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**KRISTA KOIVULA** 

Couple resilience, dyadic emotion regulation, and mental health of parents with a seriously ill child

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Krista Koivula

### Couple resilience, dyadic emotion regulation, and mental health of parents with a seriously ill child

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#### ABSTRACT

A child's serious illness is a crisis for the whole family that affects the psychological well-being and intimate relationship of parents in many ways. The purpose of this thesis was to investigate couple resilience, dyadic emotion regulation, and mental health in parents of children with serious diseases and conditions. Couple resilience is a process by which partners engage in relationship behaviors that support adaptation during stressful life situations. Dyadic emotion regulation refers to processes by which two people regulate their emotional states during mutual interactions.

Study 1 explored couple resilience, dyadic emotion regulation of the parents and its importance for the personal coping of parents, and the challenges faced in dyadic emotion regulation. The study consisted of a narrative review article and an interview study. The interview study comprised 32 parents, whose 0–6-year-old child was receiving hospital treatment due to a lifethreatening illness or condition. The semi-structured, videotaped interviews were analyzed by Interpretative Phenomenological Analysis (IPA).

The aim of Study 2 was to evaluate parents' life satisfaction, psychiatric symptoms, and posttraumatic growth after their child's diagnosis and one year after the diagnosis, and to compare their mental health to that of parents with healthy children. The exposed group consisted of 34 parents, whose

newborn infant was in the hospital because of a life-threatening illness or condition necessitating therapeutic hypothermia (TH) or urgent surgery. The control group consisted of 60 parents of a healthy newborn infant. Parents completed questionnaires measuring anxiety, depression, general stress, life satisfaction, posttraumatic symptoms, and posttraumatic growth.

Study 3 examined the parents' experiences of an emotionally focused Hold Me Tight (HMT) group intervention targeted at enhancing the intimate relationship of parents who had a child with cancer. The study consisted of 12 heterosexual couples who had a 2–19-year-old child with cancer and who participated in the HMT course. After the course, the parents participated in a focus group conversation which aimed to explore the experiences of the course and its impacts on the intimate relationship of parents. Videotaped and transcribed conversations were analyzed with IPA.

In the narrative review of Study 1, couple resilience was considered as a dynamic, multidimensional, and relational process that is affected by meanings given to adversities, experienced and expressed emotions, mutual support, and feeling of we-ness emerging between a couple. In the interview study, the main themes of analysis were the recognition and disclosure of the needs of dyadic emotion regulation, load sharing and dyadic regulation of emotions, the importance of dyadic emotion regulation in terms of coping, and the challenges of dyadic emotion regulation. The subthemes of load sharing and dyadic regulation of emotions were recognizing a partner's emotions, direct expression and avoiding emotions, nonverbal interaction, presence and intimacy, and verbal interaction. Overall, the parents described a variety of needs, forms, and challenges in dyadic emotion regulation. Dyadic emotion regulation played a particularly important role for couples' personal coping with a child's serious illness.

According to Study 2, depressive symptoms were more common in the parents of ill children than healthy children. Also, anxiety symptoms were more common in the 1-year follow-up, although they showed a decrease from baseline. Life satisfaction had an inverse correlation with all measures of psychiatric symptoms, and life satisfaction was quite high in the parents with ill and healthy children. At the baseline, mothers of ill children had more anxiety and depressive symptoms than fathers. Mothers had more posttraumatic symptoms than fathers at both times. Half of the parents experienced substantial posttraumatic growth at follow-up. In conclusion, the serious illness of an infant substantially affected the mental health of parents in the early stage of illness and one year after the diagnosis.

In Study 3, the main themes emerged in conversations were the individual-, couple- and family-related meanings. The subthemes of the couple-related meanings were identifying and processing the relationship issues, increasing understanding of the interaction within the relationship, facilitating prevention and dealing with challenging situations, and strengthening of mutual emotional connection. Conversations indicated that even a 3-day HMT course can produce experiences of strengthening parents' personal well-being and couple resilience.

This study provides information on the mental health, couple resilience, and dyadic emotion regulation of parents with seriously ill children. The results may help to identify parents who need individual or couple therapy and design suitable interventions for them. Adequate and properly timed assessment of the needs for parental support and providing the necessary support promote the whole family's coping abilities when faced with the crisis of a child's serious illness.

**Keywords:** couple resilience, dyadic emotion regulation, emotionally focused couple therapy, Hold Me Tight program, mental health, parenthood

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#### TIIVISTELMÄ

Lapsen vakava sairastuminen on koko perhettä koetteleva kriisi, joka vaikuttaa monin tavoin vanhempien psyykkiseen hyvinvointiin ja parisuhteeseen. Tämän väitöstutkimuksen tarkoituksena oli tutkia vakavasti sairaiden lasten vanhempien parisuhderesilienssiä, dyadista tunnesäätelyä ja mielenterveyttä. Parisuhderesilienssillä tarkoitetaan prosessia, jonka myötä kumppanit sitoutuvat parisuhteessaan sopeutumista tukevaan käyttäytymiseen stressaavan elämäntilanteen aikana. Dyadisella tunnesäätelyllä viitataan prosesseihin, joissa kaksi ihmistä säätelee tunnetilojaan keskinäisessä vuorovaikutuksessaan.

Ensimmäisessä osatutkimuksessa tarkasteltiin vanhempien parisuhderesilienssiä, dyadista tunnesäätelyä ja sen merkitystä vanhempien henkilökohtaisen selviytymisen kannalta sekä dyadisessa tunnesäätelyssä koettuja haasteita. Tutkimus koostui narratiivisesta katsausartikkelista ja haastattelututkimuksesta. Haastattelututkimukseen osallistui 32 vanhempaa, joiden 0–6-vuotias lapsi oli sairaalahoidossa henkeä uhkaavan sairauden tai tilan vuoksi. Puolistrukturoidut, videoidut haastattelut analysoitiin tulkitsevalla fenomenologisella analyysillä (IPA).

Toisen osatutkimuksen tavoitteena oli arvioida vakavasti sairaiden lasten vanhempien elämäntyytyväisyyttä, psykiatrisia oireita ja traumaperäistä kasvua lapsen diagnoosin jälkeen ja vuoden kuluttua diagnoosista, sekä verrata heidän mielenterveyttään terveiden lasten vanhempien mielenterveyteen. Tutkimusryhmä koostui 34 vanhemmasta, joiden vastasyntynyt vauva oli sairaalassa viilennyshoitoa tai kiireellistä leikkaushoitoa vaativan henkeä uhkaavan sairauden tai tilan vuoksi. Kontrolliryhmä koostui 60:stä terveen vastasyntyneen lapsen vanhemmasta. Vanhemmat täyttivät ahdistus- ja masennusoireita, yleistä stressiä, elämäntyytyväisyyttä, traumaperäisiä oireita ja traumaperäistä kasvua mittaavat kyselylomakkeet.

Kolmannessa osatutkimuksessa tarkasteltiin vanhempien kokemuksia tunnekeskeisestä, syöpää sairastavien lasten vanhempien parisuhteen vahvistamiseen kohdistuvasta Hold Me Tight (HMT) -ryhmäinterventiosta. Tutkimukseen osallistui 12 heteroseksuaalista paria, joilla oli syöpää sairastava, 2–19-vuotias lapsi ja jotka osallistuivat HMT-kurssille. Kurssin jälkeen vanhemmat osallistuivat fokusryhmähaastatteluun, jonka tarkoituksena oli tutkia vanhempien kokemuksia kurssista ja sen vaikutuksista vanhempien parisuhteeseen. Videoidut ja transkriboidut haastattelut analysoitiin tulkitsevalla fenomenologisella analyysillä (IPA).

Ensimmäisen osatutkimuksen narratiivisessa katsauksessa parisuhderesilienssi nähtiin dynaamisena, moniulotteisena ja relationaalisena prosessina, johon vaikuttavat vastoinkäymisille annetut merkitykset, koetut ja ilmaistut tunteet, molemminpuolinen tuki ja parin välillä ilmenevä me-tunne. Haastattelututkimuksen pääteemat olivat dyadisen tunnesäätelyn tarpeiden tunnistaminen ja ilmaisu, taakan jakaminen ja dyadinen tunnesäätely, dyadisen tunnesäätelyn merkitys selviytymisen kannalta sekä dyadisen tunnesäätelyn haasteet. Taakan jakamisen ja dyadisen tunnesäätelyn alateemat olivat kumppanin tunteiden tunnistaminen, tunteiden suora ilmaisu ja välttäminen, ei-kielellinen vuorovaikutus, läsnäolo ja läheisyys sekä kielellinen vuorovaikutus. Kaiken kaikkiaan vanhemmat kuvasivat monenlaisia dyadisen tunnesäätelyn tarpeita, muotoja ja haasteita. Dyadisella tunnesäätelylla oli erityinen merkitys heidän henkilökohtaisen selviytymisensä kannalta lapsen sairastuessa vakavasti.

Toisen osatutkimuksen mukaan masennusoireet olivat yleisempiä sairaiden kuin terveiden lasten vanhemmilla. Myös ahdistusoireet olivat yleisempiä vuoden seurannassa, vaikka ne vähenivät alkuvaiheeseen verrattuna. Elämäntyytyväisyys korreloi käänteisesti kaikkien psykiatristen oireiden kanssa, ja sekä sairaiden että terveiden lasten vanhempien elämäntyytyväisyys oli melko korkealla tasolla. Alkuvaiheessa sairaiden lasten äideillä oli isiä enemmän ahdistus- ja masennusoireita. Äideillä oli isiä enemmän traumaperäisiä oireita kummassakin vaiheessa. Puolet vanhemmista koki merkittävää traumaperäistä kasvua vuoden kuluttua diagnoosista. Kokonaisuutena lapsen sairaus vaikutti siis merkittävästi vanhempien mielenterveyteen sairauden alkuvaiheessa ja vuoden kuluttua diagnoosista.

Kolmannen osatutkimuksen keskustelujen pääteemoiksi nousivat yksilö-, parisuhde- ja perhetason merkitykset. Parisuhdetason merkitysten alateemat olivat parisuhdeilmiöiden tunnistaminen ja käsittely, parisuhteen vuorovaikutukseen liittyvän ymmärryksen lisääntyminen, haastavien tilanteiden ennaltaehkäisyn ja käsittelyn vahvistuminen sekä molemminpuolisen tunneyhteyden vahvistuminen. Keskustelut osoittivat, että jo kolmen päivän pituinen HMT-kurssi voi tuottaa vanhemmille kokemuksen henkilökohtaisen hyvinvoinnin ja parisuhderesilienssin vahvistumisesta.

Tämä tutkimus tarjoaa tietoa vakavasti sairaiden lasten vanhempien mielenterveydestä, parisuhderesilienssistä ja dyadisesta tunnesäätelystä. Tulokset voivat auttaa tunnistamaan vanhemmat, jotka tarvitsevat yksilö- tai pariterapiaa ja suunnittelemaan heille sopivia interventioita. Vanhempien tuen tarpeiden riittävä ja oikea-aikainen arviointi sekä tarvittavan tuen tarjoaminen edistävät koko perheen selviytymistä lapsen vakavan sairauden aiheuttamasta kriisistä.

**Avainsanat:** dyadinen tunnesäätely, Hold Me Tight -ohjelma, mielenterveys, parisuhderesilienssi, tunnekeskeinen pariterapia, vanhemmuus

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#### **ABBREVATIONS**

ALL	Acute Lymphoblastic Leukemia
ASD	Acute Stress Disorder
BAI	Beck Anxiety Inventory
BDI-II	Beck Depression Inventory–II
EFT	Emotionally Focused Therapy
EPDS	Edinburgh Postnatal Depression Scale
EMDR	Eye Movement Desensitization and Reprocessing
fMRI	Functional Magnetic Resonance Imaging
HIE	Hypoxic-Ischemic Encephalopathy
HMT	Hold Me Tight
IES-R	Impact of Event Scale–Revised
IPA	Interpretative Phenomenological Analysis
LS-4	Life Satisfaction Scale–4
NICU	Neonatal Intensive Care Unit
PPD	Post-Partum Depression
PSS	Perceived Stress Scale
PTG	Posttraumatic Growth
PTGI	Posttraumatic Growth Inventory
PTSD	Posttraumatic Stress Disorder
SBT	Social Baseline Theory
TF-CBT	Trauma-Focused Cognitive Behavioral Therapy
TH	Therapeutic Hypothermia

#### LIST OF ORIGINAL PUBLICATIONS

The dissertation is based on the following studies, which are referred to in the text by Arabic numerals 1–3. Original publications are referred to in the text by Roman numerals I–IV.

Study 1

- I Koivula, K. (2016). Yhdessä eteenpäin—Vakavasti sairaiden lasten vanhempien parisuhderesilienssi. *Psykologia*, *51*(6), 455-468.
- II Koivula, K., Kokki, H., Korhonen, M., Laitila, A., & Honkalampi, K. (2019). Experienced dyadic emotion regulation and coping of parents with a seriously ill child. *Couple and Family Psychology: Research and Practice*, 8(1), 45-61. https://doi.org/10.1037/cfp0000115

Study 2

III Koivula, K.\*, Isokääntä, S.\*, Tavast, K., Toivonen, I., Tuomainen, I., Kokki, M., Honkalampi, K., Sankilampi, U., & Kokki, H. (2022). Psychiatric symptoms, posttraumatic growth, and life satisfaction among parents of seriously ill infants: A prospective case-controlled study. *Journal of Clinical Psychology in Medical Settings, 29*(2), 453-465. https://doi.org/10.1007/ s10880-022-09868-7

Study 3

IV Koivula, K., Kokki, H., Laitila, A., Korhonen, M., Kalapudas, J., & Honkalampi,K. (submitted). Hold Me Tight group intervention for parents of children with cancer.

\*These authors contributed equally to this work.

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# **1** INTRODUCTION

Modern developments in medical expertise have enabled the survival of children who would have previously died because of their diseases. For example, the prognosis of childhood cancers has improved and five years after the diagnosis, on average, more than 80% of children are alive (Madanat-Harjuoja, 2019). Living with the serious illnesses of children, therefore, touches an ever-increasing number of families and in many ways also affects parental mental health and partnership.

Required medical treatments of seriously ill children change everyday life of families. Long hospital care makes parents to constantly rearrange their working schedules, the care of siblings, and family life in general. A child's symptoms, diagnosis, intense treatments, and uncertainty associated with the prognosis may cause parental distress, concern, fear, and difficulty in tolerating the physical and psychological suffering of their own child. For example, TH used in preventing and relieving the consequences of birth asphyxia, forces parents to be separated from their newborn while they are very worried about the child's survival and future (Laudi & Peeples, 2020).

A child's serious illness is a major crisis for parents and affects their psychological well-being and intimate relationship in many ways (Cabizuca et al., 2009; da Silva et al., 2010; McCarthy et al., 2012; Muscara et al., 2015; Vernon et al., 2017; Wu et al., 2009). Most parents of seriously ill children experience a heavy transient load and 25%–30% have severe or prolonged psychiatric symptoms (Kearney et al., 2015). Some parents have increased risk of mental health problems, such as posttraumatic stress disorder (PTSD) (e.g., Cabizuca et al., 2009; McCarthy et al., 2012; Muscara et al., 2015; Vernon et al., 2017). Psychological reactions related to childhood diseases may also be reflected in parental interactions and may lead to partnership problems (e.g., da Silva et al., 2010; Wu et al., 2009).

Despite the distress and concern associated with a child's illness, some parents seem to cope with the situation well and even feel that their mental health and intimate relationship are strengthened during and after a challenging experience (Hungerbuehler et al., 2011; Picoraro et al., 2014). The relationship can remain stable or even become closer when parents face a common adversity together (e.g., Gerhardt et al., 2007; Klassen et al., 2007; Syse et al., 2010; Vrijmoet-Wiersma et al., 2008). Factors that predict mental health, couple resilience, life satisfaction, and posttraumatic growth are not yet well known, but it would be essential to understand them to identify the parents who need support and develop suitable interventions for them. The experiences concerning dyadic emotion regulation, its challenges, and its importance for personal coping have not previously been studied among the parents of ill children.

The development of couple interventions for the parents of ill children has been found to be an important but demanding and sensitive task, and its timing and form should be carefully considered (e.g., Porter et al., 2019). Emotionally Focused Therapy (EFT) has been found to be an effective method for supporting parents of ill children (Cloutier et al., 2002; Walker et al., 1996), but its brief version HMT has not previously been studied in this target group. Developing and exploring easy-to-reach brief interventions is important because not all parents of ill children in need of support can participate in long-term couple therapy due to their complex life situation.

Parents' individual and couple reactions to child disease vary greatly. Understanding this variation, explanatory factors, and phenomena is important for developing effective interventions to support parents' mental health and couple resilience. Research on the mental health and dyadic emotion regulation of parents helps healthcare professionals understand and encounter parents' reactions, identify parents in need of professional help, and guide them to get appropriate support and treatment. Perceiving the psychological effects and counseling the parents to get the required help will promote the treatment of the child's illness and prevent subsequent mental health problems of ill children, their siblings, and parents.

The purpose of this thesis was to investigate the couple resilience, dyadic emotion regulation, and mental health in parents of children with serious diseases and conditions. Parents were recruited to studies 1 and 2 in 2014–2018 at Kuopio University Hospital from the Child and Adolescent Center of Excellence (Neonatal Intensive Care Unit and Pediatric Hematology and Oncology Unit). All parents of 0–6-year-old children suffering from

life-threatening illnesses and conditions were asked to take part in the study during the data collection period. The diagnoses of children included asphyxia, esophageal atresia, gastroschisis, leukemia, lymphoma, omphalocele, renal failure, rhabdomyosarcoma, and Wilms tumor. In Study 3, parents were recruited from the emotionally focused HMT courses offered by an organization supporting the families of children with cancer (Sylva ry). A diverse sample was chosen for this study because different diseases have their own special features and treatment forms that can affect the wellbeing and response of parents. The next section presents the illnesses and conditions involved in this thesis.

# **2 REVIEW OF THE LITERATURE**

#### 2.1 Serious illnesses of childhood in Finland

Serious illnesses of children include asphyxia, cancer, and congenital anomalies that are life-threatening and can lead to death despite treatments. Each illness has its own characteristics that affect the nature and duration of the treatment, prognosis, and risk of illness relapse. These special features influence the parental response and coping. For example, the nature and prognosis of a child's illness affect parents' later mental health, as well as family composition and the child's age (Metsä-Simola et al., 2022). From a psychological point of view, life-threatening illnesses also have unifying features; they cause the parent to have mental strain, fear, and a sense of helplessness. Previous studies have shown that psychosocial factors predict parents' reactions to their child's illness more than the type of child illness or associated medical factors (Kassam-Adams et al., 2009; Rayner et al., 2016; Steele et al., 2004; Woolf et al., 2016).

#### 2.1.1 Childhood cancer

Every year, about 150 Finnish children are diagnosed with cancer (about 80 boys and 70 girls). The most common childhood cancers are leukemia, lymphomas, and malignant brain tumors. Other cancers in children are Wilms tumor, retinoblastoma, soft tissue sarcoma, and bone cancer (Madanat-Harjuoja, 2019). Recent advances in childhood cancer treatments have increased survival rates substantially and treatment often works toward remission. Nowadays, over 90% of children with acute lymphoblastic leukemia (ALL), which is the most common childhood cancer, are alive five years after their diagnosis (Jensen et al., 2021). However, the prognosis varies considerably between different cancers, and 5-year survival rate after brain tumors, that are the second most common cancers in childhood, is less than 80% (Storm et al., 2019).

The treatment of children's cancer is usually a combination of multiple therapies. When the tumor is treated with medication, i.e., chemotherapy, the whole body is treated, which means that potential tumor cells in both blood circulation and elsewhere can be reached via blood flow. In addition, there is often a need for treatment targeted directly at the tumor, such as surgery or radiotherapy. Sometimes different combinations of chemotherapy, surgery, and radiotherapy are used to ensure recovery (Jensen et al., 2021; Storm et al., 2019). Childhood cancer treatments are often long-lasting and intense and are therefore strongly impactful for the whole family. A child may stay in the hospital for long periods, and the parents must arrange their daily life according to care. Intensive treatments may cause strong, immediate, and long-lasting adverse effects for the child, as well as worries and fears for the parents (e.g., van Schoors, de Paepe, et al., 2019). Also, cancers of infants and older children strongly burden parents because of the life-threatening nature and recurrence possibility of these illnesses (van Schoors, de Paepe, et al., 2019).

#### 2.1.2 Birth asphyxia and congenital anomalies

Annually, about two hundred newborns in Finland are affected by brain injury due to oxygen deficiency, sometimes leading to a condition known as hypoxicischemic encephalopathy (HIE) (Tommiska & Metsäranta, 2012). In developed countries, perinatal asphyxia is estimated to occur in 3–5 newborns per thousand, and moderate or severe HIE is caused by it in 1–3 per thousand newborns (Jacobs et al., 2013). In Finland the incidence of moderate or severe HIE is less, occurring in 0.8 per thousand newborns in the Helsinki University Hospital area (Nevalainen et al., 2020).

Most newborns with mild HIE recover quickly, but 25%–60% of cases lead to long-term neurological consequences (Schulzke et al., 2007). Severe birth asphyxia can occur in infants for several reasons, including compression of the umbilical cord, abruption of the placenta, abnormal uterine contractions, and prolonged labor or failure of the infant to initiate and maintain breathing (de Haan et al., 2006). The traditional treatment of asphyxia and HIE is focused on the prevention of secondary damage and the unique care of the symptoms of each patient such as mechanical ventilation and cardiovascular support care, renal function support, metabolic balance maintenance, restriction of fluid intake, and nutritional support as required (Leipälä et al., 2008). In recent years, there has been strong evidence supporting the effectiveness of TH in improving the outcomes of babies with moderate or severe birth asphyxia. It has already been accepted for routine use in many countries, including Finland. TH involves cooling the infant for a period of 72 h to a body temperature of 33–34°C by using an external cooling device. A prompt assessment is required to determine if the infant is eligible for TH and if TH is indicated, the treatment should be commenced during the first 6 h after birth. During TH, the infant receives medication and sedation and manipulation is kept minimal to prevent a rise of intracranial pressure. Holding or breastfeeding the infant are not possible due to the infant's vulnerable medical condition (Long & Brandon, 2007).

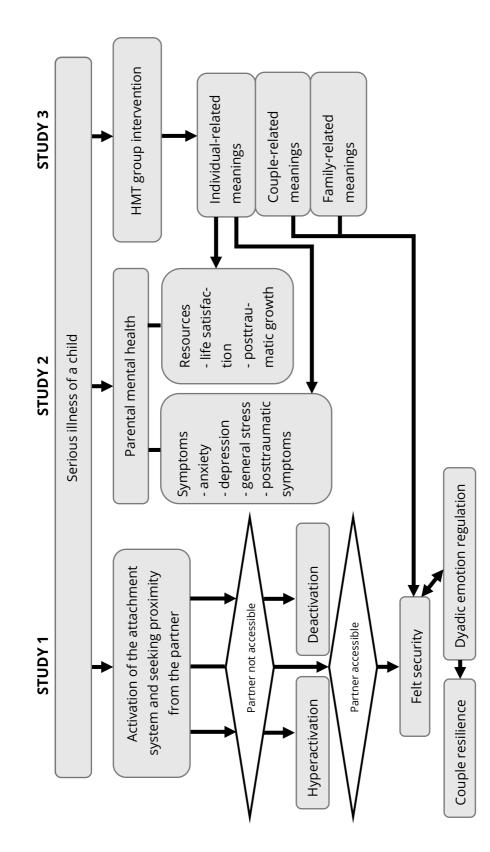
TH may be a shocking experience for the parents after a difficult birth; it may frighten them and disturb their relationship with the newborn infant. The hospital environment and intensive care technology can be scary, especially for parents without previous experience of it. Infants with birth asphyxia have an increased risk of developing functional impairments, cerebral palsy, and visual and hearing impairments. Heringhaus et al. (2013) found in their qualitative study that these parents felt they were in a chaotic and stressful emotional process, beginning with a traumatic delivery and proceeding to carrying concerns for the infant's survival and possible future disability.

Newborns may also need surgical or other invasive procedures and an admission into a NICU soon after birth. Some congenital anomalies, such as esophageal atresia, gastroschisis, and omphalocele, require intense treatment during the first days after birth and subsequently (Gamba & Midrio, 2014; van der Zee et al., 2017). The following are the mean annual operation rates for several childhood illnesses in Finland between 2011 and 2020: esophageal atresia, 13/ year [5–23] with a mean prevalence of 1/4000 newborns [1:2500–1:11600]; gastroschisis, 22/year [5–23] with a mean prevalence of 1/2400 newborns [1:1500–1:7200]; omphalocele, 10/year [7–29] with a mean prevalence of 1/4300 newborns [1:1600–1:7500]. Other conditions that may require admission to a NICU are, for example, meconium aspiration syndrome and renal failure. Supportive therapy, such as intravenous fluids and electrolytes, mechanical ventilation, oxygen supplementation, and renal replacement therapy, are crucial in treatment (Chettri et al., 2016; Nada et al., 2017).

Taken together, parents of an infant admitted to a NICU during the first days after birth are concerned about their newborn infant's current survival and future health and well-being. The birth of the first child changes a couple to a family and affects the parents' life situation, mental health, and intimate relationship in many ways. Responding to the needs of a newborn baby is rewarding, but also demanding, and the support is scarce for many families. If there is a seriously ill child in addition to the natural emotional and physical load of this life situation, parents are impacted by an elevated level of psychosocial strain, setting more challenges for a family to organize their everyday life. If a family has more than one child, the situation involves special load factors as parents must arrange for the care of their ill child in addition to the everyday care of the sibling(s). During a child's recovery, some parents develop excessive parental perceptions of child vulnerability which leads to overprotective parenting and may result in adverse developmental and behavioral outcomes in the child (de Ocampo et al., 2003; Hoge et al., 2021). Therefore, it is essential to understand and recognize the parental reactions and offer them appropriate support to prevent these long-term adverse effects.

# 2.2 Theoretical background of couple resilience and dyadic emotion regulation

The starting point for this dissertation was to study the couple resilience and mental health in parents of seriously ill children. In Study 1, the parents described their experiences of dyadic emotion regulation, its importance to couple resilience and its challenges. Based on these results, I chose the adult attachment theory and the social baseline theory for the theoretical background of the research because they make theoretically understandable the importance of mutual support and dyadic emotion regulation for the resilience and mental health of seriously ill children's parents. The concepts relevant to the research topic and questions turned out to be couple resilience, dyadic emotion regulation, and mental health. These theories, concepts and their connections to the research topic are presented in the following sections and in Figure 1.





#### 2.2.1 Adult attachment theory

During the last 50 years, the attachment theory (Bowlby, 1973, 1980, 1982) has offered an influential conceptual framework for understanding the emotion regulation and resilience of individuals, couples, and families (Shaver & Mikulincer, 2014). Attachment theory originally described childhood attachment, but later expanded into research on adult relationships and emotion regulation. According to attachment theory, the availability of a responsive attachment figure is essential for the development of sense of safety throughout life. Bowlby (1973, 1980) described and conceptualized individual differences in attachment system functioning and emotion regulation based on the degree of responsiveness and protectiveness of attachment figures.

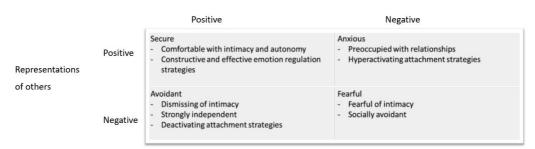
Interaction with secure attachment figures facilitates the downregulation of negative emotions and evokes positive emotions which strengthen coping and help to maintain emotional balance (Mikulincer & Shaver, 2014). The attachment system has specific anxiety-buffering functions in stressful and potentially traumatic situations; external threats or internal sources of distress automatically activate the attachment system, and this activation makes a person seek safety and comfort from their partner. When the attachment system functions appropriately and the partner is accessible, seeking and receiving intimacy in an adverse event lead to emotional safety. Activation and functioning of the parents' attachment system is central when a child becomes seriously ill, as it helps to restore their feelings of safety in a threatening situation.

According to Bowlby (1982), the sense of safety is based on positive mental representations of self and others. Experiences of secure and responsive interaction create positive mental representations, and these internal working models are available in subsequent challenging life situations even when the attachment figure is not actually present. In stressful life situations, securely attached people automatically search for internal representations of responsive attachment figures (Bowlby, 1982). Activation of positive representations creates constructive strategies for facing the stressful situation efficiently, coping and processing emotions, maintaining emotional balance, and faster recovering (Mikulincer & Shaver, 2014). Such positive learning experiences, depending on the content of the adverse situation, may be formed as key elements for the development of individual and relational resilience (Walsh,

2011). Therefore, secure attachment can be seen as a resilience resource that protects psychological, physical, and social well-being at distressing times (Mikulincer & Shaver, 2014). Activation of positive representations mentally can be particularly relevant when a child becomes seriously ill, as parents often must be separated for long periods of time.

Over the last decades, Bowlby's ideas have been expanded and organized into a theoretical model of the attachment system in adulthood (e.g., Bartholomew & Horowitz, 1991; Mikulincer & Shaver, 2007; Shaver & Mikulincer, 2002). This model focuses on the emotion-regulatory function of the adult attachment system and explains individual differences of this system's functioning. Adult attachment style means the organized pattern of relational expectations, emotions, and behavior that is based on previous interactions with attachment figures (Fraley & Shaver, 2000). Adult attachment style can be estimated with two independent dimensions: anxiety and avoidance. The low score in both indicates secure attachment which enables positive understanding of oneself and others, as well as the ability to use constructive and effective strategies in regulating emotions. Anxiously (or 'preoccupied' in a seminal article by Bartholomew and Horowitz, 1991) attached people use hyperactivating attachment strategies in which they strive to gain support, but at the same time experience distrust (Cassidy & Kobak, 1988). On the contrary, avoidantly (or dismissive) attached adults use deactivating attachment strategies; they avoid seeking support and proximity from others. A high score on both attachment anxiety and avoidance (fearful avoidant) indicates both attachment- and self-related insecurities (Figure 2).

Representations of se	f
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**Figure 2.** Model of adult attachment (adapted from Bartholomew and Horowitz, 1991).

According to previous studies, the quality of adults' attachment has a heavy impact on their psychological and physiological responses to stressful life situations. For example, avoidantly attached people tend to have an increased physiological reactivity, such as a reduction in heart rate variability, an increase in skin conductance, and increased blood pressure (Diamond et al., 2006; Maunder et al., 2006). Anxiously attached people report higher levels of distress but do not exhibit heightened physiological reactivity. The impact of attachment is also apparent in brain function. Anxiously and avoidantly attached people have heightened stress-related activation in the amygdala region (Lemche et al., 2006) and reduced hippocampal cell density, which is associated with poorer emotion regulation (Quirin et al., 2010).

The quality of attachment and activation of a mental representation of an attachment figure also influence how threatening the painful situation is perceived (Eisenberger et al., 2011; Selcuk et al., 2012). Attachment security and sense of safety are linked to the assessment of the stressful or traumatic situation as less threatening and the perception of oneself as capable of coping with it. Serious childhood illness is often accompanied by many potentially traumatic elements, such as fear of the child's death or permanent injury, and sudden and shocking situations related to medical procedures and treatments. Secure attachment and a strong mutual emotional connection may help parents experience these situations as less threatening and thus support their mental well-being also at an individual level.

#### 2.2.2 Social baseline theory

Emotion regulation refers to the conscious and unconscious processes that help us to influence our own and others' emotional states (Gross, 1998; McRae & Gross, 2020). Most theorists agree that emotion regulation is profoundly social in nature, and social context has an important role in the emotion regulation strategies that people deploy in daily life (Gross et al., 2006). Nevertheless, research and literature concerning social and dyadic emotion regulation are scarce, which may be related to the fact that the subject is challenging to explore in tightly controlled experiments. Social baseline theory (SBT) views emotion regulation as social, systemic, and dynamic phenomena. According to Beckes and Coan (2011, p. 977), *"social proximity represents an innate, prepared, default*  *or baseline strategy for human emotion regulation"*, which saves individuals' own, biological resources when they are coping with adversities of life.

The scientific background of SBT is based on the findings of neuroscientific investigations according to which the neural circuits associated with the selfregulation of emotion are actually less active in the presence of supporting people (Beckes & Coan, 2011; Coan et al., 2017). These findings surprised scientists and led them to suspect that regulation of emotion through social interaction might not be based on the activation of internal self-regulatory processes, but rather enable the restoration or maintenance of a safe baseline state (Gross & Thompson, 2007). Social proximity attunes the brain to be less vigilant in a potentially threatening situation because social support returns the brain to its innate baseline state that requires less emotional activation and self-regulatory inhibition. Interaction and social support reduce the activation of the sympathetic nervous system and consumption of stress hormones, in this way decreasing the need to use personal, metabolically costly regulation resources (Beckes & Coan, 2011). Thus, social interaction can be considered as an energy saving mechanism in challenging or stressful situations. Individuals with responsive social contacts use less self-regulatory effort and personal resources while responding to threatening situations (Coan et al., 2013). If the state of the social baseline is not achieved, an individual prepares to cope alone and use metabolically costly internal resources (Bar-Kalifa & Rafaeli, 2015). A child's serious illness loads parents mentally and physically, and the state of the social baseline produced by mutual proximity could save their metabolic resources in this stressful situation.

SBT is based on a principle called economy of action, which states that organisms must take in more energy than they consume to survive and reproduce (Proffitt, 2006). SBT explains how social resources optimize individual energy consumption and serve energy-saving functions. Social resources are mentally included in the self, and the need to use one's own resources is estimated to be lower if support is available. According to SBT, the availability of social resources is a fundamental, inherent "factory reset" of a human being. Beckes and Coan (2011, p. 977) stated that *"the human brain is designed to assume that it is embedded within a relatively predictable social network characterized by familiarity, joint attention, shared goals, and interdependence"*.

Coan et al. (2006) found in functional magnetic resonance imaging (fMRI) studies that social interaction regulates many of the brain responses to potential threats. In their study, the proximity and quality of social resources influenced, for example, how threatening a situation was perceived. Consequently, the amount and quality of social relations affect the assessment of need to use one's own resources in coping with the situation. One form of interpersonal emotion regulation is load sharing which means sharing emotional loads associated with challenging situations in social relationships (Ehrenberg et al., 2001; Lougheed et al., 2016). Load sharing affects brain encoding and interpretation of "self", available resources, and personal resource investment. The closeness and presence of a partner are interpreted as available resources, which reduces the need to use one's own energy and effort in a situation (Coan & Maresh, 2014). Diamond et al. (2008) investigated reactions of romantic couples during temporary physical separation and found substantial changes in couples' affects, stress levels, physical symptoms, and cortisol consumption. Separation of a couple when their child is seriously ill can be particularly stressful due to the load of the situation, fear, and need for support. Load sharing and interpretation of a partner as one's own resource may help parents cope with adverse situations and the additional burden of separation.

According to Beckes and Coan (2011), social contacts and proximity are essential as prerequisites of human emotion regulation. Coan and Maresh (2014) even suggest that emotion regulation is a key function of social relationships. In addition to the downregulation of negative emotions, social relations, and proximity also serve the amplification of positive emotions. The impact of a partner's positive reactions on the use of individual resources can be understood through the process of capitalization, in which the partner's positive feedback is interpreted as a personal and social resource, which reduces the need to consume one's neural resources (Coan & Maresh, 2014). Thus, SBT is in many respects in line with adult attachment theory and adds an understanding of the biological mechanisms that attune human beings from their birth to social modes of positive and negative emotion regulation and load sharing (Table 1). SBT also helps in understanding the phenomena of parenting a seriously ill child, the need for support between parents, and the importance of sharing the burden in parental coping.

#### 2.2.3 Dyadic emotion regulation

Emotion regulation can occur at an individual or interpersonal level. According to Gross et al. (2006), 98% of emotion regulation may take place in social contexts. In dyadic emotion regulation, emotions are regulated by the help of another in the interaction between two people (Zaki & Williams, 2013). In stressful and potentially traumatic situations, people tend to seek comfort and safety from their close relationships (Walen & Lachman, 2000). Secure attachment promotes safety, mental and physical health, and well-being (Coan et al., 2006; Mikulincer & Shaver, 2007). Social bonding and comfort regulate stress, negative emotions, and physiological arousal in stressful and potentially traumatic life events (Beckes & Coan, 2011; Bowlby, 1973; Johnson, 2002). According to the interpersonal emotion regulation model, emotion regulation occurs in social contexts throughout life, and emotions are regulated strongly with other people (Beckes & Coan, 2011; Butler & Randall, 2013; Coan & Sbarra, 2015; Zaki & Williams, 2013). In interpersonal emotion regulation, the emotions of interaction partners are connected to each other, and social relations contribute to both up- and down-regulation of emotions (Butler, 2011).

Consequently, close relationships, such as a couple relationship, have a key role in the sense of emotion regulation (Butler, 2011; Sbarra & Hazan, 2008). The couple relationship is often perceived as the most important and closest bond in adulthood, and experiencing it as safe contributes to an individual's psychological well-being and couple satisfaction (e.g., Cutrona et al., 2005; Sullivan et al., 2010). Supportive, dyadic relationships are connected to physical health, immune system, and resilience (Kiecolt-Glaser et al., 1993; Raglan & Schulkin, 2014). The romantic partner is among the most important sources and targets of dyadic emotion regulation (Coan et al., 2006). Effectiveness of emotion regulation strongly affects psychological well-being, for example in stress- and trauma-related disorders (Butler & Randall, 2013; Diamond & Aspinwall, 2003; Levy-Gigi & Shamay-Tsoory, 2017). This is particularly relevant when couples are adjusting to stressful and potentially traumatic events such as the serious illness of their child. The child's serious illness evokes many strong emotions, and their dyadic regulation can significantly support parental coping. Dealing with fears associated with illness and treatment and maintaining hope require both up- and down-regulation of emotions.

Study	Main findings
<b>Beckes &amp; Coan (2011):</b> Social baseline theory: The role of social proximity and economy of action.	The presence of other people helps individual to conserve metabolically costly somatic and neural resources through the social regulation of emotion.
<b>Bourassa et al. (2019):</b> The impact of physical proximity and attachment working models on cardiovascular reactivity: Comparing mental activation and romantic partner presence.	Accessing the mental representation of a romantic partner and a partner's presence each buffered against acute cardiovascular stress response to a similar degree.
Coan et al. (2017): Relationship status and perceived supportUnder threat of shock, handholding by partner attenuated both subjective distress and activity in a network associate with salience, vigilance, and regulatory self-control.	Under threat of shock, handholding by partner attenuated both subjective distress and activity in a network associated with salience, vigilance, and regulatory self-control.
<b>Coan et al. (2006):</b> Lending a hand: Social regulation of the neural response to threat.	Women in high-quality relationships showed the least threat- related brain activity when they were confronted with the threat of electric shock when holding their partner's hand.
Cohen (2004): Social relationships and health.	Perceived social support protected people from the pathogenic effects of life stress.
<b>Diamond et al. (2008):</b> Every time you go away: Changes in affect, behavior, and physiology associated with travel-related separations from romantic partners.	Romantic couples' interactions, positive and negative affect, sleeping problems, subjective stress, physical symptoms, and cortisol levels changed significantly during temporal separation.
<b>Ein-Dor et al. (2015):</b> Sugarcoated isolation: Evidence that social avoidance is linked to higher basal glucose levels and higher consumption of glucose.	After facing a stressful task, avoidant people gathered more sugar-rich food than more socially oriented people.

Table 1. Studies on the social regulation of emotion.

Study	Main findings
Henriksen et al. (2014): Loneliness, social integration and consumption of sugar-containing beverages: Testing the social baseline theory.	Participants who reported more social isolation also reported consuming more sugary beverages on average.
<b>ljzerman et al. (2012):</b> Cold-blooded loneliness: Social exclusion leads to lower skin temperatures.	Participants' finger temperatures dropped relative to baseline during social exclusion and increased during social inclusion.
López-Solà et al. (2019): Brain mechanisms of social touch-induced analgesia in females.	Holding hands with a partner reduced activity in a pain- related neural circuit, and this reduction mediated self- reported pain intensity and unpleasantness.
Lougheed et al. (2016): Sharing the burden: The interpersonal regulation of emotional arousal in mother-daughter dyads.	High relationship quality buffered against threat in a similar way to the physical comfort in mother-daughter-dyads.
Rosengren et al. (1993): Stressful life events, social support, and mortality in men born in 1933.	Perceived emotional support protected against the increased risk for mortality associated with high levels of stressful life events.
<b>Schnall et al. (2010):</b> Direct evidence for the economy of action: Glucose and the perception of geographical slant.	When participants imagined supportive others, they reported that hill slants appeared less steep than those who imagined negative individuals.

Dyadic emotion regulation is a complex and dynamic process because both partners have their own emotional motivations, strengths, and weaknesses. As Levenson et al. (2014, p. 269) stated, "couples often find themselves in a complex emotional landscape that changes continuously as partners express and regulate their own emotions, respond to each other's emotions and regulatory attempts, and try to regulate each other's emotions". Individual differences in regulatory resources can make dyadic emotion regulation even more challenging. For example, one partner may deal with their child's illness by withdrawing from contact and falling into their own thoughts or activities, while the other partner may have a strong need to unload and share her/ his feelings, for example by discussing and crying. In this case, a partner's regulatory strategy can be an emotional trigger for the other partner that challenges the dyadic emotion regulation of the couple. The challenges of dyadic emotion regulation can make parents interact in ways that move them farther apart in a crisis where the need for intimacy is strong. In a demanding situation, conflicts and feelings of inadequacy and aloneness make parents vulnerable from the point of view of attachment needs, and this can damage the confidence parents have in each other (Overall & Simpson, 2015).

Previous studies on emotion regulation focused exclusively on the downregulation of emotion, but recently also up-regulation of positive emotions has received attention (e.g., Li et al., 2018; Min et al., 2022 Tsujimoto et al., 2022). In couples, the regulation of positive emotion is at least as important as the regulation of negative emotion (Levenson et al., 2014). In previous studies (e.g., Gordon et al., 2012), positive expressions and gratitude have been found to promote the persistence of intimate relationships. According to Waugh (2014), resilient people experience positive emotions also in stressful situations. Fredrickson (2006, 2013) found that people who experience positive feelings are more likely to find positive meanings in stressful life situations. According to the theory of Fredrickson and Branigan (2005), positive emotions 1) expand people's attention and thinking, 2) invalidate negative arousal, 3) strengthen psychological resilience and 4) construct key personal resources and well-being in the future. If the relationship raises positive emotions and beliefs, it is experienced as a resource and worth taking care of even in stressful life situations. Thus,

positive emotions, assumptions, and actions may favorably influence parents' coping and resilience when their child is ill.

# 2.3 The effects of serious illness of a child on parents' mental health

#### 2.3.1 Psychiatric symptoms

Having and caring for a seriously ill infant in hospital is a heavy burden for parents and affects their mental health in several ways (Woolf et al., 2016). The uncertainty associated with child illness and survival, intense treatments, and prolonged hospital treatment cause parents distress and concern. Parents may also experience sorrow, disappointment, anger, and bitterness. The child's symptoms, diagnosis, treatments, and prognosis may be related to the parents' concern and worry and their difficulty in tolerating the physical and mental suffering of their own child. Parents may have acute, posttraumatic, and general stress, posttraumatic symptoms, depression, and anxiety (e.g., Cabizuca et al., 2009; Muscara et al., 2015; Yaman & Altay, 2015). In previous studies, 50% of the parents with a seriously ill infant had acute stress disorder (ASD) and 60% of the mothers and 47% of the fathers had PTSD (Aftyka, Rybojad, et al., 2017; Muscara et al., 2015). Generally, mothers have higher levels of stress and PTSD than fathers. One out of four parents suffers from clinical anxiety and depression (15%-27%) and from clinical symptoms of general stress (25%–31%) (Muscara et al., 2015). According to a systematic review by Khoddam et al. (2022), mothers and fathers have similar levels of psychiatric symptoms during and after a hospital admission of their child. Fathers have feelings of helplessness, and their distress often manifests later than mothers.

The psychiatric symptoms of parents strongly influence their own well-being, the parent-child relationship and, therefore, the well-being, development, and behavior of the child and siblings. For example, Korja et al. (2008) concluded that maternal depression may be a risk factor for negative interaction between preterm infants and their mothers. Parents' posttraumatic stress symptoms after a child's severe diagnosis predict higher

healthcare service utilization in the following year (Thompson et al., 2017). The mental health of parents is also crucial for the treatment of a child's illness. Posttraumatic arousal and re-experiencing symptoms may interfere with a parent's ability to understand medical instructions and communicate essential child health information to healthcare professionals (Kazak et al., 2004). On the one hand, hypervigilant parents may frequently contact medical services, which can lead to additional examinations and costs (Pelcovitz et al., 1998). On the other hand, posttraumatic avoidance symptoms can cause parents to avoid necessary medical visits and procedures (Stuber et al., 1996). Arousal symptoms can cause parents to overprotect their children and restrict their participation in activities which disturb their normal development (Hoge et al., 2021; Santacroce, 2002). Posttraumatic stress disorder is associated with an increased risk of depression and substance abuse, which may also impair the parent's ability to respond to the child's emotional and developmental needs (Cabizuca et al., 2009).

### 2.3.2 Life satisfaction, posttraumatic growth, and resilience

Extensive research of families with a seriously ill child confirms that encountering adversity jointly can also strengthen parents' well-being, the intimate relationship and family resilience. Parents whose child is experiencing pediatric medical traumatic stress have shown resilience (e.g., Gerhardt et al., 2007; Isokääntä et al., 2019; Muscara et al., 2018) and posttraumatic growth (PTG) (e.g., Barakat et al., 2006; Hungerbuehler et al., 2011; Picoraro et al., 2014). Resilience, in the broadest sense, refers to "dynamic processes that lead to adaptive outcomes in the face of adversity" (Lepore & Revenson, 2006). During the last decades, resilience has no longer been viewed just as an individual trait or skill, but also as an interactional process with its own specific qualities that are different from intrapsychic resilience (Rutter, 1999; Walsh, 1996, 2011). In the context of long-term illness, Mullins et al. (2015, p. 182) defined resilience as "a process by which individuals learn to overcome the negative effects of risk exposure (e.g., the diagnosis and its treatment), cope with traumatic events (e.g., invasive medical procedures), and avoid negative trajectories of adjustment outcomes (e.g., increased uncertainty, depression, posttraumatic stress)".

Calhoun and Tedeschi (1999, p. 1) defined PTG as "positive psychological change experienced as a result of a struggle with highly challenging life circumstances". PTG's components may include strengthening of social relations and appreciation of life, strength experience, new opportunities for life, and spiritual change (Tedeschi & Calhoun, 1996). PTG is related to social and psychological factors, such as a positive reinterpretation of a given situation (Aftyka, Rozalska-Walaszek, et al., 2017). Aftyka et al. (2020) found PTG among the parents with a hospitalized child. Fathers' PTG is predicted by seeking emotional support, positive reinterpretation, and growth. In mothers, predictors of PTG include seeking emotional support, religious coping, and planning (Aftyka et al., 2020).

Life satisfaction can be defined as *"a desired subjective feeling indicating general well-being"* (Koivumaa-Honkanen et al., 2000, p. 983). Life satisfaction has been seen as a key component of health and well-being (Gilman & Huebner, 2003). Although, no difference has been found in comparing the life satisfaction of ill or healthy children (Blackwell et al., 2019). Research concerning life satisfaction of parents with a somatically ill child is scarce. In the study of Crespo et al. (2016), family-centered services were indirectly linked to better life satisfaction of parents of a child with cancer through a reduction in the burden of care.

#### 2.3.3 Protective and risk factors

It is essential to understand the factors affecting the mental health of parents with an ill child in order to develop suitable, effective support forms and interventions. According to previous studies, demographic factors such as parents' age, gender, education, ethnic background, and relationship status have not predicted the mental health of parents (Muscara et al., 2018). Medical factors related to a child's illness, such as the prognosis and the duration of hospitalization, have earlier been either not predictive or weak predictors of parents' mental health effects (Kassam-Adams et al., 2009; Rayner et al., 2016; Steele et al., 2004). However, new research has recently been published including more detailed information on the relationship between family characteristics, a child's illness, and parents' mental health. In a Finnish register-study Metsä-Simola et al. (2022) found that a child's illness

clearly increased the use of parents' psychotropic medication in the first year following the child's diagnosis regardless of the cancer type, child's age at diagnosis, and other family characteristics. Later, the nature and prognosis of the child's illness influenced parents' mental health so that the need for psychotropic medication was reduced during the follow-up in fathers, except those fathers whose child suffered from ALL or lymphoblastic lymphoma. The medication needs of mothers of children with brain tumors remained elevated during the 5-year follow-up. Other factors that slowed down the recovery of mothers were the child diagnosed under 10 years of age and the existence of under-aged siblings (Metsä-Simola et al., 2022).

According to the studies so far, many psychosocial factors explain the variance of parental resilience and acute stress reactions (Muscara et al., 2018). For example, the parental conception of the severity of the child's illness and the fear of losing the child are associated with their acute stress reactions (Bakker et al., 2012; Kassam-Adams et al., 2009). Mothers' acute stress is related to the child's young age, and fathers' acute stress is associated with the severity of the child's illness (Mortensen et al., 2015). Previous miscarriages and chronic illnesses are risk factors reported for PTSD in mothers (Aftyka, Rybojad, et al., 2017). A mother's PTSD is related to PTSD in fathers, and the seriousness of PTSD symptoms is associated with current stressors, previous anxiety, and depressive symptoms (Lefkowitz et al., 2010). Parental anxiety symptoms are correlated with self-blaming, pessimism, illness-related uncertainty, and greater number of previous hospitalizations (Wray et al., 2011). Task-oriented coping strategies are related to higher resilience of parents (Ahn et al., 2014).

During the last decade, the dyadic processes underlying resilience and PTG have evoked growing scientific interest. These processes allow couples to cope with adversity and they promote strengthening by facing challenging situations together (Skerrett, 2015; Walsh, 2011). Social support and intimate relationship factors also contribute to partners' individual well-being and coping. For example, couple therapy has favorably influenced partners' mental health, functioning, and alcohol use (Seikkula et al., 2013). Tourunen et al. (2020) studied sympathetic nervous system synchrony in couple therapy and found that the therapy can bring partners closer on a physiological level,

which has appeared to be of particular importance to outcomes of therapy and especially to women's well-being.

The support received from family members strengthens parental coping abilities (Nabors et al., 2013). A partner's support is particularly meaningful in the crises represented by the child's illness. For example, a high-quality intimate relationship is related to mental health in parents of children with cancer (Salvador et al., 2019). Dyadic coping is associated with parents' wellbeing and experience of family adjustment soon after the diagnosis and over time (van Schoors, de Paepe, et al., 2019; van Schoors, Loeys, et al., 2019). Parents who have poorer relationship adjustment abilities following a diagnosis have more depressive symptoms, and their child and siblings have more emotional and behavioral problems (Alba-Suarez et al., 2020). Consequently, couple resilience is central to both individual coping and family dynamics when a child is seriously ill. The couple resilience of the parents also has impacts on the child's and siblings' well-being and mental health.

# 2.4 The connections of a child's serious illness to the parental intimate relationship

#### 2.4.1 Impact of illness on the intimate relationship of parents

A child's serious illness forces parents to face many existential, emotional, social, and physical challenges that may be harmful to their relationship. According to previous studies, the parents of children with chronic illnesses have an elevated risk of experiencing dissatisfaction in their intimate relationship (da Silva et al., 2010; Katz et al., 2018; Porter et al., 2019; Silva-Rodrigues et al., 2016; Yeh, 2002). The dyadic adjustment of these parents is weaker, and they also have higher levels of insecure-avoidant attachment (Cusinato et al., 2017). According to Wiener et al. (2017), 40% of parents of children diagnosed with cancer feel their relationship has changed in a negative direction. Relationship distress is reported by 20% of parents of children who have ALL (Burns et al., 2018). Fathers of children diagnosed with cancer report a wide variety of relationship changes after the child's illness: conflicts with their spouse, mental suffering, and changes in interactions (Kim

et al., 2018). In a study by Yi et al. (2021), mothers reported that their child's illness considerably affected their relationship with their spouse, and that they had tried to find solutions to marital conflicts.

The nature and intensity of the distress among parents varies according to the treatment phase. Wiener et al. (2017) found that parents experience relapses of the illness as stressful phases both for themselves and their relationship. In addition, the diagnosis is experienced as an individually stressful phase and hospital stays cause additional relationship stress (Wiener et al., 2017). In a qualitative study by Arruda-Colli et al. (2018), the factors affecting spousal relationships are related to the relationship, experience of illness, and external factors. The relationship is challenged most by physical and emotional distance and strengthened most by dyadic strategies, empathic interaction, and supportive behavior. Lavee et al. (2005) found that the negative change in the marital quality of the parents of children with cancer is associated with psychological stress of the fathers but not with the mothers' distress. General social support relieves the psychological anxiety of mothers, but fathers rely primarily on their spouse and therefore feel less anxiety in proportion to the strength of their intimate relationship (Lavee et al., 2005).

#### 2.4.2 Parents' couple resilience

In recent years, the concept of resilience has also been applied to relationship dyads, and particularly to the resilience that appears in intimate relationships. Skerrett (2015) defines the resilience as a couple phenomenon, which includes its own unique processes with their own features that differ from the combined personal resilience of partners. Sanford et al. (2016, p. 1243) define couple resilience as *"as a process in which a couple engages in relationship behaviors that help each member adapt and maintain high well-being during stressful life situations"*. In this process the partners can jointly assimilate and accommodate to varying conditions in a way that maintains and enhances the integrity of their relationship (Reid & Ahmad, 2015). According to Lepore and Revenson (2006), resilience is no longer seen as a permanent personality feature, but as a dynamic process in which individuals and couples adapt to adversities in different ways at different times. Stressful or potentially traumatic experiences can either strengthen or weaken an intimate relationship, depending on many key processes (Fergus & Skerrett, 2015). These include mutual empathy, compassion, and respect; awareness of the relationship, thoughtfulness, and priority; construction of shared meanings of a challenging situation; a joint effort to strengthen a positive relationship; safety and trust; and the wisdom of shared life experiences. The conditions for resilient adaptation of couples exist before encountering the adversity, during the adversity, and afterwards (Fergus & Skerrett, 2015).

According to Walsh (2003a), the key process of interpersonal resilience is the creation of a meaningful and positive belief system for the stressful event. Creating meanings—understanding where a couple has come from and where they are going—is the key task and part of couple resilience (Walsh, 2011). Couples who find a common meaning for adversity—especially in determining it to be "our problem" — consider the meaning as conducive to a common feeling of coherence, providing direction, and helping couples to manage cumulative stress factors and disease-related requirements (Skerrett, 1998). Over the last decade, we-ness has risen to a key process of couple resilience. We-ness refers to a couple's ability to face life challenges from a shared perspective, which co-ordinates the use of couple's common and unique resources. Singer et al. (2015, p. 124) define we-ness as "an understanding within the partners that they exist within the larger entity that transcends either of their individual selves, and entails feelings, cognitions and behaviors that seek to promote the welfare and best interests of the relationship while maintaining a simultaneous awareness of each partner's individual concerns". We-ness promotes a couple's ability to adapt and cope dyadically and facilitates the individual growth of the partners offering a protective resource (Fergus, 2011; Singer & Skerrett, 2014; Skerrett, 1998).

Thus, resilience is nowadays considered as a dynamic and interactional process in which individuals, couples, and families adapt, recover, and grow by facing adversities together (Ungar, 2015; Walsh, 2003b). Couple resilience is conceptualized as a multidimensional process, which is affected by the meanings constructed for adversity, experienced and expressed emotions, reciprocal support, and the we-ness of partners. According to Skerrett (2015, p. 10), the key components of couple resilience are *"self/other and relationship awareness; empathy and respect; mutual vulnerability; the joint creation of meaning, skill sets to support relational positivity, and the reintegration* 

*of relational wisdom."* The concept of we-ness may help to understand the differences of resilience in individuals and couples.

Several researchers have stated that the dyadic perspective and we-ness in relation to long-term illnesses reflects couple resilience and adaptability (Badr et al., 2010, Berg et al., 2008; Fergus, 2011; Skerrett, 1998). Troy and Mauss (2011) see emotion regulation as a critically important factor in determining resilience. Parents of seriously ill children can help each other to regulate the challenging emotions evoked by the situation. Dyadic emotion regulation can be an indication of a couple's resilience, support their coping both individually and relationally, and can even strengthen them by facing adversity together. Dyadic emotion regulation may also help them support the ill child and their siblings in coping and adjustment. Understanding dyadic coping and developing interventions that support it is essential, considering the strong impacts that a child's serious illness has on the parent's relationship and the adaptation of parents, the child, and the whole family (Porter et al., 2019).

# 2.5 Couple interventions for the parents of seriously ill children

Given the strong, long-term, and diverse effects of a child's illness on parents' mental health, it is natural that they feel the need to get support from their intimate relationship. Almost all (99%) parents of children with cancer need support from their partners (Kukkola et al., 2017). Parents also recognize the challenges and risks that the situation sets for their relationship, and they hope for support. Most couples with seriously ill children are interested in counseling for their relationship issues (Wiener et al., 2017). According to Yi et al. (2021), such interventions can promote the child-parent relationship and the psychosocial well-being of children with cancer.

Couple interventions for parents of children with cancer are scarce, challenging to develop and important to evaluate (Arruda-Colli et al., 2018; Burns et al., 2017; da Silva et al., 2010; Porter et al., 2019; Shields et al., 2012). According to Hooghe et al. (2018), parents of children with cancer, and professionals experience direct attention to the parents' intimate

relationship as inappropriate during the treatment of the child. Porter et al. (2019) conducted a randomized intervention study of parents of children with cancer. They concluded that there are many challenges in carrying out couple interventions for these parents, and that the optimal timing and content of interventions require more research attention.

Most group-based couple programs focus on the skill-based training of adaptive relationship behavior (Rogge et al., 2013). The effects of these interventions based on meta-analyses vary from small to moderate (Giblin et al., 1985; Hawkins et al., 2012). Generally, more distressed couples and couples with specific risk factors benefit most from interventions (Allen et al., 2012; Halford et al., 2001). Although skill-based programs affect the interaction of couples, the effect on relationship satisfaction is not that strong. Hawkins et al. (2012) did not find an association between couple interaction and relationship satisfaction in their meta-analysis. Other studies have shown that teaching interaction skills does not produce the desired changes in the relationship (Rogge et al., 2013; Schilling et al., 2003), and couples do not use their skills in distressing situations (Bodenmann et al., 2006). It seems that factors other than interaction skills are central to improving relationship satisfaction, and these factors should be considered and targeted at developing programs that support the relationship (Kennedy et al., 2019).

Attachment is one of the most important factors in supporting a partnership, and a secure attachment is related to relationship satisfaction (Lussier et al., 1997). Thus, focusing on strengthening the attachment could improve the effectiveness of relationship interventions (Kennedy et al., 2019). One of the most studied forms of couple therapy is EFT, which aims to enhance couples' attachment and mutual emotional connection. EFT and its briefer version, the HMT program, will be presented in the following sections.

#### 2.5.1 Emotionally focused interventions

EFT is a well-documented couple therapy format based on attachment theory (Johnson & Williams-Keeler, 1998; Wiebe & Johnson, 2016). Its development began in the 1980s alongside the attachment theory and social baseline theory. In these theories, a human being is seen as innately relational, social, and wired for bonding with others. The EFT model emphasizes the importance of emotion regulation and a safe emotional connection in couple interaction and therapy. EFT was developed by Leslie Greenberg and Susan Johnson into evidence-based treatment and has been found to be effective in individual and couple forms of therapy in several studies. EFT has been used for treatment of anxiety disorders, depression, eating disorders (Greenberg & Goldman, 2019), interpersonal problems, marital distress, and posttraumatic disorder. It is efficacious also in supporting social regulation of emotional responses during serious illnesses such as breast cancer (Naaman et al., 2009).

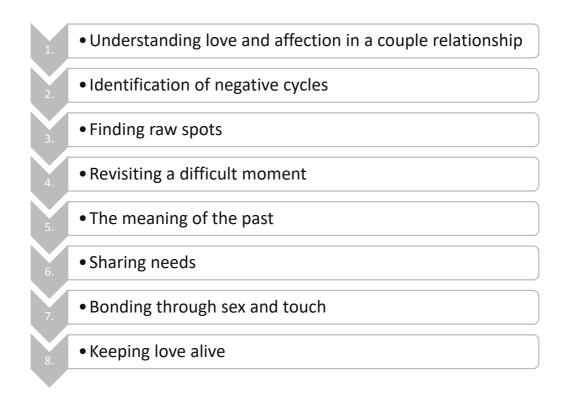
Research to date has shown that EFT can effectively reduce intimate relationship distress of parents whose child has a chronic illness (e.g., Cloutier et al., 2002; Lee et al., 2017; Rasoli et al., 2008; Stiell et al., 2007). Walker et al. (1996) conducted the first randomized controlled trial investigating EFT efficiency in reducing the marital distress of parents with a chronically ill child. In the study, the distress of pairs decreased substantially after treatment and at a 5-month follow-up compared to the control group (Walker et al., 1996). After EFT, a clinical improvement of relationships was also observed. Treatment included ten 90-minute sessions. According to the results, the marital adjustment was higher in the treatment group than the control group both at post-treatment and follow-up. Previous studies and meta-analysis have shown that the results achieved with EFT are relatively stable (Beasley & Ager, 2019; Wiebe et al., 2017). According to a follow-up study by Cloutier et al. (2002), substantial relationship improvements among parents of seriously ill children receiving EFT were maintained at a 2-year follow-up, and some couples even showed further improvements at the follow-up.

#### 2.5.2 Hold Me Tight program

A child's serious illness takes substantial parental resources, and they may not be able to seek long-lasting couple therapy, even if they recognize their need for it. There is a lack of accessible psychoeducational interventions for couples (Morgis et al., 2019), and especially for parents with an ill child. The HMT program (Johnson, 2010) is a group-based educative program for couples modeled on EFT and based on adult attachment theory (Johnson, 2008; Mikulincer & Shaver, 2007). The goal of the HMT program is to strengthen the safety of the relationship. It aims to help couples regulate and share their attachment-related emotions and needs in a way that confirms partners' emotional connection. The goal is to identify and share primary emotions that are distinguished in EFT from the secondary, protective emotions appearing in negative interaction patterns. The main difference between EFT and HMT is the educative nature of the HMT groups. HMT groups use slideshow-presentations and structured couple exercises that facilitators actively guide. EFT therapists, in turn, focus on tracking, heightening, and structuring emotional experiences as they occur in the therapy sessions. Typically, the HMT program consists of eight, 2-hour sessions (Figure 3).

There are only a few HMT intervention studies, but preliminary results have been promising. Morgis et al. (2019) found that HMT intervention increase perceived and actual knowledge acquisition about concepts related to attachment and sexual intimacy. Their pilot data suggested improvements in couples' romantic attachment patterns, sexual communication, and relationship satisfaction with a trend towards an increase in sexual satisfaction. Kennedy et al. (2019) found that relationship satisfaction and trust increased during HMT program participation but declined during 3and 6-month follow-ups. They suggested providing a booster session in the months following program completion to help couples maintain their gains. In a study by Conradi et al. (2017), the self-referred couples showed greater gains from pre- to post-intervention and maintained their improvements at a follow-up, whereas therapist-referred couples exhibited smaller effects and reduction of improvements at the follow-up. During HMT, self-referred couples improved on relationship satisfaction, security of partner-bond, forgiveness, daily coordination, maintenance behavior, and psychological complaints (Conradi et al., 2017). Recently, the HMT program has been used and evaluated with physically ill patients and their partners. For example, HMT intervention improved relationship satisfaction and well-being in patients with Huntington's disease and their partners (Petzke et al., 2022).

The HMT course investigated in the present study had been modified to suit the parents of the ill children and the impact of the child's illness was dealt with each topic. HMT group intervention helped couples to understand adult attachment, love, and affection and to identify their negative interaction patterns (negative cycles) (topics 1 and 2). The couples were then supported and encouraged to talk to each other about their emotional and behavioral triggers (raw spots), vulnerabilities, insecurities, intimacy needs, and primary emotions, and to identify how needs can be masked as a secondary reaction such as anger and frustration (topics 3 and 4). This led couples to discuss the influence of previous relationships and emotional injuries affecting the intimate relationship. Couples were supported to share these experiences empathically and to comfort each other to strengthen the emotional connection (topics 5 and 6). Finally, couples were helped to understand the relationship between emotional connection and sex life and maintain their emotional connection in everyday life with routines and rituals (topics 7 and 8). The topics of the course are compiled in Figure 3.





# **3 AIMS OF THE STUDY**

The general aim of this thesis was to explore the couple resilience, dyadic emotion regulation, and mental health of parents with a seriously ill child. More specifically, the aims of sub-studies were as follows:

- 1. To compile existing research data concerning couple resilience of parents with a seriously ill child; to explore parents' experiences of dyadic emotion regulation, its importance for their personal coping, and the challenges faced in their dyadic emotion regulation (Study 1, publications I and II).
- 2. To evaluate the anxiety, depressive symptoms, general stress, life satisfaction, posttraumatic symptoms, and posttraumatic growth among the parents of seriously ill infants requiring TH, urgent surgery, or cancer treatment (Study 2, Publication III).
- 3. To explore parents' experiences of emotionally focused HMT group intervention targeted at enhancing intimate relationships of parents of children with cancer (Study 3, Publication IV).

# **4 MATERIALS AND METHODS**

### 4.1 Study design and participants

The present study was based on three cohorts of parents with a seriously ill child and one control group of parents with a healthy child. Study 1 consisted of a narrative review article (Publication I) and an interview study (Publication II). The purpose of the review article was to compile existing research data concerning the couple resilience of parents with a seriously ill child. To identify appropriate publications, I performed a literature search from PsycInfo and PubMed databases with the following keywords: resilience, coping, posttraumatic growth, parents, child's illness. Only peer-reviewed articles were approved. The suitability of the articles for the review was critically assessed in terms of main results, limitations, methods, quality of results, and interpretation and effectiveness of foundations. In writing the review, I followed the recommendations for the narrative reviews (Ferrari, 2015; Green et al., 2006). The review described the expansion of the concept and research of resilience chronologically from an individual perspective to a relational framework. I structured the review according to key concepts and at the heart was the child's serious illness. I separated the contents by the concepts of individual and couple resilience, the effects of illness, the examination of factors supporting couple resilience, and reflections on scientific and clinical implications.

The interview group\* consisted of 16 heterosexual couples (32 participants, ages ranging from 26 to 55 years) whose child was seriously ill and in treatment in Kuopio University Hospital, Kuopio, Finland, between April 2014 and April 2018. The children were 0–6 years old and diagnosed with one of the following life-threatening illnesses or conditions: asphyxia (n = 5), esophageal atresia (n = 2), gastroschisis (n = 1), leukemia (n = 3), lymphoma (n = 2), omphalocele (n = 1), rhabdomyosarcoma (n = 1), and Wilms tumor (n = 1).

In Study 2, the exposed group\*\* consisted of 17 heterosexual couples (34 parents, ages ranging from 21 to 47 years) whose infant was seriously ill and

in treatment in Kuopio University Hospital, Kuopio, Finland, between April 2014 and April 2018. The infants were between 0 and 19 days old and had one of the following life-threatening illnesses or conditions necessitating TH or urgent surgery: asphyxia (n = 9), esophageal atresia (n = 2), gastroschisis (n = 3), omphalocele (n = 2), and renal failure (n = 1).

The control group\*\*\* of Study 2 consisted of 30 heterosexual couples (60 participants, ages ranging from 20 to 47 years) who were parents of healthy children. Infants in the control group had no need for NICU admissions. The inclusion criteria in the control group were a couple with a healthy, full-term biological newborn, both parents' agreement to participate, and voluntary written consent. Background data of the families in Study 2 is presented in Table 4.

Subjects, study and control groups, data, and methods of studies 1, 2 and 3 are presented in Table 2. Sociodemographic and characteristics of participants in studies 1, 2, and 3 are presented in Table 3.

	Stu	Study 1	Study 2	Study 3
	Publication I	Publication II	Publication III	Publication IV
Subject	Couple resilience of parents with a seriously ill child	Dyadic emotion regulation of parents with a seriously ill child	Psychiatric symptoms, posttraumatic growth, and life satisfaction of parents with a seriously ill child	Experiences of parents of an emotionally focused HMT course
Study group	I	32 parents of a seriously ill child treated in the hospital	34 parents of a seriously ill infant treated in the hospital	24 parents of a child with cancer who participated in the HMT course
Control group	1	I	60 parents of a healthy child	I
Data	Psyclnfo and PubMed databases	Semi-structured, videotaped interviews	Questionnaires (BAI, BDI-II, EPDS, IES-R, PSS, PTGI, LS-4)	Videotaped focus group conversations
Method	Narrative review	Interpretative Phenomenological Analysis (IPA)	Statistical analysis (Kolmogorov- Smirnov test, Shapiro-Wilk test, Cronbach's alpha, t-test, Mann- Whitney U test, Wilcoxon signed- rank test, Chi-Square test, Fisher exact test, McNemar's test, Spearman's rank correlation test)	Interpretative Phenomeno- logical Analysis (IPA)

Table 2. Subjects, study and control groups, data, and methods of studies 1, 2 and 3.

		_					_		
Variable		St	Study 1		Stuc	Study 2		SI	Study 3
		Intervi (I	Interview group* (N=32)	Expose (h	Exposed group** (N=34)	Contro (I	Control group*** (N=60)	Focus (I	Focus groups <del>****</del> (N=24)
Age (yrs)	Fathers	n=16	35 [21-55] 34.7 (9.5)	n=17	30 [21-47] 32 (7)	n=30	31 [21-47] 31 (6)	n=12	38 [28-48] 37.5 (6.5)
	Mothers	n=16	33 [21-47] 32.7 (8.0)	n=17	28 [21-39] 29 (5)	n=30	29 [20-38] 28 (5)	n=12	36 [25-47] 35.8 (6.5)
	Children	n=16	2 [0-5] 1.2 (1.6)	n=17	0 [0-0] 0 (0)	n=30	(0) 0 [0-0] 0	n=12	8 [2-19] 7.7 (5.6)
Illness of	Asphyxia	5	5 (31%)	6	9 (53%)	C	0 (0%)	0	0 (%0) (%0)
the child	Esophageal atresia	2	2 (13%)	2	2 (12%)	0	0 (%0) 0	0	0 (0%)
	Gastroschisis		1 (6%)	£	3 (18%)	0	0 (%0) 0		0 (0%)
	Leukemia	S	3 (19%)	0	0 (0%)	C	0 (0%)	9	6 (50%)

2 (17%) (%0) 0

(%0) 0 1 (8%) 1 (8%) 1 (8%)

> (%0) 0 0 (0%)

> (%0) 0 0 (0%)

> > 1 (6%)

Rhabdomyosarcoma

Wilms tumor

Retinoblastoma

1 (6%)

(%0) 0

(%0) 0

0 (0%)

1 (8%)

(%0) 0 (%0) 0 (%0) 0 0 (0%)

(%0) 0 (%0) 0

2 (13%)

(%0) 0

Medulloblastoma

Lymphoma

Omphalocele Renal failure

4 (24%) 1 (6%)

1 (6%) (%0) 0

Table 3. Characteristics of participants in studies 1, 2, and 3.

Variable		Study 1	Stuc	Study 2	Study 3
		Interview group* (N=32)	Exposed group** (N=34)	Control group*** (N=60)	Focus groups**** (N=24)
Miscarriages, n	s, n	2 (6%)	4 (12%)	7 (12%)	4 (17%)
Infertility tr	Infertility treatments, n	3 (9%)	4 (12 %)	3 (5%)	0 (0%)
Mothers working, n	rking, n	9 (56%)	8 (47 %)‡	24 (80%)	8 (67%)
Fathers working, n	king, n	15 (93%)	16 (94%)	27 (90%)	12 (100%)
Burden in	Economic, n	11 (34%)	7 (21%)	5 (8%)	8 (33%)
family	Other, n	9 (28%)	4 (12%)	3 (5%)	14 (58%)
Physical	Fathers, n	2 (13%)	4 (24%)	8 (27%)	1 (8%)
illnesses	Mothers, n	4 (25%)	2 (12%)	6 (20%)	7 (58%)
Mental	Fathers, n	1 (6%)	1 (6%)	4 (13%)	1 (8%)
illnesses	Mothers, n	5 (31%)	5 (29%)	7 (23%)	5 (42%)
Siblings in tl	Siblings in the family (yes/no)	22/10	9/8	11/19	24/0
Number of siblings	siblings	1 (0-5)	1 (0-7)	0 (0-6)	2 (1-7)
Illnesses of	Physical	1 (3%)	1 (3%)	NA	2 (8%)
siblings	Mental	2 (6%)	0	NA	1 (4%)

Data are median [minimum-maximum], mean (standard deviation) or number of cases (%). ‡ p = 0.020

Variable		Interest group (N=34)	t group 34)	Contro (N=	Control group (N=60)	
	Fathers	n=17	30 [21-47]	n=30	31 [21-47]	
Age (yrs.)	Mothers	n=17	28 [21-39]	n=30	29 [20-38]	
Miscarriages n (%)	-	4 (24%)	1%)	7 (2	7 (23%)	
Infertility treatments n (%)	nts n (%)	4 (24%)	1%)	3 (1	3 (10%)	
Mode of delivery n (%)	(%)					
<ul> <li>Vaginal</li> </ul>		9 (53%)	3%)	29 (5	29 (97%)	
<ul> <li>Cesarean</li> </ul>		8 (47%)	(%)	1 (	1 (3%)	
Length of NICU stay days	y days	12 [3-37]	-37]		1	
Mothers employed n (%)	l (%) u	8 (47%)	7%)	24 (8	24 (80%)	<0.020
Fathers employed n (%)	u (%)	16 (94%)	4%)	27 (9	27 (90%)	<0.627
Education n (%)						
<ul> <li>Basic level</li> </ul>		1 (3%)	(%)	1 (2	1 (2%)	
<ul> <li>Upper secondary</li> </ul>		16 (47%)	.7%)	25 (4	25 (42%)	
<ul> <li>Lower-degree tertiary</li> </ul>	tiary	11 (32%)	(%)	12 (2	12 (20%)	
<ul> <li>Higher-degree tertiary</li> </ul>	rtiary	1 (3%)	(%)	11 (	11 (18%)	
· NA		5 (15%)	5%)	11 (	11 (18%)	

**Table 4.** Background data of the families in Study 2 (N = 17 dyads/34 parents in the interest group and 30 dyads/60 parents in the control group).

Variable		Interest group (N=34)	Control group (N=60)	
Family burden	Economic n (%)	7 (41%)	5 (17%)	0.064
	Other n (%)	4 (24%)	3 (10%)	0.211
Physical illnesses	Fathers n (%)	4 (24%)	8 (27%)	0.813
	Mothers n (%)	2 (12%)	6 (20%)	0.470
Mental illnesses	Fathers n (%)	1 (6%)	4 (13%)	0.426
	Mothers n (%)	5 (29%)	7 (23%)	0.646
Siblings in the family (yes/no	ily (yes/no)	9/8	11/19	
Number of siblings		1 (0-7)	0 (0-6)	
Illnesses of	Physical n (%)	1 (6%)	NA	
sibilings	Mental n (%)	0 (0)	NA	

Data are median [range] or number of cases (%).

The parents of ill children in studies 1 and 2 were recruited from the Child and Adolescent Center of Excellence in Kuopio University Hospital in the NICU and Pediatric Hematology and Oncology Unit. The inclusion criteria were a life-threatening illness diagnosed in a biological child and requiring urgent invasive treatment (TH, surgery, or cancer treatment); an intimate relationship with the child's other parent; the ability to understand the Finnish language and to participate in research interviews without an interpreter; and a voluntary written consent from both parents. The exclusion criterion was age less than 18 years. Departments were informed about the study, and staff secretaries informed me about patients potentially suitable for the study. I asked the attending nurses to ask parents for permission to discuss the study directly with them. After receiving permission, I met with the parents, we discussed the study, and they considered participation.

I interviewed the parents of Study 1 separately for the first time within three weeks after their child's diagnosis. The interviews were videotaped, and videotapes were evaluated to separate the parts concerning the participants' intimate relationship. The selected parts of interviews were transcribed verbatim as required by the method of analysis.

The Study 2 participants fulfilled the questionnaires measuring anxiety (Beck Anxiety Inventory BAI), depressive symptoms (Beck Depression Inventory–II BDI-II and Edinburgh Postnatal Depression Scale EPDS), life satisfaction (Life Satisfaction Scale–4 LS-4), and perceived stress (Perceived Stress Scale PSS). Parents completed the questionnaire measuring posttraumatic symptoms (Impact of Event Scale–Revised IES-R) one month after their child's diagnosis. One year after the diagnosis, both parents separately completed the same questionnaires as the first time, including the PTGI (Posttraumatic Growth Inventory). The parents belonging to the control group completed all the questionnaires, except for the IES-R and PTGI, after the child was born and again one year after the child's birth. The questionnaire responses were scored and analyzed by statistical methods.

Participants of Study  $3^{****}$  consisted of 12 heterosexual couples (24 parents, ages ranging from 25 to 48 years) whose child had cancer. The children of participants were 2–19 years old and diagnosed with one of the following illnesses: ALL (n = 6), medulloblastoma (n = 2), lymphoma (n = 1),

retinoblastoma (n = 1), rhabdomyosarcoma (n = 1), and Wilms tumor (n = 1). The parents were recruited from the emotionally focused HMT courses offered by an organization supporting the families of children with cancer (Sylva ry). The courses have been arranged in Finland since 2013 for parents of children with cancer. The courses lasted three days, and they were held in April 2016, 2017, and 2018 in Kuopio and Siilinjärvi. Four couples participated in each course. I was one of the facilitators of the course, and the other facilitator was a psychiatric nurse and a sexual counselor (Janne Puranen). We had training in EFT and previous experience with the courses. Each topic included an educative slideshow-presentation, discussion, and couple exercises. We supported each couple during the exercises. In the course sessions, parents focused mostly on addressing their relationship, but during the weekend they also had the opportunity for peer support.

The inclusion criteria for Study 3 were a child diagnosed with cancer; an intimate relationship with the child's other parent; participation in the course; the ability to understand the Finnish language and to participate in focus group conversations without an interpreter; and voluntary written consent. The exclusion criterion was age of less than 18 years. After the course, the parents participated in a focus group conversation which aimed to explore the experiences of the course and its impacts on the parents' intimate relationship. The conversations were videotaped, recordings were transcribed, and the material was analyzed with IPA. Flowcharts of studies 1, 2, and 3 are presented in Figure 4.

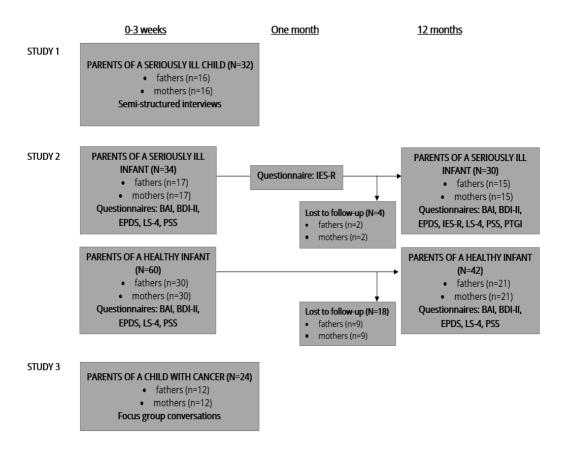


Figure 4. Flowcharts of studies 1, 2, and 3.

# 4.2 Interview procedures

## 4.2.1 Interview in Study 1

In Study 1, I interviewed the parents at the hospital within three weeks of the diagnosis of their child. The parents were interviewed individually and successively so that they did not have a chance to talk about the interviews with each other. Semi-structured interviews were carried out according to guidelines suggested by Smith (1995). I facilitated and guided, rather than dictated exactly what happened during the encounter. My aim was to create a positive and responsive 'set' to enable parents to feel comfortable. The duration of interviews varied between 20 and 100 minutes (the median duration was 47 minutes). The interviews were managed in a conversational style, and the sensitivity of the subject was considered in the situation.

The interview contained open-ended questions that directed the course of the interview but allowed for flexible discussion about specific issues raised by participants. The purpose of the interview was to explore the emotional experiences and psychological reactions of parents. The interview began by asking the parents about the situation concerning the child's illness and hospitalization, and then moved on to explore more specific psychological and interpersonal issues. Parents were asked, for example, how they had experienced the situation, what had been the most difficult part of their experiences, how the situation had affected their relationship and what helped them to cope with the situation. The parents were also asked what they needed and how they asked for and received support from each other. Further, they were asked about the significance of the support received from their partner in relation to their own coping. At the end of each interview participants were invited to add any comments related to the issues discussed. The participants were also encouraged to share their feelings during the interview to make sure that they were in a stable state of mind during and after the sensitive discussion. Among the interviewed parents of a seriously ill infant, only 12% of participants were lost to follow-up. The proportion was low compared to parents of healthy children (30%), although coming to the interview required more effort than just completing and sending the questionnaires. This difference may mean that parents did not feel that the first interview was a burden, and maybe it was even useful to them.

#### 4.2.2 Interview in Study 3

At the end of each emotionally focused HMT course, the parents participated in a focus group conversation. In these conversations the fathers discussed with me their experiences concerning the course while their partners and the other facilitator listened to the discussion. After that, a similar conversation was conducted with the mothers while their partners and the other facilitator listened. In the end, everyone had the opportunity to reflect on what they heard together. The aim of the focus group conversation was to give parents the opportunity to listen to the experiences of their partner and other parents and to reflect on their own experiences and to be heard themselves. In a qualitative analysis by Gale (1992), participants felt that the research interview conducted after the couple therapy was even more useful than therapy, which appeared to be linked to the collaborative relationship between the researcher and the couple, the contextualization of the research talk, and clarifying procedures used by the interviewer. Based on these results, it is possible that the research interview was interventive for couples, although it also demanded their effort. Gathering feedback in groups also enabled dialogue and peer support between parents.

Focus group conversations were semi-structured, according to guidelines suggested by Smith (1995). The conversations began by asking the parents about experiences related to the HMT course, and then moved on to explore more specific topics covered in the course. Parents were asked about, e.g., the possible effects of the course on their relationship, the future, and the parents' own ways of coping. They also were asked how they would like the course to be developed and what other topics they would have liked the course to cover. At the end of each conversation, parents were invited to add any additional comments related to the issues discussed that seemed pertinent to them. The conversation durations were 88 minutes for fathers and 77 minutes for mothers.

## 4.3 Analysis procedures

## 4.3.1 Interpretative Phenomenological Analysis (IPA)

IPA is a qualitative research approach based on the phenomenological philosophy of science, which emphasizes the production of knowledge through human observations and experiences. The current methods of interpretative and hermeneutic phenomenology used in psychological research are based on Heidegger's and Gadamer's thinking (Willig & Stainton-Rogers, 2008). In phenomenology the focus is on the way in which things are experienced by individuals; the reality in which people live is viewed as experiential, and experience emerges in their meaningful commitment to things and other people. According to Edmund Husserl, phenomenological philosophy

primarily served descriptive goals, whereas Martin Heidegger defined phenomenological methodology as being fundamentally interpretative (Willig & Stainton-Rogers, 2008). Hans-Georg Gadamer, a student of Heidegger, confirmed the interpretative tradition of phenomenology (Gadamer, 1986).

The research of the individual's subjective world of experience lacked a clearly articulated method based on psychology, and in the mid-1990s IPA was developed to meet this need (Willig & Stainton-Rogers, 2008). The IPA approach is idiographic, and it focuses on the specific meanings of the individual experience. The IPA strives to achieve a broader understanding of the phenomenon under study through individual examination. The advantage of the IPA is that as a phenomenon- and informant-based research method it reaches the variation of the individual experiences more broadly and deeper than nomothetic variable-oriented methods. During IPA, the individual's experience is openly approached without prior statements or pre-defined variables, which opens space for reaching different aspects of experience.

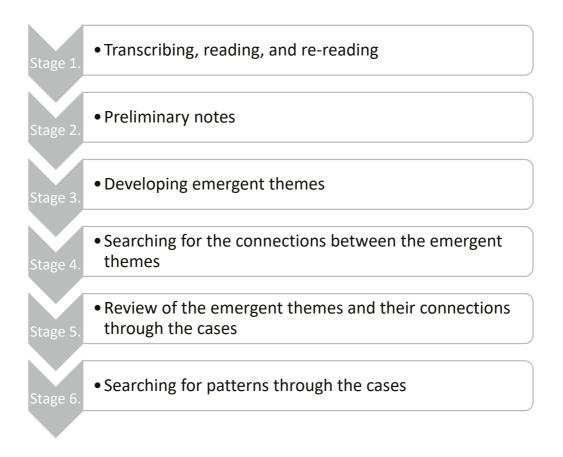
Thus, IPA focuses on exploring individual, lived experience, and individuals' ways of making sense of their experience, and through it to gain an idea of the general and universal structures and laws of humanity and experience. Lived experience refers to a socio-culturally, and historically positioned individual who lives in an intentionally interpreted and meaningful world (Willig & Stainton-Roger, 2008). The IPA approach aims to reach comprehensively all sides of this lived experience; from the individual's wishes, aspirations, feelings, motivation, belief systems to how they are manifested or missed at the level of behavior and function (Willig & Stainton-Roger, 2008).

In IPA the process of entering the participant's world usually begins by repeated reading of transcribed data aimed at immersion into the data and reading it "from within" (McLeod, 2001). In this empathic and explorative method, the attention is paid to the cognitions, emotions, expression, and speech of the interviews (Smith et al., 2012). The purpose of IPA is to create a descriptive core of comments, identify critical experiences of participants, and focus closely on the meanings produced by the participants (Smith et al., 2012). The goal of phenomenological reduction is to reach the direct experience of the subject, and this is achieved by dealing with presuppositions. In IPA the researcher forms part of the participant's meaning-making process,

and therefore reflective notes after each interview and during the analytical interpretative stages are captured (Smith et al., 2012).

In this study, the videotaped and transcribed interviews and focus group conversations were analyzed by IPA. I analyzed data using thematic analysis techniques aimed at reaching out for the meanings derived from the lived experiences of participants. In Study 3, the specific recommendations for the focus group analysis of Love et al. (2020) were followed. In focus groups, positionality, stories, and patterns and function of language should be explored at individual and group levels (Love et al., 2020). According to Love et al. (2020), in focus group analysis the researcher should consider the complexity of the group dynamics and the multiple hermeneutics that is inevitably present in analysis of focus groups. For these reasons, Tomkins and Eatough (2010) suggest that an additional iterative loop should be utilized in focus groups. In Study 3, this involved assessing how well the group-level main themes represented each participant and comparing themes across different focus groups. While emerging themes of focus groups are being considered, Palmer et al. (2010) suggest exploring how the group manages and makes sense of their shared experiences. It is important to notice what experiences are being shared, what participants are doing by sharing their experiences, how they are making their experiences meaningful to one another, what they are doing as a group, and identifying the consensus and conflictual issues (Love et al., 2020). These questions were considered while developing the emerging themes. For example, parents seemed to use the focus groups as a form of peer support, which could strengthen the consensus of the conversation and reduce their possibility to express disagreement when discussing the effects of the course.

According to Smith et al. (2012), IPA can be characterized as a group of general processes that are flexibly applied in terms of analytical purpose. The six stages of the IPA applied to this research data are as follows (Figure 5):



**Figure 5.** Stages of Interpretative Phenomenological Analysis (Smith et al., 2012).

### 4.3.1.1 Stage 1: Transcribing, reading, and re-reading

In this study, access to the data began already in the interviews, focus group conversations, and transcription phases that I conducted. After each interview and focus group conversation, I wrote down my own reflective thoughts, initial observations, and recollections on conducting the interview to ensure that the participant became the focus of analysis. I aimed to find a suitable distance to the data, enabling an exploratory attitude.

I transcribed the interviews and focus group conversations verbatim, including descriptions of participants' tone, pitch, emotion, gesticulations, and the group dynamics to help achieve immersion in the data. After this, I read all transcripts three times to actively engage with the data and become familiar with the content of the interviews and conversations. I also watched

the videotapes to recall the situation and the emotional content of the data. While watching the videotapes, I focused especially on the participants' nonverbal communication, such as positions, gestures, facial expressions, gaze, and tone of their voice to notice the different aspects of the interaction and communication.

#### 4.3.1.2 Stage 2: Preliminary notes

Next, I continued by drawing upon the close, line-by-line analysis of the experiences of each participant. This stage of IPA examined semantic content and language use on a very close and exploratory level. First, I wrote descriptive comments, then linguistic comments, and finally, I added conceptual comments to the transcript to bring the analysis to a more general, conceptual level.

In the first reading, I described the issues produced by participants and their meanings. I wrote descriptive comments in the text file and underlined the related expressions on the original transcripts. I wrote up my own observations and understandings to distinguish them from the meanings of participants.

In the second reading, I added linguistic comments to the file, focusing on the language of the interview. I indented and italicized the linguistic comments in the same text file with the descriptive comments. I focused on the participants' ways of presenting content and meanings. As Smith et al. (2012) recommended, I paid special attention to nonverbal communication, such as pronoun use, pauses, smile, laughter, tears, repetition, tone, articulation, and fluency.

The purpose of the third reading was to shift the focus towards the participants' general understanding of the issues that they were discussing. I produced the conceptual comments with the aim of departing from the explicit claims of participants and lifting the analysis to a more interpretational level. As I read the transcript, I commented on similarities, differences, echoes, amplifications, and contradictions in the discussion. These comments represented the beginning of the conceptualization process. Participants' ways of discussing a topic signified important experiences and helped to reveal the function of statements and their implicit meaning. This was achieved by exploring the positionality, stories, and their use of language, as suggested by Love et al. (2020).

In Study 3, the parents of the focus groups supported each other's expression by sharing their own personal experiences and providing peer support to participants with difficult subjects. Parents also used humor and self-irony to lighten up painful topics. I was aware how my double position as a course facilitator and a researcher might have influenced the conversation by getting participants to emphasize their positive experiences concerning courses. I also recognized the effects of the role of the course facilitator on my own prior assumptions. For example, I was aware of how my wish for the positive effects of the course may have influenced my way of interpreting the data. I consciously aimed to limit my prejudgment and expectations as well as to neutralize this bias by self-reflection throughout the research process and by using an external co-researcher (Juho Kalapudas, M. A. Psych.) outside the course context in the analysis.

### 4.3.1.3 Stage 3: Developing of emergent themes

The next step of IPA is identifying emergent themes by analyzing the exploratory comments (Smith et al., 2012; Smith & Rhodes, 2015). At this stage, I simultaneously attempted to reduce the volume of detail and maintain the complexity in terms of mapping the interrelationships, connections, and patterns between exploratory notes. I worked primarily with the initial notes rather than the transcript itself. However, my work was still closely tied to the original transcript, and I regularly checked the roots of emerging themes. At this stage the focus was considering the micro-level data alongside the macro-level interpretation of meanings across the whole text (Love et al., 2020). In Study 3, self-reflections also included how I interpreted the group members' reactions and dynamics toward each other, known as multiple hermeneutics (Tomkins & Eatough, 2010).

The analysis of exploratory comments focused on discrete sections of transcript, while at the same time maintaining an awareness of the whole process of initial noting. I aimed to produce a compact and concise statement of what was essential in the various comments attached to a section of transcript. I expressed themes as phrases, which described the psychological essence of the piece, contained enough particularity to be grounded to the transcript and enough abstraction to be conceptual. I wrote down the themes below the comments and examined them side by side with the transcript to ensure they were derived from the original data. Any themes that were not adequately grounded in the transcript were dropped. Figure 6 provides examples of emergent themes produced by one participant in a focus group conversation.

Increasing self- understanding	<ul> <li>Importance of self-exploration (feelings behind reactions)</li> <li>A new understanding of one's mind, reactions, and interaction</li> </ul>
Increasing the partner's understanding	•Raw spots from the past
Increasing the understanding of interactions in a relationship	<ul> <li>Normalization of reactions</li> </ul>
Facilitating the processing of future challenging situations	<ul> <li>Identifying the harmful interactions and an increase in sense of mastery</li> <li>Negative cycles as means for discussion of interaction</li> <li>Stopping the cycles</li> <li>Courage to talk about feelings and needs</li> </ul>
Strengthening the relationship	<ul> <li>Understanding the importance of routines that reinforce intimacy, and the agreement to increase them</li> <li>Increasing the positive interactions</li> <li>Reduction in the negative cycles</li> <li>Identifying and talking about the good aspects of the couple and family relationship</li> </ul>

Figure 6. Examples of emergent themes in Study 3.

## 4.3.1.4 Stage 4: Searching for the connections between the emergent themes

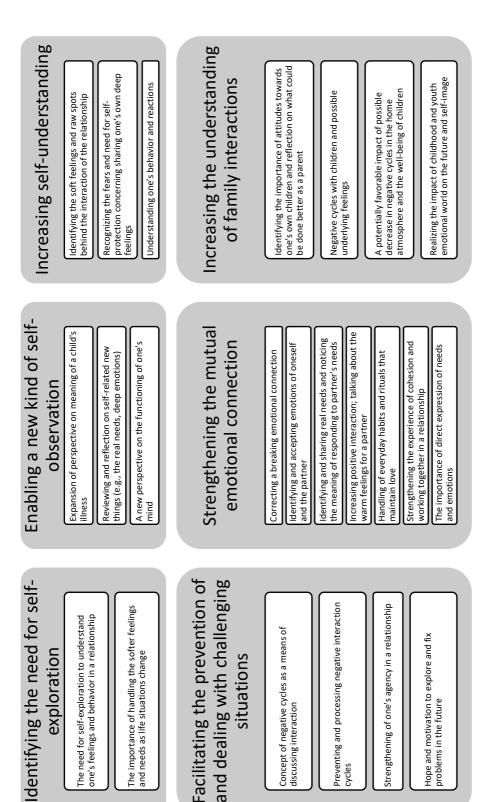
At the fourth stage of IPA, I searched for connections across emergent themes. I clustered similar themes and developed a map of themes that fit together. Then I considered the wider context and function of themes and clustered the preliminary themes into groups of related themes, according to common features in terms of meaning. A theme in a cluster became a main theme if it was able to explain or pull together other similar kinds of themes. I interpreted and then validated the main themes by crosschecking them with the original transcript. Groups of related themes in Study 3 are presented in Figure 7.

### 4.3.1.5 Stage 5: Review of the emergent themes and their connections through the cases

The identification of the emergent themes was implemented first for single cases, then subsequently across multiple cases and in Study 3, also across focus groups. The above process was repeated for each transcript in turn to identify the patterns across cases. Considering the idiographic commitment of IPA, I handled each case on its own terms, allowing new themes to emerge. I summarized the emergent themes and produced a structure, which allowed me to point to all the most important aspects of the participants' experiences. Then I combined the preliminary analyses into a consolidated summary of the main themes for the data.

### 4.3.1.6 Stage 6: Searching for patterns through the cases

At this stage, the recurrence of main- and subthemes was checked at the individual and at the focus group level. This aimed to ensure the conservation of the individual and the group's collective voice in accordance with the IPA's idiographic principles, while recognizing the importance of the focus group design (Love et al., 2020).



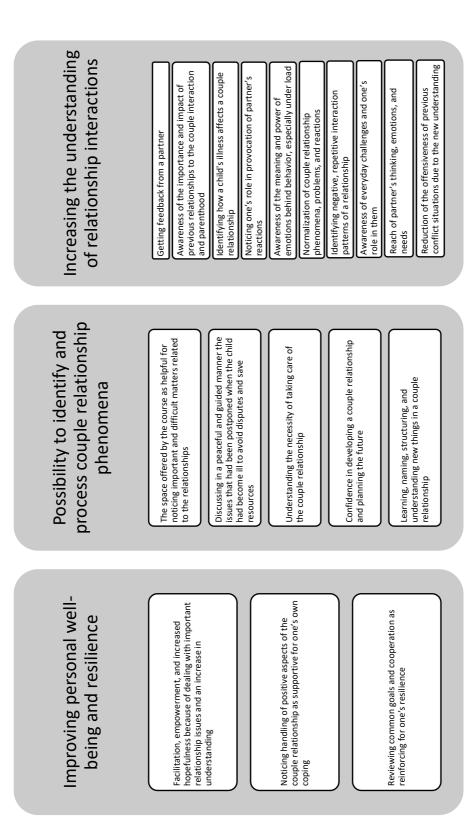


Figure 7. Groups of related themes in Study 3.

In Study 3, main- and subthemes were amalgamated across all focus groups, once the analysis for each focus group was completed. As Palmer et al. (2010) suggested, I checked all the data to ensure sufficient homogeneity between focus groups to allow for successful integration of themes. I picked out commonalities and differences between groups and frequently revisited the transcripts to check themes in relation to original text to ensure accuracy. I also considered the themes in the wider context of existing relevant theories, my research questions and aims. According to Smith et al. (2012), measuring of the frequencies through the cases is appropriate, especially with large sample sizes. In this study, the numeration of participants who produced themes indicated the relative importance of themes.

As suggested during the focus group analysis, Juho Kalapudas (M. A., Psych.), who was familiar with the data and IPA, thoroughly reviewed the process of analysis and provided written feedback about the themes and interpretations. The feedback was used to improve and amplify the analysis and to ensure the quality of the final product. Differences in themes, their connections, and interpretations were resolved by discussion and by making compromises. As suggested, I also discussed themes with my focus group co-facilitator.

At the end of this stage, I developed a full narrative, evidenced by a detailed commentary on data extracts, which took the reader through the interpretation and reflection of the researcher's perceptions, conceptions, and processes during the analysis.

### 4.4 Quantitative measures

In Study 2 (Publication III), the participants filled in the first questionnaires (BAI, BDI-II, EPDS, LS-4, and PSS) during the first days of the infant's diagnosis or delivery (baseline). An exception to this was the IES-R questionnaire, which parents of ill children completed one month after the infant's diagnosis. Parents of ill children filled in the second questionnaires at a scheduled visit in the hospital at 12 months (follow-up), and parents in the control group returned posted questionnaires in a prepaid envelope at 12 months after the birth of their infant. Only the parents of an ill child filled in IES-R and

PTGI questionnaires. Total scores from all measures were calculated and compared between the groups and between the two time points within the groups. Dichotomized scores were also calculated for all measures.

### 4.4.1 Anxiety (BAI)

The Beck Anxiety Inventory (Beck et al., 1988) was used to assess the subjective anxiety of the participants. The BAI is a 21-item self-report measure. The items were rated on a four-point scale of increasing severity. The BAI was dichotomized to no or mild anxiety (BAI score 0–15) and to moderate-severe anxiety (BAI score 16–63).

### 4.4.2 Depressive symptoms (BDI-II, EPDS)

The Beck Depression Inventory–II (Beck et al., 1996) and the EPDS (Cox et al., 1987) were used to assess the current depressive symptoms of the participants. The BDI-II is a 21-item self-report measure. The items were rated on a four-point scale of increasing severity. The BDI-II was dichotomized to no depression symptoms (BDI-II score 0–13) and to depression symptoms (BDI-II score 14–63).

The EPDS is a 10-item self-report measure. The items were rated on a four-point scale of increasing severity. The EPDS was dichotomized to no depression (EPDS score 0–9) and possible depression (EPDS score 10–30).

### 4.4.3 General stress (PSS)

The Perceived Stress Scale (Cohen et al., 1983) was used to assess subjective experiences of psychological stress. The PSS-14 is a 14-item self-report measure. The items were rated on a five-point scale of increasing severity, and seven positively stated items were reversed to obtain scores for summing. The PSS-14 score was dichotomized to low stress (PSS-14 score 0–18) and moderate or high stress (PSS score 19–56).

### 4.4.4 Posttraumatic growth (PTGI)

The Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996) was used to assess positive change due to a crisis. The PTGI is a 21-item self-report measure. The items were rated on a six-point scale of increasing growth. The PTGI score was dichotomized to no meaningful positive change (PTGI score 0–41) and at least a small positive change (PTGI score 42–105) (Sawyer et al., 2012). PTG was measured at follow-up in parents with an ill child.

### 4.4.5 Posttraumatic symptoms (IES-R)

The Impact of the Event Scale-Revised questionnaire (Weiss & Marmar, 1997) was used to assess subjective distress caused by a traumatic event. The IES-R is a 22-item self-report measure. The items were rated based on how distressing each symptom was during the past seven days on a four-point scale of increasing severity. Traumatic distress score was dichotomized to PTSD unlikely (IES-R score 0–24) and PTSD likely (IES-R score 25–66).

### 4.4.6 Life satisfaction (LS-4)

The Life Satisfaction Scale–4 (Allardt, 1973; Koivumaa-Honkanen et al., 2000) was used to assess subjective interest and happiness in life, ease of living, and loneliness of the participants. The LS-4 is a four-item self-report measure. The items were rated on a five-point scale of decreasing satisfaction. The LS-4 score was dichotomized to satisfied (LS-4 score 4–11) and dissatisfied (LS-4 score 12–20) (Koivumaa-Honkanen et al., 2000).

### 4.5 Statistical methods

The data were recorded and analyzed using SPSS software (IBM SPSS Statistics 25, International Business Machines Corporation, Armonk, NY, USA). Both continuous and categorical data were used, and for categorical data nominal, ordinal, and dichotomous data were used as appropriate. The distribution of continuous data was first checked visually, and the normal distribution assumption was checked using the Shapiro–Wilk test, and equality of variances was tested using Levene's test. Normally distributed continuous data were analyzed using a two-sample t-test assuming equal variances, and non-normally distributed data were compared with the Mann-Whitney U test. Categorical data were analyzed with the Wilcoxon signed-rank, the Chi-Squared test, Fisher exact test and McNemar's test as appropriate. The Spearman's rank

correlation test was used to test associations between variables. The internal consistency in questionnaires was tested with Cronbach's alpha. P-values  $\leq$  0.05 were considered statistically significant (See Table 5).

### 4.6 Ethical approval

Approval for the study protocol was obtained from the Research Ethics Committee of the Northern Savo Hospital District, Kuopio, Finland (studies 1 and 2: No. 88/2013, January 7, 2014, Study 3: No. 68/2016, February 9). The study had institutional approval (No. TJ\_146/2015) and complies with the American Psychological Association Ethical Principles and the Ethical Principles presented in the Helsinki Declaration regarding the treatment of participants. Participants were given oral and written information about the study and were given time to consider their participation. The participants gave written informed consent for participation in the study and video interviews. Refusal to participate in the study did not affect the treatment of parents. Parents also had the right to withdraw their participation in the study at any time and without an articulated reason.

### **5 RESULTS**

### 5.1 Couple resilience, dyadic emotion regulation and its importance for parents' personal coping (Study 1)

Study 1 examined the couple resilience, dyadic emotion regulation, its importance for parents' personal coping, and the challenges of dyadic regulation in parents of seriously ill children. In the narrative review (Publication I), resilience was considered as a dynamic, multidimensional, and relational process that emerges and evolves in the shared encounter of adversities. Dyadic resilience is affected by meanings given to adversities, experienced and expressed emotions, mutual support, and the feeling of we-ness emerging between a couple. According to the literature review, the underlying dyadic processes and interaction behind coping and posttraumatic growth have received little academic attention. Based on the review, it is essential to strengthen our understanding of the dyadic processes that enhance couple resilience and to find useful interventions to support parents' interaction as the child becomes seriously ill.

In the interview study (Publication II) the parents described in the interviews the different needs and forms of dyadic emotion regulation, as well as the challenges in dyadic emotion regulation. Parents reported offering and receiving a variety of emotional support from each other and considered it as essential to their personal coping, sense of safety and emotion regulation. The main themes of the interview study were recognition and disclosure of the needs of dyadic emotion regulation, load sharing and dyadic regulation of emotions, importance of dyadic emotion regulation. Recognition and disclosure of the needs of dyadic emotion regulation appeared to be a prerequisite for load sharing and emotion regulation. Dyadic emotion regulation was considered as meaningful for personal coping, but it also involved special challenges. The subthemes of load sharing and dyadic regulation of emotions were recognizing another's emotions, direct expression and avoiding emotions, nonverbal interaction, presence and intimacy, and verbal interaction. Dyadic emotion regulation seemed to be realized by many straight, indirect, verbal, and nonverbal means. The results of the analysis are presented in Figure 8.

### 5.1.1 Recognition and disclosure of the needs of dyadic emotion regulation

Parents identified and expressed their dyadic emotion regulation needs in relation to each other. Many parents felt that the child's illness raised the need for their mutual presence, intimacy, coexistence, and common time. The care received from the other parent and maintaining positivity in a challenging situation were also mentioned as essential needs of dyadic emotion regulation.

Mother (M): If the father (F) has seen that I have a bad feeling, he just needs to be there. The only thing that I have needed is that someone is there and listens to me. Despite everything, he still keeps on thinking about my well-being... Although this is hard also for him, he keeps taking me into account, it has meant a lot to me. -- That he takes into account, or has left his own needs aside, that first and foremost come me and our child. Our well-being and situation and needs. -- He keeps on supporting me. And also stays very positive.

Parents described that the needs for each other's presence, comfort, and approval become spontaneously and tacitly identified between the parents.

F: I have not been able to ask her for any support, it comes naturally here, we always support each other (brings his hands together).

The parents also recognized the complementarity of expressing needs and responding to them while considering each other's resources.

M: Sometimes when one feels that the other is a little more down, then one is able to provide comfort, and vice versa.

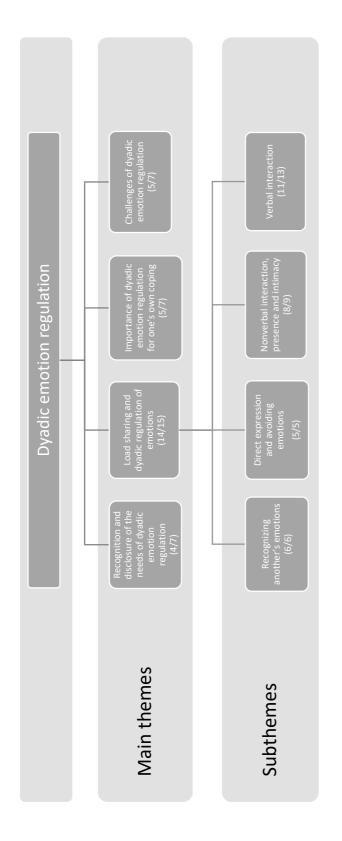


Figure 8. Main- and subthemes of interviews in Study 1. Number of respondents is presented in parentheses (fathers/mothers).

#### 5.1.2 Load sharing and dyadic regulation of emotions

In the descriptions of the parents' emotion regulation, the needs for and means of load sharing and jointly regulating emotions were essential in a scary situation.

F: It feels good that there is someone with whom to share it, actually everything. That there isn't... isn't anything in this situation which I should bear alone.

I (Interviewer): She supports you there.

F: So, yes. And I can support her as well.

Parents described the sensation, reflection, and empathic attuning of the other's emotional states that led to anticipation and identification of a partner's affliction and suffering. In their responses, they also indicated the prioritization of the load of their partner.

F: It always feels bad to leave the baby, even knowing that the care is good. The mother feels it even worse than the father. -- The most difficult thing is probably to see the bad feelings the mother has there. When you cannot handle your baby as a normal child. Then, the separation between the baby and the mother when she has to go home, although in a good mood, 'good mood' (makes air quotes with his fingers), can leave while the baby is asleep. But it impacts me heavily. -- I guess that has been the hardest thing.

Parents took care of each other's current distress, coped with excessive struggling and planned for potential future fatigue. Both fathers and mothers had the fear that the other parent would blame her- or himself for the child's illness.

Direct sharing of emotions, such as crying and speaking, as well as trying to support each other in their emotion regulation by providing physical proximity, were considered as important in a challenging situation. Parents also sought to protect each other from the stressful aspects of the situation. F: And, of course, I do not want the mother to break down by telling her directly, the doctor may then tell her what the situation is. -- I did not tell her everything, what the possibilities might be. -- I've been reading during late nights, waiting for the fading of the embers, reading about the issue, uh, questions have arisen. Of course, I have not wanted to burden the mother, and I have not told her everything.

Some parents reported that they deliberately avoided the expression of negative emotions in a stressful situation.

F: Anyway, you try to be the strong one in this situation as well, so I said to the mother that I'll go away, so she doesn't have to see me break down there.

Being with the other person and living, experiencing, and sharing the situation together were considered as essential forms of dyadic emotion regulation. Parents felt that the speechless presence, intimacy, and staying with each other were strengthening, comforting, and supportive. They reported that physical closeness enhanced the regulation of negative emotions.

F: And when she has had difficult times, when the tears have come to her eyes, either tears of joy or sorrow, I have tried to get close and support her with proximity, with physical proximity, by taking her close and hugging.

--

M: It's extremely important that you can go through this shit with a partner. -- It's just so important that the partner is close to you, even if you are not able to say anything but. -- That if you were there alone, it wouldn't work at all.

Face to face and remote interaction between the parents were considered as sources of support, proximity, trust, comfort, and calming down and as a means of communicating and structuring information. Parents comforted each other verbally and tried to alleviate each other's possible feelings of guilt. F: Immediately after giving birth, she asked if I had any accusations about this thing, that if she did something wrong. I said hell no. -- I said that you don't have anything to do with this, and you have done things just as fine as you, as any mother, could.

Listening, humor, and approval were also regarded as important forms of dyadic emotion regulation. Parents also regulated each other's emotions verbally by orienting to the future, maintaining hope, and paying particular attention to the positive aspects.

F: And I've also encouraged her by telling her that we will get through this. And the baby will survive, that she's a tough girl.

They tried to support each other in emotion regulation in dealing with conflict situations and difficult issues.

F: Well, actually, when this collapse happened, we both cried. And she said that she had believed something was going to happen, something would happen. That something did happen, however. She was just afraid that there is something... I said that we are now in the hospital, that here they can do almost miracles, that we are going to survive. And the baby survives, that was the starting point. -- Mainly, I tried to support her in this matter. It was perhaps the most important task in it. I strongly believed that they could handle it in the hospital. And then let's look at one situation at a time. -- Was hoping, and I tried also to create the trust in her. That we will get through this.

Parents considered the presence of each other as important, especially when they encountered the hospital staff and dealt with the information related to the situation of their child.

### 5.1.3 Importance of dyadic emotion regulation in terms of resilience

Dyadic emotion regulation with another parent was considered as essential and, in some parents, as a primary resilience resource for oneself. Parents reported that dyadic emotion regulation reinforced their sense of security and confidence in their coping and reduced stress, rumination, and fears.

I: How have the ways he (F) has supported you influenced your own coping in this situation?

M: Yes, it certainly has created such a security and trust for our coping.

Couples felt the other parent's presence was soothing and helpful in receiving and dealing with information about the child's situation. Providing emotional support to the other parent was also experienced as important to oneself. Parents felt, for example, that the soothing of their partner's fears supported their own calming down in the situation.

F: It calms me when I support the mother in it. That she, tomorrow we'll go back to look, and the baby is in good hands, and so there is nothing to worry about.

I: Mm, at the same time you calm yourself in that.

F: Yes, yes, that's it for sure.

The expressions of love were perceived as essential ways of reinforcing the resilience of the partner in the challenging situation.

### 5.1.4 Challenges of dyadic emotion regulation

Parents also described the challenges and obstacles in jointly regulating their emotions. The differences between parents and the challenges of dealing with the situation manifested, for example, as wishes concerning the other parent's talkativeness. Some parents stated that other parent avoided the handling of difficult things and wished to know more details about the experiences, emotions, and thoughts of the other parent. M: I just wish he would not keep it inside, just think about all that stuff alone, that he would always say it aloud. He does not always, he does not always want the sorrows on my shoulders. He thinks about them in his mind alone.

Some fathers also described the difficulty of recognizing and expressing their own needs for support and proximity to the other parent.

F: I guess that I do not ask my partner to fulfill them. I guess that I do not ask about my needs.

--

F: I only try to provide support, but then I myself try to make my own, or by myself. It's just like it, like you do not talk about your feelings. I do not demand support from anybody, either.

Among the fathers appeared an unwillingness to share strong early-stage feelings of shock with the mother and the desire to deal with these feelings alone in order to protect the mother from their reactions.

# 5.2 Psychiatric symptoms, posttraumatic growth, and life satisfaction among parents of ill and healthy infants (Study 2)

Study 2 examined the anxiety, depressive symptoms, general stress, PTG, posttraumatic symptoms, and life satisfaction among parents of seriously ill infants from the acute diagnostic period up to 12 months after their child's initial NICU admission. The study compared the parents of infants requiring TH or urgent surgery to the parents of healthy infants, and a comparison of fathers' and mothers' responses was also conducted.

Both parents of ill and healthy infants had general stress, but it was more prevalent in the parents with an ill infant. In addition, depressive symptoms and anxiety were more common among the parents with an ill infant. At follow-up, anxiety decreased from the baseline in both groups. Life satisfaction had an inverse correlation with all measures of psychiatric symptoms, and it was lower among the parents of ill infants at the baseline, but similar at follow-up. Mothers of ill children had more anxiety and depressive symptoms than fathers at the early stage. In addition, mothers had more posttraumatic symptoms than fathers did at both times. Approximately half of the parents experienced substantial posttraumatic growth at follow-up.

No formal sample size calculation was performed before the study, but it was assumed that parents of 30 children in both groups would be sufficient to obtain appropriate power for the study. However, it appeared that the power of the study was relatively low with the current numbers of subjects. For the desired significance  $\alpha$ -level of 0.05, the power to detect a difference in values between the two groups at baseline and at 12 months, respectively, was the following: for anxiety 0.53 and 0.35; for depression (BDI-II) 0.40 and 0.17, and (EPDS) 0.93 and 0.41; for perceived stress 0.50 and 0.52; and for life satisfaction 0.40 and 0.47. Classification of different questionnaire scores at baseline and at 12 months is presented in Table 5.

### 5.2.1 Anxiety

Soon after birth of the infant (baseline) anxiety (BAI-score  $\geq 16/63$ ) was more common among parents with an ill infant than in the control group (p = 0.032). Anxiety was more common among mothers of an ill infant than in fathers (p = 0.024), and similar in both sexes among the parents of a healthy infant (p = 0.103). At follow-up, symptoms of anxiety were less common. Two out of 30 parents, one mother and one father of an ill infant, had a BAI score of  $\geq$  16/63 (p = 0.021 compared to baseline), and no anxiety was reported among the parents of a healthy infant.

Table 5. Classification of different questionnaire scores at baseline and at 12 months.
Data are number of cases in each category.

Variable	Interest-group	t-group	p-value Base-	Contro	Control group	p-value Base-	p-value between groups	letween ups
	Baseline (N=34)	12 mo. (N=30)	line/ 12 mo	Baseline (N=60)	12 mo. (N=42)	line/ 12 mo.	Baseline	12 months
Anxiety (BAI) <sup>1</sup>	24/10	28/2	0.021	53 / 7	40 / 0	0.025	0.032	0.180
Mothers, n	9/8	14/1		24/6	21 / 0			
• Fathers, n	15/2	14/1		29 / 1	19/0			
Depression (BDI-II) <sup>2</sup>	32 / 2	28/2	0.897	60 / 09	40 / 1	0.406	0.128	0.570
• Mothers, n	15/2	14/1		28/2	19/2			
• Fathers, n	17 / 0	14/1		28/2	18/1			
Depression (EPDS) <sup>3</sup>	16 / 18	10 / 20	0.265	40 / 20	24/18	0.873	0.063	0.046
• Mothers, n	5 / 12	4/11		18 / 12	11/10			
• Fathers, n	11/6	6/9		22 / 8	13/8			
Perceived stress (PSS-10) <sup>4</sup>	16/18	10 / 20	0.265	40 / 20	24/18	0.328	0.063	0.046

<sup>&</sup>lt;sup>1</sup> No - mild anxiety / moderate - severe anxiety;

<sup>&</sup>lt;sup>2</sup> No - mild depression symptoms / moderate - severe depression symptoms;

<sup>&</sup>lt;sup>3</sup> No depression / depression symptoms;

<sup>&</sup>lt;sup>4</sup>Low stress / moderate - high stress;

		Interest-group	p-value Base-	Contro	Control group	p-value Base-	p-value between groups	oetween ups
	Baseline (N=34)	12 mo. (N=30)	line/ 12 mo	Baseline (N=60)	12 mo. (N=42)	line/ 12 mo.	Baseline	12 months
• Mothers, n	5 / 12	4/11		18/12	11/10			
• Fathers, n	11 / 6	6/9		22 / 8	13/8			
Life satisfaction (LS-4) <sup>5</sup>	32 / 2	24/6	0.088	60 / 09	40 / 2	0.167	0.161	0.060
• Mothers, n	16/1	11/4		30 / 0	19/2			
• Fathers, n	16/1	13/2		30 / 0	20 / 1			
Posttraumatic stress dis- order symptoms (IES-R) <sup>6</sup>	23 / 9	24/6	0.455	AN	NA			
• Mothers, n	10/6	11/4		NA	NA			
• Fathers, n	13/3	13/2		NA	NA			

<sup>5</sup> Satisfied with life - intermediate / dissatisfied with life;	<sup>6</sup> No - some PTSD symptoms / PTSD - severe PTSD.	
<sup>5</sup> Satisfied wit	6 No - some P	

#### 5.2.2 Depressive symptoms

At baseline, depressive symptoms (BDI-II score  $\geq 14/63$ ) were more common in parents of an ill infant than in the control group (p = 0.003). Depressive symptoms (assessed with BDI-II) were equally common in fathers and mothers of an ill infant (baseline: p = 0.398, follow-up: p = 1.0) and in the control group (baseline: p = 1.0, follow-up: p = 0.343). When assessed with EPDS at baseline, the prevalence of possible depression was higher in parents of an ill infant than in the control group (p<0.001). Mothers of an ill infant had more possible depression than fathers did (p = 0.004). At follow-up, the prevalence of possible depression was similar in parents of an ill infant and in the control group (p = 0.733; p = 0.087).

#### 5.2.3 General stress

Perceived stress was common in parents of an ill infant and in the control group at both time points, and the parents of an ill infant had more moderate or high perceived stress (PSS-14 score  $\geq$ 19/56) than the control group (baseline: p = 0.063; follow-up: p = 0.046). At baseline, the mothers of an ill infant had more moderate or high stress than the fathers did (p = 0.001) but not at follow-up (p = 0.068). The prevalence of general stress was similar between the sexes in parents of an ill infant and in the control group.

#### 5.2.4 Posttraumatic growth

Posttraumatic growth was measured at follow-up and in parents with an ill infant only. Eight mothers out of 15 and seven fathers out of 15 had posttraumatic growth (PTGI score  $\geq$ 42/105, p = 0.715). Among the parents of an ill infant, PTGI total scores correlated positively with IES-R scores (r = 0.388, p = 0.034), and correlations with other measures at follow-up were not statistically significant.

#### 5.2.5 Posttraumatic symptoms

Posttraumatic symptoms were measured in parents with an ill child only, first at one month after the birth (baseline) and the second time at follow-up. The prevalence of traumatic distress (IES-R score ≥25/66) was similar at both time points (p = 0.141) and in mothers and fathers (baseline: p = 0.433, follow-up: p = 0.390). Previous miscarriages (n = 4 mothers) did not correlate with the IES-R (baseline: p = 1.0, follow-up: p = 1.0).

### 5.2.6 Life satisfaction

Life satisfaction was similar between the parents of an ill and healthy infant (baseline: p = 0.161; follow-up: p = 0.060). All parents in the control group were satisfied with life (LS-4 score 4–11) at baseline compared to one dissatisfied mother and one dissatisfied father of an ill infant. At follow-up, two mothers in the control group were dissatisfied with life compared to four dissatisfied mothers and two dissatisfied fathers of an ill infant. There was no difference between mothers and fathers in life satisfaction (baseline: p = 1.0, follow-up: p = 0.260).

# 5.3 Experiences of parents of children with cancer during an emotionally focused HMT course (Study 3)

Study 3 examined the parents' experiences of an emotionally focused HMT course that was held for the parents of children with cancer. In the focus group conversation, parents expressed the individual-, couple- and family-related meanings they had experienced during the course. The subthemes of the individual-related meanings were identifying the need for self-exploration, enabling a new kind of self-observation, increasing self-understanding, and improving personal well-being and resilience. The subthemes of the couple-related meanings were identifying and processing couple relationship phenomena, increasing understanding of relationship interactions, facilitating prevention and dealing with challenging situations, and strengthening of the mutual emotional connection. The subtheme of the family-related meanings was increasing understanding of family interactions. The temporal dimensions

of the experiences were related to the past, the current situation, and the future. The results of the analysis are presented in Table 6. The numbers indicate respondents who have expressed themes verbally. Representative conversation extracts are associated with each theme.

Parents' experiences of HMT course Main- and subthemes	Fathers n=12	Mothers n=12
Individual-related meanings	12	8
<ul> <li>Identifying the need for self-exploration</li> </ul>	4	2
<ul> <li>Enabling a new kind of self-observation</li> </ul>	4	2
Increasing self-understanding	12	7
Improving personal well-being and resilience	6	3
Couple-related meanings	12	10
<ul> <li>Possibility to identify and process couple relationship phenomena</li> </ul>	3	6
<ul> <li>Increasing the understanding of relationship interactions</li> </ul>	11	8
<ul> <li>Facilitating the prevention and dealing with challenging situations</li> </ul>	10	9
• Strengthening of the mutual emotional connection	10	6
Family-related meanings	3	2
<ul> <li>Increasing the understanding of family interactions</li> </ul>	3	2

Table 6. Main- and subthemes of parents' experiences

### 5.3.1 Individual-related meanings

During the course, the parents had identified the need for self-exploration to find the root causes of their own behavior in a relationship.

M1 (Mother 1): You learned that you dare to talk, and you must explore a bit to find what causes the fit of rage. What is it there, the deepest feeling. A kind of self-exploration. And you learned through the examples as you thought that, well yeah, so it is this, and this causes that. They had recognized their own role in everyday challenging situations and began to better understand their own behavior and responses.

M3: And on the other hand, this is the way it is for everyone, and it follows a certain pattern; and the problem isn't in oneself, and it's natural. And maybe because of what's there underneath the surface, you don't always realize yourself why you behave in a certain way. It sort of clarifies one's own behavior, too.

Naming relationship phenomena eased guilt related to one's own behavior and gave hope for recognizing and correcting problems. Mothers had identified their fears and self-protection related to the sharing of their own deep feelings and needs. Parents felt it was important to review the significance of the past and recognized that it had helped them to understand and accept their own reactions and underlying emotions.

M11: In myself, the raw spot was something that I became more increasingly aware of. And I found the real raw spot and found the deep emotions there, saw how it appears to others, and what is behind it. And then, as my partner said, our roles have changed following our child's illness. Realizing what has happened here, and even with a long relationship behind us, you see how things can change... Even when you think you know yourself, but here I learned something new (laughs). I was surprised.

Parents reported that the course increased their flexibility and optimism, strengthened their resilience, and encouraged them to plan for the future.

I (Interviewer): What has this course meant for your relationship and for the future?

M7: For me, this has given at least a lot of hope that things will get better. We now have concrete means that we can use to handle things in the future. We haven't had those means before.

### 5.3.2 Couple-related meanings

Parents felt that the course had helped them to identify difficult issues related to the relationship that were left out in everyday life and to deal with them in peace and with supportive guidance. The issues that couples had previously discussed together were given more specific names in the course; they were structured, and better understood, reinforcing a sense of safety.

F6 (Father 6): Also, how you can tell your partner about your own needs. However, in real life, it feels like even if you want to express your needs, it is still quite difficult to do that. In the course, when you stop and think about it, however, it is easier to bring up the topic; while in everyday situations, it is awkward, and you don't really know how to do it...

Parents also felt that it was possible to track and process deep feelings, needs, and issues that had not been dealt with before.

M6: At least for me, my eyes opened to see that my spouse has those soft, soft feelings and deep fears. Somehow, I had identified them in myself, but the fact is that he has them, too.

The fathers recognized that the course had helped them to talk about things that both parents had thought about but had been postponed after the child became ill to avoid conflicts and save resources. The experienced increase in understanding of relationship interactions was related to the identification of negative interactions, awareness of the meaning and power of deep emotions behind behavior, recognition of the significance and effects of previous relationships, identifying the relationship effects of a child's illness, and identifying and sharing the real needs with each other.

M7: We had somehow processed it at home, in our own heads and on paper, too, that our quarrels always go like this. What's the real problem now, and who is the guilty one? We have tried to assign blame. But here, we realized that it's really a cycle, where both of us are in a way guilty and feeding one another, and it was quite wonderful to realize (smiles). --

F6: It was also quite an eye-opening experience when I started thinking about things from my own point of view and from the point of view of a relationship...

F5: Mmm (nods)...

F6: I noticed that actually everything goes according to the same pattern. It was true, we found a unified course of action, and it was then easy to identify as well.

F5: I do agree with that, it was an eye-opening thing.

F8: Yeah, I found myself and our relationship in those negative cycles right away, and I could go back to the moments when we were in those cycles and noticed our own part in the situation, even though it may not have been so clear then... How I have pushed my partner further into the negative cycle. Yes, as my eyes opened to this, I became more aware that this is what we have been dealing with, and we have been wrestling with this over the years.

According to the parents, the course gave them ways to prevent and deal with challenging situations and negative interactions for their relationship in the future. Some parents felt uncertainty about the transition of insights from the course to everyday life and wished to have more teaching and even an advanced course.

F10: I think it was instructive that you could recognize it, how that negative cycle starts, and it kind of swells like rising bread dough after that. When the conflict happens again, we can hopefully remember this, so the cycle does not go deeper, but rather, we would get out of it as soon as possible. Both of us clearly identified how we behave, so it could then help us get out of the cycle faster in the future.

F12: Yeah, it became surprisingly clear, and now it's so obvious (smiles). By being able to recognize those roles, somehow maybe we can handle the situation better and move in the right direction.

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F5: You start to feel like, no, I haven't spoiled everything (laughs) if there's a problem, but you understand it's the kind of thing that can be explored and fixed. -- And also, a feeling of togetherness in that job, not like you are alone in that mess.

Parents felt that the course had strengthened their relationship by increasing positive interaction, reinforcing their sense of togetherness and the confidence to cope together.

F1: Yes, in the course we have noticed that we need each other to get through tough times.

I: What has it been like to notice this?

F1: Well, really nice. Both of us have the perception that we have common goals and objectives in life. Both of us have the feeling that we're going on together, we are on the same team.

I: Mm, and how does that affect your confidence that you will figure this out together?

F1: Yeah, it increases our confidence.

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F4: Yes, as you say, you love this woman, but this has shed a little more light on it: how I love and care about her a hell of a lot.

I: What your partner means to you has been clarified?

F4: Mm, mm.

I: Mm (nods).

F4: And we've talked together about how much she means to me. I have said it out loud.

### 5.3.3 Family-related meanings

Parents experienced that the course increased their understanding not only of their relationship, but also of the interactions of the whole family. During the course, they recognized the importance of how they treat their children and the impact this will have on their future. They also wondered about ways to improve their parenting. Mothers felt that the course helped them to identify the strengths of the family and discussing these. The course had evoked discussions about parenthood, and how childhood and adolescent experiences inevitably guide one's reactions as a parent. Parents believed that the course improved not only their relationship but also the well-being of the whole family and thought that the reduction of negative cycles had a positive effect on the atmosphere in the home and the well-being of the children.

F10: Maybe that's how it opens; how you treat your own children now and how you behave towards them. So that's how you might have thought about how you can raise your kids even better. You don't like how your own childhood may have been, but you don't want to subject your own children to the same misbehavior; instead, you try to improve things for them a little, because, at some level, it affects the rest of their life. I hadn't considered these kinds of things.

F12: Yes, well said. I meant this, too.

I: Yeah, yes, that you were able to think of the next generation, too? F12: Yeah, how important it is in both childhood and adolescence... I: Yes...

F12: ...the world of emotions.

### **6 DISCUSSION**

#### 6.1 Individual and couple resilience of parents

The main purpose of this thesis was to explore the couple resilience, dyadic emotion regulation, and mental health of parents with a seriously ill child. The first aim was to compile existing research data concerning couple resilience of parents with a seriously ill child and to explore parents' experiences of dyadic emotion regulation. The second aim was to evaluate the mental health of the parents of seriously ill infants. The third aim was to explore parents' experiences of an emotionally focused HMT group intervention targeted at enhancing the intimate relationship of parents of children with cancer.

The main contribution of Study 1 was that the experience of a child's serious illness aroused needs for emotion regulation in parents, and they sought to respond to each other's needs by nonverbal, verbal, and behavioral means based on their personal capacity and dyadic resources. Parents offered and received a variety of emotional support from each other and considered it as essential to their personal coping. The support was experienced as reinforcement of their sense of safety, and dyadic emotion regulation was considered as an essential source of resilience. The challenges parents experienced in dyadic emotion regulation were related to different ways of dealing with situations and expressing their emotional needs.

The main finding of Study 2 was that the serious illness of an infant substantially affects the mental health of the parents in the early stages of illness and one year after the diagnosis. Symptoms of depression, general stress, and posttraumatic distress were common and relatively persistent. Anxiety was more common in parents of ill infants, although a decrease was shown at follow-up. Mothers had more psychiatric symptoms than fathers. Although the child's illness influenced parents' mental health, half of them showed PTG and life satisfaction remained at a quite high level.

The main contribution of Study 3 was that a 3-day HMT course can produce experiences of strengthening personal well-being and couple resilience for

parents with seriously ill children. The main themes of analysis were the individual-, couple- and family-related meanings. The subthemes of the individual-related meanings were identifying the need for self-exploration, enabling a new kind of self-observation, increasing self-understanding, and improving personal well-being and resilience. The subthemes of the couple-related meanings were identifying and processing couple relationship phenomena, increasing the understanding of the interactions of the relationship, facilitating the prevention of and dealing with challenging situations, and strengthening of mutual emotional connection. The subtheme of the family-related meanings was increasing the understanding of family interactions.

As medicine advances, an increasing proportion of critically ill and injured children will survive. These findings have implications for the assessment, support, and care of parents with seriously ill children. A special novelty of this study is that it increases the understanding of how a child's serious illness affects parents' mental health and intimate relationship. A child's illness increases the psychiatric symptoms of parents, but on the other hand their life satisfaction remains quite high and half of them experienced posttraumatic growth at follow-up. A child's illness can also adversely affect parents' interaction, but an intimate relationship can support the parent's resilience by providing a channel for the regulation of difficult emotions evoked by their child's illness. The study also provides novel information on the suitability of an emotionally focused group intervention for parents of ill children. The results can be used to identify parents in need of support and develop appropriate couple interventions for them. In the following sections, the findings are discussed in more detail with respect to previous research.

### 6.1.1 Couple resilience and dyadic emotion regulation of parents with a seriously ill child (Study 1)

A child's serious illness has many impacts in terms of parental psychological welfare and their intimate relationship. In earlier literature, the adverse effects of child illnesses have been highlighted in patients, parents, and siblings, but today it is known that the life-changing situation may also contribute to the growth and resilience of family members (e.g., Isokääntä

et al., 2019; Picoraro et al., 2014). Previously, resilience research has focused on exploring the internal strength of the individual in coping with adversities (Wagnild & Young, 1993). These properties were assumed to be associated with personality or individual strategies that made coping with burdening situations possible. In this millennium, resilience has been understood as a continuous gene-environment interaction that is influenced by social context (e.g., Ungar, 2015; Walsh, 2011). During last several years, there has been a wealth of scientific evidence on the importance of social interaction and support in alleviating the impact of stressful situations and increasing neurobiological flexibility (e.g., Coan et al., 2017; Li et al., 2018; Min et al., 2022; Tsujimoto et al., 2022).

Attachment theory and social baseline theory (SBT) create a solid basis for understanding resilience, emotion regulation, and dyadic coping of parents of seriously ill children. According to previous studies, interaction with an accessible attachment figure strengthens the sense of safety, coping, resilience, emotion regulation, and recovery in stressful situations (Beckes & Coan, 2011; Cohen, 2004; Mikulincer & Shaver, 2014; Walsh, 2011). Contact with other people protects people from posttraumatic symptoms. According to Johnson (2002), people who can share their experience, get support from others, and jointly seek meanings for their experiences cope better with adversities. Perceived social support protects people from the adverse effects of life-stress (Cohen, 2004). It has a particular meaning for people in the case of potentially traumatic situations because an externally or internally activated sense of safety relieves the symptoms of PTSD (Mikulincer & Shaver, 2014). The results of the Study 1 were in line with these findings: a child's serious illness aroused the parents' need for support and they regulated emotions dyadically.

In Study 1, the verbal interaction between the parents of a seriously ill child appeared as an important source of emotional support and as a way of communicating and structuring information concerning the illness and treatment of the child. The mutual conversation was seen as an opportunity to share and deal with concerns about the child's situation, and the felt intimacy and trust with the partner was experienced as reinforcing. The serious illness of a child may threaten the sense of parental safety in many ways. It forces the parents to witness illness-related suffering of their own child and causes them to fear losing their child (Bakker et al., 2012; Kassam-Adams et al., 2009; van Schoors, de Paepe, et al., 2019). Therefore, the sense of safety can be seen as a strong psychological resource when encountering the adversities caused by the child's illness. According to Study 1, parents seem to seek support and comfort quite automatically from each other when their child has a serious illness. This result suggests that if parents find an emotional connection in a difficult situation, it becomes a shared issue and is thus easier to face. In this case, the risks and threats associated with the child's situation may be experienced as milder and parents' perceptions of their own coping ability can be strengthened. Confidence in dyadic coping may improve the management of negative emotions and enhance positive feelings, hence fostering individual emotional balance.

Previous studies (e.g., Fredrickson, 2013; Gordon et al., 2012; Levenson et al., 2014; Waugh, 2014) have identified the importance of positive emotions in terms of dyadic resilience, especially in stressful life situations. Hope is an essential internal resource for parents of children with a serious illness (e.g., Bally et al., 2014; Barrera et al., 2013; Granek et al., 2013). In Study 1, parents reported regulating their emotions dyadically by focusing on the future, maintaining hopeful attitudes and warm communication, and paying particular attention to positive aspects of the situation. In addition, parents experienced hope as a crucial form of soothing another parent and oneself in a stressful situation. According to Horn et al. (2018), humor serves as a dyadic emotion regulation strategy in couples' daily life. In Study 1, parents used humor in emotion regulation also in the stressful situation caused by their child's illness. Parents found positivity and hope to be especially supportive of the fear regulation.

According to Walsh (2003b), one of the key processes of relational resilience is the creation of a meaningful and positive belief system for facing adversity. Creating meaning for a difficult life experience helps one to psychologically cope with it (Janoff-Bulman & Yopyk, 2004). In Study 1, a shared meaning was experienced as strengthening the couple resilience of the parents. In addition, offering emotional support to the other parent was perceived to be essential to one's coping and emotion regulation. Parents, for example, experienced the comforting of their partner as supportive of their own calming down in the situation. This is consistent with previous studies (e.g., Brown & Okun, 2014) according to which the provision of aid also facilitated the helper's psychological and physical well-being.

According to SBT, social proximity is a baseline strategy in coping with adversities of life (Beckes & Coan, 2011). The spontaneous emergence of needs and forms of dyadic emotion regulation in parents' responses found in Study 1 is in line with the SBT. When a child becomes seriously ill, parents find and receive regulative support from each other-and this seems to happen relatively automatically, even nonverbally, and without asking for it. SBT suggests that individuals in close relationships need to utilize less of their own neural resources when coping with stressful situations and regulating emotions evoked by it (Beckes & Coan, 2011). This can have a special meaning in a stressful life situation caused by a child's illness, as parents simultaneously must care and support the child and to take care of the changed everyday life. According to SBT, load sharing may be one way in which social proximity decreases costs related to engaging with the environment. In Study 1, load sharing was an important way of regulating emotions. Sharing the adversity jointly was experienced as supporting the regulation of both parents' emotions. The parents perceived the other parent's positivity as their own resource and sought to actively maintain a view of dyadic coping.

In addition to linguistic communication, also nonverbal interaction, presence, and proximity proved to be experienced as essential means of parental dyadic emotion regulation in Study 1. Being with another person and sharing the situation was experienced as strengthening and comforting. Burleson and Davis (2014) have also stated that physical proximity can foster resilience by waking positive feelings and alleviating stress. The importance of intimacy and nonverbal presence for parents' coping is essential to recognize and consider in our Western culture, which often over-emphasizes the importance of speaking. Experiences and emotions related to the illness of a child are not always verbally reachable and shareable, and therefore physical proximity may be particularly relevant in these situations.

In Study 1, some parents tended to attenuate the expression of negative emotions to avoid burdening the other parent in a vulnerable state. Hooghe et al. (2017) found that parents who had lost their children regulated their feelings in their daily lives by not talking. According to Hooghe et al. (2017, p. 226), *"the process of talking and not talking can partly be understood as an emotional responsive process on an intrapersonal and interpersonal level. In this process partners search for a bearable distance from their own grief and their partner's and attune with their relational context".* The feelings associated with losing a child naturally differ from the emotions associated with an ill child, but it seems that the parents in both situations attempt to regulate their emotions by avoiding expression of their feelings.

Thus, parents seem to seek a sense of safety and regulate emotions dyadically when faced with the crisis of a child's serious illness. The comfort obtained from a partner can be seen as an evolutionary mechanism, which enables resilience and recovery (Johnson, 2002). Results of Study 1 support the view that parents are seeking and finding resilience together in conjunction with the illness of their child. SBT, attachment theory, and resilience research help in the understanding of the importance of dyadic emotion regulation for parental coping. In Study 1, the parents of seriously ill children felt that their dyadic emotion regulation was an essential source of resilience. Consequently, the dyadic emotion regulation and couple resilience appear to be relevant and understudied concepts in the development and investigation of interventions for the parents of ill children.

# 6.1.2 Mental health among parents with seriously ill and healthy infants (Study 2)

In Study 2, severe and moderate anxiety was more common in parents of ill infants after diagnosis than in parents of healthy infants as was predictable. Although anxiety declined in both groups, the parents of the ill children were still more anxious than the control group after one year. This is consistent with previous studies (e.g., Cabizuca et al., 2009; Muscara et al., 2015; Yaman & Altay, 2015). Parents have concerns about their child's survival and health and these issues can cause anxiety (Wray et al., 2011). Kong et al. (2013) found that the low level of social support and the high level of stress had

the strongest association with parental anxiety. In parents of infants with asphyxia, the anxiety may also be due to the separation during TH (Laudi & Peeples, 2020). In the study by Craig et al. (2020), the parents indicated that the physical separation caused by hypothermia had adversely affected their ability to be attached to their child. Challenges and pressures related to parenting and affection can cause anxiety for parents and this is common also in the parents of healthy children. In the previous study of Korja et al. (2018), the pregnant mothers of healthy children reported more depressive and anxiety symptoms than the fathers. Korja et al. (2018) suggested that increased depression and anxiety symptoms during pregnancy may be related to future childbirth, parenting, or child health concerns.

In Study 2, depressive symptoms were common among parents with an ill infant, and they did not decline in the 12-month follow-up. Mothers had more depressive symptoms than the fathers as measured by EPDS. Bergström et al. (2012) found that the incidence of postpartum depression (PPD) among mothers of seriously ill infants was 15% at one month and mothers who had PPD at one month had an almost eight-fold risk for PPD at four months. Mothers who were not offered psychological support during the NICU period had a 60% increased risk for PPD. Mothers of infants with HIE were at high risk for PPD, which may be partially associated with TH that interferes with maternal-infant bonding (Laudi & Peeples, 2020). Therefore, it would be important to evaluate anxiety and depressive symptoms and support the mental health of parents in the NICU.

In Study 2, moderate or high general stress was common among parents of both ill and healthy children. The perceived stress was not relieved by followup in either group, which may indicate that the baby's first year is burdensome not only for parents of an ill child but also for the parents of healthy children. In addition, the prevalence of PPD is relatively high (10%–15%) in mothers of healthy children (e.g., Norhayati et al., 2015). In the extensive meta-analyses and systematic reviews, the main risk factor for PPD has been identified as the lack of social support from the spouse (Beck, 2001; Norhayati et al., 2015; O'Hara & Swain, 1996; Robertson et al., 2004). Also, in a Finnish study by Kettunen and Hintikka (2017), poor spousal support was linked to the PPD. For these reasons, it would also be important to pay attention to the support of the intimate relationship of parents with healthy children in health care.

In Study 2, the posttraumatic symptoms were relatively common among parents, especially in mothers, of ill infants. At follow-up, the level of posttraumatic symptoms declined in fathers, but not in mothers. In previous studies (e.g., Aftyka, Rybojad, et al., 2017), mothers were found to have a higher risk and severity of PTSD than fathers. Craig et al. (2020) found that infant's birth asphyxia was often experienced as traumatic because of chest compressions, excessive blood loss, and silence of the infant. Also, the perception of a shivering infant was considered as traumatic by parents (Craig et al., 2020). Infants treated in the NICU often have a risk of severe complications that can enhance the parental perceptions of vulnerability of the infant, increase worry about the child's survival, and cause posttraumatic symptoms. It is important to prevent and screen the traumatic distress of parents in the hospital to avoid PTSD development. In addition, PTSD should be treated by evidence-based methods such as Eye Movement Desensitization and Reprocessing (EMDR) and Trauma-Focused Cognitive Behavioral Therapy (TF-CBT) (Chen et al., 2015; Ho et al., 2012; Lewis et al., 2020; Mavranezouli et al., 2020; Roberts et al., 2019).

In Study 2, half of the parents with a seriously ill child reported PTG. In previous studies, PTG's prevalence among the parents of ill children has varied by 37%–88% (Barr, 2011; Colville & Cream, 2009; Hungerbuehler et al., 2011; Rodríguez-Rey & Alonso-Tapia, 2019). PTG has been greater in mothers than in fathers (Aftyka et al., 2020). Parents with a ventilated or older child have reported statistically higher PTG than other parents. In Study 2, the PTG correlated with the amount of posttraumatic symptoms, which supports the assumption of the connection between PTSD and PTG. According to Aftyka et al. (2020), PTG among fathers was predicted by seeking emotional support and positive reinterpretation of the stressful situation. PTG's predictors among mothers were seeking emotional support, religious coping strategy and planning. Aftyka et al. (2020) concluded that parents should be offered psychological and psychotherapeutic support aimed at dealing with emotions and they should receive help in interpreting their difficult experience positively. Also, the results of Study 1 supported this conclusion because

parents described the challenges of providing and receiving dyadic emotional support, such as difficulties in identifying and sharing their own needs.

Both parents of ill and healthy infants had quite high life satisfaction, which declined during the follow-up in parents with a healthy infant, but not in parents with an ill infant. Consequently, despite their psychiatric symptoms and strain, parents of seriously ill infants succeed in maintaining overall satisfaction with their lives. This may be related to their resilience and is consistent with previous studies (e.g., Isokääntä et al., 2019; Picoraro et al., 2014). Ferrand et al. (2018) found that parental resilience was a key factor connected to a good quality of life after the NICU, and parents with lower resilience were more pessimistic about their baby's recovery. The parental forecast of the future quality of life was not related to the child's disability risk. The stress of the hospital situation itself did not decrease the parental resilience and three quarters of the parents had good resilience (Ferrand et al., 2018). Taken together, these findings raise awareness of the importance of life satisfaction, PTG and resilience and help to identify and support parents with lower resilience.

## 6.1.3 Emotionally focused interventions in supporting parents of seriously ill children (Study 3)

The serious illness of a child influences the parent's relationship, but a safe relationship can also support parents' personal coping in a burdened life situation. EFT is an effective intervention in dealing with marital distress of the parents of children with chronic illnesses and autism spectrum disorders (Rasoli et al., 2008; Stiell et al., 2007). Marital distress decreased at posttreatment and follow-ups at five months, six months, and two years (e.g., Cloutier et al., 2002; Lee et al., 2017). Thus, EFT could be effective in supporting the parents of children diagnosed with a cancer. However, applying for long-lasting and binding couple therapy can be challenging for parents whose daily life is burdensome due to a child's serious illness. Therefore, it is important to develop and study alternative, shorter treatments for these parents. The group form of interventions can have a special value in this target group, as many parents also need peer support during the time of their child's life-threatening illness.

The HMT program has been found to produce positive changes in relationship satisfaction, trust, attachment security, and family functioning, and to decrease marital distress and depression (Conradi et al., 2017; Kennedy et al., 2019; Lesch et al., 2018; Morgis et al., 2019; Petzke et al., 2022; Stavrianopoulos, 2015; Wong et al., 2018). Despite the promising results of the program, there is no previous research on its feasibility with parents whose child is seriously ill. Study 3 provided preliminary, qualitative information on the HMT group intervention in this target group. The main finding was that parents of children with cancer linked the meanings of an emotionally focused HMT course to themselves as an individual, to their relationship, and to their family life. In particular, the couple-related meanings were perceived as diverse and strong, even though the course was a brief intervention. The meanings produced by the parents manifested on the levels of emotions, thought, and action, and were temporally related to the past, present, and future. The parents talked about the meanings opened by the course related to their own position, their partner, and themselves as parents.

Study 3 produced many new perspectives on parents' experiences of HMT courses. Parents felt that they had been given tools to deal with things they had not been able to deal with before. They reported that the course had helped them to talk about things that both parents had thought about, but which had been postponed after the child became ill to avoid conflicts and save resources. The parents felt that the temporal and spatial framework of the course, the peer group and professional support, made it possible to process even difficult illness-related couple relationship issues and feelings better than in everyday life. Parents felt that emotionally focused information and the course context provided them with a safe framework to face their own needs as individuals and as partners in a relationship. They felt it eased feelings of shame and guilt and that taking responsibility for dealing with emotions and their own actions was made possible in a new way. It is noteworthy that this kind of brief intervention evoked a sufficient sense of security that allowed even difficult issues to be addressed. The educative nature of HMT enabled participants to receive information that helped them to identify and normalize their own process in a particularly difficult life

situation. The validation of emotions and reactions appeared to be central to their processing and made it possible to work with emotions.

According to Cloutier et al. (2002), EFT increases the experience of comfort and support and protects parents from stressful situations by strengthening emotional bonding and commitment. They concluded that a jointly faced and shared crisis can increase the ability of couples to rely on each other, build their relationship and enhance the couple's common ability to deal with their child's chronic illness. In Study 3, it was also noteworthy that even a short course allowed for identifying and sharing the deep emotions and needs of both partners—not just the processing of negative cycles on a cognitive level. Treatment length and intensity of couple therapy may prevent parents from seeking support, and brief psychoeducational programs may be a more suitable prevention and treatment option for them (Cummings et al., 2008; Hawkins et al., 2008). The weekend course has many advantages compared to weekly sessions in supporting the parents of ill children. A group setting is cost-effective, courses are less time consuming and less intensive in nature, and they do not include as much one-on-one time between partners or with the therapist on specific personal issues (Hawkins et al., 2008). The group format allows parents' peer support and a focus on the intimate relationship for one weekend which may otherwise be impossible in the middle of a busy family life with an ill child. Peer support may also ease the experience of parents' loneliness with a child's rare illness and strong emotions evoked by the illness.

### 6.2 Strengths and limitations

This thesis has strengths and limitations that need to be considered. The strength of this thesis is that it provides new and clinically relevant information on the couple resilience, dyadic emotion regulation, mental health, and an emotionally focused brief intervention for parents with seriously ill children. The data was rich and analyzed by mixed methods. If necessary, the parents were offered psychological support and guidance when collecting data. My close familiarity with the studied phenomenon might have increased the

study validity (Creswell & Miller, 2000). Working in the research environment helped me to create confidential relationships with participants and enabled the comparison of the interviews with the empirical observations of the work. It can be assumed that my long-term stay in the research field opened more polyphonic perspectives and gave a better understanding of the context, experience of the participants and clinical implications of the results. On the other hand, the familiarity of parents and the subject may also have impaired my objectivity and the reliability of the research.

In the review of Study 1 (Publication I), a systematic review would have ensured a comprehensive literature search from all available sources, minimizing subjective selection bias. On the other hand, through the narrative review, I was able to use the intuition and tacit knowledge brought by my professional experience in the field in dealing with the research topic. Another strength of the review is that the couple resilience of parents of seriously ill children had not previously been studied. In the interview study of Study 1 (Publication II), detailed, densely described, and well-saturated data enabled development of strong themes and subthemes in the analysis. On the other hand, the breadth of the research data may also limit the depth of the analysis.

Studies 1 and 3 aimed to increase credibility for interpretations and conclusions by using a co-researcher during analysis. Love et al. (2020) suggest that during focus group analysis the researcher should discuss the development and interpretation of the themes with independent IPA researchers and the focus group assistant. During the collection, transcription, and analysis of the data, I had several conversations with Juho Kalapudas with the purpose of self-reflection to help me to identify my bias, perceptions, and views of the research topics and participants. I also discussed themes with my focus group co-facilitator Janne Puranen. According to Smith et al. (2012), self-reflective annotation is important to capture the researcher's own bias, emotions, and thoughts about the evolving interpretative process. The limitation of studies 1 and 3 was approaching the research topics merely through parents' own reports. The research context and the parents' situation-specific choices defined the manifesting aspects of the research topic, and essential aspects of the experience could remain invisible due to,

for example, a socially desirable response style. The results of qualitative studies are not directly generalizable outside the data, but on the other hand, the aim of studies 1 and 3 was to reach the deep individual experiences of these subjects.

The strength of Study 2 was expanding of the understanding of life satisfaction, PTG, and psychiatric symptoms of parents with a seriously ill infant. One of the novelties of Study 2 was the inclusion of parents with infants treated with TH, resulting in new insight into their mental health and PTG. One of the main limitations of Study 2 was the small sample size, and thus the power of the study was relatively low. Sample size was small since it was not possible to recruit more parents during the 4-year study period. Based on the small sample size it was not possible to evaluate the effects of demographic variables in the analysis more deeply. On the other hand, a small and rare sample provided a variety of information because the study measured not only psychiatric symptoms but also life satisfaction and PTG. The sample was representative for describing those parents whose child became seriously ill during the data collection in the Kuopio University Hospital area, as all 54 consecutive parents were asked, and 34 parents agreed to participate. A longer follow-up would have provided more information on the mental health of parents as the child grows.

A particular strength of Study 3 concerns empirical research of the experiences of a brief emotionally focused group intervention (HMT) among parents of a child with a cancer diagnosis. Previous research has focused on long-term interventions and quantitative methods in this target group. A limitation of Study 3 can be seen as the positive contribution of the course that can be over-emphasized since the focus group conversations were conducted by the facilitators immediately after the course. The dual position produced by roles of researcher and course facilitator can be both a strength and limitation in terms of research reliability. On one hand it can make it challenging to preserve scientific objectivity in collecting, analyzing, and interpreting the data. On the other hand, knowledge of the course context may have allowed deeper immersion into the data and may have strengthened my understanding of the participants' experience.

The IPA's idiographic nature and the recommendations considering the size of the samples raise questions about whether the qualitative part of this dissertation was sufficiently detailed for reaching in adequate accuracy the individual experience of parents. In Study 1 I interviewed 32 parents individually, and in Study 3 there were 24 parents in four participant focus groups. The use of the data produced by the focus groups in the IPA analysis has been criticized (e.g., Blake et al., 2007; Dunne & Quayle, 2001; Flowers et al., 2001) because of the effect of group dynamics on each participant's individual voice and the complexity produced by multiple hermeneutics. On the other hand, homogeneity of the sample can support the deep, detailed, and rich expression of experience. In this study, the child's illness was an experience unifying all participants, and those involved in the focus groups had the common experience of the HMT course.

#### 6.3 Clinical implications and suggestions for future research

This thesis has clinical and theoretical implications. The serious illness of a child is a powerful crisis for a family, and it can also cause tensions and conflicts in the parent's relationship. Hospital staff should identify the challenges posed by a child's illness when these issues threaten parents' focus on their child (Hooghe et al., 2018). The hospital staff should communicate empathetically with both parents and particularly help at-risk parents to reduce their stress levels. Parents should receive emotional support or therapy if needed. Healthcare professionals need education and training in psychological wellbeing related to the challenges parents face in order to identify the parents in need of help and to guide them to the psychological support they need. It is also important to identify challenges of parents' interactions and to support their intimate relationship in a burdensome life situation. The presence of both parents in the hospital should be allowed, especially in challenging stages of treatment to enable their dyadic emotion regulation.

In Study 2, the psychiatric symptoms were evident and long-lasting and therefore, it would be important to screen parents' needs for psychological support even after the initial phase. It is critical to consider the psychiatric symptoms of parents and their resilience when treating their child's illness. The total amount of posttraumatic symptoms declined in fathers but not in mothers. Therefore, it would be essential to recognize and treat the posttraumatic symptoms of parents of seriously ill children during the baby's first year and beyond. The prevalence of the depression symptoms of the control group was in line with a Finnish cohort study that investigated the symptoms of parents during the pregnancy (Korja et al., 2018). Depressive symptoms of parents with healthy children were found to be increased at follow-up. Thus, it would also be important to screen their mood and stress level during the baby's first year, for example, when visiting a child health clinic. Recognizing depressive symptoms, anxiety, and stress would be relevant not only for the parents' mental health, but also for the child's and siblings' well-being.

Resilience can be seen as a dynamic and interactive process in which individuals, couples, and families adapt to, recover from, and grow with adversity (Ungar, 2015; Walsh, 2003b). According to Study 1, the parents also seem to seek and find resilience together as the result of the challenges caused by the child's illness. This view raises the question of whether resilience should be understood as a relational process that cannot be reduced solely to the individual's ability, even though in many ways it reflects to individual psychological well-being and functionality. In the light of SBT and resilience research, it can also be considered whether resilience phenomena are basically the products of interaction. Observations and interpretations of the relationality of resilience raise a wide range of scientifically and clinically relevant questions, for example, for the meaning of mentalization, emotion regulation, touch, and mind-body connection to the development of resilience. The transgenerational perspective to resilience resources and risks would also be relevant to the research. Finding the answers to these questions may help to design and implement couple interventions that focus on factors that strengthen parental resilience.

Resilience research is justified not only because of parents' psychological well-being and intimate relationship, but also because the mental health of parents and the child are related to each other (e.g., Robinson et al., 2007). Flykt et al. (2010) found that maternal prenatal and postpartum depressive

symptoms were associated with an unresponsive dyadic interaction with their infant. In addition, maternal social anxiety at 18 months of the child's age was related to a lower level of triadic interaction within the family (Korja et al., 2015). Korja and McMahon (2021) found that mothers' anxiety and depression during pregnancy were associated with weaker early interaction with the child. Therefore, by identifying, understanding, and strengthening the resilience of the parents, the mental health, interaction, and coping of children are also supported.

In future studies, it would be important to further explore the nature of parents' anxiety and distress, and to develop and evaluate interventions to alleviate these. It would also be necessary to investigate the factors that explain the differences of psychiatric symptoms—for example, how mothers' experiences of giving birth to a child and the delivery type affect their symptoms and experiences of a child's illness. Longitudinal, prospective research would also capture more about the development of parental life satisfaction, PTG, and psychiatric symptoms when the child grows. In the future, it would also be important to investigate the factors that allow parents to maintain a relatively high life satisfaction despite their child's serious illness. For example, the importance of parenting and couple satisfaction to general life satisfaction should be investigated.

According to previous studies, single parenting seems to be a special risk factor for parental mental health effects (Dellve et al., 2006; Floderus et al., 2008; Metsä-Simola et al., 2022). This study could not evaluate single parents' psychological well-being and need for support, but this would be an important research topic in the future. Also, considering factors related to the child, illness, and treatment in subsequent studies would be central to examining the effects of the situation on parents' mental health and intimate relationship. For example, it would be important to study the associations between the age and prognosis of a child in relation to the couple resilience of parents. Also, the importance of parents' resilience as a protective mental health factor would be a relevant research topic in the future. Studies 1 and 2 were targeted at the parents of children under school age, so in the future it would be necessary to also study the mental health of parents of school-aged children and adolescents.

Study 1 showed the experienced importance of dyadic emotion regulation in terms of parents' coping. It also shed light on the challenges of giving and receiving dyadic emotional support. Interventions that strengthen dyadic emotion regulation should be developed and used, and their effectiveness should be explored. The importance of parents' dyadic emotion regulation to their later intra- and interpersonal coping should also be investigated. It is also important to clarify the potential connections between the parents' dyadic emotion regulation, the psychological and physical well-being of the ill child, and the recovery from illness. Deeper research of dyadic emotion regulation through smaller data, for example in an in-depth individual interview, would be recommended for the future. This topic should be examined also by means of direct observation or physiological measurements (e.g., heart rate variability, skin conductance, and cortisol levels). It would be justified to approach research topics from a physiological point of view, as parental reports highlighted the nonverbal forms of dyadic support, and posttraumatic reactions are also bodily. Sympathetic nervous system synchrony between couples has previously been studied (Karvonen et al., 2016), but this has not yet been done among the parents of seriously ill children. Questionnaires on couple resilience and coping would also give valuable information on the subject. In addition, it would be necessary to explore the actual mutual interaction between parents and jointly constructed meanings.

According to previous studies, EFT will help to relieve both marital and individual problems and the results remained at follow-up studies (Beasley & Ager, 2019). In Study 3, the parents felt that the HMT course was useful for their personal well-being and coping, as well as for their couple and family relationships. These qualitative results encourage the development and application of emotionally focused brief interventions for this target group and provide a basis for further research concerning their qualities and effectiveness. A follow-up study would be necessary to find out how the perceived positive experiences would be carried on in family life. Identification and sharing of deep emotions and normalization of the reactions aroused by the child's illness were considered as important and comforting. The couples also found useful the emotionally focused psychoeducation, identification, and stopping of negative interaction cycles, and discussion of the means to

maintain emotional connection in the future. These topics should be adhered to when developing couple interventions for parents of seriously ill children.

Emotionally focused psychoeducation normalized parents' attachment needs and aroused interest in exploring their own reactions. They began to recognize their need for self-exploration, and the information concerning natural human needs eased a sense of shame associated with their own reactions. The parents experienced that dealing with the negative interaction cycles enabled a new kind of self-observation and increased their selfunderstanding because they recognized their own role in challenging everyday situations and began to better understand their own behavior and responses. Parents felt that this topic also helped them to understand their own potential for preventing and dealing with negative cycles. Considering conflicts as cycles was experienced as an important normalization that relieved the sense of defectiveness and strengthened their feeling of selfefficacy in regulating their couple and family interaction. Couples recognized the need to explore their deeper emotions, needs, and the root causes of their own behavior in the relationship. Finding the raw spots enhanced couples' awareness of interactions and particularly the meaning and power of primary emotions behind behavior. Revisiting a difficult moment enabled identifying the emotions behind the interaction although it was challenging or even impossible in daily life. Identifying and sharing needs and fears enabled the couples to enhance their understanding of couple interactions.

According to Study 3, the parenting of a seriously ill child seems to be a special contextual factor that influenced the parents' experiences of the HMT course. Some parents found dealing with certain issues (for example, earlier difficult experiences, meaning of the past, and negative cycles) as challenging and even painful, albeit necessary. They considered it important that the facilitators were able to support them in the tasks. Long-term and diverse types of burden caused by a child's serious illness may have increased the parents' need for support during the course. Parents also described that they had postponed dealing with couple relationship issues due to the child's illness, which can cause strong emotions to emerge in the course. These things should be considered when designing interventions in this context— especially in defining the number of participants and resources of the courses.

Sufficient staff should be reserved for running the courses for parents of seriously ill children, as some topics arouse strong emotions and there is a high need for support. Also, careful consideration of the timing and content of these heavy themes would be important in the future while working with parents who are overwhelmed by their child's illness. Later booster sessions recommended by Kennedy et al. (2019) would also be necessary, based on this study, because some parents were uncertain about applying the gained insights to everyday life.

In the future, it would be necessary to explore the efficiency of emotionally focused couple interventions in this target group with larger samples and a mixed methods approach—for example, by collecting feedback forms from courses. Particularly, more research is needed on brief interventions and their long-term effects, as they might be cost-effective and easier for parent participation. In the future, it would be important to explore the mediating role of intimate relationships in the adaptation of parents, children, and siblings to serious illnesses, as well as the persistence and change of experience with longitudinal studies. In addition, it would be necessary to use and study emotionally focused brief interventions in supporting parents with a child suffering from other serious illnesses.

The importance and multi-dimensionality of couple resilience appeared in this thesis in the context of the serious illness of a child, and it should be considered in the treatment of an ill child and with the family. The presence of both parents in a threatening situation seemed to strengthen the sense of safety, dyadic emotion regulation, and coping, and parents should be offered this opportunity at the hospital. In particular, the joint reception of information and guidance related to the child's situation was important for parents, which should be considered for inclusion in the practices of hospitals. At the hospital, parents should be offered the chance to participate together in the treatment discussions.

Paying more attention to the strengths and resources of the child and parents would be justified to maintain hope and to enhance the experience of coping. Understanding and supporting parents' relationships can contribute to the recovery of the child and the well-being of the whole family. It may also prevent the development of mental health problems of family members in the future. Parents can offer strong support for each other, for example by sharing the emotional burden, regulating emotions, and handling the information about the illness. Parents who are in close emotional contact can jointly support each other, their ill child, and siblings, too.

Social proximity, connection, and interaction can be considered as human energy-saving mechanisms. In this thesis, most parents acknowledged the need for support of emotion regulation and naturally responded to it. However, some parents had difficulties in identifying and expressing their needs, which made it difficult to respond to their needs as well. According to the SBT, people must rely on metabolically costly self-regulatory processes if they do not get support from others, which further increases the difficulty of the situation. If social support is unavailable, the brain typically interprets the situation as a threat because an individual must use more personal resources to cope with a situation (Beckes & Coan, 2011). A lonely parent must use energy for self-regulation that would otherwise be released to support the child and family.

Couple therapeutic interventions for parents of ill children should consider the importance of dyadic emotion regulation for parents' coping. Interventions that strengthen parental coping should be developed and used, and their effectiveness should be investigated. A strong nonverbal component emerged in parents' dyadic emotion regulation, and it should be reinforced in couple therapy along with the verbal means. Silence and avoiding emotional expression have functions that may serve individual and dyadic coping, which the therapist should recognize and consider in therapy. The therapist should also help the clients to regulate their emotions and arousal so that they feel safe, connected, and able to process their experiences. All in all, increased understanding of couple resilience, dyadic emotion regulation, and mental health can substantially contribute to the research on and development of interventions for families with seriously ill children.

#### 6.4 Conclusions

This thesis focused on couple resilience, dyadic emotion regulation, and mental health of parents with a seriously ill child. Couple resilience was considered as a dynamic, multidimensional, and relational process that is affected by meanings given to adversities, experienced and expressed emotions, mutual support, and feeling of we-ness emerging between a couple. The results revealed a variety of needs, forms, and challenges in dyadic emotion regulation of parents with a seriously ill child. Dyadic emotion regulation included both direct expression and avoidance of emotions and happened at both verbal and nonverbal levels. It was particularly meaningful for parents' personal coping abilities related to a child's serious illness, but the parents also encountered specific related challenges. Also, it was found that the illness of a child substantially affects the mental health of the parents in the early stages of illness and one year after the illness. Life satisfaction had an inverse correlation with all measures of psychiatric symptoms, and life satisfaction was quite high in parents with ill and healthy children. Half of the parents experienced substantial posttraumatic growth at follow-up. The results showed that even a 3-day HMT course can produce experiences of strengthening personal well-being and couple resilience for parents. Parents participating in the HMT course expressed individual-, couple- and family-level meaningfulness when describing the experiences concerning the course.

In conclusion, these findings are consistent with notions that a child's serious illness impacts parents' well-being in many ways, and that the intimate relationship can support parents' coping, resilience, and emotion regulation. The results emphasize the importance of evaluating parents' mental health, offering appropriate support and the development of emotionally focused couple interventions for this target group.

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# **STUDIES**

The dissertation is based on the following studies, which are referred to in the text by Arabic numerals 1–3. Original publications are referred to in the text by Roman numerals I–IV.

## **STUDY 1**

- I Koivula, K. (2016). Yhdessä eteenpäin—Vakavasti sairaiden lasten vanhempien parisuhderesilienssi. *Psykologia*, *51*(6), 455-468.
- II Koivula, K., Kokki, H., Korhonen, M., Laitila, A., & Honkalampi, K. (2019). Experienced dyadic emotion regulation and coping of parents with a seriously ill child. *Couple and Family Psychology: Research and Practice,* 8(1), 45-61. https://doi.org/10.1037/cfp0000115

### **STUDY 2**

III Koivula, K.\*, Isokääntä, S.\*, Tavast, K., Toivonen, I., Tuomainen, I., Kokki, M., Honkalampi, K., Sankilampi, U., & Kokki, H. (2022). Psychiatric symptoms, posttraumatic growth, and life satisfaction among parents of seriously ill infants: A prospective case-controlled study. *Journal of Clinical Psychology in Medical Settings, 29*(2), 453-465. https://doi.org/10.1007/ s10880-022-09868-7

### **STUDY 3**

IV Koivula, K., Kokki, H., Laitila, A., Korhonen, M., Kalapudas, J., & Honkalampi,K. (submitted). Hold Me Tight group intervention for parents of children with cancer.

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# STUDY I

- I Koivula, K. (2016). Yhdessä eteenpäin—Vakavasti sairaiden lasten vanhempien parisuhderesilienssi. *Psykologia*, *51*(6), 455-468.
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# Psychiatric Symptoms, Posttraumatic Growth, and Life Satisfaction Among Parents of Seriously III Infants: A Prospective Case-Controlled Study

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#### Abstract

We evaluated psychiatric symptoms, posttraumatic growth, and life satisfaction among the parents (n = 34) of newborns (n = 17) requiring therapeutic hypothermia or urgent surgery (interest group). Our control group included 60 parents of healthy newborns (n = 30). The first surveys were completed soon after diagnosis or delivery and the follow-up surveys 1 year later (participation rate 88% in the interest group and 70% in the control group). General stress was common in both groups but was more prevalent in the interest group as were depressive symptoms, too. Anxiety was more common in the interest group, although it showed a decrease from the baseline in both groups. Life satisfaction had an inverse correlation with all measures of psychiatric symptoms, and it was lower in the interest group in the early stage, but similar at 12 months due to the slight decline in the control group. Mothers in the interest group had more anxiety and depressive symptoms than fathers in the early stage. Mothers had more traumatic distress than fathers at both time points. Half of the parents experienced substantial posttraumatic growth at 12 months. In conclusion, the serious illness of an infant substantially affects the well-being of the parents in the early stages of illness and one year after the illness.

Keywords Anomaly · Asphyxia · Infant · Parent · Psychiatric symptoms · Resilience

Having and caring for a seriously ill infant in a neonatal intensive care unit (NICU) is a heavy burden for parents and affects their psychological well-being in several ways. The uncertainty associated with child's illness and survival, intense treatments, and the prolonged hospital stay cause distress and concern. Parents may experience posttraumatic

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stress and trauma symptoms, as well as anxiety, depression, and general stress (e.g. Cabizuca et al., 2009; Muscara et al., 2015; Yaman & Altay, 2015).

In previous studies, half of the parents of children with a life-threatening illness treated in cardiology, oncology, and pediatric intensive care units have met the criteria for acute stress disorder (Muscara et al., 2015). Fathers appear to experience the same level of psychological distress and psychiatric symptoms as mothers when their child is hospitalized in a pediatric intensive care unit (Khoddam et al., 2021). Despite research on stress in the parents of infants in intensive care, data on the parents of infants suffering from birth asphyxia and severe congenital anomalies are limited, and little attention has been paid to posttraumatic growth (PTG) and life satisfaction (LS) in these families. Moreover, previous research has paid less attention to the symptoms in fathers than in mothers, even though fathers are closely involved in the care of their newborn infant in current family centered wards with single family rooms. The inclusion of both parents in research is justified, because recent studies have demonstrated that fathers also have clinically

important anxiety and risk factors for posttraumatic stress disorder (PTSD), and their coping strategies differ compared to mothers (Aftyka et al., 2017a, 2017b; Dhingra, 2020; Khoddam et al., 2021). In the study of Aftyka et al. (2017a, 2017b), PTSD was present in 60% of the mothers and 47% of the fathers of infants who were hospitalized in the NICU during the neonatal period, and the mothers had higher levels of stress and a higher severity of PTSD than the fathers. Despite having less stress, fathers often experienced a sense of lack of control and helplessness when they had an extremely ill infant in intensive care (Arockiasamy et al., 2008; Khoddam et al., 2021).

Parents whose child is experiencing pediatric medical traumatic stress caused by pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences, have also shown resilience (e.g. Isokääntä et al., 2019) and PTG (e.g. Hungerbuehler et al., 2011). PTG appears to be more pronounced in mothers than fathers (Aftyka et al., 2020). Resilience, in the broadest sense, refers to dynamic processes that lead to adaptive outcomes in the face of adversity, and PTG is defined as "positive psychological change experienced as a result of a struggle with highly challenging life circumstances" (Tedeschi & Calhoun, 2004). Components of PTG may include improved interpersonal relating, a greater appreciation for life, a sense of personal strength, new life possibilities, and spiritual change (Park, 2017; Tedeschi & Calhoun, 1996). In order to develop appropriate interventions, it is important to understand the factors that affect parental PTG, distress, and anxiety, and data on both parents are needed. It is known that PTSD in fathers is related to that in their partners (Lefkowitz et al., 2010). Higher anxiety scores of parents have been associated with the use of self-blame, lower optimism scores, higher levels of illness-related uncertainty, and a greater number of previous hospital stays (Wray et al., 2011). Shame and fear of death have substantial actor effects on distress in both mothers and fathers, whereas chronic guilt has a stronger effect on maternal distress (Barr, 2015). Pregnancy and childbirth are intensive emotional and physical experiences for the mother, which may also contribute to explaining the differences in parental experiences.

The psychiatric symptoms of parents strongly influence their own well-being, the parent-child relationship, and, through interaction and care, also the well-being, development, and behavior of the child. Posttraumatic stress symptoms in parents following their child's severe diagnosis or hospital admission predict higher healthcare service utilization in the following 12 months (Thompson et al., 2017). The psychological well-being of parents is also crucial for the treatment of a child's illness. Posttraumatic arousal and re-experiencing symptoms may impair the ability of parents to comprehend medical guidelines and communicate essential information about the child's well-being to healthcare professionals (Kazak et al., 2004). On the one hand, hypervigilant parents may request extra doctor visits or have frequent contacts with medical services, consequently overburdening the healthcare system and leading to additional costs (Pelcovitz et al., 1998). On the other hand, posttraumatic avoidance symptoms can cause parents to avoid important medical visits and procedures (Stuber et al., 1996). Arousal symptoms may induce parents to overprotect their children and restrict their participation in activities, thereby hindering their normal development (Santacroce, 2002). Traumatic stress disorder is associated with an increased risk of depression and substance abuse, which may also impair the ability of parents to respond to the child's developmental needs (Cabizuca et al., 2009).

Birth asphyxia and its treatment is an example of a medical condition that can cause substantial traumatic stress in parents (de Haan et al., 2006). Birth asphyxia with hypoxicischemic encephalopathy is treated with therapeutic hypothermia, and manipulation is kept minimal. Thus, it is not possible for parents to hold the newborn during the first 72 h (Long & Brandon, 2007). These specific circumstances may affect the experience of becoming a parent and the establishment of the parent-infant relationship (Heringhaus et al., 2013). Newborns may also need surgical or other invasive procedures and admission to the NICU soon after birth. Some congenital anomalies, such as omphalocele, gastroschisis, and esophageal atresia, require surgical treatment during the first days after birth (Gamba & Midrio, 2014; van der Zee et al., 2017). Taken together, parents of an infant admitted to the NICU during the first days after birth are concerned about their newborn infant's current and future health, well-being, and survival. During the child's recovery, some parents develop heightened parental perceptions of child vulnerability, which leads to a pattern of overprotective parenting and may result in adverse neurodevelopmental and behavioral outcomes in the child over time (De Ocampo et al., 2003; Hoge et al., 2021).

Parents use several strategies for adapting to these challenging situations, and nurses play a pivotal role in providing support for parents in the NICU (Nassef et al., 2013). Hall's study (2005) implies that healthcare professionals need to help parents understand events related to the treatment of their infant and to instill hope, despite the unknown outcome. Healthcare professionals should also accept and respect the parents' coping strategies for stress and their concerns. Hence, it is important for healthcare professionals to know and recognize the impact of the illness and the treatment on the psychological well-being of the parents to maximize the quality of family centered care in hospital.

In this study, we compared symptomology across the parents of ill and healthy infants and between fathers and mothers. Research on the psychological well-being of both parents of critically ill infants helps healthcare professionals to understand parents' reactions, identify parents in need of professional help, and guide them to obtain appropriate support, treatment, and counselling. Identification of the psy-

chological effects and counselling of parents to obtain the required help will improve the quality of healthcare services

and facilitate the treatment of the infant's illness. Respond-

ing to the need for parental support may also prevent subse-

quent mental health problems in children and parents. The

aim of this study was to examine the prevalence of psychiat-

ric symptoms, PTG and LS among these parents.

#### Participants

This study included two cohorts: parents of infants (n = 17) with a serious illness, forming the interest group (n = 34; 17) dyads), and parents of healthy infants (n = 30), forming the control group (n = 60; 30) dyads). The parents were recruited from Kuopio University Hospital, Kuopio, Finland, between April 2014 and April 2018. In the interest group, the parents of 24 infants were invited to participate and 17 couples agreed, while in the control group, 30 couples of the 34 who were invited agreed to participate.

Family characteristics are listed in Table 1. The participants were all heterosexual couples, and the age distribution

Variable	Interest group $(N=34)$		Control grou	Control group ( $N = 60$ )	
Age (years)					
Fathers	n = 17	30 [21-47]	n=30	31 [21-47]	
Mothers	n = 17	28 [21-39]	n=30	29 [20-38]	
Miscarriages n (%)	4 (24%)		7 (23%)		
Infertility treatments n (%)	4 (24%)		3 (10%)		
Mode of delivery <i>n</i> (%)					
Vaginal	9 (53%)		29 (97%)		
Cesarean	8 (47%)		1 (3%)		
Length of NICU stay days	12 [3-37]		-		
Mothers employed $n$ (%)	8 (47%)		24 (80%)		
Fathers employed $n$ (%)	16 (94%)		27 (90%)		
Education n (%)					
Basic level	1 (3%)		1 (2%)		
Upper secondary	16 (47%)		25 (42%)		
Lower-degree tertiary	11 (32%)		12 (20%)		
Higher-degree level tertiary	1 (3%)		11 (18%)		
NA	5 (15%)		11 (18%)		
Burden in family					
Economic $n$ (%)	7 (41%)		5 (17%)		
Other $n$ (%)	4 (24%)		3 (10%)		
Physical illnesses					
Fathers n (%)	4 (24%)		8 (27%)		
Mothers n (%)	2 (12%)		6 (20%)		
Mental illnesses					
Fathers n (%)	1 (6%)		4 (13%)		
Mothers n (%)	5 (29%)		7 (23%)		
Siblings in the family (yes/no)	9/8		11/19		
Number of siblings	1 (0–7)		0 (0–6)		
Illnesses of siblings					
Physical n (%)	1 (5.9)		NA		
Mental n (%)	0(0)		NA		

Data are median [range] or number of cases (%)

NICU neonatal intensive care unit

**Table 1** Background data ofthe families (N=17 dyads/34parents in the interest groupand 30 dyads/60 parents in thecontrol group)

of the participants was similar in both groups. The cohorts had similar rates of previous miscarriage, but the interest group had slightly higher rates of infertility treatment (24% vs. 10%). Paternal employment rates were similar in both groups, but in the interest group, only half of the mothers were employed compared to 80% in the control group. Furthermore, the level of education was higher in the control group than in the interest group. Seven of the 94 parents had a background in healthcare; there were three nurses in the interest group and three physicians and one nurse in the control group. All except one couple in the interest group were first-time NICU parents. Economic (unemployment/ low incomes/debts/distraints) and other burdens in the family (stress at work, divorce, lack of social support, moving to a new house, selling a house) were also more common in the interest group. Physical and mental illness rates were relatively similar, but physical illnesses in mothers and mental illnesses in fathers were slightly more common in the control group, and mental illnesses in mothers in the interest group.

At recruitment, the infants were between 0 and 19 days old, and half of them had siblings, 53% in the interest group and 37% in the control group. Only a few of the siblings had illnesses. Infants in the interest group had a life-threatening illness or condition necessitating therapeutic hypothermia or urgent surgery and were admitted to the NICU for a median of 12 days; the diagnoses were asphyxia and hypoxic-ischemic encephalopathy (n = 9), gastroschisis (n = 3), esophageal atresia (n = 2), omphalocele (n = 2), and renal failure (n = 1). All infants in the control group were healthy and there was no need for NICU admissions.

#### Procedure

Approval for the study protocol was obtained from the Research Ethics Committee of the Northern Savo Hospital District, Kuopio, Finland (No. 88/2013; January 7, 2014). The study had institutional approval (No. TJ\_146/2015) and complied with the American Psychological Association Ethical Principles and the Ethical Principles presented in the Helsinki Declaration regarding the treatment of participants. The participants in the interest group were recruited by the first author (KK) in the NICU between April 2014 and April 2018 and those in the control group (HK, IT) in the labor ward of the hospital in May 2015. The inclusion criteria in the interest group were a life-threatening illness diagnosed in a full-term newborn and requiring urgent invasive treatment, either therapeutic hypothermia or surgery, a couple relationship with the child's other parent, and voluntary written consent from both parents. The inclusion criteria in the control group were a couple with a healthy, full-term biological newborn and that both parents consented to participate.

Participants were given oral and written information about the study and time to consider participation. The participants provided written informed consent. Refusal to participate in the study did not affect the treatment of an infant or parents in the hospital. Parents also had the right to withdraw their participation in the study at any time and without reason. The participants completed the first questionnaires during the first days after the infant's diagnosis or delivery (Time 1). An exception to this was the first Impact of Event Scale-Revised questionnaire (IES-R; Weiss & Marmar, 1997), which was completed by the parents in the interest group one month after the infant's diagnosis or delivery. Parents in the interest group completed the second questionnaires at a scheduled in-person visit in the hospital at 12 months, and parents in the control group returned mailed questionnaires in a prepaid envelope at 12 months after the birth of their infant (Time 2). Only the parents in the interest group filled in the IES-R and the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996).

Seventy-two participants (77%) were reached for the follow-up at 12 months; the interest group had a participation rate of 88% (n=30) and the control group 70% (n=42). The missing data were due to the fact that the subjects declined participation (n=18 in the control group), were not reached (n=2), or they had moved away (n=2). In the interest group, there were no cases of attrition, but one couple in the control group had divorced during the 12-month follow-up period.

#### Measures

In addition to demographic variables (Table 1), the participants filled out the seven following measures (five of these in both groups, and the IES-R and PTGI in the interest group only). Total scores from all the measures were calculated and compared between groups, and between the two time points within the groups. Dichotomized scores were also calculated for all measures.

#### Anxiety

The Beck Anxiety Inventory (BAI; Beck et al., 1988) was used to assess the subjective anxiety of the participants. The BAI is a 21-item self-report measure. The items were rated on a four-point scale of increasing severity. The BAI was dichotomized to no or mild anxiety (BAI score 0–15) and moderate to severe anxiety (BAI score 16–63). The internal consistency with the current sample was very high at both time points (Cronbach's alpha=0.961).

#### Depressive Symptoms

The Beck Depression Inventory—Second Edition (BDI-II; Beck et al., 1996) and the Edinburgh Postnatal Depression Scale (EPDS; Cox et al., 1987) were used to assess the current depressive symptoms of the participants. The BDI-II is a 21-item self-report measure. The items were rated on a four-point scale of increasing severity. The BDI-II was dichotomized to no depressive symptoms (BDI-II score 0-13) and depressive symptoms (BDI-II score 14–63). Internal consistency with the current sample was very high at both time points (Cronbach's alpha=0.911). The EPDS is a 10-item self-report measure. The items were rated on a four-point scale of increasing severity. The EPDS was dichotomized to no depression (EPDS score 0–9) and possible depression (EPDS score 10–30). Internal consistency with the current sample was also very high at both time points (Cronbach's alpha=0.905).

#### **General Stress**

The Perceived Stress Scale (PSS-14; Cohen et al., 1983) was used to assess subjective experiences of psychological stress. The PSS-14 is a 14-item self-report measure. The items were rated on a five-point scale of increasing severity, and seven positively stated items were reversed to obtain scores for summing. The PSS-14 score was dichotomized to low stress (PSS-14 score 0–18) and moderate or high stress (PSS-14 score 19–56) (Cohen et al., 1983). Internal consistency with the current sample was very high at both time points (Cronbach's alpha = 0.861).

#### Posttraumatic Growth

The Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996) was used to assess positive change as a result of the struggle with stressful experiences that the participants identified. The PTGI is a 21-item self-report measure. The items were rated on a six-point scale of increasing growth. The PTGI score was dichotomized to no meaningful positive change (PTGI score 0–41) and at least a small positive change (PTGI score 42–105) (Sawyer et al., 2012). Posttraumatic growth was measured at 12 months in the interest group. Internal consistency with the current sample was very high (Cronbach's alpha=0.934).

#### **Traumatic Distress**

The Impact of Event Scale–Revised questionnaire (Weiss & Marmar, 1997) was used to assess subjective distress caused by a traumatic event. The IES-R is a 22-item self-report measure. The items were rated according to how distressing each symptom was over the past seven days on a four-point scale of increasing severity. The traumatic distress score was dichotomized to PTSD unlikely (IES-R score 0–24) and PTSD likely (IES-R score 25–66). Internal consistency with the current sample was very high at both time points (Cronbach's alpha=0.915).

#### Life Satisfaction

The 4-item Life Satisfaction Scale (Koivumaa-Honkanen et al., 2000) was used to assess subjective interest and happiness in life, ease of living, and the loneliness of the participants. The LS-4 is a four-item self-report measure. The items were rated on a five-point scale of decreasing satisfaction. The LS-4 score was dichotomized to satisfied (LS-4 score 4–11) and dissatisfied (LS-4 score 12–20) (Koivumaa-Honkanen et al., 2000). Internal consistency with the current sample was high at both time points (Cronbach's alpha=0.716).

### Statistics

The data were recorded and analyzed using SPSS software (IBM SPSS Statistics 25, International Business Machines Corporation, Armonk, NY, USA). The normal distribution of continuous data was tested with the Kolmogorov-Smirnov test, the Shapiro-Wilk test, and visually from histograms. The internal consistency of each questionnaire was tested with Cronbach's alpha. Normally distributed quantitative data were analyzed with two-sided unpaired and paired t-tests assuming equal variances. Non-normally distributed data were compared with the Mann–Whitney U-test. We used the Wilcoxon signed-rank test for dependent data, and the Chi-squared test, Fisher's exact test, and McNemar's test for categorical data. Spearman's rank correlation test was used to test for correlations between variables. The data are displayed as the number of cases and median (range), unless otherwise specified. *p*-values of  $\leq 0.05$  were considered statistically significant.

### Results

Sociodemographic and other characteristics of families after the birth of the infant (N=47 dyads) are listed in Table 1. The medians (minimum, maximum) of the survey scores are listed in Table 2 and categorized data in Table 3. The dichotomized data of the two groups and at two time points are presented below, along with correlations between the LS-4 score and other measures.

#### Anxiety

Early after the birth of the infant (Time 1), anxiety (BAI score  $\geq$  16/63) was more common in the interest group than in the control group (p=0.032). Anxiety was more common among mothers than fathers in the interest group (p=0.024), and similar in both sexes in the control group (p=0.103) (Table 3).

		-					
Variable	Anxiety (BAI), scale 0–63	Depression (BDI-II), scale 0–63	Depression (EPDS), scale 0–30	Perceived stress (PSS-14), scale 0–40	Life Satisfaction (LS-4), scale 4–20	Posttraumatic Growth (PTGI), scale 0–105	Posttraumatic Stress Disorder Symptoms (IES-R <sup>7</sup> ), scale 0–66
Interest group at 7	$\Gamma 1 (N=34)$						
All	6 [0-42]	4 [0-22]	7 [0–21]	18 [7-40]	7 [5–16]	-	13 [1-41]
Mothers	15 [1-42]	8 [2-22]	12 [2-21]	23 [7-40]	8 [5-14]	-	18 [6-41]
Fathers	5 [0-25]	2 [0-18]	4 [0–18]	16 [8-31]	7 [5–12]	-	9 [1-30]
Control group at	$\Gamma 1 (N = 60)$						
All	5 [0-26]	2 [0–19]	3 [0–13]	16 [4-33]	5 [4-9]	-	_
Mothers	5 [0-26]	3 [0–11]	4 [0–13]	17 [4–33]	5 [4-9]	-	-
Fathers	3 [0–19]	1 [0–19]	2 [0-10]	16 [6-28]	5 [4-9]	-	-
<i>P</i> -value between the groups at T1	0.048	0.019	< 0.001	0.006	< 0.001	NA	NA
Interest group at 7	$\Gamma^2 (N = 30)$						
All	5 [0-28]	8 [0-32]	7 [0–19]	20 [9-34]	7 [4–18]	42 [8-89]	9 [1-47]
Mothers	7 [1–27]	8 [2-32]	12 [2–21]	21 [9-34]	8 [5-13]	45 [19-89]	18 [1-47]
Fathers	2 [0-28]	7 [0-22]	4 [0–16]	19 [11–32]	7 [4–18]	41 [8-65]	5 [1-30]
<i>P</i> -value T1 vs. T2 in the interest group	0.018	0.265	0.242	0.874	0.411	NA	0.008
Control group at	t T2 ( $N = 42$ )						
All	3 [0-15]	4 [0-21]	3 [0–15]	18 [3–34]	6 [4–12]	-	-
Mothers	3 [0-15]	7 [0–21]	5 [0-14]	18 [3–34]	6 [4–12]	-	-
Fathers	3 [0–13]	2 [0-14]	3 [0–15]	18 [12–27]	6 [4–10]	_	-
<i>P</i> -value T1 vs. T2 in the Control group	0.005	0.002	0.094	< 0.001	< 0.001	NA	NA
<i>P</i> -value between the groups at T2	0.029	0.021	0.026	0.093	0.109	NA	NA

Table 2 Median [range] scores of surveys in the two cohorts after birth (T1) and after 12 months (T2)

BAI Beck Anxiety Inventory, BDI-II Beck Depression Inventory II, EPDS Edinburgh Postnatal Depression Scale, PSS-14 Perceived Stress Scale-14, LS-4 Life Satisfaction Scale-4, PTGI Posttraumatic Growth Inventory, IES-R Impact of Event Scale-Revised

Twelve months later (Time 2), anxiety was less common. Two out of 30 parents in the interest group, one mother and one father, had a BAI score of  $\geq 16/63$  (p = 0.021 compared to Time 1), and no anxiety was reported at 12 months in the control group (Table 3).

#### **Depressive symptoms**

Early after the birth, depressive symptoms (BDI-II score  $\geq$  14/63) were more common in the interest group than in the control group (p=0.003), but the prevalence was similar at 12 months (p=0.733). Depressive symptoms were equally common in mothers and fathers in the interest group (Time 1: p=0.398, Time 2: p=1.0) and in the control group (Time 1: p=1.0, Time 2: p=0.343) (Table 3).

Depressive symptoms were more common when measured with the EPDS (score  $\geq 10/30$ ) than with the BDI-II (p < 0.001 at Time 1 and Time 2). At Time 1, when assessed with the EDPS, the prevalence of possible depression was higher in the interest group than in the control group (p < 0.001). In the interest group, mothers had more possible depression than fathers (p = 0.004). At 12 months, the prevalence of possible depression was similar between the two groups (p = 0.087) and between mothers and fathers (p = 0.736). In the interest group, the prevalence of depressive symptoms was similar at 12 months to that early after the birth (p = 0.296) (Table 3).

Deringer

Table 3	Classification of different	questionnaire scores after	r the birth (T1) and after	12 months (T2). Data are	number of cases
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Variable	Interest group at T1 $(N=34)$	Interest group at T2 $(N=30)$	Control group at T1 $(N=60)$	Control group at T2 ( $N$ =42)
Anxiety (BAI) <sup>a</sup>	19/5/8/2	20/8/0/2	44/9/6/1	36/4/0/0
Mothers, n	7/2/6/2	8/6/0/1	20/4/5/1	19/2/0/0
Fathers, n	12/3/2/0	12/2/0/1	24/5/1/0	17/2/0/0
Depression (BDI-II) <sup>b</sup>	27/5/2/0	25/3/1/1	59/1/0/0	36/4/1/0
Mothers, n	12/3/2/0	12/2/0/1	30/0/0/0	17/3/1/0
Fathers, n	15/2/0/0	13/1/1/0	29/1/0/0	19/1/0/0
Depression (EPDS) <sup>c</sup>	22/6/6	23/4/3	56/4/0	37/1/2
Mothers, n	7/6/4	11/2/2	28/2/0	19/1/1
Fathers, n	15/0/2	12/2/1	28/2/0	18/0/1
Perceived stress (PSS-14) <sup>d</sup>	16/18/0	10/20/0	40/20/0	24/18/0
Mothers, n	5/12/0	4/11/0	18/12/0	11/10/0
Fathers, n	11/6/0	6/9/0	22/8/0	13/8/0
Life satisfaction (LS-4) <sup>e</sup>	12/20/2	9/15/6	47/13/0	21/19/2
Mothers, n	4/12/1	2/9/4	23/7/0	10/9/2
Fathers, n	8/8/1	7/6/2	24/6/0	11/10/0
Posttraumatic growth inventory (PTGI) <sup>f</sup>	NA	15/15	NA	NA
Mothers, n	NA	8/7	NA	NA
Fathers, n		7/8		
Posttraumatic stress disorder symptoms (IES-R) <sup>g</sup>	20/3/3/6	21/3/2/4	NA	NA
Mothers, n	9/1/1/5	8/3/1/3	NA	NA
Fathers, n	11/2/2/1	13/0/1/1	NA	NA

<sup>a</sup>No/mild/moderate/severe anxiety

<sup>b</sup>No/mild/moderate/severe depression symptoms

<sup>c</sup>No depression/depression/severe depression

<sup>d</sup>Low/moderate/high stress

<sup>e</sup>Satisfied/slightly dissatisfied/dissatisfied with life

<sup>f</sup>At least a small positive change/no meaningful positive change

<sup>g</sup>No PTSD symptoms/some PTSD symptoms/PTSD/severe PTSD

### **General Stress**

Moderate and high perceived stress (PSS-14 score  $\geq$  19/56) was common in both groups at both time points, but the groups did not differ in perceived stress at either time point (Time 1: p = 0.134; Time 2: p = 0.615). At Time 1 in the interest group, mothers had more stress than fathers (p = 0.001), but not at 12 months (p = 0.068). The prevalence of general stress was similar between the sexes in both groups; Time 1: p = 0.146 and p = 0.390, and Time 2: p = 0.142 and p = 0.254 in the interest group and the control group, respectively (Table 3).

### **Posttraumatic Growth**

Posttraumatic growth was measured at 12 months and in the interest group only. We did not have this data in the control

group. Eight mothers out of 15 and seven fathers out of 15 had PTG (PTGI score  $\geq 42/105$ , p = 0.715) (Table 3).

In the interest group, PTGI total scores correlated positively with IES-R scores (r=0.388, p=0.034), but correlations with other measures at 12 months were not statistically significant. The correlation coefficient was 0.041 with LS-4 scores (p=0.830), 0.021 with PSS-14 (p=0.912), 0.185 with EPDS (p=0.328), 0.006 with BDI (p=0.973), and 0.209 with BAI (p=0.267).

#### **Traumatic Distress**

Traumatic distress was measured in the interest group only, first at one month after the birth and for a second time at 12 months. The prevalence of traumatic distress (IES-R score  $\geq 25/66$ ) was similar at both time points (p=0.141) and in mothers and fathers (at 1 month after the birth: p=0.433, at 12 months: p=0.390). Previous miscarriages

(n = 4 mothers) did not correlate with the IES-R (at 1 month after the birth: p = 1.0, at 12 months: p = 1.0) (Table 3).

### Life Satisfaction

Life satisfaction was similar between the two groups (Time 1: p=0.161; Time 2: p=0.060). In the control group, all the participants were satisfied with life (LS-4 score 4–11) early after the birth compared to one dissatisfied mother and one dissatisfied father in the interest group, and at 12 months in the control group, two mothers were dissatisfied with life compared to four dissatisfied mothers and two dissatisfied fathers in the interest group. There was no difference between mothers and fathers in LS (Time 1: p=1.0; Time 2: p=0.260) (Table 3).

In the interest group, the LS-4 score early after the birth correlated inversely with the BAI (r = -0.612, p < 0.001), EPDS (r = -0.765, p < 0.001), BDI-II (r = -0.688, p < 0.001), PSS-14 (r = -0.646, p < 0.001), and IES-R scores (r = -0.428, p = 0.015). The inverse correlations were similar at 12 months: BAI (r = -0.543, p = 0.002), EPDS (r = -0.615, p < 0.001), BDI-II (r = -0.773, p < 0.001), PSS-14 (r = -0.539, p = 0.003), and IES-R scores (r = -0.534, p = 0.002).

In the control group, the LS-4 score had a significant inverse correlation with the BAI score early after the birth (r = -0.398, p = 0.001), and at 12 months (r = -0.314, p = 0.049). There was a significant inverse correlation between the LS-4 score and the EPDS score at Time 1 (r = -0.443, p < 0.001) and at 12 months (r = -0.722, p < 0.001), and also at both time points between the LS-4 score and the BDI-II score (r = -0.425, p = 0.001) and r = -0.640, p < 0.001, respectively) and PSS-14 score (r = -0.373, p = 0.003, and r = -0.585, p = 0.001, respectively).

### Discussion

This study examined anxiety, depressive symptoms, general stress, PTG, traumatic distress, and LS among parents of seriously ill infants from the acute diagnostic period up to 12 months after their child's initial NICU admission. The study compared the parents of seriously ill infants with those of healthy infants, and it also allowed a comparison of responses between fathers and mothers. The current study broadens our understanding of LS, PTG, and psychiatric symptoms in the parents of seriously ill infants. One of the novelties of this study was the inclusion of parents of infants treated with therapeutic hypothermia, thus providing new insight into their psychological well-being and PTG.

Severe and moderate anxiety was more common in the parents of seriously ill infants soon after the diagnosis than in those of healthy infants. Even though anxiety decreased in both groups, the parents of the ill infants were still more anxious than the control group after 12 months. This is consistent with earlier studies (e.g. Cabizuca et al., 2009; Muscara et al., 2015; Yaman & Altay, 2015). According to Kong et al. (2013), the level of social support and perceived stress are the most important factors related to parental anxiety. Psychological intervention programs individualized to the needs of parents are effective in reducing anxiety compared to standard care (Cano Giménez & Sánchez, 2015). In a single-blind randomized controlled trial, preoperative preparation was found to substantially reduce parent state anxiety (Fincher et al., 2012). The anxiety of parents of severely ill infants can be caused by concerns about the child's survival and health (Wray et al., 2011). In parents of an infant with asphyxia, it may also be due to the separation from the infant caused by therapeutic hypothermia (Laudi & Peeples, 2020). In the study of Craig et al. (2020), parents reported that the physical separation imposed by hypothermia adversely impacted on their ability to bond with their infant. In future studies, it would be important to further investigate the nature of anxiety in these parents, and to develop and evaluate interventions to alleviate it.

Depressive symptoms were common in the interest group, and they did not decrease at the 12-month follow-up. Mothers had more depressive symptoms than fathers measured with the EPDS. In the longitudinal cohort study of Bergström et al. (2012), the incidence of postpartum depression (PPD) among mothers of infants cared for in the NICU was 15% at one month and 14% at four months. Mothers who experienced PPD at 1 month had an almost eightfold increased risk of experiencing PPD at four months. Women who were not offered counseling during their infant's stay in the NICU had a 60% increased risk of PPD onset. Mothers of infants with neonatal hypoxic-ischemic encephalopathy (HIE) were at high risk of developing PPD, which may in part be related to therapeutic hypothermia interfering with maternal-infant bonding (Laudi & Peeples, 2020). The results of our research support earlier findings that infant care in the NICU, and particularly therapeutic hypothermia, adds to the risk of maternal depression. According to our research, depressive symptoms were long-lasting, and it would therefore be important to screen parents' needs for psychological support even after the initial phase.

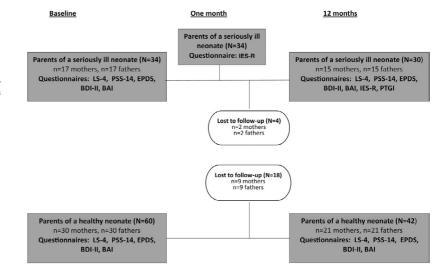
In our research, moderate or high perceived stress was common among the parents of both seriously ill and healthy infants. The perceived stress had not reduced at the 12-month follow-up in either group, which may indicate the burden of the baby year not only for parents of ill infants but also for those of healthy infants. The depressive symptoms of parents with healthy infants had increased on follow-up, so it would also be important to screen their mood and stress level during the first baby year, for example, when visiting a child health clinic. In a previous study by Enke et al. (2017), parents of a younger age and those of infants with severe prognoses were more likely to experience stress. Staff in the NICU should communicate empathetically and help to reduce stress in parents particularly at risk. Recognizing mood symptoms and stress would be relevant not only for the parents' own but also for the child's well-being. Azak et al. (2013) found that infants of mothers with comorbid anxiety and depression had relatively higher cortisol production from morning to bedtime and higher bedtime values than infants of non-depressed mothers (Fig. 1).

The risk of PTSD was relatively high among the parents, especially the mothers, of ill infants. During the 12-month follow-up, PTSD symptoms decreased in the fathers but not in the mothers. In previous studies (e.g. Aftyka et al., 2017a, 2017b), mothers have been found to have a higher prevalence and severity of PTSD than fathers. The present study found no difference between the parents in dichotomized results; nonetheless, the total amount of traumatic distress decreased in the fathers but not in the mothers. Thus, it would be important to screen and treat the trauma symptoms of parents of severely ill children during and after the baby year. In the future, it would be important to investigate the factors that explain the differences between parental trauma symptoms. It would be interesting to study, for example, how mothers' experiences of giving birth to a child and the type of delivery affect their psychiatric symptoms and experiences of the child's illness. According to Craig et al. (2020), the birth was frequently described as traumatic with descriptions of chest compressions, excessive blood loss, and infants not crying. Trauma was also described in the parental observations of the shivering hypothermic infant. Infant care in the NICU is also associated with a risk of a variety of complications that can intensify parental perceptions of vulnerability of the child and their worry about the child's survival.

In our research, half of the parents of seriously ill infants reported PTG in the PTGI. In earlier studies, the prevalence of PTG among the parents of seriously ill children has varied between 37 and 88% (Barr, 2011; Colville & Cream, 2009; Hungerbuehler et al., 2011; Rodríguez-Rey & Alonso-Tapia, 2019). Posttraumatic growth has been higher in mothers than in fathers (Aftyka et al., 2020). Parents of children who were ventilated and parents of older children have reported statistically higher PTG than other parents. Aftyka et al. (2020) found that in the fathers, a significant predictor of PTG in stressful situations was the use of strategies aimed at seeking emotional support and positive reinterpretation and growth. The predictors of PTG in the mothers were seeking emotional support, religious coping, and planning. Aftyka et al. (2020) concluded that the parents should be provided to a greater extent with psychological and psychotherapeutic help, which would provide them with both emotional support and the possibility of a positive reinterpretation of difficult events.

Parental LS was quite high for the parents of both seriously ill and healthy infants. Life satisfaction declined in the parents of healthy infants at the 12-month follow-up, but not in the parents of seriously ill infants. Thus, despite their psychiatric symptoms and strain, the parents of seriously ill infants managed to maintain overall satisfaction with their lives. This may be related to their resilience and is consistent with previous studies (e.g. Isokääntä et al., 2019; Picoraro et al., 2014). According to Ferrand et al. (2018), parental resilience was a key factor in their envisioning good quality

Fig. 1 Flow chart for the study. The questionnaires were the 4-item Life Satisfaction Scale (LS-4), the Perceived Stress Scale-14 (PSS-14), the Edinburgh Postnatal Depression Scale (EPDS), the Beck Depression Inventory—Second Edition (BDI-II), the Beck Anxiety Inventory (BAI), the Impact of Event Scale–Revised (IES-R), and the Posttraumatic Growth Inventory (PTGI)



of life after the NICU, and less resilient parents were 10 times more likely to predict that their newborn would remain chronically ill. Parental projection of the future quality of life was not associated with the child's risk of disability. Parental resilience was not diminished by the stress of hospitalization itself and 75% of parents had good resilience (Ferrand et al., 2018). Taken together, these findings should lead to increased awareness of the importance of LS and resilience, as well as identifying and supporting parents with lower resilience.

#### **Limitations and Future Research Implications**

The main limitation of the present study was its small sample size. However, we were not able to recruit more dyads of seriously ill infants during the 4-year study period. Second, qualitative and mixed-methods research could shed more light on the nature of parental experiences. Longitudinal, prospective research would also capture more about the development of parental PTG and psychiatric symptoms as the child grows (Tennen, & Affleck, 2009). In the future, it would also be important to investigate the factors that make it possible for parents to maintain LS, despite their child's serious illness. For example, the importance of parenting and couple relationship satisfaction for overall LS should be explored.

At the university hospital where this research was carried out, the psychosocial support services of the NICU were available. All the parents in the interest group had the opportunity to use the services of a crisis worker, a social worker, a baby family worker, and a priest. When considered necessary, a baby family nurse made home visits and appointments with a child psychiatrist were provided. This study was limited to the quantitative data obtained through the questionnaires, but previously published qualitative studies provide important perspectives on the parental needs for support in NICUs. Nurses have an essential role in providing family centered care in NICUs; they provide individual support, educate parents, promote open communication, and encourage meaningful involvement (Gilstrap, 2021; Nassef et al., 2013). These sense giving strategies enhance the understanding of the parents and their participation in neonatal care practices. According to Segre et al. (2016), nurse-delivered depression screening and counseling could increase the detection of depression as well as treatment use among at-risk mothers. Moreover, neonatologists have a central role in facilitating parental participation in decisionmaking (Axelin et al., 2018). In addition, peer support has been very influential in development of the maternal role in the NICU (Rossman et al., 2015). Psychological, artbased, and musical interventions have also been effective in supporting the psychological well-being of parents in the NICU (e.g. Ettenberger et al., 2017; Mendelson et al., 2018;

Mouradian et al., 2013). Support for the parents should continue after the hospitalization of the child, because they have many uncertainties after their child's discharge from the NICU (Dellenmark & Wigert, 2014; White et al., 2017). In the future, it would be important to assess the impact of the existing supportive methods, as well as develop new interventions and investigate their effectiveness in supporting parental well-being.

#### Conclusions

In this study, the parents of newborn infants receiving therapeutic hypothermia and surgical treatment in the NICU had a variety of psychiatric symptoms after the infant was diagnosed with the severe condition and a year after the diagnosis. Symptoms of depression, general stress, and traumatic distress were common and relatively persistent. Parents also had traumatic growth, and they were rather satisfied with their lives, despite their symptoms. Healthcare professionals need education and information on the psychological well-being of parents to identify those parents in need of help and guide them to the psychological support they need.

Author Contributions KK, IT, KH, HK and US contributed to the study conception and design. Material preparation and data collection were performed by KK, SI, KT, IT, IT, MK, KH and HK. Data analysis was performed by SI and HK. The first draft of the manuscript was written by KK and SI. All authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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#### Declarations

**Conflict of interest** Krista Koivula, Siiri Isokääntä, Kati Tavast, Iines Toivonen, Iina Tuomainen, Merja Kokki, Kirsi Honkalampi, Ulla Sankilampi and Hannu Kokki declare that they have no conflict of interest.

**Ethical Approval** Approval was obtained from the ethics committee of the Northern Savo Hospital District, Kuopio, Finland (January 7, 2014/ No. 88/2013). The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

**Consent to Participate** Written informed consent was obtained from the participants.

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# **STUDY III**

IV Koivula, K., Kokki, H., Laitila, A., Korhonen, M., Kalapudas, J., & Honkalampi,K. (submitted). Hold Me Tight group intervention for parents of children with cancer.

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# **KRISTA KOIVULA**

A child's serious illness substantially affects parents' mental health in the early stages and one year after diagnosis. Parents' intimate relationship can be a resource for coping through dyadic emotion regulation. In this study, a 3-day emotionally focused course produced experiences of strengthening parents' personal well-being and couple resilience. It is essential to evaluate parents' mental health and offer appropriate individual and couple interventions for this target group.



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