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What about the parents?

Sleep quality, mood, saliva cortisol response
and sense of coherence in parents with
a child admitted to pediatric care

Charlotte Angelhoff

Division of Nursing Sciences
Department of Social and Welfare Studies
Linköping University, Sweden
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What about the parents? Sleep quality, mood, saliva cortisol response and sense of coherence in parents with a child admitted to pediatric care

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*To my family
Ivo, Alexander, Paulina and Isabelle*

*"sleep is one of the natural goods of life,
beautiful in itself,
like flowers,
like the songs of birds.
It is the touchstone of health;
as the man sleepeth, so is he.
Where virtue is,
it is more virtuous,
and where beauty is,
more beautiful"*

*J.F. Pyre, Shakespeare's Pathos
(Portrayals of sleep)*

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ABSTRACT

Parents experience many stressful situations when their child is ill and needs medical care, irrespective of the child's age, diagnosis or the severity of the illness. Poor sleep quality and negative mood decrease the parents' ability to sustain attention and focus, to care for their ill child, and to cope with the challenges they face.

The overall aim of this thesis was to evaluate sleep, mood, cortisol response, and sense of coherence (SOC) in parents caring for children in need of medical care, and to identify factors that may influence parents' sleep.

This thesis includes four original studies; two of these are quantitative, prospective, descriptive and comparative studies including parents ($n=82$) accommodated in six pediatric wards with their ill child, using questionnaires and sleep logs to measure sleep, mood and SOC, and saliva cortisol to measure cortisol response. A follow-up was performed four weeks later at home, after hospital discharge. The other two studies are qualitative, inductive and explorative interview studies, including parents ($n=12$) staying overnight with their preterm and/or ill infant in three neonatal intensive care units, and parents ($n=15$) with a child receiving hospital-based home care in two pediatric outpatient clinics. The interviews were analyzed with a phenomenographic method.

Being together with one's family seems beneficial for sleep and may decrease stress. The ability to stay with the child, in the hospital or at home, was highly appreciated by the parents. When caring for a child with illness, parents' sleep quality was sufficient in the hospital; however, sleep quality improved further ($p<0.05$) at home after discharge. The parents reported frequent nocturnal awakenings in the hospital caused by the child, medical treatment and hospital staff. Concern and anxiety about the child's health, and uncertainty about the future were stressors affecting the parents' sleep and mood negatively. The parents had lower ($p=0.01$) morning awakening cortisol levels in the pediatric ward compared to at home, and parents accommodated for more than one night had lower ($p<0.05$) post-awakening cortisol levels compared to parents staying their first night.

The findings of this thesis conclude that being together as a family is important for the parents' sleep. The ability to be accommodated in the hospital and gather the family around the child may have given the parents time for relaxation and recovery, that in turn may lead to a less stressful hospital stay. When it is beneficial for the child, the whole family should be included in the pediatric care. Moreover, pediatric nurses must acknow-

ledge parents' sleep, in hospital and at home. Medical treatment and care at night should be scheduled and sleep promoted for the parents in order to maintain health and well-being in the family.

SVENSK SAMMANFATTNING

Föräldrar sover bättre och blir på bättre humör när familjen får vara tillsammans i sjukvården

Sömn är viktigt för hälsan. Vi behöver en god sömn för att kroppen ska återhämta sig och fungera normalt. När barn blir sjuka är det extra viktigt att föräldrarna får en god sömn för att orka med uppgiften att vårda sitt barn. Resultaten i denna avhandling visar att möjligheten till övernattnings på sjukhuset och att kunna vara tillsammans som en familj när barnet blir sjukt kan ge föräldrarna en känsla av trygghet i en stressfylld situation, vilket bidrar till en bättre sömnkvalitet och bättre humör.

Avhandlingen innehåller fyra studier och det övergripande syftet var att studera föräldrars sömn, sinnesstämning, stress och förmåga att hantera situationen (KASAM), när deras barn behöver medicinsk vård. Föräldrar som övernattat med sitt barn på sex olika barn- och ungdomsavdelningar har fyllt i frågeformulär om sömn, sinnesstämning och KASAM, samt lämnat salivprover för analys av stresshormonet kortisol. Dessutom har föräldrar till för tidigt födda barn på tre olika neonatalavdelningar och föräldrar till barn som är anslutna till hemsjukvård på två barn- och ungdomsmottagningar intervjuats om sina uppfattningar kring sömn.

Resultaten visade att många föräldrar led av sömnbrist, som inte var relaterad till barnets sjukdom, redan innan deras barn blev inskrivna på sjukhuset. Bland de föräldrar som vårdade sitt barn i hemmet beskrev en del hur brist på sömn påverkade deras humör och hur detta gick ut över den övriga familjen vilket fick dem att må ännu sämre psykiskt. Föräldrar som övernattat med sitt barn på barn- och ungdomsavdelning rapporterade en tillfredsställande sömnkvalitet trots att de hade haft fler uppvaknanden under natten och lägre sinnesstämning än hemma. Föräldrar som var ensamma med sitt barn på sjukhuset beskrev hur det påverkade sömnen negativt att inte familjen var samlad och att de kände sig isolerade och ensamma.

Sömnbrist och stress leder till att höga halter av kortisol utsöndras. Sker detta under en längre tid kan det leda till förändringar på hjärnan som påverkar beteendet och förmågan att minnas och att lära in nytt. Funktioner som är viktiga för föräldrar som ska ta hand om sina barn. Föräldrarna hade lägre kortisolvärden när de hade sovit på sjukhuset jämfört med hemma, om de hade sovit på sjukhuset mer än en natt, och om de förväntade sig att få vara tillsammans med sin familj under dagen. Detta resultat tyder på att föräldrarna kände en trygghet och kunde slappna av när de var

tillsammans med sitt barn på sjukhuset. Föräldrar till barn på neonatalavdelning och föräldrar som vårdade sitt barn i hemmet beskrev hur de uppskattade möjligheten att få vara tillsammans med sitt barn och hur detta underlättade deras sömn och minskade känslor av stress.

Vissa personer hanterar påfrestningar och stressiga situationer bättre än andra. Vi fann ett samband mellan föräldrarnas sömn, sinnesstämning och KASAM som indikerade att ju bättre sömn desto bättre sinnesstämning och starkare KASAM. Detta förstärker argumentet om att en god sömnkvalitet är viktigt för att upprätthålla förmågan att hantera olika situationer som uppkommer när barnen blir sjuka.

Föräldrarna hade olika strategier för att få en bättre sömnkvalitet. De ändrade sina rutiner efter barnets behov för att öka sin sovtid. Att få göra något bara för sig själv eller med sin partner, så kallad egentid, var bra för både välmående och sömn. Fysisk aktivitet var en annan viktig faktor för god sömnkvalitet. Föräldrarna beskrev även betydelsen av att få stöd från omgivningen för att kunna finna tid för avkoppling och sömn.

Avhandlingen ökar kunskapen om och belyser vikten av att uppmärksamma föräldrars sömn för att upprätthålla hälsa och välmående i hela familjen. Sjuksköterskan som möter familjen på BVC, i skolhälsovården eller inom sjukvården har en viktig funktion i att identifiera föräldrar med sömnproblem då detta indirekt också påverkar barnens utveckling och hälsa. Genom att fråga föräldrarna om deras sömnvanor och ge råd om hur en god sömnkvalitet kan uppnås förebyggs ohälsa hos föräldrarna och därmed även barnen.

LIST OF PAPERS

- I. Angelhoff, C., Edéll-Gustafsson, U. and Mörelius, E. Sleep quality and mood in mothers and fathers accommodated in the family-centred paediatric ward. A descriptive and comparative study. *Submitted*.
- II. Angelhoff, C., Edéll-Gustafsson, U. and Mörelius, E. Salivary cortisol response and sense of coherence in mothers and fathers accommodated in the family-centered pediatric ward. A descriptive and comparative study. *Submitted*.
- III. Edéll-Gustafsson, U., Angelhoff, C., Johnsson, E., Karlsson, J. and Mörelius, E. (2015) Hindering and buffering factors for parental sleep in neonatal care. A phenomenographic study. *Journal of Clinical Nursing* 24: 717-727.
- IV. Angelhoff, C., Edéll-Gustafsson, U. and Mörelius, E. (2015) Sleep of Parents Living With a Child Receiving Hospital-Based Home Care: A Phenomenographical Study. *Nursing Research*, 64: 372-380.

ABBREVIATIONS

ACTH	Adrenocorticotrophic hormone
CAR	Cortisol awakening response
CRH	Corticotrophin-releasing hormone
EACH	European association for children in hospital
FCC	Family-centered care
HBHC	Hospital-based home care
HPA	Hypothalamic–pituitary–adrenal
HRQoL	Health-related quality of life
MACL	Mood adjective checklist
MBSR	Mindfulness-based stress reduction
NCU	Neonatal care unit
NICU	Neonatal intensive care unit
N-REM	Non-rapid eye movement
REM	Rapid eye movement
SE%	Sleep efficiency (percentage)
SF-36	Medical outcomes study short form health survey
SOC	Sense of coherence
SOC-13	Antonovsky’s 13-item Sense of coherence Scale
SSC	Skin to skin care
USI	Uppsala sleep inventory

PREFACE

People often ask me why my research is focused on the parents and not the children. The answer is rather simple: I am a pediatric nurse and that includes working with families. I have been working in the Pediatric and Adolescent Emergency Department at Linköping University Hospital as a registered nurse since 2008, and I became a specialist in pediatric nursing in 2010.

Most often, the children or adolescents are accompanied by their parents when they arrive at the emergency department. As a pediatric nurse, the child is my patient and my medical responsibility. However, the parents are an important source of knowledge about the child's health condition, normal behavior and development, and they are the ones providing the basic care for their child when the child's own capacity is lacking. Moreover, as a pediatric nurse I have the responsibility to inform, advise and educate the parents about their child's condition, examinations, treatment, self-care, and further planning.

I have noticed that some parents seem to never fall asleep during their hospital stay, while others seem to relax as soon as they enter the hospital. I have met parents with a lack of energy, who are passive, dejected and powerless, and even aggressive and threatening because of exhaustion, but also parents filled with gratitude for something as trivial as a cup of coffee or an extra blanket. This has led me to reflect on how parents are cared for by the pediatric nurses and what parents need for a satisfying stay in the pediatric ward.

When the opportunity appeared to become a PhD student in a research project focusing on parents' sleep and stress when having a child in need of healthcare services, I accepted almost immediately, as I wanted to gain new knowledge and find some answers.

You are now holding the results of my research education. The academic world was new and unfamiliar to me when I started this journey, but I found it exciting and stimulating. I have learned a lot, both in terms of scientific knowledge and as an individual. However, as much as I look forward to continue my profession as a researcher, I hope I will never lose my passion for working clinically with children, adolescents and their families.

It is my wish that the results of this thesis will provide nurses in pediatric care increased knowledge in and understanding of parents' sleep quality and mood when having a child in need of pediatric care, and that they

will find ways to help the parents manage their situation, in order to maintain health and well-being in both parents and child.

Charlotte Angelhoff
April 2017

INTRODUCTION

A child can never be treated as a single patient in health care, as the parents and family are central to the child's well-being (Shields, 2015). The United Nations Convention on the Rights of the Child, article 9.1 (1989), states that children should not be separated from their parents against their will. Regardless of age, children admitted to hospital have the right to have their parents with them 24 hours/day (European Association for Children in Hospital, 2001). Both parents and nurses have stated that family-centered care (FCC) is essential for the child's welfare as it reduces the stressful aspects of being admitted to hospital (Coyne et al., 2016, Shields et al., 2006, Shields et al., 2012, Feeg et al., 2016).

But what about the parents?

Parents have reported that they desire to take part in the hospitalized child's care, but nurses need to be prepared to support parents' participation at the level parents choose (Romaniuk et al., 2014). Over-reliance on parents may have a negative effect on parents and children's emotional welfare and in the long term have a detrimental effect on family functioning (Coyne, 2015).

Previous studies report that parents accommodated with their child in hospital have poor parental sleep quality and frequent nocturnal awakenings (McCann, 2008, Franck et al., 2014, Meltzer et al., 2012). Stress in parents of infants in neonatal intensive care is correlated with anxiety, fatigue, depression and sleep disruption (Busse et al., 2013), and they are at greater risk of postpartum depression and posttraumatic stress disorder compared to parents of healthy children (Vigod et al., 2010). Moreover, parents of chronically ill children suffer from frequent sleep disruption (Yuwen et al., 2016, Mörelius and Hemmingsson, 2014) and have high levels of anxiety and depression (van Oers et al., 2014).

Acute sleep loss may result in decreased cognitive performance, memory deficits, and depressive mood. Prolonged sleep deprivation (loss of deep sleep) and poor sleep quality increase the risk of several adverse health effects, e.g. depression, type II diabetes, obesity and cardiovascular diseases (Porkka-Heiskanen et al., 2013, Koren et al., 2016, Morin and Jarrin, 2013, Altman et al., 2012).

To be able to find evidence-based nursing interventions and self-care activities to improve parents' health and well-being when they care for a child in pediatric care, it is important to identify factors affecting sleep and

stress. Studies investigating sleep, mood, saliva cortisol response and SOC in parents of children in need of medical care are scarce. Therefore, this thesis focuses on both mothers and fathers of children of all ages, from pre-term infants to adolescents, with different severe illnesses, in different pediatric care settings, to get a holistic view of the subject.

BACKGROUND

Families in pediatric care

Parents with children in hospital

The most common reasons for children and adolescents, 0-18 years old, to visit the pediatric emergency department are injury and poisoning, followed by respiratory disorders, abdominal pain, infections, fever and vomiting (Socialstyrelsen, 2015a, Wier et al., 2013). The average age for children and adolescents visiting the pediatric emergency department in Region Östergötland, Sweden, during the year 2016, was eight years old. Most children are treated and released from the emergency department without being admitted for further care (Wier et al., 2013). However, sometimes the child needs to be admitted to hospital as the treatment and care cannot be given in the home or in primary care.

According to the European Association for Children in Hospital (EACH) (2001), parents with a child admitted to hospital should be offered accommodation and should be helped and encouraged to stay with the child without additional cost. In Sweden, there are generous terms for temporary parental benefit with economic compensation from the state. If a child <12 years old becomes ill, the parents are allowed to take temporary parental benefit to stay home from work and care for the child, and if the child becomes critically ill the parents are allowed to take temporary parental benefit until the child is 16 years old (Ministry of Health and Social Affairs, 2014). These terms make it easier for parents to be present when their child is admitted to hospital.

Parents staying overnight with their child in hospital have experienced that poor sleep quality leads to negative consequences for both child and parents, e.g. decreased ability to make decisions and to cope with the challenges of the child's illness (Stickland et al., 2016). Franck et al. (2014) report that parents experience more sleep disruption when they are accommodated at their child's bedside in hospital than when having a room at the hospital's onsite Ronald McDonald house. Stremler et al. (2014) found in an observational study that parents of children with critical conditions met the criteria for acute sleep deprivation for more than a quarter of nights in hospital, and that sleep was interrupted with frequent nocturnal awakenings during. Hospitals are environments that primarily focus on patient care and are not conducive to sleep due to excessive noise, bright lights,

and frequent interruptions and activity from hospital staff (Stremmer et al., 2015).

To become parent to a preterm infant

An estimated 15 million infants are born preterm (i.e. before 37 completed weeks of gestation) every year, and the preterm birth rates are increasing (WHO, 2016). In the year 2014, about 6500 infants (5.5%) were born preterm in Sweden (Socialstyrelsen, 2015b). Prematurity is the leading cause of death in children <5 years old. In low-income countries, 50% of the infants born <32 weeks die due to a lack of feasible, cost-effective care. In high-income countries, almost all of these infants survive (WHO, 2016). In Sweden, neonatal death (0-27 days) occurs in 1.5‰ of the infants born preterm (Socialstyrelsen, 2015b). Multiple pregnancies, infections, and chronic conditions e.g. diabetes and hypertension in the mother are risk factors for preterm birth (WHO, 2016).

Becoming a parent of a preterm infant is a stressful experience for the parents. The stress is due to the infant's condition, parental role alternation, and the unfamiliar environment in the neonatal intensive care unit (NICU) (Al Maghaireh et al., 2016, Baia et al., 2016). Separation of mothers and their preterm infants after birth, when the infant is admitted to a high-technology NICU, is a common and well-documented stressor for both mothers and infants (Flacking et al., 2012, Franck et al., 2005, Nyqvist et al., 2010).

Infants treated in neonatal care are exposed to several handling and invasive procedures around the clock. The NICU environment itself with equipment such as incubators and breathing support, creates a barrier to parenting (Aagaard and Hall, 2008), which may negatively influence parent-infant interaction and the infant's long-term developmental outcome.

Many West European countries encourage parents to participate in the care of their infant at the NICUs, meaning that they are expected to stay and care for their child around the clock. However, there are still many countries in Europe that have more restrictive policies (Pallas-Alonso et al., 2012). A lack of physical and emotional closeness can affect emotional and cognitive development, with long-term health consequences for the infant (Flacking et al., 2012) and feelings of a lack of control, uselessness, and negative mood in the parents (Feeley et al., 2016). Moreover, mothers of preterm infants who experience stress while the infant is hospitalized tend to be less responsive towards their infants (Habersaat et al., 2013).

Hospital-based home care for children

In Sweden, 9% of all the girls and 11% of all the boys, 0-15 years old, have chronic conditions that requires regular medication (allergic conditions are

not included) (Statistiska Centralbyrån, 2007). Chronic conditions in children are described as any health problem that lasts, or is expected to last, more than three months, and for which the level of functional impairment or the use of medical attention is greater than expected for a child of the same age (Perrin et al., 1993, Mokkink et al., 2008). Some of the most common chronic conditions in children are asthma, cystic fibrosis, diabetes type 1, cerebral palsy, consequences of premature birth including chronic lung disease and retinopathy of prematurity, and developmental disabilities including attention-deficit/hyperactivity disorder (ADHD) and autism spectrum disorders (Torpy et al., 2010).

A child with a chronic condition often requires significant caregiving from a parent, which impacts the parent's role and functioning (Meltzer and Booster, 2016). Some hospitals offer hospital-based home care for children (HBHC). The aim of HBHC is to increase quality of life for children with chronic conditions or long-term illness by avoiding hospital admission in the first place, shortening the time of hospitalization, reducing the number of emergency visits and increasing compliance (Hanberger, 2001).

With HBHC, children with chronic conditions and children who need frequent medical care can be treated by caregivers in their homes instead of being admitted to hospital. The HBHC-team consists of pediatric nurses and pediatricians who work in cooperation with social workers and physiotherapists, and who provide practical support for families with children suffering acute illness, children with chronic conditions with complications, children with complications from prematurity, and children in palliative care. HBHC can include children who need intravenous treatments, tube-feeding, oxygen treatment, or tracheostomy care. The nurses help the families in their home by providing advice and support, performing basic examinations, taking blood samples, educating the families regarding care and drug administration, and coordinating contact with pharmacies, physicians, social workers, dieticians, and social services (Hanberger, 2001).

Studies report that HBHC safely replaces hospital visits for children, for an equal or lower cost, and that it is greatly preferred by the parents (Tiberg et al., 2012, Hansson et al., 2013, Hansson et al., 2012). However, sleep deprivation and sleep disruption are common problems for parents caring for a child with a chronic condition (Matthews et al., 2014, Yuwen et al., 2016, Herbert et al., 2015, Bourke-Taylor et al., 2013, Mörelius and Hemmingsson, 2014), leading to poor physical and mental health (Bourke-Taylor et al., 2013, Mörelius and Hemmingsson, 2014, Gravdal Kvarme et al., 2016), and they have a negative impact on the parents' caregiving responsibilities (Meltzer and Booster, 2016).

Sleep

Wakefulness is a state in which the person is aware of and responds to sensory input from the environment. Sleep is a state characterized by immobility, typical sleeping posture, and elevated arousal threshold, leading to decreased ability to communicate with the surroundings (Lee-Chiong, 2008, Porkka-Heiskanen et al., 2013). Sleep is a basic need that is essential for health, and plays an essential role in our well-being and performance. Sleep is needed for regulation of somatic growth, neural growth and processing, memory consolidation, thermoregulation, and energy conservation (Lee-Chiong, 2008).

Sleep physiology

Human existence could be described as having three distinct states, based on behavioral and physiological criteria; wakefulness, non-rapid eye movement (N-REM) sleep and rapid eye movement (REM) sleep.

N-REM sleep is subdivided into three stages. Sleep starts with the first stage of N-REM sleep, where the individual is in transition from wakefulness to sleep. The onset of light sleep occurs during stage 2, and sleep deepens through stage 3 with an increase of low-frequency, high amplitude waves in the brain, called slow-wave activity, before it proceeds to REM sleep (Lee-Chiong, 2008, Porkka-Heiskanen et al., 2013). Formerly, stage 3 was divided into two stages, stage 3 and stage 4, depending on the frequency of delta waves. Following the guidelines of the American Academy of Sleep Medicine (Silber et al., 2007), this is now described as stage 3.

REM sleep is characterized by activity in the autonomous nervous system, a high arousal threshold, loss of muscle tone, and more frequent and complex dreaming than in N-REM sleep.

The duration of a sleep cycle is about 90 minutes, and after the REM sleep, the sleep cycle starts over from the beginning. Commonly, there are three to five sleep cycles during the night, where N-REM predominates during the first part of the night and REM sleep predominates during the last part of the night (Figure 1).

It is easiest to wake up during N-REM stage 1 when the arousal threshold is lowest, whereas it is most difficult to wake up during N-REM stage 3 sleep when the arousal threshold is highest (Lee-Chiong, 2008, Porkka-Heiskanen et al., 2013). However, the responsiveness to stimuli is

Figure 1. Hypnogram showing the sleep stages and the sleep cycles in adult normal sleep. Image from www.howsleepworks.com, with kind permission from Luke Mastin, 2017.

not completely absent. Some sensory information continues to be processed during sleep, and meaningful stimuli may produce arousals. The sound of one's own name or the cry of one's infant is more likely to arouse a sleeper than some other sound (Markov and Goldman, 2006).

Sleep quality

Sleep quality is subjective and is described as duration of sleep followed by a spontaneous awakening, which leaves one feeling refreshed and alert throughout the day (Porkka-Heiskanen et al., 2013, Harvey et al., 2008). According to Borbely's Two-process model of sleep regulation (2016), sleep quality is determined by the combination of sleep depth and sleep duration.

Sleep depth is regulated by the homeostatic sleep drive, which is related to the duration of prior wakefulness e.g. the previous night's sleep depth, nocturnal awakenings, and activity. Sleep duration is regulated by the circadian drive for arousal, i.e. the biological clock. These two separate biological processes interact and balance each other to regulate the sleep-wake cycle. Sleep homeostasis is characterized by an increase in sleep pressure following sleep deprivation wakefulness (i.e. one is sleepier the longer one is awake). When the homeostatic sleep drive is at its greatest distance from the circadian drive for arousal the "sleep-gate" opens (Figure 2). The need for sleep decreases as sleep accumulates. Moreover, external factors e.g. stress, exercise, daily schedules, previous wakefulness, health status, alarm clocks etc., can have a direct or indirect effect on an individual's sleep-wake cycle (Borbely et al., 2016, Lee-Chiong, 2008).

The homeostatic regulation of sleep compensates for a previous sleep loss and adjusts the sleep duration and sleep depth to match the physiological need for sleep in healthy individuals. A prolonged waking period will be followed by a prolonged period of sleep, called recovery sleep. This

Figure 2. Sleep-wake regulation: interaction between the homeostatic sleep drive and the circadian drive for arousal. Modified image inspired by Borbely's Two-process model of sleep regulation, 2016.

provides a possibility to stay awake during certain periods when necessary and then regain the sleep loss when possible (Porkka-Heiskanen et al., 2013). Two days of extended recovery sleep in healthy adults reverses the impact of one week of sleep loss on daytime sleepiness and fatigue, but is not sufficient to improve performance ability (Pejovic et al., 2013).

Sleep efficiency (SE%) is a common parameter used to get an overall sense of sleep quality. SE% refers to the total time in bed spent asleep, and is calculated as the ratio of reported nocturnal sleep duration and time in bed times 100 to yield a percentage. SE% should be kept steady between 85% and 90% (Reed and Sacco, 2015, Shrivastava et al., 2014).

Mood

Mood is a subjective description of a person's emotional state and emotional expression at a given time, determined by disposition and circumstances. Mood affects self-satisfaction, perception of the world, and behavior, and is the main feature in the diagnosis of depression. Usually, one has an awareness of one's mood, especially when asked about it, and the characterizing of mood is based on the individual's own description (Trzepacz and Baker, 1993).

Positive mood has been described in terms of enthusiasm, energy level, mental alertness, interest, joy, and determination, whereas negative mood includes fear, anger, guilt, sadness, scorn and disgust (Clark et al., 1989). Disturbances of mood may be present in stress reactions in previously healthy individuals. In literature and in clinical work, there are several de-

scriptions of different negative mood states; anxious mood, i.e. an uncomfortable, tense, apprehensive, and vigilant emotional state that generally occurs in response to psychologically perceived threats or danger, and depressive mood, i.e. an emotional state consistent with sadness and dysphoria. A depressive mood may also be described as sad, low, blue, down or dysphoric (Trzepacz and Baker, 1993).

A positive mood may influence sleep by modifying the effects of stress (Ong et al., 2016) and increasing activity in neural regions in the brain that assign meaning and value, motivation, and attention (Young and Nusslock, 2016). In parents, positive mood is strongly related to supportive parenting whereas negative mood is related to negative parental behavior (Rueger et al., 2011).

Stress

Stress describes experiences that are emotionally and physiologically challenging. Experiences that are of limited duration and that can be mastered, leaving a sense of exhilaration and accomplishment are often referred to as “good stress”, whereas experiences where the sense of control and mastery is lacking, prolonged, irritating, emotionally draining, and physically exhausting or dangerous are referred to as “bad stress” (McEwen, 2007).

Stressors

Various stressors are associated with actual and potential threats that induce stress in various situations. A stressor is indicated by an unpleasant sensory, emotional and subjective experience, associated with potential body damage, or by situations of social threat, e.g. social evaluation, social exclusion and situations requiring goal-directed performance.

Physiological and psychosocial stressors activate as well as deactivate distinct neural regions (Kogler et al., 2015). Physiological stressors activate a motoric fight-or-flight reaction; the heart rate and blood pressure increase to help the person handle the stressful situation and are a necessary physiological response for survival (McEwen, 2008, McEwen, 2007, Kogler et al., 2015). Psychosocial stressors are directed towards emotion regulation and cognitive functions (Lupien et al., 2009, Gotlib and Joormann, 2010, Verweij et al., 2014, Kogler et al., 2015), and thus affect the parents’ ability to comprehend information and make decisions.

Stress physiology

Stress begins in the brain with activation of the autonomic nervous system and hypothalamic–pituitary–adrenal (HPA) axis. The HPA axis increases

the secretion of the corticotrophin-releasing hormone (CRH) from parvocellular neurons of the paraventricular nucleus of the hypothalamus. This leads to the secretion of adrenocorticotrophic hormone (ACTH) from the anterior pituitary. ACTH travels through the circulatory system to the adrenal cortex, where glucocorticoid hormones, mainly cortisol, are released into the blood stream (Figure 3). After cortisol is released, about 90% binds to corticosteroid-binding globulin, albumin, and erythrocytes. Between 5% and 10% of the released cortisol circulates as unbound cortisol (Herman et al., 2016, Kudielka et al., 2012).

Cortisol regulates its own release via the negative feedback loop. Glucocorticoids bind to specific receptors throughout the limbic system, including the hippocampus, the amygdala, and the prefrontal cortex, to the hypothalamus and the pituitary gland. The negative feedback loop is a way of regulating the secretion to keep hormone levels within an appropriate physiological range. When a desired level of glucocorticoids has reached the brain, the release of CRH and ACTH stops and the system returns to its normal state (Herman et al., 2016, Kudielka et al., 2012, Dedovic et al., 2009).

The HPA axis stress response is designed to help the individual to cope with stressors (Herman et al., 2016). Acute stress, i.e. a recent, passing occurrence of a single stressor, leads to a subsequent release of cortisol to provide energy for dealing with the current stressor (Shonkoff et al., 2009, McEwen et al., 2015). Stress becomes chronic when stressors remain in the environment for an extended period of time (Miller et al., 2007), e.g. parents taking care of an ill child for a longer time. A chronic activation of the HPA axis damages the cardiovascular system and can over time result in disorders such as stroke and heart attack, and reduce the capability of handling stress-related demands (Lupien et al., 2009, McEwen, 2008, Slavich, 2016).

Figure 3. A simplified illustration of the activation of the HPA axis with the negative feedback loop.

The HPA reactivity is also associated with the limbic system, including the medial prefrontal cortex, amygdala, and hippocampus, which is central for mood and stress regulation (Dedovic et al., 2009, Madsen et al., 2012, McEwen et al., 2012, Elder et al., 2014). An increase in the cortisol levels has a damaging effect on the hippocampus (Elder et al., 2014), which affects memory and cognitive function, such as new learning, attention and executive functions (Bremner, 1999, Lupien et al., 2009, Gotlib and Joormann, 2010, Oken et al., 2015), and on the medial prefrontal cortex, leading to a delay of the shut-off in the HPA axis responses to stress (Herman et al., 2012).

Saliva cortisol

Salivary cortisol is the primary biomarker of stress and well-studied in different contexts to evaluate HPA axis activity. Salivary cortisol reflects the biologically active fraction of cortisol because only unbound cortisol can enter saliva. Cortisol is a lipid-soluble steroid hormone, and unbound cortisol enters saliva by passive diffusion through the cells of the salivary glands (Kudielka et al., 2012).

There is a distinct diurnal variation in cortisol with high levels in the morning and low levels in the evening. The transition from sleep to wake in the morning causes a phasic activation of the HPA axis with an increase in cortisol levels of 38-75%, i.e. the cortisol awakening response (CAR) (Figure 4) (Wust et al., 2000, Kudielka et al., 2012).

Figure 4. The cortisol awakening response (CAR) based on data from Wust et al., 2000.

The cortisol response is influenced by several factors, e.g. sleep-related factors and environmental changes (Elder et al., 2014, Herman et al., 2016) and behavioral factors e.g. nicotine use (Koopmann et al., 2016, Tweed et al., 2012, Kudielka et al., 2009).

Saliva cortisol is suitable to use for assessment of cortisol regulation as the sampling of saliva cortisol is non-invasive. The handling of the collected saliva samples is easy to perform and can be conducted within short intervals.

Sleep, mood and stress in parents of children in need of medical care

Young and middle-aged adults usually have one long sleep period during the night, and little or no daytime napping. Bedtime and awakening time are often delayed during nonworking days compared to work days. The amount of sleep varies and is influenced by factors such as genetics, preferences, lifestyle, and environment (Redeker, 2011). Previous studies have found that women report more sleep problems, even though they objectively have better sleep quality than men (Mong and Cusmano, 2016, Mallampalli and Carter, 2014).

Becoming a parent is associated with sleep disturbances (Hagen et al., 2013). In general, the postpartum period is a time of reduced stress responsivity and increased calmness. However, mood disorders, e.g. depression, are common medical complications for mothers (Hillerer et al., 2012, Becker et al., 2016, Practice, 2015). Parents of young children sleep less than adults without children, but as the children become older parents obtain more sleep, and parents of grown up children do not have different sleep times than childless adults (Hagen et al., 2013). Subjective reports of poor sleep quality are strongly associated to negative mood and postpartum depression in new mothers (Park et al., 2013, Coo et al., 2014).

Sleep loss in parents is associated with frustration, impatience and irritability towards the child, and frequent irritable actions towards their child affect the parents' sense of confidence, competence and self-esteem (Cooklin et al., 2012). Poor sleep quality may result in sleep-related daytime dysfunctions such as maintaining enthusiasm to complete daily tasks, and the parents' ability as well as motivation to perform care for their child (Herbert et al., 2015).

Parents to children with chronic conditions have reported poorer sleep quality and greater sleepiness than parents to healthy children (Park et al., 2013, Coo et al., 2014), and mothers of children with physical disabilities report more headache, psychological exhaustion and pain due to heavy lifting than fathers (Mörelus and Hemmingsson, 2014).

Up to one quarter to one third of parents of children with serious childhood illnesses or injuries experience traumatic stress symptoms at a clinically significant level (Woolf et al., 2016). Parents of infants born preterm or with a very low birth weight report higher levels of mental health problems, higher levels of stress associated with being a parent, and an increased negative impact on family systems in the early years, compared with parents of infants born full-term (Treyvaud, 2014). Fathers of infants in the NICU have described an emotional roller coaster, feeling unprepared for their infants' birth, and how they need to be reassured of about their partner's well-being before they start to worry about their infant's health status (Provenzi and Santoro, 2015). Parents of children undergoing heart surgery have described how they shift between feelings of sadness and despair and being happy and hopeful, depending on the child's changing condition and the uncertainty levels in a specific situation (Wei et al., 2016). Similar findings are reported in parents of children diagnosed with juvenile idiopathic arthritis (Gomez-Ramirez et al., 2016).

Stress impacts the parents' ability to manage to perform care for their child, e.g. diabetes management (Whittemore et al., 2012). Moreover, stress in parents of children with chronic illness is associated with anxiety and depression, especially among mothers (van Oers et al., 2014). However, stress does not only impact the parents' own health and their ability to perform care for their child, but can ultimately affect their child's health. Previous studies have reported how parents' stress and behavior influence the pain experience and functioning in children with chronic pain (Chow et al., 2016) and contribute to elevated depressive symptoms in adolescents with inflammatory bowel disease (Guilfoyle et al., 2014).

If sleep deprivation and stress become a chronic condition, cortisol secretion increases and multiple signaling pathways in the hippocampus are disrupted, which causes a reduction in hippocampal volume leading to plasticity and memory impairments that contribute to cognitive disorders and psychiatric diseases (Kreutzmann et al., 2015, Minkel et al., 2014, Prince and Abel, 2013, Kim et al., 2015).

Coping and sense of coherence

Parents of children with serious illness often find ways to endure the situation and even learn to benefit from the experience, for example through greater appreciation of life, greater personal strength, and recognition of new possibilities (Picoraro et al., 2014). Morin et al. (2003) state that it is the way a person cope with the stressful situation, not the actual stress itself, that causes sleep deprivation. Lazarus and Folkman (1984) describe coping as cognitive and emotional efforts that are used to manage the demands and feelings that are generated in stressful situations.

The medical sociologist Aaron Antonovsky introduced the salutogenesis theory in the late 1970's, focusing on what generates and maintains a healthy outcome even for people who are exposed to illness or disability (Antonovsky, 1979). He termed the capacity to use internal and external resources to maintain and improve health in stressful situations "sense of coherence" (SOC).

SOC includes three main components; comprehensibility, manageability, and meaningfulness. Confronted with a stressor, a person with a strong SOC will believe that the challenge is understood, and that they have the capacity to meet the world, i.e. comprehensibility. Moreover the person will believe that resources to cope are available, and that they have the capacity to manage environmental challenges by using their own resources or with help from their network, i.e. manageability. Ultimately, the person wishes to and is motivated to cope, and has the capacity to find meaning in life i.e. meaningfulness. These three components are close to concepts used in literature about coping, e.g. optimism, will to live, and self-efficacy. However, SOC does not refer to a specific coping strategy, but to factors that are the basis for successful coping with stressors, regardless of gender, social-economic status or culture (Antonovsky, 1996, Antonovsky, 1979, Antonovsky, 1993). Moreover, SOC focus on the combination of the cognitive, behavioral and motivational resources. What matters is that the person has had the life experiences which lead to a strong SOC that allows him or her to use and apply the resources appropriate to the stressor in any given situation (Antonovsky, 1996, Antonovsky, 1993).

In parents in early parenthood, poor SOC is related to high parental stress, described as an adverse psychological reaction to the demands of being a parent (Widarsson et al., 2014), and to depressive symptoms (Kerstis et al., 2013). Ahlborg et al. (2013) report that SOC is higher in fathers than in mothers among first-time parents during the child's first years.

Poor SOC may decrease the parents' management of the hospital accommodation and the ill child's care. If individuals have a strong SOC, this improves the likelihood of a positive outcome to the situation, and reduces the risk of adverse effects on health and well-being (Pallant and Lae, 2002). Moreover, the parents' SOC may also affect the child's health and development; Goldberg and Wiseman (2014) found that strong SOC in the parents positively correlated to physical health in adolescents with diabetes type 1. Huhtala et al. (2014) suggest that mothers of preschool aged children born preterm may be better able to support their child in their developmental challenges, when they have a strong SOC.

Health-related quality of life

The parents' sleep and stress may be associated with their health-related quality of life (HRQoL). Therefore, HRQoL was considered as an important background variable in this thesis. HRQoL covers the full range of health states, including levels of well-being and personal evaluations of health (Sullivan et al., 1995). Associations have been found between sleep quality and HRQoL in parents of children with cancer (Klassen et al., 2012) and in mothers with a low birth weight infant (Lee and Hsu, 2012), and between mood and HRQoL in parents of children with epilepsy (Reilly et al., 2015, Jones and Reilly, 2016). Moreover, a strong SOC correlates with a better HRQoL (Eriksson and Lindström, 2007, Nilsson and Kristenson, 2010).

Previous studies report a diminished HRQoL in parents of children 0-18 years old, with different chronic conditions, compared to parents of healthy children (Aras et al., 2014, Bella et al., 2011, Reilly et al., 2015, Meltzer et al., 2015). Furthermore, mothers caring for children with cerebral palsy have reported low HRQoL, especially in the domain of vitality, along with low CAR (Bella et al., 2011). The dimension of vitality is based on four questions asking for subjective well-being ratings in terms of energy and fatigue (Sullivan et al., 2002).

Moreover, mothers report lower HRQoL than fathers (Aras et al., 2014, Reilly et al., 2015), which is consistent with the Swedish reference population, where women report lower HRQoL than men (Sullivan et al., 2002).

Theoretical framework

Parents' dual roles when they care for a child

The self-care deficit nursing theory was developed by Dorothea Orem between the years 1959 and 2001 (2001). She viewed the "self" as the totality of an individual, including physical, psychological and spiritual needs, and "care" as the activities that an individual performs to maintain life and develop in a way that is normal for that individual (Cavanagh, 1991). According to Orem, all individuals have the responsibility to perform activities to maintain life, health and well-being, i.e. self-care demands. The universal self-care demands are; the maintenance of a sufficient intake of air, water, and food; the provision of care associated with elimination; the balance between activity and rest, and between solitude and social integration; the prevention of human functioning and human well-being; promotion of human functioning and development within social groups i.e. normalcy.

Figure 5. Parents' dual roles when they care for a child. Modified figure inspired by Dorothea Orem, 2001.

The ability to meet the self-care demands depends on the individual's self-care requisites. A loss of self-care requisites is described as a self-care deficit (Orem, 2001).

Infants and children require care of others to meet the self-care demands for a healthy life and normal development, i.e. dependent care, particularly when they are ill. It is primarily the parents that knows and meet the child's self-care demands and are the child's dependent care agent. This gives parents dual roles; as the self-care agent and the dependent care agent. Not only should parents meet their own self-care demands, but also their child's. This leads to continuing self-care and dependent care systems, each of which have a conditioning effect on the other. If the parents know and meet their own self-care demands it will be easier for them to meet the child's self-care demands and vice versa (Figure 5). For the pediatric nurse the situation is complex as both the child's needs and the needs of the parents, who may be adolescents or adults, must be met (Orem, 2001).

Family-centered care and child-centered care

Family-centered care (FCC) is described as a way of caring for children and their families within health services, ensuring that the care is planned around the whole family, and that all family members are recognized as

care recipients (Shields et al., 2006). The concept of FCC includes accommodation for parents, bathrooms, laundries, places to keep their belongings, places to eat, and free parking. Moreover, school and play facilities, television and computer games (for both child and parent) are needed (Shields, 2015). Both parents and nurses have expressed the view that FCC is essential for the child's welfare as it reduces the stressful aspects of being admitted to hospital (Coyne et al., 2016, Shields et al., 2006, Shields et al., 2012, Feeg et al., 2016).

FCC was established back in 1958 by Sir H. Platt (Platt, 1961). The seminal Platt report highlighted the importance of making accommodation available for mothers, preferably with the mother sleeping in the same room as the child, as the separation from home might be more distressing than the illness itself. He also encouraged parents to visit children of all ages as much as possible and claimed that there should be no limit to the length of visit. Today, FCC appears as a natural way of caring in pediatrics in both developed and developing countries. However, it is important to see FCC as a way of delivering care to children and their families, and not as a way of using the parents as caregivers because of poorly resourced and staffed health services (Jolley and Shields, 2009).

A range of benefits from FCC have been reported in the literature, such as improved child and family outcomes, and increased satisfaction among child, family and health care professionals (Shields, 2015, Coyne et al., 2016). However, some recent studies have expressed criticism of FCC, as it does not always provide care from the child's perspective (Shields, 2015, Coyne et al., 2016). Coyne et al. (2016) suggest that FCC should be provided with a child-centered care approach, where the care is planned around the child's perspective and preferences, and does not set the parents in the center.

Bronfenbrenner's Ecological systems theory (1977) may be used as the basis for FCC with a child-centered approach as it describes the relations and the interaction between children, parents and the health care system (Figure 6). Ecological systems have been described as the dynamic interactions and interrelationships of humans and the healthcare system characterized by actions, reactions, and coactions between the health-care providers, the child, the child's family, and the healthcare environment (Laustsen, 2006). The Ecological systems theory includes four environmental systems that influence our development and behavior; The child is in the center with the parents; the microsystem includes family, friends, teachers and nurses; the exosystem includes the local community e.g. the health care system and the school system, while the macrosystem includes laws, policies and social and cultural values of the wider society (Bronfenbrenner, 1977).

Figure 6. Family-centered care as an ecological system: Children, adolescents and parents are treated as partners in care. The services around the child's and the family's needs are coordinated by the nurses who are affected by the health care systems and the laws and policies they are obliged to follow.

The systems in the Ecological systems theory are interdependent of each other. By changing routines or conducting an intervention in one system, several systems can be affected (Bronfenbrenner, 1977). Laws and policies affect the health care system and thus the nurses' ability to provide care, which in turn affect the parents and the child (Bronfenbrenner and Morris, 2007). Moreover, nursing actions that improve parents' self-care and dependent care capacity may not only affect the child, but the nurses, family and friends as well.

Rationale for this thesis

Being accommodated at a child's bedside in hospital might be stressful and demanding for the parents, as they are expected to stay in an unfamiliar environment and care for their child around the clock. Sleep plays an important role in the health and well-being of ill children and their parents. For the children, good sleep quality contributes to healing, the immune process, and the growth. For parents, good sleep quality, positive mood, low stress and a high sense of coherence might contribute to their ability to make important medical decisions and provide emotional support for their child.

In the year 2008, an Australian study was published reporting that parents staying overnight in the pediatric clinic experienced sleep deprivation and poor sleep quality. The parents' sleep was reported at an average of 4 hours and 36 minutes (sd 2h 6 min.) per night, which led to agitation and aggression against the staff. The conclusion in that study was that parental sleep deprivation needs to be acknowledged in pediatric clinics (McCann, 2008). However, studies focusing on sleep in parents accommodated with children in a non-intensive pediatric care setting are scarce, and no previous study has been found exploring and describing parents' sleep, mood, cortisol response and sense of coherence in parents with a child in family-centered pediatric care, irrespective of the child's age, diagnosis or severity of illness.

This thesis intends to give a first overview of the subject and a foundation for future research, which is important for the development of evidence-based nursing interventions aiming to maintain the health and well-being of the whole family when a child needs medical care.

AIMS

The overall aim of this thesis was to evaluate sleep, mood, cortisol response and sense of coherence in parents caring for children in need of medical care, and to identify factors that may influence parents' sleep.

Specific aims were:

- to describe sleep quality, mood, cortisol response and sense of coherence in parents accommodated with their sick child in a family-centered pediatric ward (Study I and II).
- to compare sleep quality, mood, cortisol response and sense of coherence between mothers and fathers in the pediatric ward (Study I and II).
- to compare the parents' sleep quality, mood, cortisol response and sense of coherence between the pediatric ward and in a daily life home setting after discharge (Study I and II).
- to explore and describe how parents of preterm and/or sick infants in neonatal care perceive their sleep (Study III).
- to explore and describe parents' perceptions of circumstances influencing their own sleep when living with a child enrolled in hospital-based home care (HBHC) (Study IV).

METHODS

Design

This thesis includes two quantitative and two qualitative studies. An overview of the design, participants, data collection, and data analysis are presented in Table 1, and are further described below.

Quantitative studies (I-II)

Studies I and II were prospective studies with a descriptive and comparative design. Study I and II include the same sample but are presented separately in order to highlight sleep (sleep quality and mood) and stress (saliva cortisol response and SOC) respectively. The studies also included background data of habitual sleep (I) and HRQoL (II). Analyses to find possible correlations between sleep quality and saliva cortisol response were made before the studies were separated. Additional comparisons between background data and the reference population, that was out of the scope in the studies, were performed for the frame of this thesis.

Qualitative studies (III-IV)

Studies III and IV were phenomenographic studies with an inductive and exploratory design. Phenomenography is the empirical study of the qualitatively different ways various phenomena and aspects of the surrounding world are experienced, conceptualized, understood, perceived, and apprehended (Marton, 1981). The distinction between first- and second-order perspectives deals with the difference between being and considering a statement about the world or a situation. The first-order perspective refers to statements about the world, the phenomena, and specific situations as experienced by people. The second-order perspective refers to the ways of experiencing the world, the phenomena, and/or the situation, in a 'what' and 'how' aspect (Marton and Booth, 1997). We focused on the second-order perspective and aimed to describe the parents' different experiences and perceptions of sleep and the variations between them. The different ways the parents experienced the phenomena was interpreted in terms of distinctly different descriptive categories to capture the essence of variation in an outcome space, which is the result of a phenomenographic study (Marton and Booth, 1997).

Table 1. Overview of designs and methods in the thesis

	Study I	Study II	Study III	Study IV
Design	Quantitative, prospective, descriptive and comparative study		Qualitative, inductive and explorative interview study	
Participants	82 parents accommodated with their child in hospital (descriptive) 36 parents accommodated with their child in hospital and four weeks after discharge (pairwise comparisons)		12 parents accommodated with their preterm and/or ill infant in hospital	15 parents with a child receiving hospital-based home care
Setting	Six pediatric wards Follow up in the parents' home		Three neonatal intensive care units	In the parents' home
Data collection period	September 2013 - October 2015		January 2012 - March 2012	March 2011 – October 2011, April 2013 – May 2013
Data collection methods	Sleep log, questionnaires	Saliva cortisol, questionnaires	Semi-structured interviews	
Data analysis	Descriptive statistics, Kolmogorov-Smirnov test, Spearman's correlation coefficient, Mann Whitney U-test, Wilcoxon signed-rank test, Univariate ANOVA, Quantitative content analysis		Phenomenography	

Participants and procedures

Participants

Participants included in the thesis were Swedish-speaking parents of children in need of medical care. In studies I and II data were collected from the same population. Parents accommodated with their child in a pediatric ward irrespective of the child's age, diagnosis or severity of illness, were included. Study III included parents of preterm and/or sick infants, who had stayed >24 hours in the NICU with their infant. Exclusion criteria were parents of infants with major congenital malformations, regular use of medication interfering with sleep, and parents participating in any other ongoing study. Study IV included parents of children with various diagnoses and conditions enrolled in the HBHC. Exclusion criteria were parents of children in palliative care and parents participating in any other ongoing study.

Sample size

A convenience sample was chosen for studies I and II, as it was desirable to include as many parents as possible for the description of sleep quality and saliva cortisol response in the parents. To get a statistical power of 80% ($p < 0.05$), effect size Cohen's d 0.25 (Cohen, 1992), power calculations were performed using G*power 3.1 (Faul et al., 2007) to determine the sample size for the pairwise comparisons. Thirty-five parents were calculated to be an adequate sample for the variable sleep quality (I), and 31 parents for the morning awakening cortisol (II). As parents withdrew from the study before the follow up, the sampling was ongoing until the required number of participants from the follow up was achieved to make the pairwise comparisons.

In studies III and IV a purposeful sampling was used, based upon the parents' appropriateness to the purpose of the research study, i.e. they had experience of the phenomenon being explored. The sample size for a phenomenographic study is influenced by two factors; first, the number of conducted interviews needs to be sufficient to allow variation in the conceptions to be found. Secondly, the sample size must ensure that the amount of resulting data remains manageable (Yates, 2012). The sample size was discussed in the research group and considered to cover the different ways of understanding the phenomenon.

Setting and procedures

The studies in this thesis were performed in one university hospital and four general hospitals in south-eastern Sweden. In line with the structural aspects given by Shields (2015), the concept of FCC in the participant hospitals included free accommodation for parents in single rooms at the child's bedside (I-III) or in a parent room close to the ward (III), access to a shared or private bathroom (I-III), and access to laundry facilities (III). The pediatric wards provided play facilities, school, television in the room, free Wi-Fi, and free parking, and the children were provided with food for free (I-II). The parents had access to a kitchen 24 hours/day where they could cook and store food, and which was fully equipped with a stove, microwave oven, refrigerator and freezer (I-III).

Six pediatric wards for children 0-18 years in one university hospital and three general hospitals were included in studies I and II. One pediatric ward specialized in oncology, diabetes and neurology, one in acute and elective surgery, one in acute medicine and infections, and three wards were general pediatric wards. All pediatric wards provided FCC and offered accommodation possibilities for the parents at the child's bedside. The parents were recruited by the nurses and nurse assistants at the pediatric wards on Tuesday evenings. After informed consent, the parents received

an envelope with instructions for the study, questionnaires, a sleep log for seven consecutive days, and saliva sample tubes.

The parents filled out questionnaires at the pediatric ward on Tuesday evening and Wednesday morning. A saliva sample was collected by the parents directly on awakening on Wednesday morning and 25 minutes later. The parents also started to fill out the sleep log at Wednesday morning. Saliva samples and questionnaires were collected and returned by the nurses at the wards. The parents returned the sleep log in a pre-paid envelope after completion.

Four weeks later, the parents received material for a follow up. They started to fill out a new sleep log. After one week, saliva samples were collected by the parents directly on awakening on Wednesday morning and 25 minutes later, and questionnaires were filled out to capture potential variations in the outcome between the hospital and at home. All data was returned by the parents in a pre-paid envelope. Reminders were sent by e-mail to non-responders once, 1-2 weeks after expected response. Detailed descriptions of the data collection for studies I and II, and number of responses are presented in Table 2.

Study III was performed in three NICUs at one university hospital and two general hospitals in south-eastern Sweden. The smallest, sickest and most fragile infants, who needed ventilation support and constant monitoring, were cared for in intensive care rooms in the NICU. Those parents slept in a parent room close to the ward. They had free access to the NICU and could take part in the infants' care 24 hours a day. Infants not in need of ventilation support or constant monitoring were cared for by the parents, with support from the staff, in single family rooms where the parents slept in the same room as the infant(s). The parents were asked to participate in the study during their NICU stay by two nurses at the ward. After receiving oral and written information about the study, the time and setting for the interview were arranged.

In study IV, parents of children enrolled in HBHC in pediatric outpatient clinics at one university hospital and one general hospital were included. Contact with the parents was established by the HBHC nurses. After a phone call, during which the parents received more information about the study, the date, time and setting for the interview were arranged.

Table 2. Description of the data collection, studies I and II

In the pediatric ward		At home
Tuesday evening	Wednesday morning	Wednesday morning
Uppsala Sleep Inventory (<i>n</i> =82)	Sleep log 1 (<i>n</i> =55)	Sleep log 2 (<i>n</i> =36)
SF36 (<i>n</i> =82)	Morning awakening cortisol (<i>n</i> =72 ^a)	Morning awakening cortisol (<i>n</i> =36)
	Post-awakening cortisol (<i>n</i> =69 ^a)	Post-awakening cortisol (<i>n</i> =36)
	Study specific questionnaire 1 (<i>n</i> =79)	Study specific questionnaire 2 (<i>n</i> =36)
	The mood adjective checklist (<i>n</i> =76)	The mood adjective checklist (<i>n</i> =36)
	Sense of coherence (<i>n</i> =78)	Sense of coherence (<i>n</i> =36)

a) missing samples were excluded due to an insufficient amount of saliva

Data collection

Demographics

For studies I and II the parents filled out a study-specific questionnaire to provide basic demographic data such as gender, age, marital status, level of education, nicotine use, the child's age, diagnosis and previous health status, and whether they had previous experience of having their child admitted overnight. Demographic data for the parents in studies III and IV were obtained during the interviews (Table 3).

Questionnaires

Habitual sleep (I)

For habitual sleep patterns, used as background data, the parents filled out 40 items from the self-reported questionnaire Uppsala Sleep Inventory (USI). USI evaluates perceived sleep during the past four weeks, data on sleep quality (five-point scale; 1 = bad, 5 = good), time of going to bed, sleep onset latency (time from light off to falling asleep in minutes), morning awakening time, and sleep duration. The USI has shown good validity and reliability compared to polysomnography and actigraphy (Hetta et al., 1998, Edell-Gustafson, 2002). Cronbach's alpha (α) was calculated on 27 items from the USI in this sample. Items measuring time and frequencies

were excluded. The internal consistency indicated good reliability ($\alpha=0.89$).

Health-related quality of life (II)

The parents filled out the Medical Outcomes Study Short Form Health Survey (SF-36), used as background data, on Tuesday evening at the pediatric ward. SF-36 measures health-related quality of life (HRQoL) for the past four weeks in two overall dimensions; a physical component summary and a mental component summary. These dimensions consist of eight health domains: physical functioning, role limitations due to physical health problems, bodily pain, and general health, which measure primarily physical aspects of health. The dimensions also include vitality, social functioning, role limitations due to emotional problems, and mental health, measuring mainly mental aspects. The health domain scales range from 0-100, where high scores indicate better health. SF-36 is a validated and reliable questionnaire (Sullivan et al., 1995). The internal consistency in this sample was $\alpha=0.86$, which indicates good reliability. The SF-36 was primarily used to gain background information about the parents.

Sleep variables in the pediatric ward and at home (I)

A sleep log was used in the morning to measure sleep-quality after the parents had slept at the pediatric ward, and at home after discharge. The sleep log provided data on sleep quality (five-point scale; 1 = bad, 5 = good), time of going to bed, sleep onset latency, morning awakening time, nocturnal awakenings (minutes), and daytime napping (minutes). The sleep log also consisted of one repeated, open-ended question about what the parents perceived had influenced their sleep during the previous night. Several reasons could be stated in the response. The sleep log has been validated against polysomnography (Edéll-Gustafsson, 1999) and has been used previously to measure sleep over time (Johansson et al., 2013).

The study-specific questionnaires had one open-ended question about how the parents had perceived their sleep and stay in the pediatric ward and at home after discharge.

Mood (I)

The Mood Adjective Checklist (MACL) is a self-administered instrument measuring six dimensions of mood (Figure 7). The instrument consists of 71 items in the form of single adjectives (36 negative and 35 positive), measured on a four-point scale; 1 = that definitely disagrees with what I feel right now, 4 = that definitely agrees with what I feel right now. The MACL is divided into six dimensions; control (11 items; six negative, five positive),

calmness (10 items; six negative, four positive), social orientation (11 items; five negative, six positive), pleasantness (12 items; six negative, six positive), activation (16 items; eight negative, eight positive), and extraversion (11 items; five negative, six positive) (Sjöberg et al., 1979). The dimensions of mood are analyzed separately (min/max; control 11/44, calmness 10/40, social orientation 11/44, pleasantness 12/48, activation 16/64, extraversion 11/44) as well as total sum mean score (min/max; 12/47). Higher values indicate better mood (Sjöberg et al., 1979). The MACL has shown good validity and reliability in previous studies (Persson et al., 1980, Sjöberg et al., 1979, Persson and Sjöberg, 1987), and there was a good internal consistency of the different dimensions of mood in the sample of this thesis (Cronbach's α ; control 0.83, calmness 0.87, social orientation 0.84, pleasantness 0.90, activation 0.86, extraversion 0.73).

Figure 7. The Mood Adjective Checklist (MACL) consists of 71 negative and positive adjectives, divided into six bipolar dimensions, inspired by Sjöberg et al., 1979.

Sense of coherence (II)

To measure sense of coherence (SOC), the parents filled out Antonovsky's 13-item Sense of coherence Scale (SOC-13) on Wednesday morning in the hospital and four weeks later at home. Each item is rated on a Likert-scale from 1 (never) to 7 (very often), with a total possible score between 13 and 91. A higher score indicates a stronger SOC. The Swedish reference population mean score is 70 (Lindmark et al., 2010). SOC-13 is a reliable, valid, and cross-culturally applicable instrument (Eriksson and Lindström, 2007, Eriksson and Lindström, 2005), and holds equally well for both men and women (Hittner, 2007). The internal consistency of the SOC-13 was good in this sample (Cronbach's $\alpha = 0.83$).

Activities (II)

The study-specific questionnaires included two open-ended questions about what the parents had done the day before and what they were going to do on the coming day, to determine whether the parents' activities had a statistically significant effect on the cortisol levels.

Saliva cortisol

After oral and written instructions, the parents were asked to take their own saliva samples in the pediatric ward directly on waking on Wednesday morning, i.e. the morning awakening cortisol, and 25 minutes later, i.e. the post-awakening cortisol. Four weeks later the parents repeated the procedure at home. Salimetrics oral polymer swabs and tubes were used to collect the saliva samples. The parents were asked to report the actual date and time of sampling as timing is important for the sensitivity of analysis (Smyth et al., 2013, Hansen et al., 2008), and were instructed not to eat, drink or use nicotine before sampling, as it may compromise the assay by lowering the pH in the saliva and increase bacteria growth (Hansen et al., 2008, Schwartz et al., 1998). To avoid blood contamination, the parents were told not to brush their teeth until after the sampling (Granger et al., 2007).

The saliva samples were returned to the author by the nurses at the ward, and by the parents at home in pre-paid envelopes. The saliva samples were centrifuged and stored at -80°C before analysis, to minimize freeze-thaw cycles. The analysis of the saliva cortisol was performed at Klinisk kemi, Diagnostikcentrum, Linköping, using a commercial enzyme immunoassay method; Salivary Cortisol Enzyme Immunoassay Kit, Salimetrics LLC, Pa, USA. Inter assay coefficients of variation were 10% for 2 nmol/L and 6% for 30 nmol/L.

The morning awakening cortisol, post-awakening cortisol, CAR (the difference between post-awakening cortisol and morning awakening cortisol), and cortisol index (CAR divided by morning awakening cortisol) were considered measures of the cortisol response. The cortisol index was used to adjust for intra-individual differences. By creating the cortisol index potential outliers did not have to be excluded. A change of at least 10% between the morning awakening cortisol level and the post-awakening cortisol level was required to be defined as an increase or decrease in the CAR (Ivars et al., 2012).

Interviews

Semi-structured interviews were conducted in studies III and IV. Interview guides were designed for the two studies respectively, to ensure that they contained general questions about the parent and the infant (III) or child (IV), and specific questions about the parent's sleep with follow-up questions on the parents' responses (Table 3). In phenomenography, it is important to make it clear that the interview is open and that the respondent is permitted to think aloud, to be doubtful, and to pause. The researcher must not assess the answers as being right or wrong but to have a real and honest interest in getting the respondents to express themselves as clearly and thoroughly as possible. Moreover, the interviewer needs to interpret immediately what the respondent is saying in order to be able to decide about further questioning or probing (Sjöström and Dahlgren, 2002).

All interviews were conducted in Swedish, digitally recorded and transcribed verbatim. Two pediatric nurses conducted the interviews and transcriptions in study III, and the author of this thesis conducted the interviews and transcriptions in study IV. To test the interview guides, two pilot interviews were performed in study III, and one pilot interview was performed in study IV. As there were no revisions of the interview guides, all interviews were included in the analyses.

All parents ($n=15$) who were asked to participate in study III accepted. The parents were interviewed in quiet rooms at the NICUs.

In study IV, 18 parents were asked for their participation, of which two parents declined and one parent was excluded as he had a child who had been discharged from HBHC at the time for the interview. Five parents choose to be interviewed in their homes; the other interviews took place in quiet rooms in the two included hospitals.

In families where both parents wanted to participate, the interviews were conducted separately, directly after each other (III-IV).

Table 3. Interview guides for study III and IV

Study III	Study IV
Demographic data <ul style="list-style-type: none"> ○ male/female ○ parent's age ○ the infant's gestational and postnatal age ○ marital status ○ siblings 	Demographic data <ul style="list-style-type: none"> ○ male/female ○ parent's age ○ the child's age ○ marital status ○ siblings living at home ○ working status ○ living conditions
Specific questions <ol style="list-style-type: none"> 1. How long have you been here? 2. Can you tell me little about your infant? 3. Can you tell me about the last 24 hours? Diet, exercise, rest, feelings 4. What is it like to sleep here? Sleep quality, time, arousals – how/why, light, dark, quiet, disturbing noises 5. How do you feel when you are going to sleep? 6. How do you feel in the morning when you wake up? 7. Where do you sleep? 8. Where does your infant sleep? 9. What affects your sleep? Makes you sleep good/bad 10. How did you perceive your sleep before your infant was born? 11. Can you mention anything that could facilitate/improve your sleep? 	Specific questions <ol style="list-style-type: none"> 1. Tell me about your child's disease. How long has he/she been ill and why are you receiving HBHC? 2. How did you perceive your sleep before your child was ill? 3. How would you describe your sleep now? Sleep quality? Sleep duration? 4. What affects your sleep? Positive/negative factors? 5. How do you feel in the evening when you are going to sleep? 6. How do you perceive that your sleep – or sleep loss – affect you as a parent? 7. Can you mention anything that could facilitate/improve your sleep?
Probing questions Tell me...how was it? Can you tell me more...Can you expand on? What do you think is the reason for that? You previously said that...can you give an example? How do you mean?	

Data analysis

Statistical analyses used in study I and II

Descriptive statistics were used to present the study variables and characteristics of the parents and their children. Continuous data, e.g. age and scale scores were described by means with standard deviations (sd), medians (md) with quartiles (Q1, Q3), and/or range. Categorical data, e.g. gender, education, and marital status, were described by frequency (*n*) and percentage (%).

The 24-hour clock time notations were converted into decimal hours before analysis. When data were missing, the parent was excluded from the

paired analyses but included in other non-paired analyses. Single missing values ($n=76$, 1.6%) in the MACL were replaced by the sample mean. One single outlier on sleep onset latency (light off 240 minutes after falling asleep) was removed, but the remaining data from the participant was retained.

To determine if the data was normally distributed, the Kolmogorov-Smirnov test of normality was used, together with normality plots. The Kolmogorov-Smirnov test can be used to see if a distribution of scores differs significantly from a normal distribution (Field, 2013a). As most data were not normally distributed, comparison analyses were made with non-parametric tests.

Friedman's ANOVA was used for pairwise, repeated measures in the different sleep variables, to find statistical significant differences between habitual sleep before admission (USI), sleep in the hospital (sleep log 1), and sleep at home after discharge (sleep log 2). The Friedman ANOVA is a non-parametric test, comparing repeated measures in related samples by ranks, and calculates the effect over time. The results of a Friedman ANOVA should be followed up by a Wilcoxon signed-rank test. The Wilcoxon signed-rank test is a non-parametric test for comparing two repeated variables in a related sample. It is based on ranks calculated from the differences between the scores in the two variables that are compared (Field, 2013b).

A Wilcoxon signed-rank test was used in the pairwise comparisons between the pediatric ward and at home after discharge on sleep variables from the sleep logs, MACL, morning awakening cortisol, post-awakening cortisol, CAR, cortisol index, and SOC.

Spearman's correlation coefficient (ρ) was used to study correlations between the sleep variables in sleep log 1, MACL, morning awakening cortisol, post-awakening cortisol, CAR, cortisol index, SOC, and the different domains in SF-36 in the pediatric ward. Spearman's correlation coefficient is a measure of the strength of a relationship between two non-parametric variables. First, data is ranked and then Pearson's equation is applied to the ranks. The coefficients lie between -1 and +1 (Field, 2013c).

A stepwise, backward regression method was employed using a univariate ANOVA to adjust for the effect of the different domains in SF-36, gender, the child's diagnoses, the different hospitals, the parents' ages, and the child's ages on sleep variables (sleep log), MACL, morning awakening cortisol, post-awakening cortisol, CAR, cortisol index, and SOC respectively, and of smoking on morning awakening cortisol, post-awakening cortisol, CAR, and cortisol index. The backward method places all predictors in the model and calculates the contribution of each one by looking at the

significance value for each predictor. If the predictor does not make a statistically significant contribution to how well it affects the outcome variable it is removed from the model. The contribution of the remaining predictors is then reassessed (Field, 2013d).

A Mann Whitney U-test was used to find differences in sleep variables, morning awakening cortisol, post-awakening cortisol, CAR, cortisol index, SOC, and the different domains in SF-36 between mothers and fathers in the hospital. The Mann Whitney U-test is a non-parametric test for differences between two independent samples (Field, 2013b).

To compare SOC and saliva cortisol levels between the parents and the reference population an independent *t*-test was used, which is a test that establishes whether two means from different samples differ significantly (Field, 2013e). As means, SD and frequency were given for the reference population in total, the *t*-test was calculated manually using a formula in Microsoft Excel.

For statistical data analysis, SPSS versions 23 and 24 were used. The level of statistical significance was set at <0.05 .

Further statistical analyses for the thesis

Further analyses, not included in previous studies, were performed for this thesis:

Pearson's chi-square test was performed to analyze categorical data from the USI to see whether there was a relationship between the sleep quality variables and gender. Chi-square test compares observed frequencies to expected frequencies, to find associations between categorical outcomes (Field, 2013f).

An Independent *t*-test was used to compare the different domains in SF-36 between the parents in the present study and the reference populations.

Pearson's correlation coefficient (*r*) was used to study correlations between habitual sleep variables (USI) and mood (MACL), cortisol levels, and SOC respectively. Moreover, correlations were made between SOC and mood and between SOC and HRQoL. Pearson's correlation coefficient is a standardized measure of the strength of the relationship between two variables (Field, 2013c).

Table 4. Example of the analysis process used in study I and II.

Open-ended question	Answer	Category
What influenced your sleep in the pediatric ward? (Study I)	<i>Helping <u>my son</u>. <u>Nurses</u> have been in to the room several times during the night. <u>The son</u> wanted me to sleep in his bed.</i>	The child The staff
What were you doing yesterday? (Study II)	<i>I was <u>at the hospital all day</u>. <u>Slept late</u> in the morning. <u>Read a book</u>, <u>watched TV</u>.</i>	Passive
What are you going to do today? (Study II)	<i>We have arranged for a babysitter so that <u>the dad can be here</u> a lot. <u>The oldest daughter will come</u> and visit. <i>Probably <u>discharge</u>. Meeting in the child's school at 1 p.m. Then I will participate in a running event at 7 p.m.</i></i>	Stay with the family Discharge

Analysis of open-ended questions (I-II)

A quantitative content analysis was used to analyze the open-ended questions about what the parents had perceived influenced their sleep in the pediatric ward and at home after discharge (I), and what the parents were doing the day before and what they were going to do during the coming day (II), focusing on counting the frequency of specific words or content (Table 4).

Content analysis is a convenient, scientific method for evaluation of textual types of data such as open-ended questions in questionnaires, and can be applied in both qualitative and quantitative studies. The content was identified and quantified, and further analyzed to create categories (Kondracki et al., 2002).

Six categories explaining what influenced the parents' sleep were detected: *the child*; *the staff*; *medical treatment*; *the environment*; *worries*; and that *nothing affected the sleep* (I).

Three categories explaining the parents' activity grade the day before the night in the pediatric ward were identified: *Physically active*, i.e. the parents had taken walks outdoors or exercised; *Active*, i.e. the parents had played games, done school work or physical therapy with their child, had

visits from family and relatives, or had the possibility to go home, go shopping or go to work; *Passive*, i.e. the parents had been waiting, resting, sleeping, watching TV/movies (II).

Four categories explaining the parents' expectations and plans for the upcoming day were identified: *Discharge*, i.e. the parents who expected their child to be discharged from the hospital during the day; *Be passive*, i.e. the parents who did not expect to go out from the pediatric ward during the day, just rest and wait for surgery, examinations, information or treatment; *Stay with the family*, i.e. play games, read, do school work or physical therapy with the child, and have visits from the family (the other parent, siblings, the child's grandparents); and *Going out of the hospital*, i.e. someone else was going to take care of the child so that they could go out of the hospital, go shopping, go home, go to work, or go out for a walk (II).

The categories from study II were subsequently used as categorical variables in a stepwise, backward regression method, using a univariate ANOVA, to adjust for a probable effect on the morning awakening cortisol, post-awakening cortisol, CAR and cortisol index.

Phenomenographic analysis (III-IV)

To capture the variations in perception of the phenomenon, data in study III were analyzed according to Dahlgren and Fallsberg (1991) and in study IV according to Sjöström & Dahlgren (2002). The choice of the two different phenomenographic approaches for analyzing the data was made as a way to gain knowledge about different ways to handle data, even though the analysis methods are similar;

1. The interviews were transcribed verbatim and read several times to gain familiarity with the data. As the author of this thesis did not conduct the interviews and transcriptions in study III, the recorded interviews were listened to the first times they were read, to avoid misinterpretations.
2. The most significant perceptions of the phenomenon were identified and a condensation was made of the most significant ones from every participant. These first steps of getting to know the material were given a much time and were extensively discussed in the research group.
3. Similar perceptions were grouped into sub-categories.
4. A comparison of the subcategories was made to reduce them, to establish borders between them, and to find variations and similarities between them.

5. The sub-categories were revised several times before descriptive categories were found with clear borders between them.
6. The descriptive categories were named to emphasize their essence.
7. The unique character of every category as well as the similarities with the other categories were described in an outcome space.

The outcome space in study III included four descriptive categories: *Impact of stress on sleep*; *How the environment affects sleep*; *Keeping the family together improves sleep*; and *How parents manage and prevent tiredness*.

The outcome space in study IV included four descriptive categories: *Sleep influences mood and mood influences sleep*; *Support influences safeness and safeness influences sleep*; *The child's needs influence routines and routines influence sleep*; and *"Me-time" influences sleep*.

Data analysis using a phenomenographic approach requires that the researcher connect with the data. A researcher's unique background and values are inherent in all phases of the research process. Therefore, a replication of the outcome space by other researchers is unlikely and not requested (Cope, 2004). Examples of the analysis process used in studies III and IV are presented in Table 5. Throughout the data analysis, co-authors carefully discussed the process to find an outcome space that was trustworthy and close to the collected data. The quotations were translated by a native English speaker to capture the nuances of language.

Table 5. Example of the phenomenographic analysis processes used in study III and IV.

	Condensation of answers	Sub-categories	Descriptive category
Study III	<p><i>sleep, try to sleep or rest at least until it's time again</i></p> <p><i>breastfeed, tube feed, express milk</i></p> <p><i>I go to bed again</i></p>	<p>trying to sleep</p> <p>factors hindering sleep</p> <p>trying to sleep</p>	How parents manage and prevent tiredness
Study IV	<p><i>"I sleep like a log the nights when he takes charge of everything. I just let go of everything, I suppose, and I guess I let go of all responsibilities too. And trust the other person"</i></p>	<p>support</p> <p>safeness and trust</p>	Support influences safeness, and safeness influences sleep

Ethical considerations

Ethical approval for all studies in this thesis was obtained by the Regional Committee for Medical Research (DNR 2011/1631). The studies were performed in accordance with the Declaration of Helsinki (World Medical Association, 2013). There was no risk of harm connected to participation in the studies. The questionnaires and the sleep logs used in study I and II are well established instruments and not considered harmful in any way. The cortisol sampling was non-invasive, not painful, and did not carry any risk for the parents.

The parents received oral and written information about the study before they gave written, informed consent. They were informed that they could decline to participate or could withdraw from the study at any time without explanation or consequences for their child's future care. All collected data were coded and are stored in separate, secure locations. Saliva samples were collected and stored according to the Swedish law SFS 2002:297 on biobanks in healthcare (Sveriges Riksdag, 2002), with approval from the Regional Biobank Center. All saliva samples were destroyed after analysis.

The children in studies I-III had been admitted to hospital because of several different diagnoses, e.g. infection diseases, surgery, chronic diseases and preterm birth. The parents could therefore have perceived that they were approached at a difficult and stressful time when they were asked for participation in the studies. The parents in studies III and IV were interviewed by nurses who might meet the parents in other health care situations. The research group discussed the ethical and moral aspects of this carefully. The benefits with the study outweighed the risks. The parents were informed about the situation, but no one declined to participate because of this. Some of the parents in studies III and IV expressed a positive experience of participating in the studies, saying that they felt acknowledged and that no one ever had asked them about themselves and their own sleep before.

The nurse's primary professional responsibility is to provide nursing care, in which the human rights of the family are respected (International Council of Nurses, 2012). According to the Convention on the Rights of the Child (1989), children have the right to the best health care possible and the interests of the child must be of primary concern. When adults make decisions that affect a child, the child has the right to obtain and share information that is important for health and well-being. However, children who are not competent enough to understand the consequences or make their own decisions need support and guidance from the parents or from another adult. In order to take important decisions regarding the child's care, the parents need to be alert and sensitive to the child's needs

(Söderbäck et al., 2011). The desired consequences of this thesis include an increased awareness among pediatric nurses of parents' sleep and mood when they are caring for a child in need of medical care, which would be favorable for the health and well-being of the whole family.

RESULTS

Characteristics of the parents

In total 109 parents (80 mothers and 29 fathers) participated in the studies included in this thesis. The mean age for the total sample was 37 years (sd 7.8) within a range of 22–59 years.

Studies I and II included 82 parents (61 mothers and 21 fathers, median age 37 years, range 22–59 years) accommodated with their child (median age 6.1 years, range 0–20 years) in a pediatric ward. Two parents reported that they shared room with another child and parent. Twenty-seven parents (33%) had children with chronic conditions and/or impaired health before the admission. In three families, both parents participated. Thirty-six parents were included in the pairwise comparisons. An analysis of the drop outs was made to find possible relationship between drop out and the parent's gender, the parent's age, the child's age, the child's diagnosis, the hospital they were admitted to, or reported scores on sleep variables, mood and SOC. No such relationships were found.

Study III included 12 parents (eight mothers and four fathers, median age 33 years, range 23–42 years) of 11 preterm and/or ill infants born between gestational age 29+1 to 39+6 weeks (median postnatal age: 13 days, range 7–46 days). Six parents were accommodated in family rooms with their infant, and four parents were accommodated in a parent room close to the NICU. Six parents (three mothers and three fathers) were parents of twins, and six parents (five mothers and one father) were parents of singletons. In four families both parents participated in the study.

Study IV included 15 parents (11 mothers and four fathers, median age 32 years, range 27–43 years) of 14 children (median age one year, range five months–12 years) enrolled in HBHC. In one family both parents participated in the study. Seven of the parents slept in the same room as the child enrolled in HBHC, four parents had a younger child in the room, and one family had night time nursing assistance.

Sleep and mood

The parents' sleep

The parents' perceptions and scoring of sleep quality varied in the different contexts in this thesis, and are described below as parents' habitual sleep (USI) and parents' sleep when they have a child in need of medical care (sleep logs and interviews).

Parents' habitual sleep

Most parents ($n=75$, 92%) in the pediatric ward reported that they usually had none or few problems falling asleep at home (I). The parents' habitual sleep quality was reported at a mean of 3.1 out of 5.0 (sd 1.2) and sleep duration at a mean of 6.5 hours (sd 1.3). Fifty-six parents (68%) reported insufficient habitual sleep, and 12 parents (14.7%) used to take a nap during the day more than three times a week. The parents' habitual SE% was calculated to a mean of 79.4% (sd 3.1) (I). Questions from the USI about the parents' habitual sleep (range 1-5) were dichotomized into yes (scores 3-5) and no (scores 1-2), and are presented in Table 6. No statistically significant differences were found between mothers and fathers.

Table 6. Parents' habitual sleep^a, $n = 82$

	Mothers		Fathers		<i>p</i> -value ^b
	Yes <i>n</i> (%)	No <i>n</i> (%)	Yes <i>n</i> (%)	No <i>n</i> (%)	
During the past four weeks, have you...					
...had too little sleep	40 (68%)	19 (32%)	16 (76%)	5 (24%)	n.s.
...slept too much	2 (3%)	56 (97%)	1 (1%)	20 (99%)	n.s.
...had trouble falling asleep at night	6 (10%)	55 (90%)	1 (1%)	20 (99%)	n.s.
...awakened during the night	25 (41%)	36 (59%)	7 (33%)	14 (67%)	n.s.
...awakened during the night and not being able to fall back to sleep	13 (21%)	48 (79%)	2 (10%)	19 (90%)	n.s.
...awakened too early in the morning	12 (20%)	49 (80%)	5 (24%)	16 (76%)	n.s.
...not felt rested after sleep	22 (36%)	39 (64%)	8 (38%)	13 (62%)	n.s.
...felt sleepy during the day	25 (41%)	36 (59%)	7 (33%)	14 (67%)	n.s.
...felt tired in the body during the day	25 (41%)	36 (59%)	7 (33%)	14 (67%)	n.s.
...felt tired in the head during the day	26 (43%)	35 (57%)	7 (33%)	14 (67%)	n.s.
...felt exhausted	15 (25%)	46 (75%)	6 (29%)	15 (71%)	n.s.

^a Uppsala Sleep Inventory (USI), ^b Chi-square test

Parents' sleep when they have a child in need of medical care

The parents in the NICU were longing to go to sleep, and fell asleep without problems in the evening. They expressed satisfaction and had adapted well to sleep in the hospital (III). Parents in the pediatric ward went to bed and fell asleep at the same time as they did at home (I), whereas most parents with a child receiving HBHC had difficulties falling asleep, were kept awake because of troubling thoughts, and said that they did not want to go to bed in the evening (IV). Some parents said that they chose not to fall asleep, or slept lightly not allowing themselves to fall into deep sleep, in case something happened and the child needed immediate attention (III-IV).

Fifty-five parents (67%) accommodated in the pediatric ward filled out sleep variables in sleep log 1 for the night in the hospital (I). When the reported sleep quality score (range 1-5) was dichotomized into good (3-5) and poor (1-2), 29 parents (53%) reported a good sleep quality in the pediatric ward.

Thirty-five parents (43%) completed the study at home (Table 7). The parents reported sufficient sleep quality in the pediatric ward (3.0 out of 5.0). Pairwise comparisons found that sleep quality improved further ($p < 0.05$) at home after discharge. No statistically significant differences were found in sleep duration and sleep efficiency between the pediatric ward and home or in the sleep variables between mothers and fathers (I).

Table 7. Pairwise comparison of sleep in the pediatric ward and at home, $n = 35$

Sleep variables^a	In the pediatric ward		At home		p-value^b
	Mean (sd)	Median (Q ₁ , Q ₃)	Mean (sd)	Median (Q ₁ , Q ₃)	
Sleep quality	3.0 (1.4)	3 (2, 4)	3.7 (1.2)	4 (3, 5)	<0.05
Sleep duration	6h 48 min (1h 48 min)	6h 55min (6h11min, 8h 0min)	6h 54 min (1h 30 min)	7h 5min (6h 5min, 7h 50min)	n.s.
Nocturnal awakenings (minutes)	33.0 (40.3)	20 (10, 60)	17.5 (26.3)	5 (0, 30)	<0.05
Sleep efficiency	77.3 (18.5)	82.9 (72.1, 89.9)	82.6 (13.1)	85.8 (77.2, 92.5)	n.s.

^a Sleep log 1 and 2 ^b Wilcoxon Signed Rank Test

Nocturnal awakenings

Thirty-two parents (39%) in the pediatric ward reported that they used to have frequent nocturnal awakenings at home. Twenty of them (24%) woke up due to them worrying about the child. Nocturnal awakenings minutes were fewer ($p < 0.05$) at home after discharge than in the pediatric ward (Table 7). A further pairwise comparison of mothers and fathers respectively, showed that it was the mothers who reported more nocturnal awakenings minutes ($p < 0.05$) in the pediatric ward compared to at home after discharge, no differences were found in the fathers (I).

The main reason for nocturnal awakenings, both at home and in the pediatric ward, was that the parents woke up because of the child (I, III-IV) (Figure 7). This could be due to the child's normal behaviors, such as nightly awakenings and breastfeeding for the younger children, but also to coughing or pain, depending on the child's current health. The child's age did not have any statistically significant effect on the parents' nocturnal awakenings (I). Vital sign checks, noises made by the staff (I, III) and medical treatment (I, III-IV), such as tube-feeding, breathing support, drugs, infusions and blood samples, were other given reasons influencing sleep. Eleven parents (20%) reported that nothing had affected their sleep in the pediatric ward (I), and some parents with a child in HBHC did not experience any sleep disturbances at all, unless the child was in a worse condition than usual, or if something worrying had happened during the day (IV).

Figure 7. Main reasons for nocturnal awakenings for the parents in the pediatric ward

Mood

Concern and anxiety about the child's health, and uncertainty about the future affected the parents sleep and mood negatively (III-IV). The parents described psychological tiredness which led to forgetfulness, tiredness, impatience with the family and partner, and depressive mood, and physical tiredness, with dizziness and loss of energy (III-IV). Even though private rooms at the NICU were valuable, most parents had a feeling of being isolated and locked up in the rooms. This feeling was particularly mentioned by mothers who were breastfeeding. It was hard to make contact with friends and others outside the hospital as cell phones were not allowed in the ward at the time the interviews were conducted (III). Parents caring for their child at home, described a constant bad conscience about not doing enough for their ill child, and for making the other family members step aside as the ill child demanded all their attention (IV). The loss of energy and their negative behavior led to feelings of loneliness, sadness and isolation, which affected their sleep negatively (III-IV).

Seventy-six parents (93%) completed the MACL about mood in the pediatric ward (Table 8). The parents reported lower scores ($p < 0.05$, $n = 35$) in the dimension of activation (MACL) in the pediatric ward than at home after discharge, e.g. they were less alert, less interested, and less able to concentrate, and more tired, dull and passive, when staying in the hospital. Moreover, mothers reported lower ($p = 0.01$) mood in the dimension of control (less confident and more insecure) than the fathers. A pairwise comparison of mothers and fathers respectively, showed that mothers had lower mood ($p = 0.05$) in the total mean score and in the dimension of activation in the pediatric ward compared to at home after discharge (I). Pearson's correlation coefficient showed relationships between mood and sleep quality and sleep variables in the USI affecting sleep quality (Table 9). The parents' gender and age, the child's age, diagnosis, or hospital had no statistical significant effects on mood.

Table 8. Parents' mood^a in the pediatric ward, $n = 76$

	Possible score		
	Min/Max	Mean (sd)	Median (Q ₁ , Q ₃)
Control	11/44	32 (6)	33 (27, 36)
Calmness	10/40	27 (6)	27 (22, 32)
Social orientation	11/44	34 (6)	35 (30, 39)
Pleasantness	12/48	33 (7)	33 (27, 39)
Activation	16/64	41 (8)	41 (36, 48)
Extraversion	11/44	31 (6)	31 (25, 36)
Total mood	14/47	33 (5)	33 (28, 37)

^a Mood Adjective Checklist (MACL)

Table 9. Pearson's correlation coefficient for mood^a and sleep quality^b, $n = 76$

Mood variables	Habitual sleep quality	Troubles falling asleep	Nightly awakenings	Awakened, not falling asleep	Awakened too early	Not rested	Feeling sleepy during the day	Tired in the body	Tired in the head	Feeling exhausted
Control	0.26*	-0.10	-0.34**	-0.23*	-0.19	-0.22	-0.16	-0.16	-0.30**	-0.32**
Calmness	0.34**	-0.14	-0.38**	-0.39**	-0.20	-0.24*	-0.28*	-0.28*	-0.28*	-0.31**
Social orientation	0.23*	-0.13	-0.31**	-0.26*	-0.18	-0.22	-0.11	-0.11	-0.24*	-0.21
Pleasantness	0.43**	-0.25*	-0.43**	-0.30**	-0.23*	-0.35**	-0.33**	-0.33**	-0.36**	-0.37**
Activation	0.49**	-0.16	-0.40**	-0.32**	-0.27*	-0.26*	-0.38**	-0.38**	-0.41**	-0.50**
Extraversion	0.34**	-0.09	-0.28*	-0.11	-0.27*	-0.30**	-0.32**	-0.32**	-0.37**	-0.32**
Total mean score	0.44**	-0.18	-0.44**	-0.33**	-0.27*	-0.33**	-0.33**	-0.33**	-0.40**	-0.42**

^a Mood Adjective Checklist (MACL), ^b Uppsala Sleep Inventory (USI), * correlation significant at $p < 0.05$ (2-tailed), ** correlation significant at $p < 0.01$ (2-tailed)

Saliva cortisol response

Of 157 collected saliva samples in the pediatric ward, 141 samples (90%) were included in the analysis. Sixteen samples were excluded due to an insufficient amount of saliva. The reported mean time of day for collected morning awakening cortisol was 7:16 (sd 59 min.) in the pediatric ward and 6:40 (sd 1h 10 min.) at home. The reported mean time of day for collected post-awakening cortisol was 7:48 (sd 1h 2 min.) in the pediatric ward and 7:09 (1h 13 min.) at home.

The cortisol level increased on average by 49% between the morning awakening cortisol level and the post-awakening cortisol level. Forty parents had an increasing CAR >10%, and 20 parents had a decreasing CAR >10%. The parents' age, the child's age, gender or nicotine use did not have a statistical significant effect on the cortisol levels (II).

Parents accommodated for more than one night had lower ($p<0.05$) post-awakening cortisol levels (md: 9.6 nmol/L; Q1, Q3: 7.2, 15.1) compared to parents staying their first night (md: 14.8 nmol/L; Q1, Q3: 9.4, 16.0). This difference did not occur at home (II).

A pairwise comparison showed that the parents had lower ($p=0.01$) morning awakening cortisol levels in the pediatric ward (md 7.4 nmol/L, Q1, Q3: 5.5, 11.9) compared to at home (md 10.1 nmol/L, Q1, Q3: 6.2, 15.0). No statistically significant differences were found in the morning awakening cortisol, post-awakening cortisol, CAR or cortisol index between mothers and fathers. No correlations were found between the parents' cortisol levels and the sleep variables, mood, SOC or HRQoL. A t -test showed that the parents had lower ($p<0.01$) morning- and post-awakening cortisol levels in the pediatric ward compared to a reference population of 508 adults presented in Wust et al. (2000) (Table 10).

Table 10. Parents' saliva cortisol response levels in the pediatric ward

		Ref.- value ^a mean (sd)	Mean (sd)	Median (Q ₁ , Q ₃)	t -val- ue ^b
Saliva cortisol concentration ^c					
Morning awakening cortisol	72	15.1 (6.3)	9.9 (5.2)	8.8 (6.1, 12.2)	7.7**
Post-awakening cortisol	69	23.0 (9.1)	12.0 (5.6)	12.0 (7.8, 15.5)	14.0**
Cortisol Awakening Response (CAR)	67		2.4 (6.1)	2.4 (-2.2, 6.8)	
Cortisol index ^d	67		0.5 (0.9)	0.2 (-0.2, 1.0)	

^a Wust et al. 2000, ^b Independent t -test ^c nmol/L, ^d CAR divided by the morning awakening cortisol,

** t -distribution significant at $p < 0.01$ (2-tailed)

Sense of coherence

Seventy-eight parents (95%) filled out the SOC-13 in the pediatric ward. The parents scored their SOC at a mean of 64 out of 91 (sd 11), which was lower ($p<0.05$) compared to a reference population of 526 Swedish adults (Lindmark et al., 2010) (Figure 8). Thirty-six parents (46%) filled out the SOC at home after discharge. No statistically significant difference was found in SOC between being in the pediatric ward and at home, or between mothers and fathers (II). An independent t -test showed statistically significant differences between fathers when they were at home and the Swedish male population ($p<0.05$), and between mothers in the pediatric ward and the Swedish female population ($p<0.01$) (Figure 8).

Figure 8. Differences in sense of coherence (SOC) between the parents in the study and the Swedish reference population (Lindmark et al. 2010).

Sleep, mood and sense of coherence

A further analysis for this thesis, showed correlations between the parents' habitual sleep quality (USI), mood (MACL) and SOC (SOC-13), indicating that the higher the sleep quality the higher the SOC and mood, the higher mood the higher the SOC and sleep quality, and the higher SOC the higher the sleep quality and mood, and vice versa (Figure 9). Statistically significant correlations were found between SOC and eight out of nine sleep variables in the USI affecting sleep quality (Table 11) and between SOC and all dimensions of mood (Table 12). However, no correlations were found between SOC and sleep quality when the parents had stayed overnight in the pediatric ward (sleep log 1) or at home after discharge (sleep log 2).

Figure 9. Pearson's correlation coefficient (r) for the parents' habitual sleep quality (USI), mood (MACL) and sense of coherence (SOC-13).

Table 11. Pearson's correlation coefficient for sense of coherence and sleep quality^a

	Sense of coherence	Sleep quality	Troubles falling asleep	Nocturnal awakenings	Awakened, not falling asleep	Awakened too early	Not rested	Feeling sleepy during the day	Tired in the body	Tired in the head	Feeling exhausted
Sense of coherence	-										
Sleep quality	0.35**	-									
Troubles falling asleep	-0.23*	-0.17	-								
Nocturnal awakenings	-0.30**	-0.55**	0.20	-							
Awakened, not falling asleep	-0.36**	-0.23*	0.31**	0.27*	-						
Awakened too early	-0.22	-0.37**	0.17	0.39**	0.30**	-					
Not rested	-0.32**	-0.42**	0.31**	0.43**	0.10	0.17	-				
Feeling sleepy during the day	-0.27*	-0.46**	0.29**	0.49**	0.07	0.15	0.64**	-			
Tired in the body	-0.27*	-0.46**	0.29**	0.49**	0.07	0.15	0.64**	1.00**	-		
Tired in the head	-0.40**	-0.44**	0.19	0.31**	0.00	0.01	0.46**	0.57**	0.57**	-	
Feeling exhausted	-0.40**	-0.40**	0.32**	0.33**	0.16	0.18	0.48**	0.56**	0.56**	0.60**	-

^a Uppsala Sleep Inventory (USI), * correlation significant at $p < 0.05$ (2-tailed), ** correlation significant at $p < 0.01$ (2-tailed)

Table 12. Pearson's correlation coefficient for mood and sense of coherence, $n = 76$

Mood	Sense of coherence
Control	0.36**
Calmness	0.42**
Social orientation	0.39**
Pleasantness	0.48**
Activation	0.53**
Extraversion	0.41**
Mood total mean score	0.53**

** correlation significant at $p < 0.01$ (2-tailed)

Table 13. Parents' health-related quality of life, $n = 82$

	mean (sd)	Reference population mean (sd)	t -value ^a
Physical functioning	91 (15)	92 (15)	0.52
Role physical	77 (36)	87 (28)	2.71**
Bodily pain	73 (24)	76 (26)	1.38
General health	68 (22)	78 (21)	3.94**
Vitality	47 (23)	69 (23)	8.53**
Social functioning	76 (27)	89 (21)	4.28**
Role emotional	66 (40)	88 (27)	4.75**
Mental health	66 (22)	81 (19)	6.12**

^a Independent t -test, ** t -distribution significant at $p < 0.01$ (2-tailed)

Table 14. Pearson's correlation coefficient for health-related quality of life and sense of coherence, $n = 76$

Health-related quality of life	Sense of coherence
Physical functioning	0.17
Role physical	0.16
Bodily pain	0.21
General health	0.42**
Vitality	0.49**
Social functioning	0.41**
Role emotional	0.40**
Mental health	0.54**

** correlation significant at $p < 0.01$ (2-tailed)

Health-related quality of life

The scores of the parents' HRQoL are presented in Table 13. Mothers reported lower ($p<0.05$) scores on physical functioning and bodily pain than fathers (II).

The parents' HRQoL was statistically significantly lower compared to the Swedish reference population (Sullivan et al., 2002), in total (Table 13, Figure 10a) as well as in fathers (Figure 10b) and mothers (Figure 10c) respectively, except for physical functioning where the fathers in our study reported a statistically significant higher mean score than the reference population (Figure 10b). Correlations were found between five of the eight dimensions of HRQoL and SOC (Table 14).

A further analysis of the parents' HRQoL showed that four mothers and one father scored ≤ 5 out of 100 on the domain vitality. These were parents of children aged 5-14 years old. The children had different diagnoses: previously diagnosed epilepsy, asthma and allergy, severe chronic muscular disease, recurring urinary infections, and lymphoma. One mother took care of her child around the clock as the child's care assistant, and one mother had been diagnosed with fatigue syndrome (II). A new analysis was made with these parents excluded. The mean for vitality was then 50 out of 100 (sd 20) compared to 47 (sd 23) for all parents.

Figure 10a. Differences in HRQoL between the parents in the study and the Swedish population (Sullivan et al. 2002). Independent t -test, * $p<0.05$, ** $p<0.01$.

Figure 10b. Differences in HRQoL between the fathers in the study and the Swedish male population (Sullivan et al. 2002). Independent *t*-test, * $p < 0.05$, ** $p < 0.01$.

Figure 10c. Differences in HRQoL between the mothers in the study and the Swedish female population (Sullivan et al. 2002). Independent *t*-test, * $p < 0.05$, ** $p < 0.01$.

Resources to manage the situation

The importance of staying together as a family

One family in the NICU and three families in the pediatric wards choose to stay overnight at the hospital with the whole family, including siblings (I-III). Six parents stayed overnight at the pediatric ward together with their partner (I-II). The possibility for the family to stay together when caring for their ill child was appreciated among the parents (III-IV). Having a room to oneself was considered positive by the parents accommodated in the hospital. They expressed their satisfaction with having their own room where they could have their private belongings, be by themselves and manage their own time (I, III). Staying together gave a feeling of safeness which was important to gain a good sleep quality (III-IV).

The category “Stay with the family”, which was one of the categories from the quantitative content analysis in study II, had a statistically significant effect on the morning awakening cortisol level $F(1, 70) = 6.25$, $p < 0.05$, and on the post-awakening cortisol level $F(1, 65) = 8.16$, $p < 0.01$. Further analysis showed that the parents who expected to stay with the family had lower morning awakening cortisol levels and lower post-awakening cortisol levels than the parents who did not ($p < 0.01$) (II).

Parents in the NICU expressed how they appreciated the ability to practice skin-to-skin care (SSC). Being close to the infant was a stress-reducing factor that gave a feeling of control. Those moments were experienced as relaxing, cozy and joyful (III).

Changed routines to optimize time for sleep

The parents put their child and their child’s needs first. They changed their routines to optimize time for sleep. They planned and prepared their tasks and activities before bedtime, and changed their own bedtime routines according to the child’s sleep pattern (III-IV). The routines included ordinary daily activities but could also include preparation and administration of medication and special food, breastfeeding, training schedules, habilitation, and meetings with healthcare staff (IV). Mothers in the NICU needed to find time to express milk for the infants, but also to get some food for themselves (III). Some of the parents with a child receiving HBHC tried to adjust their own needs to the child’s routines. While the child was sleeping, they could take a nap, go for a walk, or manage as many as possible of the everyday household tasks (IV).

Support is needed for relaxation and sleep

The nurses provided important support (III-IV). The parents wanted continuous information about the child's health, and expressed trust in the nurses' caring skills. Medical knowledge and emotional support were highly valued (III). Parents with a child receiving HBHC appreciated the option to contact the HBHC nurses when they needed advice, prescriptions, or practical support. The possibility to have a nurse come to their home was much appreciated, especially among those who did not live in the cities where the hospitals were located. This gave rise to a feeling of safeness, and improved the ability to relax and to sleep (IV).

Practical and emotional support from a partner was perceived to be of the utmost importance. Shared responsibility for the child's care and everyday household tasks, and having someone to talk to during difficult times improved feelings of safeness and influenced sleep positively (IV).

Me-time influence well-being and sleep in a positive way

It was considered important to have an adult life and spend time with the partner. Time to discuss and exchange thoughts with the partner was perceived as valuable time that helped the couple to reflect upon and handle the situation (III-IV). Me-time, e.g. time for hobbies, meeting with friends, work, and relaxation, influenced the parents' well-being and sleep in a positive way. However, me-time depended on support from family and friends, and that the parents feeling confident enough to give up control and leave the child with someone else. Feelings of guilt when leaving the child hindered some parents from taking me-time even though they wanted and needed this time to manage life and improve sleep (IV).

Physical activity is an important source for well-being and sleep

Physical activity was perceived as another important source of well-being and as aiding sleep for the parents (III-IV), especially among the fathers in the NICU, who expressed a wish for activities within the hospital area so that they could be physically active without being too far away from their infant (III). Parents who used to be physically active felt frustrated if they missed an opportunity to exercise and found it harder to fall asleep in the evening on those days (IV). Physical activity was also the only dimension of HRQoL where the fathers had higher ($p < 0.01$) scores than the reference population (Figure 10b) (II).

DISCUSSION

Discussion of the results

This thesis focuses on parents of children admitted to pediatric care, and aims to evaluate sleep, mood, cortisol response, and sense of coherence in parents caring for their ill children, and identify factors that may influence parents' sleep, in order to find strategies to manage the situation. The results revealed that: being together as a family improves sleep and decreases stress; parents report more nocturnal awakenings and lower mood, but sufficient sleep quality in the hospital; and parents are sleep-deprived before the child's admission. Moreover, this thesis reports first time data of parents' cortisol response when they are accommodated in a pediatric ward.

Being together as a family improves sleep and decreases stress

The importance of being together as a family was a recurrent theme in all studies included in this thesis. The ability to be with the child and family improved the parents' sleep quality and mood, and affected their cortisol response. The possibility of being accommodated in the hospital and gather the family around the ill child might have given the parents time for relaxation and recovery, and make the hospital stay less stressful. To be with the family improved the sense of safeness, and safeness facilitated sleep and decreased feelings of stress.

Children must be protected from harm, neglect and abuse, but also from fear, pain and loneliness (Coyne et al., 2016). In previous studies, children and adolescents in hospital have expressed satisfaction and happiness about parents staying the night, and about being able to receive visits from family members and friends (Schalkers et al., 2015, Pelander and Leino-Kilpi, 2010, Coyne, 2015). In a qualitative study, children diagnosed with cancer and their parents described that being together was vital for both the child and parents, and both parents and siblings were important for the child as they provided a sense of security in the child's everyday life (Darcy et al., 2014).

Parents in the NICU described the importance of being close to their infant and how practicing SSC, where the infant lies skin to skin between the parent's breasts, improved relaxation and sleep. Previous studies have reported that SSC leads to decreased feelings of stress and decreased heart rate, and improves the ability to relax among parents of infants in the NICU

(Mörelus et al., 2005, Gathwala et al., 2008, Altman et al., 2012, Neu et al., 2014, Neu et al., 2009). Blomqvist et al. (2013) suggest that fathers providing SSC improve their paternal role. SSC may also help parents to feel in control and feel needed which in turn may increase their presence in the NICU (Heinemann et al., 2013). A recent qualitative meta-synthesis concludes that SSC can not only be interpreted as a family-including and important health care intervention, but also in terms of becoming parents under unfamiliar circumstances (Anderzen-Carlsson et al., 2014). Moreover, SSC improves bonding (Moore et al., 2016), which in a long term affect the child's SOC, stress reactions and well-being in the adulthood (Ohtaki et al., 2016).

Parents should be permitted to stay with the child and participate in the child's care when feasible, and the pediatric nurse should be able to work cooperatively with both parents for the child's well-being (Orem, 2001). Moreover, families should be given available accommodation options and services that are designed to better meet the needs of families (Franck et al., 2015). The hospitals included in this thesis provided FCC and offered free accommodation for the parents and siblings and free visits for family and friends. This gave the parents the opportunity to be close to, and care for, their child all the time. However, few parents in present studies chose the opportunity for the whole family to stay at the hospital. This could have been due to that the data collection was ongoing on weekdays and not the weekends. The other parent maybe had to go to work and older siblings go to school, and therefore they maybe chose to stay at home. Another explanation could be that they were not informed that they could stay, as it is not common practice in all pediatric wards to offer the whole family the option to stay during a child's admission. If it is safe and favorable for the ill child and if it is feasible for the family, the pediatric nurse should encourage the family to stay together at the hospital and offer accommodation options for the whole family, especially during long-term admissions, to improve feelings of safeness and reduce feelings of stress.

Some hospitals offer accommodation for families in a Ronald McDonald house. This has been reported beneficial for parents' psychosocial well-being and perceptions of child recovery (Franck et al., 2013, Franck et al., 2015) and for parents' sleep (Franck et al., 2014). One of the hospitals could offer families access to a Ronald McDonald house, but these parents were not included in the studies as we focused on parent's staying at the hospital or in home care. However, sleep and mood in parents staying in a Ronald McDonald house during their child's admission to hospital would be of interest to study further.

Parents report more nocturnal awakenings and lower mood but sufficient sleep quality in the hospital

The parents reported more nocturnal awakenings and lower mood at the pediatric ward than at home after discharge. Negative mood affected the patience with the family and partner, and led to feelings of loneliness, sadness and isolation.

The child was mentioned as the main reason for nocturnal awakenings. This could be due to normal behavior, but also disease symptoms e.g. coughing or pain depending on the child's current health. A child's disease symptoms or medical management influence sleep for both the child and the parents, which might have an impact on family functioning (Meltzer and Montgomery-Downs, 2011). In Stremmler et al. (2011), parents stated that uncertainty and worry over their child's health, changes in their child's condition, and lack of knowledge of their child's health influenced their sleep. These points were also made in our studies, particularly among the parents in NICU.

The nursing staff was another factor influencing nocturnal awakenings in the hospital. This has been described previously by parents (Stremmler et al., 2011) and nurses (Grossman et al., 2017, Stremmler et al., 2015). Vital sign checks and treatment are important in the care for the child, but noise from nurses talking in the corridor and slamming doors could be avoided. The parents with children receiving HBHC described how they prepared their activities and scheduled care and medical treatment during the night, to prevent frequent nocturnal awakenings. Scheduling nursing care and medical treatment during the night should be done even in the pediatric wards, and the nurses should avoid going to the patient room at night, unless it is really necessary, in order to improve the parents' and the children's sleep. However, patient safety must always be prioritized.

Nocturnal awakenings were correlated to poor sleep quality. Poor sleep quality may lead to postpartum depression in new mothers (Okun, 2016, Okun, 2015), which in turn can lead to decreased infant bonding (Hairston et al., 2016) and family dysfunction (Piteo et al., 2013). A well-functioning relationship between the parent and the child is important for the infant's physical and psychological development (Jiang et al., 2014, Pawlby et al., 2008). Furthermore, parents have reported that suppressing negative and amplifying positive emotions in caregiving give feelings of poorer emotional well-being and less responsiveness to their child's needs (Le and Impett, 2016).

Even though the parents had children in need of medical care, and there were frequent nocturnal awakenings during the night, they reported

sufficient sleep quality in the hospital. Parents in the NICU longed to go to bed, and parents in the pediatric ward went to bed and fell asleep at about the same time as when they were at home. The parents in the NICU had adapted to the situation and fell asleep even though the situation and environment were unfamiliar and sometimes stressful. Another explanation why the parents reported that they had a sufficient sleep quality in the hospital could be that they felt safe when they were at the hospital and could rely on the nurses' care, and therefore found the hospital stay less stressful. However, this hypothesis was not tested in this thesis.

In a recent study, 35% of the mothers and 59% of the fathers reported having sufficient sleep during their infants' hospital stay at the NICU (Blomqvist et al., 2017). Other studies report that parents might have indecisions about staying overnight in the hospital with their ill child or not (Stremmler et al., 2011, Foster et al., 2017). To stay and keep watch over their child and their child's care prevents good parental sleep for some parents (Stremmler et al., 2011), while others struggle with meeting the demands of life and family outside the hospital (Foster et al., 2017). When a child is admitted to hospital the pediatric nurse should make an assessment when meeting the parents to see if a self-care and a dependent care system is in progress; otherwise, the care requisites should be met by the nursing staff (Orem, 2001). That could be done by distributing the care responsibilities for the child between the parents and the nurse and thereby reducing the demands for the parents.

Another contributing factor for the parents' sufficient sleep quality in the hospital could be that almost all parents were accommodated in single rooms. Privacy was considered an important factor affecting sleep for the parents. The need for integrity and privacy in hospital has been expressed previously in qualitative studies by both parents (Stremmler et al., 2011) and children (Schalkers et al., 2015). In Meltzer et al. (2012), 43% of the families in pediatric wards shared a room with another patient, and reported that roommates making noises interfered with sleep. Single rooms for patients reduce the noise-level (Dolan et al., 2016, Kol et al., 2015) and improve patients' sleep (Dolan et al., 2016, Morgan, 2010). Single rooms are reported to be the only variable that significantly influence parental sleep duration positively in hospital (McCann, 2008). However, in this study some of the parents expressed feelings of loneliness and isolation when they cared for their infant in the NICU. Curtis and Northcott (2016) reported in a study based on observations, individual interviews and focus

group interviews, that single rooms do offer privacy and enhanced amenities, but also increase feelings of loneliness and isolation, while shared rooms offer informal support networks for both children and their parents.

In Stremmer et al. (2011), parents have described the importance of self-care through exercise, healthy eating and taking opportunities for rest to achieve good sleep in the hospital. In this thesis, the importance of me-time and physical activity was highlighted by several parents in the qualitative studies, and the fathers in the pediatric wards had higher scores on physical activity in the SF-36 than the reference population. Participating in health-promoting activities reduces sleep disruptions in mothers of children with disabilities (Bourke-Taylor et al., 2013), whereas mothers with low activity levels report sleep loss and more postpartum depressive symptoms compared to high-activity mothers (Lee et al., 2012). According to Orem (2001) it is an essential self-care requisite to balance activity and rest. The pediatric nurse should encourage parents to be more physically active and to take me-time as this may improve the parents' sleep and mood.

Parents are sleep-deprived before the child's admission

The results indicate that parents with a child admitted to a pediatric ward had a lack of energy and were already sleep-deprived before their child's admission. Of these parents, only a third had a child with a chronic condition. The parents reported low habitual SE% and poor HRQoL, and scores on general health and vitality were particularly low.

Low SE% has been reported previously in parents of children with cancer as well as in parents of healthy children (McLoone et al., 2013, Matthews et al., 2014). According to Borbely et al. (2016), three nights of sleep deprivation is enough to affect the circadian rhythm. Moreover, the parents included in this study were at the age of peak onset of sleep-related diseases, e.g. hypertension and type 2 diabetes (Redeker, 2011, Liu et al., 2013). A recent study showed that parents reporting sleep difficulties of their own may also overestimate sleep problems in their children (Rönnlund et al., 2016). The conclusion in that study was that future diagnostic methods and treatments in the field of pediatric sleep disorders, should not only take the child into consideration, but the whole family, including the parents. It would be desirable for the pediatric nurses in primary child healthcare to acknowledge the importance of parents' sleep when the parents visit with their child, by asking them about their and their child's sleep habits and giving advice on obtaining better sleep quality for both the child and the parents.

Foster et al. (2017) report how parents defer and ignore their own emotional needs during the acute hospital phase. In this thesis, we suggest that this behavior occurs even when parents care for their child at home. The child was always put in the first place, and the parents changed their routines and behavior to optimize time for sleep and to cope with the situation, even though it affected their sleep negatively. It is common for adults to minimize the importance of obtaining adequate sleep (Redeker, 2011). For parents of a child with illness, the focus lies on the child's needs rather than their own, and the importance of their own sleep might therefore be neglected. Therefore, it is important that the pediatric nurse acknowledges and informs the parents about the importance of good sleep quality, so that they can regain energy to perform the care that the child's health demands.

The parents with children receiving HBHC perceived difficulties falling asleep at home and were kept awake because of troubling thoughts. Some parents said that they did not want to go to bed or slept very lightly in case something bad would happen to the child, which had a negative influence on their mood and energy. These findings are confirmed by McCann et al. (2015), who report that the need to always be vigilant in order to meet the child's needs is both relentless and draining, and that the sleep deprivation affects the parents themselves and their relationships. In McBean and Schlosnagle (2015), parents of children with special healthcare needs have reported longer sleep onset latency, shorter sleep duration, and poorer sleep than parents of healthy children. In that same study parents of children with special healthcare needs also reported worse prospective memory and poorer general health. Parents that are responsible for ensuring the continuing self-care for the child in their home must develop knowledge and skills, and maintain their willingness to provide dependent care, but also bear responsibility for their own health and well-being (Orem, 2001). The pediatric nurse needs to make appraisals, not only of the parents' dependent care capabilities, but of the health states of the parent including the effects of the burden of care that might occur.

Parents' cortisol response when they are accommodated in a pediatric ward

As there are no other studies of cortisol response in this context to support or reject the results of this thesis, these results need to be interpreted in different ways.

Almost half of the parents in the pediatric ward reported that they had been passive, e.g. resting and waiting for surgery, examinations, infor-

mation or treatment, in the pediatric ward the day before the sampling procedure. Waiting has been described as the most stressful aspect of the hospital experience for family members, with a constant struggle to maintain a balance between negative and positive thoughts (Trimm and Sanford, 2010). In a recent study parents described waiting as a time of anxiety, stress, fear and boredom (Corsano et al., 2015). Appraisals of high stress are associated with an increase in cortisol levels during the day of exposure to a stressful event, followed by lower secretion the following morning (Gartland et al., 2014). This could explain the lower morning cortisol level in the pediatric ward.

Moreover, Hibel et al. (2012) have shown that high self-reported parental stress, combined with stress from another domain of life, e.g. work or studies, increase the morning awakening cortisol level in mothers of healthy children on work days compared to non-work days, whereas parental stress alone is not enough to physiologically arouse the mothers. This could be another explanation of the lower morning awakening cortisol level in the pediatric ward, where the parents were focusing solely on the care for their ill child. One hypothesis is that when the parents were back in their daily lives, struggling with parental stress combined with work stress, their morning awakening cortisol increased. To confirm this hypothesis, further studies are needed following parents' experiences of stress and cortisol levels for several days in the hospital and at home.

Twenty of the parents had a negative CAR with higher morning awakening cortisol levels than post-awakening cortisol levels. One explanation of this could be that the parents did not collect the saliva sample at once when they woke up. Sample timing is important in assessment of CAR. The longer the morning awakening cortisol is delayed, the higher the cortisol concentration, and the probability that the post-awakening sample is taken when the cortisol levels decrease again is greater. According to Griefahn et al. (2011), a delay of 10 minutes is acceptable, whereas delays >10 minutes might become critical for the analysis. However, Smyth et al. (2016, 2013) report that a delay of 5 minutes is enough to negatively impact the analysis of CAR.

Parents' sleep quality, mood and sense of coherence influence each other

The connection between sleep and mood in healthy adults has been reported earlier (Finan et al., 2015, Bower et al., 2010, Coe et al., 2012) and was confirmed by the parents in the qualitative studies in this thesis. Poor

sleep quality leads to negative mood, which in turn leads to poor sleep quality. This vicious cycle of negative outcomes has been described previously by Kahn et al., (2013) and Morin and Jarrin (2013). What this thesis adds is that SOC may be an important variable associated with sleep and mood; the higher SOC, the better the mood and sleep quality, and vice versa. However, this needs to be investigated further as the correlations in this study were found between habitual sleep from the USI, which the parents filled out on Tuesday evening, and data from SOC and MACL, that were assessed during Wednesday morning. There were no correlations found on the variable sleep quality in the sleep logs and SOC.

The result indicates that parents' SOC is of more importance for sleep quality than the severity of the child's illness. Previous studies have reported that parents' stress levels are not associated with the severity of the child's illness, but with their ability to cope with the situation (Mörelus et al., 2002, Vrijmoet-Wiersma et al., 2009, Muscara et al., 2015). Parents with poor SOC might focus on the negative emotions and remain hyper-aroused at bedtime, which affects their sleep quality. Meanwhile, parents with a strong SOC might adapt to the situation and therefore reduce their bedtime arousal and maintain a good sleep quality, despite the stressful situation.

The pediatric nurse should help the parent to understand the situation and to identify the resources that can be used to deal with specific stressors. Parents who have not thought about their self-care and dependent care role may need to be helped to look at themselves as self-care and dependent care agents in order to strengthen their ability to meet different self-care demands at specific moments (Orem, 2001). An intervention to strengthen the parents' SOC and increase their ability to manage stressful situations and to search for resources that could help them to overcome the stressors could be beneficial for the parents, as SOC is not stable over time (Bergh and Björk, 2012, Super et al., 2016).

An intervention program based on mindfulness-based stress reduction (MBSR) may help people to deal with difficult situations by focusing on the present, rather than being carried away by emotions and worrying about possible problems in the future (Super et al., 2016). Using MBSR is reported as feasible and well received by parents of children with developmental delays (Roberts and Neece, 2015), and could be a way for the parents to meet their own self-care demands. Previous studies show a significant reduction in stress, depression, and anxiety, and improved sleep and life satisfaction in mothers of children with autism and other neurodevelopmental disabilities (Dyken et al., 2014), and significantly less stress and

depression as well as greater life satisfaction in parents of children with developmental delays (Neece, 2014), when using MBSR. One study was found that evaluated MBSR in parents of children with various chronic conditions. That study reported decreased stress symptoms and mood disturbance after an eight-week program (Minor et al., 2006). Moreover, a recent meta-analysis indicates that MBSR may have a beneficial effect on salivary cortisol secretion in healthy adults (Sanada et al., 2016).

Methodological discussion

Study limitations

A strength of the studies in this thesis is that they were conducted in three neonatal intensive care units, six pediatric wards, and two hospital-based home care settings, in five different hospitals, in two county councils. The sample includes both mothers and fathers of different ages, with a variety of earlier experiences of the pediatric healthcare. The infants and children were of different ages, with different diagnoses and severity of illness. This gives a wide perspective on the subject and a base for further studies.

The prospective designs in studies I and II were chosen to enable repeated data collection from the same parents, making it possible to evaluate potential changes in sleep quality, mood, saliva cortisol response and SOC when the parents were at home after discharge, in a normal daily life setting. A disadvantage of this design is that it was hard to get the parents to complete the study, and there were many drop-outs. A probable explanation for the drop-outs could be that the parents were back in their daily life setting, coping with daily struggles, and did not see the importance of completing the study. There is a chance that those who answered were those who had the most energy to deal with the study. However, an analysis of the drop outs did not find any relationship between drop out and the parent's gender, the parent's age, the child's age, the child's diagnosis, the hospital they were admitted to, or reported scores on sleep variables, mood and SOC.

The separation of study I and II could lead to consequences such as missing statistically significant correlations between the primary outcomes. Therefore, analyses were made between sleep quality and saliva cortisol response before the separation of data. No correlations were found. As previous studies have reported connection between sleep and mood (Finan et al., 2015, Bower et al., 2010, Coe et al., 2012), mood was applied as

secondary outcome in study I. To investigate if the parents ability to manage the stressful situation affected their saliva cortisol response, SOC was applied as secondary outcome in study II.

Only two parents declined to participate in study IV, and none in study III. However, there were difficulties enrolling parents from the pediatric wards in studies I and II. It was a challenge to convince the parents of the importance of studying parental sleep when the parents had sought help for their children who needed medical care. Some parents thought that they should not participate in the study as they did not have any problems with their sleep, even though the aim was to study parents' sleep, not sleep disorders. Some parents mentioned the amount of data to fill out as a reason for not participating. Unfortunately, there is a lack of information from the pediatric wards about the number of parents asked for participation that declined.

Validity and reliability

This thesis is based on four studies using both quantitative and qualitative data in order to evaluate sleep and stress in parents with a child admitted to pediatric care. Qualitative and quantitative research are complementary approaches, seeking to address different types of questions and provide different kinds of answer (Stenfors-Hayes et al., 2013). Therefore, the use of different research designs and methods in this thesis strengthen the results (Polit, 2017).

Validity is the degree to which a measurement measures what it is developed to measure, whereas reliability is the consistency of the measurements (Polit, 2017). All questionnaires used in this thesis have been validated and reliability tested with good results. However, USI and SF-36 measure sleep and HRQoL for the previous four weeks. These results could have been affected as the parents filled out the questionnaires at the pediatric ward after the child's admission. The parents' focus was most likely on the child and the hospital stay, which might have caused the parents to give answers based on how they felt right then, instead of thinking four weeks back.

Several statistical analyses were chosen and performed depending on sample size, level of data, and data distribution. As most data were not normally distributed non-parametric tests were chosen in the primary analyses, and medians and quartiles were used to describe data. However, in this thesis, data frequencies are also described with means and standard deviations as a supplement to previously submitted data. The statistical

analyses were discussed with statisticians at Linköping University. The significance level was set at <0.05 , which means that there is a 5% chance that a type I error will occur, which is a false-positive result where the null hypothesis is rejected even though it is true (Giuliano and Polanowicz, 2008).

The parents were given oral and written instructions about the sampling procedure of saliva cortisol that were consistent with the recently published expert consensus guidelines for assessment of saliva cortisol response (Stalder et al., 2016). In this thesis, we focused on the acute stress that might occur during the hospital stay, therefore cortisol in saliva was considered as a reliable variable to measure the cortisol response.

Justification of validity of a phenomenographic study lies in a full and open account of the method and results. The judgement of credibility and trustworthiness lies with the person reading the study (Cope, 2004). To enhance credibility in the phenomenographic studies, we aimed to make a careful description of the research process, the interview guides, the analyses and the conclusions, that make it possible to replicate the study (Sjöström and Dahlgren, 2002). The analysis of the phenomenographic studies included in this thesis was approached with the pre-understanding from a pediatric nurse with clinical experience. A different result would possibly occur if the analyses were made within another discipline.

Phenomenography's ontological assumptions are subjectivist, i.e. the world exists and different people experience it in different ways and from a non-dualist viewpoint (Marton and Booth, 1997). The outcome space is the researcher's abstraction of the identified different ways of understanding the phenomenon. The outcome space refers to a collective level and describes the different ways the phenomenon can be understood (Stenfors-Hayes et al., 2013). The research group continuously discussed the analysis process in studies III and IV to find outcome spaces that were trustworthy and close to the collected data (Sjöström and Dahlgren, 2002).

However, the findings of this thesis must be interpreted with some caution in order to be generalized or transferred to all parents with a child admitted to pediatric care. First, the samples in the studies were small. Neither do we know if all parents following the inclusion criteria were asked to participate or if there was a selection of parents found eligible by the nurses at the wards or at the HBHC. Therefore, this sample may not be a representative sample of all parents with a child admitted to pediatric care. Nevertheless, the results are important as this is the first study investigating sleep and stress in both mothers and fathers of children in all ages, with different severe illnesses, in different pediatric settings. The

results may therefore be of interest for all pediatric nurses, regardless of specialty, and a foundation for future research.

Implications for nursing practice

The implications for nursing practice are based on the results of the descriptive material of this thesis. However, the suggestions need to be further investigated and evaluated in future studies before implementation. To be effective, new routines or an intervention must take place on a regular basis, over an extended period of time (Bronfenbrenner and Morris, 2007). Looking at FCC as an ecological system, pediatric nurses might need to make changes both within and outside their own system to improve health and well-being in the family. To improve self-care, the nurse should help the individual with physical and emotional help, and secure help from others, such as family and friends (Orem, 2001).

It could be beneficial for the whole family if FCC with a child-centered focus was provided in all neonatal and pediatric wards. However, as there is no consensus on a definition of FCC, the pediatric nurses need to base their nursing care on the Conventions of the rights of the child (United Nations, 1989) and the EACH charter about the rights of children and their families before, during, and after the stay in hospital or other health care services (European Association for Children in Hospital, 2001).

When it is for the child's best, the whole family should be included in the pediatric care, as the family is an emotional unit of interconnected individuals, dependent on each other. It is desirable that parents and siblings are offered accommodation possibilities close to the child to facilitate their support and participation in the child's care. Free visits from the extended family and friends should be mandatory in all pediatric wards if it is safe for the child's health. Families may benefit from nurses encouraging them to communicate with their relatives and friends about their expectations and the practical and emotional support they need to manage the situation and reduce feelings of stress. By receiving practical and emotional support, parents may be helped to initiate or endure a task, think about the situation, or make decisions. These decisions could be of great importance to their child's care and future. Parents with severely injured children in hospital have reported in a recent study how practical support, including access to accommodation, food and affordable parking, was considered essential to the ability to support their children. However, that same study concludes that the emotional well-being needs of parents of children in need of medical care are not fully addressed (Foster et al., 2017).

Nurses in pediatric care should be encouraged to acknowledge signs of parental sleep deprivation and negative mood through information and education about the importance of good sleep quality, as this can affect the child's health. Vital sign checks, procedures and medical treatments should be scheduled during the night to prevent interrupted sleep in the hospital, although patient safety must always be prioritized. Parents should be given continuous information and guidance when they care for a child with illness to prevent increased feelings of stress. The pediatric nurse could also encourage and give the parents opportunities to take turns, in order to provide an environmental change, me-time and a chance to regain lost sleep.

To improve parents' sleep in the NICU, parents might provide SSC. In Sweden, shorter periods of SSC are initiated for extremely preterm infants at a median postnatal age of six days (Mörelus et al., 2012). Moreover, SSC improves breastfeeding (Moore et al., 2016) which increases sleep duration prospectively in both mothers (Doan et al., 2007, Doan et al., 2014) and fathers (Doan et al., 2007).

In order to prevent stress-related disorders and maintain the health of the whole family, interventions such as MBSR could be initiated by the nurses in primary child health care and in school health care. This could be done by asking the parents about their own health and life situation during the child's ordinary health care visits.

Future research

The work with this thesis, and the results it has produced, have raised further questions and ideas that would be of interest to study in the future;

To gain a deeper understanding of how parents perceive their sleep and factors influencing sleep when they are accommodated in the pediatric ward, a Scandinavian, qualitative interview study is planned.

The findings from study III indicate that SSC is beneficial for parents' sleep in the NICU. An intervention study to evaluate the effect of continuous SSC on parents' sleep quality is currently in progress, using questionnaires, a sleep log and actigraphy, which is a validated, objective measurement of sleep and physical activity (Lee and Suen, 2016).

A study about parents' sleep and mood when they stay at Ronald McDonald house would also be of interest, in order to find variations in different accommodation possibilities for the families.

To acquire more knowledge about parents' sleep and stress response when they care for an ill child at home, a study measuring sleep quality with

actigraphy, a sleep log and cortisol in saliva or hair is desirable, as the parents may suffer from chronic stress and sleep deprivation. Lately, several studies have proposed to analyze cortisol in hair to measure chronic stress (Herane Vives et al., 2015, Russell et al., 2012, Stalder and Kirschbaum, 2012). Cortisol in hair measures the HPA axis function retrospectively, over periods of months (Karlen et al., 2011), and has previously been studied in mothers and fathers caring for children with disabilities in relation to obesity in the child (Chen et al., 2015).

To confirm the hypothesis that the morning cortisol levels decrease in the pediatric ward, parents' cortisol levels and their experiences of stress need to be followed for several days.

Another interesting finding of this thesis was the parents' poor habitual sleep quality and HRQoL. Is this a result of filling out the questionnaires in hospital or do parents have poorer sleep quality and HRQoL than the reference population? It would be interesting to conduct a population-based study comparing parents sleep quality and HRQoL with a control group of people without children to strengthen the results of this thesis and to generalize them.

Finally, an intervention study to evaluate the effect of physical activity and MBSR on parents' sleep and mood could be of interest for maintaining the health and well-being in the family.

Conclusion

The findings of this thesis highlight the importance of acknowledging parents' sleep, irrespective of the child's age, diagnosis or severity of illness.

The parents reported sufficient sleep in the pediatric ward and the parents' morning awakening cortisol level was statistically significantly lower in the pediatric ward than at home after discharge. No effects were found of the child's diagnosis on the parents' sleep or saliva cortisol.

To be together as a family is of importance for the parents' sleep and mood. The ability to be accommodated with the child in the hospital or care for the child at home may give the parents a feeling of safeness which may help them to relax, despite the stressful situation. When it is beneficial for the child, the whole family should be included in the pediatric care.

The child, nursing staff and medical treatment were the main reasons for nocturnal awakenings. The pediatric nurse should acknowledge the importance of parents' sleep, in hospital and as well as at home. Medical treatment and care at night should be scheduled and sleep should be facilitated for the parents in order to maintain the health and well-being of the family.

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“I have never tried that before,
so I think I should definitely be able to do that”

(Astrid Lindgren; Pippi Longstocking)

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