLBW children. The effect of depressive symptoms and poor SoC of the fathers on child development may fade off over time, or, alternatively, the fathers of preterm children with developmental impairments learn to cope. In families with a depressive father, there might be other persons, or the mother, who compensate for the effect on the child's development. This assumption is supported by a recent population-based study, which found that the effect of paternal depression on child behavior is strongly mediated by family environment (Gutierrez-Galve et al. 2015). Other previous studies have shown that fathers may leave the major responsibilities of routine child care to the mothers (Craig and Mullan 2011, Craig 2006). Therefore, the depression of the mothers may have a stronger effect on the development of the prematurely born child of preschool age. The parenting stress of both parents was associated with the social, behavioral and functional development of the VLBW children of preschool age, adding important information on the long-term impact of parental psychological well-being on the development of preterm children.

In summary, the associations between different aspects of parental and family well-being and child development in the preterm populations are complex and multidirectional. It is impossible to distinguish whether the psychological well-being of the parents is the cause or the consequence of the child's development. Relationships most probably are bi-directional and time-dependent (Miceli et al. 2000). In addition, the development of the child may be impaired in the families where risk factors cumulate. The precursors of a suboptimal development may lie in the early pre- and postnatal period. The preterm birth of a vulnerable child at high risk may initiate a transactional process, as the parents are not prepared emotionally and may find the situation threatening (Lindberg et al. 2007, Dudek-Shriber 2004, Jackson et al. 2003) with feelings of anxiety, loss of control, role alteration, separation from the infant, and fear for the survival of the infant (Rogers et al. 2013, Sloan et al. 2008, Miles et al. 2007). However, the experiences and stressors of having a prematurely born child are different between mothers and fathers (Pohlman 2005).

The behavioral cues of the premature baby may be difficult to interpret, and require a high level of parental sensitivity to create and promote a supportive parent-child relationship (Clark et al. 2008). Prematurely born children may express different regulation patterns compared with full-term children, which may affect the parenting styles and the responsiveness of the parents (Hughes et al. 2002). The early parent-child relationship affects the later development and skills of the child (Boyce et al. 2015, Ramchandani et al. 2013, Trautmann-Villalba et al. 2006, Miceli et al. 2000). Prematurity and child disability have a long-lasting negative effect on the psychological well-being of the parents (Treyvaud et al. 2014, Cacciani et al. 2013, Singer et al. 2007). Long-term distress, even subclinical, carries the potential risk for affecting the development of the child disadvantageously (Pierrehumbert et al. 2003, Poehlmann and Fiese 2001, Singer et al. 1999). Likewise, a stimulating home environment enhances the cognitive development, behavioral regulation and socio-emotional competence of children born very preterm (Treyvaud et al. 2012).

Figure 8 shows graphically the associations between the psychological well-being of the parents and the development of prematurely born children. The figure is based on the relevant literature and the findings of the present studies.

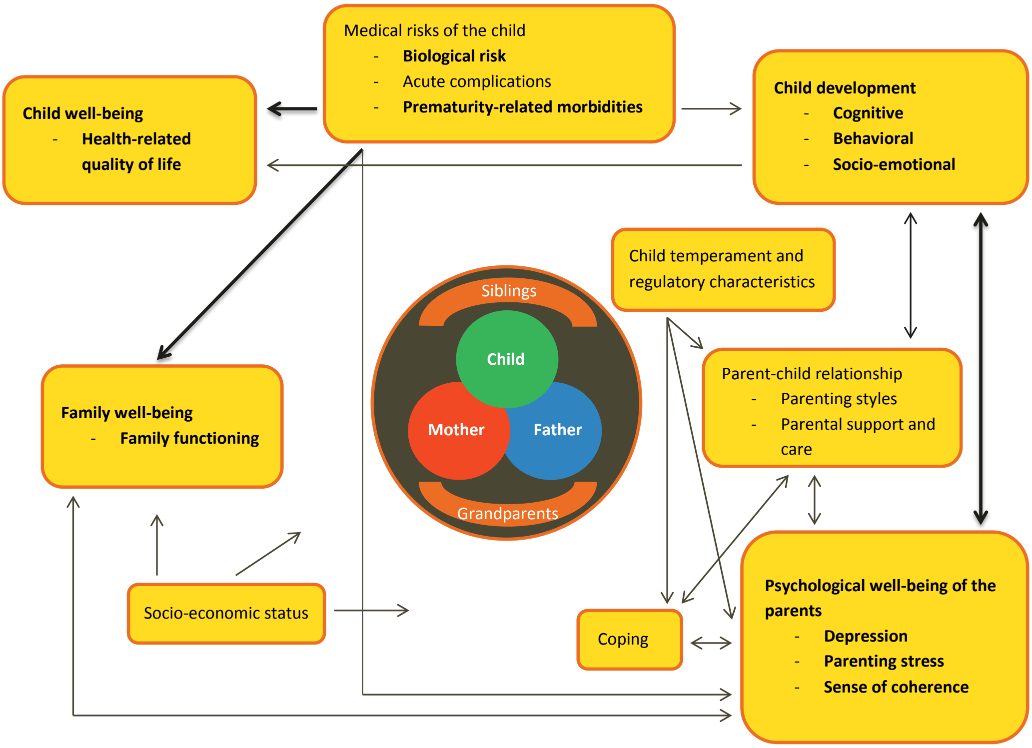

Figure 8 Complexity of the associations between the psychological well-being of the parents and child outcomes of the prematurely born children based on the present and previous studies. Findings of the present study are bolded.

6.4 Strengths and limitations of the study

6.4.1 Participants

This study included the preterm infants born with a birth weight ≤1500 g and included also the infants with intrauterine growth retardation (small for gestational age, SGA) and multiple pregnancy infants. In previous studies, the preterm infants have commonly been grouped by birth weight, since the accuracy of estimating the gestational age has been uncertain (Hack & Fanaroff 1999). Nowadays, the determination of gestational age is more accurate with the use of obstetrical sonography, but the birth weight continues to be a significant marker of the degree of prematurity. Accordingly, a birth weight-based inclusion criterion facilitated comparison of the results with previous studies. We also consider the unselected study population of ours (SGA infants, the infants with neurosensory and neurodevelopmental impairments and infants born from multiple pregnancies) as strengths of this study since all of these subgroups are well-represented in preterm populations.

This study had a monocentric setting and was therefore vulnerable to selection bias. This study was conducted in one of the five university hospitals in Finland. The preterm births in Finland are, however, usually centralized to level III hospitals and therefore the population in this study represents a larger region than only a single city. There are no differences between the university hospital districts of Finland in the rate of prematurity, nor are there significant differences in the background factors (PERFECT Preterm Infant report, Institution of Health and Welfare: https://www.thl.fi/fi/tutkimus-ja-asiantuntijatyo/hankkeet-ja-ohjelmat/perfect/osahankkeet/keskoset/perusraportit). The variation in socio-economic background characteristics within Finland is small and this may be a limitation as well as a strength of this study. The Finnish VLBW population may not be representative of other preterm populations, such as more disadvantaged or culturally more diverse populations, where the prematurity is often associated with a low socio-economic status of the parents. The parents of the VLBW children of this study were, on average, older and less educated than the parents of the control children. This difference may not have been significant for a larger study sample. In addition, the full-term control children of this study were extremely healthy, since we excluded all children with congenital genetic anomalies or syndromes, with birth weight < -2.0 SD according to age and gender-specific Finnish growth charts (small for gestational age), all whose mother self-reported use of illicit drugs or alcohol during pregnancy, and all who had been admitted to neonatal intensive care for any reason during the first week of life. The strength of the limited socio-economic variance reduces the impact of confounding effects of socio-economic factors on the results.

6.4.2 Methods

The methods of this study were not only valid and reliable, but they are also used by the international scientific community and often mainstream assessments were employed. The cognitive development of the children was assessed by clinical examinations. Although the examiners were not blinded with respect to the birth status of the children, all assessments were done according to highly standardized testing instructions. For children aged 3 years, we relied only on parental ratings of behavior and emotion of the children. Therefore, it is not possible to estimate the degree of the parents' subjective opinions on the answers. Previous studies have shown that maternal psychopathology may influence the ratings of the behavior of their preschool children (Müller et al. 2011) and that depressive symptoms of the mothers are associated with a negative perception of the social skills of their children (Silverstein et al. 2010). Therefore, we do know if the parents experiencing poor psychological well-being have perceived and reported the behavior of their child more negatively than other parents. However, any non-optimal psychological well-being of the parent may have affected the parent-child relationship and the childrearing practices influencing the behavioral development of the child. Or, vice versa, the behavioral problems of the child may have caused psychological distress for the parents. The reports of other caregivers may have produced different results. Nevertheless, for reports by proxy, parents are the natural and obvious experts for evaluating the behavior of their own child.

When the children were 5 years old, we were able to explore whether the parents' psychological well-being had an influence on how they perceived and reported their child's behavior and development by asking the day-care providers to complete the questionnaire on the child, as well. We found that the psychological well-being of the parents did not affect the amount of problems they reported for their children when compared to the reports of the day-care providers. As expected, the day-care providers reported that the children born preterm had more social problems, attention deficits and hypoactivity than did the parents. The challenging group situation of the day-care environment may provoke problems in social skills and in executive function even if the child can compensate for them at home.

The 17D questionnaire (Apajasalo et al. 1996) was used to assess the self-reported health and functioning, and health-related quality of life (HRQoL) of prematurely born children. At 7 to 8 years, the children were asked to anwer the questions on several dimensions of their HRQoL at home. If the children were not able to read, or had some other problems in filling in the questionnaire, the parents were allowed to help. We are aware of the fact that the parents of the VLBW and of the control children may have helped their children to answer the questionnaire. The items were quite simple to choose from with explanatory illustrations and time was unlimited for filling in the questionnaire. However, the answers of the children whose parents helped them may have been different if they had completed the questionnaire by themselves. The HRQoL questionnaire of this study has been developed for 8-to-11-year-old children. The children of the current study were almost 8 years old (mean age of VLBW children 7.8 years and of FT children 7.9 years) at the time of when they filled in the questionnaire. The reading skills of Finnish children are quite sufficient by that age, and most children in this study were able to read the questions. At the end of first grade, the reading accuracy level of Finnish children is around 85% (Aro and Wimmer 2003). 75% of the 5-year-old Finnish VLBW children have normal pre-reading skills (Munck et al. 2012b). In addition, children can self-report their HRQoL already at age 5, when an age-appropriate instrument is used (Varni et al. 2007).

The total HRQoL scores of the 17D are calculated from the preferences of a sample of parents of healthy 8-to-11-year-old children. The choice of using the parents in the valuation of HRQoL domains was discussed in the study which originally introduced the 17D (Apajasalo et al. 1996). The authors concluded that parental input was necessary because pre-adolescent children are not usually capable of abstract thinking, which is required for evaluation of the dimensions in relation to each other (Apajasalo et al. 1996). The evaluation system based on parental preferences may have affected the total HRQoL scores of the children. However, it had no effect on the dimensional scores of HRQoL or on the comparison of the dimension scores between the different study groups. The HRQoL questionnaire of the present study focuses mostly on the child's ability to carry out usual tasks, the functional status, with little regard to children's psychosocial state. Even if some of the parents helped the children (both VLBW and FT children) to fill in the questionnaire, the previous research has found rather good agreement between the children and their parents in the observable and physical domains of HRQoL (De Civita et al. 2005, Eiser&Morse 2001). Some of the questions of the 17D questionnaire may carry emotional implications and the children may have answered these questions in a socially desirable way. This shortcoming may have introduced some bias in the data collection.

6.4.3 Results

The major strength of this study (and the PIPARI Study) is that the data were based on a controlled follow-up study of virtually all VLBW infants of a given geographic area and a given time period. The attrition rates for all the studies were rather small although no reminders were sent for some of the questionnaires. The response rates to some of the questionnaires (SoC-13, 17D) were lower than desired, but still adequate from the point of view of a regional study population, and the drop-out analyses were accurate. The drop-out status in each original study was related to an unfavorable socio-economic status (i.e., the non-responders smoked more often, were more often divorced, had fewer educational years or were more often unemployed compared to the responders) and including these responses may have strengthened our findings even further.

In Finland, the health and development of each and every child, independent of if they are born prematurely or full-term, are systematically followed up in the well-baby clinics. However, our study did not have access to the medical records of the primary health care, well-baby clinics, private health care, or to the medical records of other hospital districts. The morbidities were gathered from the medical records of the hospital and additional information was asked from the parents and the school nurses. We think that this was needed since we did not have access to the medical records of the well-baby clinics, the primary health care, the private health care, or other hospitals. However, all the major disabilities (CP, delayed development, disabilities in hearing and vision, epilepsy, and ADHD) are always diagnosed in the special health care in Finland. The diagnosis of an obstructive airway disease can also be done in the primary health care and the diagnosis of it has national criteria. The diagnoses reported by the parents of the 5-year-old Finnish preterm children have shown to be reliable (Rautava et al. 2010).

Most of what we know about the associations between parental well-being and child development has been based on studies focusing on the mothers. This is the case for studies on preterm infants (Silverstein et al. 2010, Veddovi et al. 2004, Miceli et al. 2000) and other populations (Kim-Cohen et al. 2005, Herwig et al. 2004). In the present study, also the fathers were included and data was collected independently from the mothers and the fathers. The associations between the psychological well-being of the mothers and of the fathers, and child development were analyzed and discussed separately. This is important, as in many societies the fathers provide only little child care and when they do so, it is of a different kind and quality compared to the maternal care (Craig 2006, Garfield and Isacco 2006, Hewlett 2000). In Finland, as in the other Nordic countries, the fathers are often more involved in child care than in many other countries, and they tend to spend more time with their children than in the past (Craig and Mullan 2011, Hobson 2002). The fathers in Finland have the opportunity to become involved in the care of their child during paternal and parental leaves, and they can be the primary care-giver to the child. Involving and including the fathers in the current study is a strength, but the results cannot be generalized to all countries due to cultural variation (Hobson 2002, Hewlett 2000). In Finland, all of the children with special needs have the opportunity to attend either special schools or mainstream schools where they are integrated with the support of special educational services. Finland provides services of antenatal clinics and well-child clinics free of charge, and this enables close monitoring of the pregnancies, the child and the family. The duration of the maternity leave is nine months (from term age in premature infants) and of the paternity leave about nine weeks. In addition, family stability is high. In the present study, only 7% of the parents had divorced or separated by the time the child was 2 years old. All these factors may have influenced our positive results on child development and quality of life.

A limitation of this study was not to assess the psychological well-being of the parents of the control children nor the behavioral and socio-emotional development of the FT children. Thus, it is not possible to state whether the associations between the psychological well-being of the parents and the outcomes of the child are typical for the families with a premature infant in Finland. This may, in fact, not be the case, since the psychological well-being of the mothers, as well as the fathers, is associated with developmental and behavioral problems of children in several pediatric and general populations (Verkleij et al. 2015, Weitzman et al. 2011, Hassall et al. 2005, Kim-Cohen et al. 2005, Herwig et al. 2004, Baker et al. 2003, Smith et al. 2001). Questions addressing general family functioning were, however, asked from the parents of the FT children. Examining the effect of parity on the psychological well-being of the parents would have strengthened the results, since first-time parents may experience dissimilar depressive symptoms and parenting stress compared to parents with more than one child.

Assessing the quality of life of children is not simple. According to the definition of the WHO (WHO 1995), the quality of life is subjective and should be self-reported whenever possible. Previous studies on preterm populations at early school age have mainly relied on proxy-reports for assessment of the HRQoL (Berbis et al. 2012, Vederhus et al. 2010, Stahlmann et al. 2009). The parents report lower HRQoL for their children through the preschool years until adult age compared to the reports by the children themselves (Zwicker and Harris 2008). One of the strengths of the current study was that as many as 17 dimensions of HRQoL were self-reported by the VLBW and the FT children, who were born in the same hospital and during the same years as the VLBW children. Although the mean HRQoL scores of the VLBW children with prematurity-related morbidities were lower than the scores of the control children, it is important to emphasize that the scores were by no means poor. This may reflect good support to the child from their families and an adequate overall level of well-being and societal support also for the children with chronic conditions. This may partially be brought about by the free well-child clinics, which pursue close monitoring of children and families, and by special educational services provided for those who need such services.There is no pre-set cut-off limit for what makes the quality of life good or bad, and we believe that the good scores reflect the level of overall well-being and support from the the society and the culture.

7 CONCLUSIONS AND CLINICAL IMPLICATIONS

The psychological well-being of the parents was related to the developmental impairments of the VLBW children, and the level of family functioning was related to prematurity-related morbidity of the VLBW children. This study concludes that the psychological well-being not only of the mothers but also of the fathers is a significant contributor to the development of prematurely born children. A strong sense of coherence of the parents may be a protective factor for child development. However, it is important to emphasize that the longitudinal design of this study can only suggest, not establish causality. The associations between the psychological well-being of the parents and child development reflect multifactorial processes related to prematurely born children. The directions of the impact of these associations may not only be unclear but also bi-directional. It may well be that the early events of a preterm birth cause depression and stress to the parents. If the child is at high risk, the parenting and parent-infant relationship may become impaired and the psychological well-being of the parents may remain poor. Parents with a high sense of coherence may manage and adjust better than parents with poor sense of coherence. The parents of the most vulnerable children face multiple stressors and may remain distressed for many years after the postpartum period. If the depressed and distressed parents are not able to provide a positive and supporting environment for the child, the child has fewer opportunities to develop age-appropriately.

The present study showed very positive outcomes for children born with very low birth weight compared to previous research. The cognitive development of VLBW children at corrected age 2 years was at or above the average of the current research results on premature children of the same age born in the first decade of the 2000's. Only 3% of our VLBW infants had a significant cognitive delay both at corrected age 2 years and at age 5 years. Most of the VLBW children (93%) did not have behavioral problems at 3 years. At age 5 years, 63% of the VLBW children had normal social skills, 64% did not have emotional or behavioral problems, and 62% did not have problems in executive functioning. A total of 65% of the VLBW survivors had no prematurity-related morbidity. Their health-related quality of life was as good as that of the control children.

The majority of the children born prematurely and with very low birth weight develop normally or without major developmental delays, without prematurity-related morbidities and with a good health-related quality of life. However, there is a small group of infants with disabilities, morbidities and developmental impairments. The major goal of modern neonatal care is to optimize the long-term developmental trajectories and to prevent chronic disabilities of vulnerable children.

The results of the current study have implications for counselling parents of preterm children and for planning cost-effectiveness and intervention studies. The study demonstrated that the psychological well-being of the parents is associated with the development of their prematurely born child. Depressive symptoms and parenting stress turned out to be risk factors for suboptimal child development while the good sense of coherence was protective. However, one may also assume that the developmental problems of the child cause poor psychological well-being for the parents. It is impossible to distinguish whether the parental state of psychological well-being is the cause or a consequence of the child's development. Most probably the associations are bi-directional and many confounding factors are involved.

The clinical challenge for the future is to identify the infants and families at highest risk for non-optimal sequelae and to establish ways to target help and resources at the right time and in the right way. Interventions to alleviate the stress and depression of both the mothers and the fathers should be made available and become part of routine neonatal care as well as of the follow-up of these families. The psychological well-being of the parents should be addressed systematically and the follow-up services should consider the well-being of the whole family of the prematurely born children.

ACKNOWLEDGEMENTS

This study was carried out in the Departments of Public Health and Pediatrics, University of Turku and the Turku University Hospital during the years 2008–2015. I acknowledge Professor Jussi Vahtera of the Department of Public Health and Professor Jussi Mertsola of the Department of Pediatrics and Adolescent Medicine for providing me with the possibility to do research. I express my sincerest gratitude to all the families, children and parents, who have participated in this study by giving hours of their time for filling in the questionnaires and by participating in the clinical assessments. Without them this study would never have been possible.

My greatest and warmest gratitude is directed to my supervisors, Professor Päivi Rautava and Docent Riikka Korja. It has been an honor to work with two skilled women. Päivi, you have an admirable amount of expertise for doing research and your hands full of job. Still, you always found a blank space in your calendar for me, and every time I visited you I got your full attention and support. Riikka, thank you for being also my mentor, the closest person I could contact in small details I didn't want to bother the seniors for. I also thank all the members of the PIPARI Study Group. It has been a privilege to be part of this unique multidisciplinary study group. It has been fascinating to understand how our mission can be approached from different points of view to get a comprehensive picture. You are all important pieces of a "preemie-puzzle". My special thanks go to Professor Liisa Lehtonen, Professor Leena Haataja, and Docent Helena Lapinleimu for guidance and encouragement throughout this project. It has always been easy to ask anything of you despite your hurries. Liisa, thank you for opening the doors of your home during your free-time in order to finalize my manuscripts to brilliance. I sincerely admire your endless ambition for science and the support you give to junior researchers. Thank you, Petriina Munck, for your expertise in study I, and Liisi Rautava for your contribution to study IV. My special thanks go to Jaakko Matomäki for the statistical analyses and for help in interpreting the results through these years. You have patiently explained all the weird terms over and over again. Maybe I even learned something.

I own my thanks and gratitude to the reviewers of this thesis, Professor Anu-Katriina Pesonen and Docent Timo Saarela, for their careful revision of this study. Their valuable comments and criticism helped me to deepen the view on many matters and to improve the quality of this work. I am also grateful to Professor Tuula Tamminen for being my opponent in the doctoral dissertation. I sincerely thank the supervisory committee of the thesis whom I have had the privilege to collaborate with annually during this project, Professor Pekka Niemi, Professor Hannele Räihä, and Doctor Elina Savonlahti. You have always encouraged me to carry on with my work and given me insightful suggestions from your fields of expertise. I express my appreciation to Docent Robert Paul for editing and revising the English of the thesis and study II.

I am grateful to Professor Olli Ruuskanen for the opportunity to work in the Research Unit ("Tutkari") of the Turku University Foundation. I thank all my co-workers at Tutkari over the years for sharing the ups and downs of making science, especially Anna N., Anna P., Johanna O., Johanna U., Katja, Kjell, Lauri, Liisa, Marika, Miia, Nora, Paula, Sari, Sergey, and Sirkku. The lunch and coffee breaks with you have been filled with laughter and conversations, and the best peer-support one could ever ask for. Thank you, Liisa, for numerous practical advises e.g. how to publish my thesis and how to boil an egg. Sirkku and Mikael, thank you for the unforgettable moments in San Diego, Hollywood, and Santa Monica. Jonna, I really enjoyed your company in Istanbul.

I warmly acknowledge Professor Heikki Minn of the Department of Oncology and Radiotherapy for approving my applications for leave of absence – this made my research possible. I also thank all my colleagues in oncology clinic. I truly appreciate being surrounded by a vast amount of expertise and talent, not only professional. Thank you for your encouragement when finishing this thesis.

I thank all my friends. With you I don't have to pretend to be more than I am or different from what I am. With you I don't have to talk about research or work. Life is an adventure (and dancing) with you all. I thank especially my closest friends Mirkku and Tommi, Kikka and Miku, Iina and Jani, Mira and Petri, Sinikka and Makke, Heidi and Ville, Kati and Kimmo, Minna and Sami, Satu and Pikkis, Veera and Titti, Sini, Tapsa, Marjo, and Hanna. I am very lucky to have you in my life!

Writing this thesis has reminded me of what really is the most important in life, one's family. I am more than grateful to my family. My parents, Raili and Ilkka, äiti ja isi, thank you for raising me to be me. You have never questioned my decisions in life and supported me even when you haven't known exactly what I was doing. You have taken care of my children whenever needed and you have taught them so many things I never could have. Thank you, Kaija and Tommi, for being near supporting our family. Thank you, Tuomas and Tiina, for the happy moments together with your children, Miska and Mea. Thank you, Mira and Petri, for long evenings, late nights and early mornings together. I know you are always there for us, no matter what comes around in life. Finally, I owe my deepest gratitude to my husband, Mikko. Thank you for being such a loving husband and a perfect father to our children. You have tolerated my fluctuating moods and helped me in every way in raising and taking care of our children and the household. Thank you, Sanni and Otto, for giving me other things than research to think about. Every day with you is a new experience of joy, happiness, and learning. I know that you're going to grow up to be wonderful and right-minded teenagers and one day you are going to be loving parents for your own children.

The research project was financially supported by the Emil Aaltonen Foundation, Research Funds from Specified Government Transfers (EVO), the Finnish Cultural Foundation, the Päivikki and Sakari Sohlberg Foundation, the Signe & Ane Gyllenberg Foundation, the South-Western Finnish Foundation of Neonatal Research, and the Turku University Hospital Foundation.

Turku, September 2015

Mira Huhtala

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