



Dalarna Doctoral Dissertations

Parenthood and couple relationship after neonatal care

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Abstract

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Background: In neonatal intensive care units (NICUs), parents experience stress and trauma related to separation from the infant, uncertain health outcomes, and difficulties finding their parental role. There is a lack of studies describing how NICU experiences affect parents' mental health and family outcomes long-term, especially in contexts that facilitate rooming-in for both parents. The overall aim of this thesis was to describe mental health, couple relationships, and parenting outcomes in parents from NICUs compared to parents from maternal units (MUs) and to explore NICU parents' experiences of family relationships up to 3 years postpartum.

Methods: Study 1 (papers I–III) used a comparative longitudinal cohort design in which parents from NICUs and MUs answered four questionnaires during the first 3 years postpartum. Study 2 (paper IV) employed a constructivist grounded theory design where interviews with 20 NICU parents were conducted up to 3 years postpartum. **Results:** There were no differences between NICU and MU parents regarding symptoms of depression (EPDS) 1 month postpartum (I), the quality of their couple relationships (QDR36) 1 year postpartum (II), and their parenting sense of competence (PSOC) and coparenting (PPC) three years postpartum (III). Rooming-in together as parents with the infant in the NICU and social support were positively associated, and symptoms of depression were negatively associated with the outcomes of the QDR36 and PSOC. QDR36 was also associated with PSOC and PPC outcomes. Study 2 (IV) showed that being together in NICU and having stability and support made parents experience being in a “safe zone,” which strengthened their relationship after discharge. Separation, instability, and a lack of support negatively influenced parents' well-being and the couple relationship.

Conclusion: In NICU contexts that facilitate family togetherness, parents' symptoms of depression, the quality of their couple relationship, and their parenting do not differ from MU parents. To optimize long-term family outcomes, the togetherness of parents and infants, and support from staff, family, and friends, should be prioritized during NICU hospitalization. Furthermore, there is a need for better emotional and practical support after discharge for parents at risk for decreased mental health and a strained couple relationship.

Keywords: comparative, couple relationship, mental health, NICU parents, parenting, rooming-in, social support

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I would like to dedicate this thesis to all parents initiating their parenthood in a NICU.

I would also like to dedicate it to my sister, who has been there for me, providing support and laughter, in the middle of her own journey.

List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals:

- I. Persson C, Ericson J, Salari R, Eriksson M, Flacking R. *NICU parents' mental health: A comparative study with parents of term and healthy infants*. *Acta Paediatrica*, 2023, 112(5):954–966.
- II. Persson C, Ericson J, Salari R, Eriksson M, Flacking R. *Quality of couple relationship and associated factors in parents of NICU-cared infants during the first year after birth*. *Journal of Perinatology*, 2024, 44(12):1738–1745.
- III. Persson C, Ericson J, Eriksson M, Salari R, Flacking R. *Parenthood after neonatal care – parenting sense of competence and coparenting three years after discharge*. *Early Human Development*, 2026, 214:106462.
- IV. Persson C, Ericson J, Flacking R. *Parental well-being and the couple relationship the first years after experiencing neonatal care – A grounded theory study*. Submitted.

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Abbreviations

BFST	Bowen Family Systems Theory
CGT	Constructivist Grounded Theory
CHS	Child Health Services
COVID-19	Coronavirus disease 2019
EFCNI	European Foundation for the Care of Newborn Infants
EPDS	Edinburgh Postnatal Depression Scale
FCC	Family-Centered Care
gw	Gestational Weeks
IFCDC	Infant- and Family-Centered Developmental Care
MCAR	Missing Completely At Random
MOS-SSS	Medical Outcomes Study Social Support Survey
MU	Maternity Unit
NICU	Neonatal Intensive Care Unit
PPC	Parenting Problem Checklist
PSOC	Parenting Sense of Competence
QDR36	Quality of the Dyadic Relationship
RAND-36	Research ANd Development Health Survey
SSC	Skin-to-Skin Contact

Background

In the neonatal unit

The infant

Globally, approximately 30 million infants require specialized or intensive care in a hospital each year, and half of these infants are born preterm, before 37 gestational weeks (gw). The percentages of infants needing care in a neonatal intensive care unit (NICU) differ between countries; in total, 18% of all infants worldwide require care in an NICU (1, 2). In Sweden, about 10% of all infants (10,000–11,000 infants) need care in an NICU each year, affecting not only these infants but also their parents (3). About half of Swedish NICU infants are born preterm, which is among the lowest incidences of preterm infants in the world. In addition, Sweden has among the highest survival rates for extremely preterm infants (1-3).

The most common medical reasons why term infants (≥ 37 gw) require neonatal care are difficulties breathing sufficiently, infections, hyperbilirubinemia, and hypoglycemia. Preterm infants have the same reasons for hospitalization as term infants but more often require care for multiple medical reasons and for a longer duration of time. Moreover, they also require other forms of supportive care because of their immaturity; these include extended thermal regulation, nutritional support, and breathing support (1, 3, 4). Thermal regulation is preferably supported by skin-to-skin contact (SSC) between parent and infant. Other sources of heating include warm madras in bed and incubators (5, 6). Preterm infants have difficulties coordinating their eating (suckling, swallowing, and breathing), and they have shorter durations of time awake. Therefore, they often need supplementary feeding by a nasogastric tube until full oral feeding (4). Immature breathing may necessitate mechanical breathing support from a ventilator, continuous positive airway pressure, or high-flow nasal cannula therapy (3-5).

Preterm birth is divided into groups based on gestational age at birth: extremely preterm (< 28 gw), very preterm (< 32 gw), and moderately preterm (< 37 gw). Preterm infants born in earlier gw require intensive care for the longest period of time due to their immaturity (1, 5). The neonatal care in Sweden is organized by level of care, where most NICUs are level 2-3. Level

2 NICUs care for infants born ≥ 32 gw, and level 3 care for infants born ≥ 28 gw. Level 3 NICUs offer more advanced breathing support than level 2. The highest level of care is level 4; level 4 NICUs involve caring for extremely preterm infants (< 28 gw) and offer full intensive care (i.e., high-frequency ventilation and surgery). Each of the six regions in Sweden has a level 4 NICU, where the most premature and/or ill infants are cared for (3, 7, 8). In total, there are 38 NICUs in Sweden (3). Since not every hospital offers every level of care, infants requiring a high level of care may need to be transported far away from their home; when stabilized, they are transported back to their local NICU (3). Depending on illness at birth, gestational age, and immaturity, some infants may simply need extra breathing support for a few days, whereas others might need intensive care for months, sometimes in different NICUs (1, 3).

Giving birth to a sick or preterm infant

Most parents of infants in NICUs experience the birth as traumatic (9-11). Mothers experience the birth as traumatic if they believe the infant or themselves will be seriously injured or die, or if they experience intense negative feelings such as fear, helplessness, and dread (12). About 70% of mothers of preterm infants fear for their infant's life while giving birth (13). Fathers also experience birth as traumatic if they fear for the infant's and/or the mother's life/health, or if they experience feelings of helplessness or perceive themselves as being uninformed or abandoned by staff (9). Traumatic birth experiences are subjective and have been described as "a series of related experiences of, and negative psychological responses to childbirth. Physical trauma in the form of injury to the infant or mother may be involved, but is not a necessary condition" (p2, 14).

Many parents and their infants in Sweden are routinely separated immediately after birth due to the infants' and/or the mothers' health conditions (15-17). Being separated from the infant immediately after birth is mentioned as traumatic (18-20) and may entail a situation in which the parent feels powerless and unimportant (21), which also may limit parent-infant bonding (22). Both Swedish law and government agencies state that separating infants from their parents should be avoided. The Convention on the Rights of the Child has been law in Sweden for 6 years, and it states that no child should be separated from their parents unless it is necessary for the child's health (23). Moreover, the Swedish National Board of Health and Welfare writes the following in their recommendations for neonatal care: "ensure that children and parents do not need to be separated" and "ensure parental involvement in the care of the child, by actively encouraging their presence and care for the child" (p.16, 24).

Being a parent in the NICU environment

The NICU is an unfamiliar and stressful environment for parents to enter; in it, they encounter many different types of medical equipment and numerous staff, and they may also face surreal, chaotic, and deeply distressing situations in the health and care of their infants (11, 25). NICU parents are more likely to exhibit decreased mental health, such as symptoms of depression or psychological trauma, compared to other parents. These symptoms appear to decrease when parents are included in their infant's care (20, 26). Mental health is part of well-being, and examples of decreased mental health include symptoms of depression, psychological trauma, and anxiety (27).

There have been significant advances in the medical care of NICU infants over the last few decades (28, 29), and there is a paradigm shift in the nurturing care of infants going on, in which the importance of parent-infant closeness and bonding has been acknowledged (28, 29). A major stressor for NICU parents is the challenge of finding their longed-for parental role in the stressful and unfamiliar NICU environment, which offers limited possibilities of caring for their newborn as imagined (30, 31). Different approaches to family-centered care (FCC) have been implemented in NICUs (32). With these approaches, parents are supposed to assume the role of primary caregiver in partnership with staff (28, 29, 33). However, there have been discussions that the infant's best interests may be lost in the FCC framework (34). Thus, the framework has been updated by a group of experts from the European Foundation for the Care of Newborn Infants (EFCNI) to include the best evidence available for the development of the infant, such as a supportive sensory environment and very early and continuous SSC. This updated framework is known as infant- and family-centered developmental care (IFCDC) (35). FCC and IFCDC have many benefits for both the infant and the parents, such as stabilized infant physiological parameters (36, 37), lower infant mortality rates (38), more successful breastfeeding (36), increased bonding and attachment (36, 39), increased parental well-being (40-42), and a strengthened parenting role, all of which improve long-term outcomes regarding the child's cognitive and socioemotional development. It has even been suggested that NICU parents' symptoms of depression might decrease to the same level as in the general population when the care is family-centered and when parents have opportunities to be close to their infants (19, 26, 43, 44). However, despite knowledge about these benefits, the international implementation of such approaches has been slow (28, 29, 32, 33, 35, 40, 41). To promote family closeness during NICU hospitalization, which is a necessity in FCC and IFCDC, parents need facilities to stay 24/7 during hospitalization (26, 45). Facilities for parents to room-in together with their infant differ between countries, and

even within countries with generous parental leave and highly developed NICU care, such as in Sweden (7, 28, 32, 45, 46).

Many parents in NICUs exhibit symptoms of psychological trauma, anxiety, or depression due to their experiences of a stressful birth, separation from the infant, having a sick or preterm infant with uncertain outcomes, and unclear expectations regarding their parental role during hospitalization (19, 20). However, there is evidence that parental presence and infant-parental closeness in NICUs have health benefits for the infants and their parents during hospitalization and after discharge. Most studies evaluating parental presence and closeness in NICUs have only included preterm infants and their parents (19, 20, 25, 26, 40-47).

Support during hospitalization

Even in units with an FCC approach, parents are a vulnerable group. Mothers may blame themselves for giving birth prematurely and feel a large burden regarding being the primary person to nurse the infant. Fathers may experience strain when trying to live up to the assumed expectations of mothers, staff, employers, and extended family. Both parents can have an ambivalent relationship with the staff; sometimes they feel ignored and uninformed, whereas sometimes they feel supported (11, 48).

Social support is a broad concept containing different kinds of support/dimensions: These include informational, practical/tangible, and emotional support (49, 50), as well as affectionate and positive social interaction (51). Support is a key part of FCC and IFCDC: The main elements of both FCC and IFCDC are the parents having 24/7 access to their infant, the staff-parent partnership (informational and practical support), and emotional support for parents in their parental role (33, 35).

A study on parental satisfaction with FCC, conducted in 15 countries, showed that parents were least satisfied with the physicians-parent partnership during medical rounds and with the emotional support provided by staff (26). It has also been shown that staff, through their actions, can be “gatekeepers” who limit parents’ possibilities of participating in the care of their infants (33). The EFCNI’s expert group states that healthcare professionals require counselling and training in supporting parents: “Well-trained and supported healthcare professionals who receive counselling and regular clinical supervision in communicating with and providing emotional support for parents are the prerequisite for proficient successful implementation of IFCDC” (p.2, 35).

If parents have their own room (single family room) in the NICU, their parental presence and involvement in care, the support they receive from staff, and their mental wellbeing increases (43, 52). NICU parents cope with the

NICU experience more easily when they are together, and mothers feel less stress if their partner is present. It has also been shown that parents who are together during hospitalization are more satisfied with the NICU care (53). However, it has been suggested that even if parents are together, they may have difficulties supporting each other because of their different coping strategies; fathers seem to be more practical and problem-solving, while mothers are more occupied with strong emotions regarding the unexpected situation of being a mother to a preterm infant (11, 48).

It is also important for parents to receive social, emotional, and practical support from their family and friends (17, 54, 55), and that their family and friends get to meet the infant already in NICU (17). Social support can take the form of company and conversations that help parents maintain their own identity beyond being NICU parents. Emotional support includes allowing them to talk about their experiences and share personal matters. Practical support comprises many activities, such as helping out with meals, taking care of older siblings, taking care of their home, and sometimes even financial support (54). Support from family and friends is important for coping, managing trauma, and increasing parents' satisfaction in NICUs (54-56). However, it is difficult for family and friends to know how and when to provide support, and parents' support needs may vary depending on the changing and challenging circumstances they face (54, 56). Another hindering factor for receiving support is visiting restrictions for friends and family; in Sweden, 80% of NICUs had such restrictions in 2018 (7).

To be present in NICUs 24/7, parents need to have the financial means to be off work during this time. How the welfare system functions and whether families have insurance are of the highest importance for their possibilities of being present in the NICU taking care of their infant (57, 58). In Sweden, parents in NICUs receive economic support, with no private insurance required. Both parents get temporary parental leave concerning ill children and do not have to take any days from general parental leave. This makes it possible for most parents in Sweden to be off work and care for their infants in the NICU.

Since NICU parents go through a challenging period and may have different emotional responses to the experience, it is recommended that both social workers and psychologists work in the NICU (59). In 2018, all NICUs in Sweden had a hospital social worker linked to the unit, but 56% of the units lacked access to a psychologist (7). Several studies indicate that parents in NICUs need better-tailored support from both nurses and physicians in which their individual needs are acknowledged (48, 55, 60).

Coming home

The infant

After a traumatic birth and worrying NICU journey, parents are discharged home with their infants. The amount of NICUs providing early discharge and home care for families is increasing. In the Nordic countries, almost every NICU provides some sort of home care; some units provide home visits for checkups of the infant, and in other NICUs the parents must take the infant to the hospital for checkups (61). NICU infants may have additional care needs after discharge when compared to healthy and term-born infants, due to their prematurity or illness at birth (62). All preterm infants are at higher risk for long-term medical and neurodevelopmental complications, and extremely preterm infants have the highest risks (63-65). Lower gestational age at birth increases the risks of, for example, respiratory and attention disorders (64, 66), speech delays (67), and hearing and visual impairment (68). In Sweden, the rates of severe neonatal morbidity or mortality in preterm infants are among the lowest worldwide and have not changed in the last decade (3). A national follow-up program for high-risk infants discharged from NICUs has been established at Swedish pediatric clinics. In the program, it is stated that the infants should have regular follow-ups with a multidisciplinary team consisting of a physician, pediatric nurse, psychologist, physiotherapist, and, if needed, a nutritionist (69).

Being a NICU parent at home

Increased parental presence and involvement in care during NICU hospitalization facilitates earlier discharge, as parents feel more confident in caring for their infants. However, NICUs often lack both medical and informational/practical guidelines to prepare parents for discharge (61), and parents therefore often feel unprepared when it is time for the family to go home. They experience a mix of joy, worry, fear, and practical challenges (62, 70), and they attempt to structure a new reality at home, being both parents and primary caregivers (62). The experiences from the NICU and at home after discharge influence their mental well-being and parenting (62), and therefore, they require emotional support, information, and sometimes financial support (71). Parents of preterm infants may have feelings of alienation from other parents because their infants have care needs that term infants do not normally have. They may also socially isolate themselves from family and friends due to risks of infections (70, 72).

Symptoms of depression are more common in mothers of NICU infants compared to mothers of term and healthy infants (20, 73, 74). The symptoms

decrease over time (26, 73), but about 30–50% of those with depression symptoms continue to suffer from prolonged postnatal depression beyond the first year (20, 75, 76). Long-term studies regarding symptoms of depression among NICU fathers are scarce; these studies have only measured depression symptoms for some months after discharge and only include fathers of preterm infants (20, 26, 77). Reducing levels of depression symptoms in parents has clinical relevance, since these symptoms have both short- and long-term negative consequences for parents, their relationship to their infant, and the infant's development (20). Studies indicate that NICU parents' levels of depression symptoms might decrease with a family-centered approach (26, 78) and that this approach might even reduce symptoms of depression up to 2 years after discharge (78). Furthermore, parents' health is not only a concern for the parents; associations between prematurity and later developmental outcomes for the child are compounded by the parents' health and family life. Thus, it is important to ensure parents' well-being and supportive relationships, not only for parents themselves but also for infants' development (19, 20, 79-81).

There is no routine counselling for Swedish NICU parents after discharge, but it is stated in the national follow-up program for high-risk infants discharged from NICUs that counselling should be offered when needed (69). In 2018, none of the 34 neonatal units in Sweden that answered a survey provided any systematic support to parents after discharge from the NICU (7). Several studies have indicated that the support offered by other healthcare services, mainly by child health services (CHS), is not tailored to the needs of NICU parents (82, 83). Thus, there appears to be a lack of professional counseling support for parents after discharge from NICUs.

Parenthood and the couple relationship

People become parents and enter parenthood when they have a child (27, 84). Becoming a family and entering parenthood is life-changing for most people, where the partners go from two people giving each other attention to having an infant who needs their full attention (85). Going into parenthood together is both joyful and stressful. Parents may experience feelings of closeness and completeness in becoming a family, but also potential strain in the couple relationship (27, 85-91). In the general population, satisfaction in couples' relationships decreases after entering parenthood and increases again about 7 years later. Having paid parental leave, fathers taking parental leave, and a more equal workload related to parenting and household tasks are positively associated with higher satisfaction in the couple relationship (27). Factors such as a parent's own health, the relationship with the child, changes in relationships with family and friends, the economy, and sleep deprivation also

contribute to how the couple's relationship and parenthood are experienced (85-91). In a study from Sweden, findings showed that for first-time parents, their relationship quality at 6 months after birth was associated with their mutual support and adjustment to parenthood, intimacy and love, communication, and social support (92).

The NICU environment makes it more challenging for parents to support one another, communicate effectively, and show love to each other at the beginning of their parenthood (93, 94). Studies examining the couple relationship among NICU parents show diverse results. Some studies have shown that couple relationship quality decreases from admission to discharge (93, 95), which may lead to long-term negative effects on the couple relationship (96, 97). However, it has also been shown that the couple relationship might be strengthened by the NICU experience if the parents communicate their experiences and feelings to each other and manage to support each other through the stressful NICU experience (94). Thus, while NICU hospitalization might be challenging for the couple, since they are exposed to more worries and stress at the beginning of their parenthood, they may also provide stability and support for each other in a stressful situation, which can strengthen their relationship (94, 98). The quality of the couple relationship is of importance not only for the well-being of the parents (99) but also for their coparenting (100), their parenting sense of competence (101), and subsequently for the development of their child (100-103).

Parenting

Parenting refers to the actions parents take in their parenthood, actions that aim to care for their child and prepare them to manage life's tasks (104). Examples of parenting actions are raising, supporting, and socializing the child (27). Parents who have a sick or preterm infant may perceive a loss of their parental role in the beginning of their parenthood due to the NICU's unfamiliar environment, its medical equipment, staff taking care of their infant, and unclear expectations of them as parents in the NICU (19, 20, 31).

How a parent feels regarding their own parenting can be described by parenting sense of competence, which comprises two dimensions: 1) how competent and confident the parent feels in handling child-rearing issues, also known as parental efficacy, and 2) the enjoyment and fulfillment the parent feels within their parental role, also known as parental satisfaction (105). Higher parental efficacy and satisfaction affect parental mental health, parental-infant attachment and interaction positively. Parental mental health issues, problems in attachment and interaction are associated with dysfunctional parenting (102, 105-107). Several studies show that parents of preterm infants are

more likely to feel higher levels of parenting stress, exhibit more controlling behavior, have less positive interactions with their infants, and experience poorer family functioning (108-112). Parenting sense of competence is important for the development of the child (101, 113-116), and children who begin their life in a NICU may have more developmental challenges than children born term and healthy. Studies on parenting sense of competence in parents of preterm infants have shown diverse results (116-118). In one study, symptoms of depression and a lack of support were negatively associated with parenting sense of competence 1 year after discharge (116), and in another, support during the transition to the home was positively associated with parenting sense of competence 30 days after discharge (117).

Another important aspect of parenting is how parents relate to each other and cooperate in raising their children. Coparenting is essential, since it affects child development, attachment, and the whole family's well-being and functioning (44, 100, 102, 103). Parents with a better couple relationship 6 months postpartum tend to have better coparenting when the child is 3 years old (119).

There are numerous studies examining the developmental or medical outcomes of NICU infants, as well as the challenges parents (especially mothers) of preterm infants experience. However, there is a lack of studies examining long-term parental outcomes in parents of all NICU infants (not just preterm infants) in contexts with the opportunity for both parents to room-in together with the infant during hospitalization (44). Studies on parental outcomes have even been requested by NICU parents (120).

Theories and terms

In this doctoral thesis, Bowen family systems theory (BFST) and the ecological model of coparenting are employed when interpreting the results. They are described in general below and are further described in relation to NICU parents' togetherness, couple relationships, parenting, social support, and mental health in the discussion section.

Bowen family systems theory

In BFST, Kerr and Bowen describe how the interplay between individuality (differentiation of self) and togetherness leads to emotionally significant relationships within couples, families, and the extended family. The family can be seen as an emotional unit in which every member's feelings and behavior (emotional processes) affect one another and govern the relationship. A family member's well-being affects the other family members, and how they are affected depends on their differentiation of self. For example, people with low self-differentiation are more likely to be in symbiosis with another individual's negative feelings, and the interplay between individuality and togetherness becomes unbalanced. This interplay needs to be balanced to establish stability, cohesiveness, and cooperation within relationships. In balanced and healthy relationships, individuals put an equal amount of energy into the relationship, which increases their sense of togetherness. For families who are exposed to stressful events and do not have a balance between individuality and togetherness, the subsequent chain of emotional reactions within their emotional unit may be a greater source of stress than the event itself. On the other hand, if the relationship is in balance, an individual's decreased well-being can be appropriately managed in that relationship (121).

At the center of the theory is the individual and the nuclear family (one-generation parents and their children); surrounding the nuclear family is the extended family (closest family and friends). Those in the nuclear family affect each other the most, but everyone in the system affects everyone else (121, 122). People manage reactions and well-being primarily through their relationships with others; the extended family can therefore be "a significant stabilizing force" for a nuclear family experiencing stress and decreased well-

being (p.267, 121). This highlights the importance of receiving support from family and friends during NICU hospitalization to increase relational resilience and well-being.

BFST was selected because the NICU family (the parents and their infants) is central to this thesis, as the parents' well-being, relationships, and social support may affect the development of the infants. In the BFST, the nuclear family is also at the center, and surrounding the family is the extended family (closest family and friends). The theory highlights how members of the nuclear family affect one another, and how important it is to receive support from family and friends (121). BFST has similarities with FCC approaches, since both have the family at the center and highlight the importance of social support (35, 121). However, FCC is used within NICUs during hospitalization, and the main focus of this thesis was the time after discharge.

Ecological model of coparenting

Feinberg developed an "ecological model of coparenting" based on family systems theories, relational theories, and previous studies on coparenting. He defines coparenting as "the extent to which parents relate to each other," describing how individuals with shared responsibility over a child support and coordinate their child-rearing. Coparenting is described as a key aspect of family functioning that affects parenting (parental adjustment, i.e., efficacy and well-being) and subsequently the child's adjustment (socioemotional and cognitive development). The model defines coparenting and its four components: child-rearing agreement, division of (child-related) labor, support for/undermining the parental role, and joint family management. Each component affects the others. The model also describes the factors that affect parents' coparenting: the parents' overall relationship, support, individual characteristics such as gender and mental health, and the child's characteristics. One part of the model concerns interparental conflict, describing how such conflicts may affect children's outcomes from infancy throughout childhood and beyond. Coparenting and effective conflict resolution are important for family functioning, family well-being, and children's developmental outcomes (100).

The focus of this thesis is NICU parents' outcomes. However, these outcomes may affect the whole family, including the child. NICU infants may have more medical problems or developmental challenges than healthy and term infants, and NICU parents may struggle more to find their parental role in the beginning of their parenthood. NICU parents and infants are, therefore, a more vulnerable group. The ecological model of coparenting has been employed in the discussion, since it acknowledges the importance of factors

influencing coparenting, and that problems in coparenting may affect family functioning and the development of the child (100).

The terms “mother” and “father”

In this thesis, a decision was made not to refer to the father/non-birthing mother as a “partner” when writing about them as parents, as they are indeed parents, not just partners. Using the terms “birthing parent” and “non-birthing parent” would be repetitive in this text, so for simplicity, we chose the terms “mother” and “father,” though we acknowledge that some parents did not identify as such. The term “partner” is used when the text refers to the parents as partners within the couple relationship.

Rationale

NICU parents experience more distressing situations at the beginning of their parental journey compared to parents of term and healthy infants, including more traumatic birth experiences, uncertain outcomes for their infants, separation from the infant, and difficulties finding their parental role in the NICU environment. These experiences are key risk factors for decreased parental mental health, and parental mental health is in turn associated with family outcomes, such as couple relationship quality, parenting outcomes, and subsequent child development.

Parental involvement in care and parental presence are known as important factors in preventing decreased parental mental health and promoting the parental role in NICUs. However, most studies examining NICU parents' outcomes after discharge have focused on the short term, have been conducted on mothers of preterm infants only, and have been conducted in contexts in which parents have few opportunities to stay together at the NICU with their infant 24/7. There is a lack of research evaluating how parents' well-being, couple relationships, and parenting are affected long-term in a context where both parents had the possibility of rooming-in together with the infant during NICU hospitalization.

Aims

The overall aim of this thesis was to describe mental health, couple relationships, and parenting outcomes in parents who initiated their parenthood in a NICU, compared to parents of term and healthy infants, up until 3 years of the infant's age, and to explore NICU parents' experiences of family relationships after discharge.

Specific aims

Study 1, paper I

To compare mental health in parents of NICU cared infants and parents of term and healthy infants before birth and up to 1 month after discharge.

Study 1, paper II

To describe factors associated with NICU parents' quality of couple relationship 1 year after birth. Further, we aimed to describe the trajectory in the quality of the couple relationship the first year after birth, compared to parents of term and healthy infants.

Study 1, paper III

To compare parenting sense of competence and coparenting in parents of NICU cared infants who had possibilities of rooming in, and parents of non-NICU infants 3 years postpartum. In addition, the study aimed to identify factors that may influence NICU parents' sense of competence and coparenting.

Study 2, paper IV

To explore how parents of NICU infants experienced their first years at home after NICU hospitalization, with a focus on their relationship with their partner.

Methods

Study designs

Study 1 featured a comparative longitudinal quantitative design in which parents answered questionnaires at 1 and 6 months after discharge and when the infants were 1 year and 3 years old. In paper I, cross-sectional data were used from the 1-month questionnaire; in paper II, data were used from the 1-month, 6-month, and 1-year questionnaires; and in paper III, data were used from the 1-month, 1-year, and 3-year questionnaires (Table 1).

A qualitative design using a constructivist grounded theory (CGT) approach formulated by Charmaz (123) was chosen for Study 2. The method acknowledges social contexts, interactions, different viewpoints, subjectivity, and the researcher's involvement and interpretations. The aim of CGT is to generate a useful theory that increases the knowledge about social processes in specific contexts (123, 124). Data were collected through individual or couple interviews up to 3 years after discharge.

Parental involvement in the project

This project, Parenthood After Neonatal Care – PANC, was designed together with parents of children who required neonatal care when born, to include perspectives important for the studied population. This parent advisory board had experiences from different NICUs in Sweden and comprised single and cohabiting parents as well as parents of extremely preterm infants (<28 gw), very preterm infants, and preterm infants. They were involved in developing the aim of the project, discussing how parents could be informed and recruited, and testing the instruments and questionnaires. They were also invited to discuss some of the results.

Other parents of NICU infants who were not part of the advisory board were invited to a meeting discussing circumstances and factors that could influence NICU parents' family life and couple relationship in the long term, and which of those that would be relevant and valuable to explore in the studies. This group discussion was held during the planning phase of the studies. As a result of the discussions in this group, the parent advisory board, and previous research, this study includes background questions on different

topics (i.e., birth and NICU experiences, economic factors, and support from society), as well as instruments regarding health, quality of the couple relationship, social support, and parenting.

Table 1: Design and description of Studies 1 and 2.

Study 1	Design	Data collection	Participants	Primary outcomes
Paper I	Quantitative. Cross-sectional comparative cohort	Questionnaires	439 NICU parents 484 MU parents	Symptoms of depression (EPDS) 1 month after discharge. Traumatic birth and EPDS.
Paper II	Quantitative. Comparative longitudinal cohort	Questionnaires	323 NICU parents 364 MU parents	Quality of the couple relationship (QDR36) 1 month to 1 year postpartum. Associated factors.
Paper III	Quantitative. Comparative longitudinal cohort	Questionnaires	275 NICU parents 286 MU parents	Parenting competence and coparenting (PSOC and PPC) 3 years postpartum. Associated factors.
Study 2	Design	Data collection	Participants	Primary outcomes
Paper IV	Constructivist grounded theory approach	Qualitative Interviews	20 parents from NICUs (16 individual and 2 couple interviews)	Experiences of the couple relationship in the first years after discharge from NICU.

NICU = neonatal intensive care unit; MU = maternity unit; EPDS = Edinburgh Postnatal Depression Scale; QDR36 = Quality of the Dyadic Relationship; PSOC = Parenting Sense of Competence Scale; PPC = Parenting Problem Checklist

Setting

Parents from six NICUs were recruited over a year, from March 2020 to March 2021. The NICUs varied in level of care, with one level 2 NICU, four level 3 NICUs, and one level 4 NICU. In addition, parents from four maternity units (MUs) were recruited over 10 weeks in 2020 (5 weeks in the spring and 5 weeks in the fall). All NICUs and MUs were situated in the central and southern regions of Sweden. During this period, there were visiting restrictions due to the coronavirus disease 2019 (COVID-19) pandemic. At all six NICUs, the parents had access to their infants 24 hours a day without any restrictions (unless they had COVID-19 symptoms). In five of the NICUs, both parents had their own beds and could stay at the unit day and night, and in those five units, the mother could get care from the MU when she was staying in the NICU, an approach known as couplet care. Siblings were allowed

to visit in the level 4 unit, but not in any other NICU or MU. Other family and friends were not allowed to visit at any NICU or MU. In two MUs, there were restrictions for the fathers, such as not being able to stay at the unit with the mother and infant during the year 2020. In the other two MUs, the fathers could stay if there was space, but there was an increased need to have two mothers sharing a room, which limited these possibilities.

The number of staff was the same before and during times of COVID-19 restrictions in all but one NICU, which had one to two staff members fewer during the day shift. The number of experienced physicians and neonatologists did not change in any unit during times of COVID-19 restrictions. At all NICUs and in each shift, in total, there were about 50% nurses and 50% assistant nurses working, often with less staffing on evening and night shifts. The amount of specialized nurses in the NICUs varied between 25% to 75% of all nurses in the units. All NICUs had access to a counsellor, and four of them also had access to a psychologist. The provision of services by hospital social workers and follow-up care for infants functioned as usual in all units. No NICU had any routine psychosocial support for parents after discharge.

The staffing in MUs was the same before and during times of restrictions at all but one unit, which reduced staffing during the day shift to the same number as during the nights. The other units kept more staff during the day shift than the night shift. About half of the total staff were nurses or midwives (50–90% midwives), while the other half were assistant nurses. All MUs had counsellors available to be contacted, and one MU also had a psychologist. All follow-up care functioned as usual, with checkups for the infant at the MU/reception during the first week postpartum. Thereafter, checkups were performed by CHS.

Inclusion and recruitment

During hospitalization, parents received information about the studies through posters and brochures. In the brochure, they were also provided with a link to a website featuring video clips about the studies. All written information and the video clips were available in four languages: Swedish, English, Arabic, and Somali. Arabic and Somali were chosen because they were the most commonly translated languages by an interpreting service in Sweden at the time of the study.

Parents were invited to participate in Study 1 and Study 2 if they were at least 18 years old, if they could speak any of the four included languages, if they had been discharged from the NICU or MU to their home (and not to another unit in the hospital), if social services had not been involved in caring

for the infant, and if their infant did not require palliative care. However, for the interviews in Study 2 specifically, the parents had to understand and speak Swedish, since the researcher conducting the interviews was Swedish-speaking, and there were no resources to use an interpreter.

Study 1

Information about the study, the consent form, the first questionnaire, and a prepaid envelope to return the forms were sent to the parents 1 month after discharge. In total, 4,456 parents from both NICUs and MUs were invited. Of the 954 parents who returned the forms, 31 were excluded because they had only sent back the consent form or the questionnaire. Thus, 923 parents (21%) were included in Study 1. Those who consented received follow-up questionnaires 6 months after discharge and 1 year and 3 years postpartum. Swedish-speaking parents could choose to get the follow-up questionnaires by email (RedCap, Research Electronic Data Capture, version 12.0.13, hosted at Uppsala University). Arabic-, Somali-, and English-speaking parents had to receive the questionnaires by post, due to limited time and resources for transferring their questionnaires to RedCap. Participants were informed that they could withdraw their consent whenever they wanted, with no explanation required. The follow-up rates of participating parents through the study period of 3 years were 63% among NICU parents and 59% among MU parents. See Figure 1 for follow-up rates at every time point.

Parents consenting to participate received two reminders to answer the follow-up questionnaires. Parents who wanted to receive the questionnaire by email got one reminder by SMS and a final reminder by post. Parents who wanted the questionnaire by post got the first reminder by post and the final by SMS.

Of the 923 participating parents who answered the first questionnaire, 58% ($n = 532$) received the second questionnaire by post, and 42% ($n = 391$) received it by email/RedCap, in accordance with their wishes. The response rates for the second questionnaire 6 months after discharge were as follows: 86% ($n = 456$) by post and 64% ($n = 251$) by email. The participants who had received the questionnaire through email and who were not responding ($n = 140$) got the second reminder by post, and of those, 54% ($n = 76$) ended up responding by post. Thus, ultimately, the amount of participants answering the 6-month questionnaire by post was 68% ($n = 532$), and by email 32% ($n = 251$). The third questionnaire 1 year postpartum was also sent by both post and email, with 74% ($n = 510$) answering by post and 26% ($n = 177$) answering by email. Of the answers by post, 90 were from participants wanting email who had received reminders by post. Due to many reminders and lower

response rates for the questionnaire via email, a decision was made to send the 3-year questionnaire by post only.

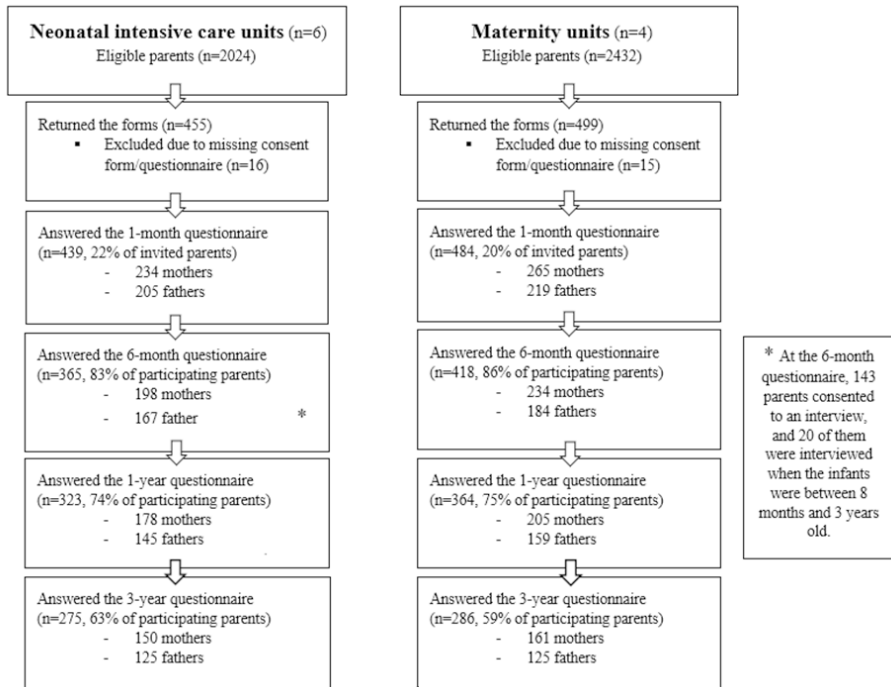


Figure 1: Flowchart of participating parents over 3 years

Study 2

Participants from NICUs in Study 1 could tick a box at the end of the 6-month questionnaire to indicate that they also consented to participate in the interview study, focusing on their relationship with their partner, other family relations, and their need for support after discharge. In total, 143 NICU parents consented to be interviewed (Fig 1). Purposeful sampling was used to select participants based on their characteristics, with the aim of representing a diverse group of NICU parents. The characteristics considered were gestational week of the infant at birth, gender (mother/father), age, place of birth (inside/outside Sweden), education, having previous children, multiple births (twins/triplets), and age of the infant at the time of the interview. The parents received more detailed information about the interviews through email and/or telephone, and if they still consented to participate, they received a consent form. They were interviewed individually or as a couple according to their wishes, and they were informed that they could stop the interview and

withdraw their consent whenever they desired. In total, 20 parents were interviewed; there were 16 individual interviews and 2 couple interviews.

Data collection, Study 1

Data collection at all time points comprised questions about the parents' sociodemographic background (e.g., employment, civic status, number of children, health) and instruments regarding health, relationships, support, and parenting. Several different instruments were first tested and discussed by the advisory board of NICU parents involved in designing the study. Not all chosen instruments were available or validated in all study languages (Table 2). All study instruments were validated in English; instruments not available in Swedish were translated into Swedish and discussed by native English- and Swedish-speaking researchers. Instruments not available in Arabic or Somali were translated into the target languages by professional interpreters. Then, other independent interpreters translated these versions back into the original language to detect eventual discrepancies. The discrepancies were resolved through iterative discussions with NICU staff and senior lecturers who were fluent in both languages until a consensus was reached. The translation procedure was inspired by a guideline written by the Professional Society for Health Economics and Outcomes Research (125). The feasibility of the full questionnaire was then tested by the same group of parents designing the study, as well as by other NICU and MU parents known by the authors.

Table 2: Instruments validated and/or available in the four study languages

Instrument in languages	Swedish	English	Arabic	Somali
RAND-36	Yes	Yes	Yes	No
EPDS	Yes	Yes	Yes	Available, not validated
MOS-SSS	No	Yes	No	No
QDR36	Yes	Yes	No	No
PSOC	Available, not validated	Yes	No	Available, not validated
PPC	Available, not validated	Yes	No	No

RAND-36 = The Research ANd Development 36-item health survey; EPDS = Edinburgh Postnatal Depression Scale; QDR36 = Quality of Dyadic Relationship; MOS-SSS = Medical Outcomes Study Social Support Survey; PSOC = Parenting Sense of Competence scale; PPC = Parenting Problem Checklist

Questionnaires were sent four times: at 1 month and 6 months after discharge, and when the infant was 1 year and 3 years old. The first questionnaire (at 1 month) included the most background questions, such as those regarding pregnancy, birth, and hospital experience (e.g., length of hospital stay, characteristics of the infant, and whether the parents were rooming in together in the unit). To capture whether the parents were rooming in with each other and the infant during the hospital stay, they were asked where they mainly slept (at the NICU, at a hotel/the MU, or at home), where their partner was staying, and whether they slept in the same room as the infant. The NICU parents answered five questions about their time in the NICU, and mothers had four additional questions related to giving birth. To capture experiences of a traumatic birth, three questions based on the Diagnostic and Statistical Manual of Mental Disorders criterion A1 (two questions) and A2 (one question), inspired by Devilly et al. (12), were used: “During and immediately after birth, did you: 1) believe you/your partner or your baby would be seriously injured; 2) believe you/your partner or baby would die; 3) have intense negative feelings (for example, fear, helplessness, and feelings of dread)?” Parents answered the three questions by stating “yes” or “no.”

The following three questionnaires (at 6 months, 1 year, and 3 years) also contained sociodemographic questions about civil status, health, and occupation, and they were the same for NICU and MU mothers and for NICU and MU fathers.

Instruments included in the questionnaires at different time points were the Research AND Development health survey (RAND-36, one item), the Edinburgh Postnatal Depression Scale (EPDS), the Medical Outcomes Study Social Support Survey (MOS-SSS), the Quality of Dyadic Relationship (QDR36), the Parenting Sense of Competence scale (PSOC), and the Parenting Problem Checklist (PPC; Table 3).

Measures

The RAND-36 is an instrument for self-rated health (126), and a single question was used: “Compared to 1 year ago, how would you rate your health in general now?” The question had five response options, ranging from “much better” as the best option to “much worse” as the least good option. The RAND-36 has been translated into and validated in Swedish, English, and Arabic (126-128).

The EPDS is an instrument for detecting symptoms of postnatal depression (129). It consists of 10 questions with four statements. Respondents select which of the four best describes the past seven days. The statements are scored between 0 and 3, with a total sum of 0–30. Higher scores indicate more

depression symptoms, and the cutoff for having symptoms of depression is recommended to be ≥ 13 for mothers (130) and ≥ 10 for fathers (131). The EPDS was available in the four study languages; all but the Somali version have been previously validated (129-133).

Social support from extended family and friends was measured with the MOS-SSS, which is an instrument consisting of 19 items. The parents were asked to think about people other than their partner and children when answering the instrument. Each item is scored on a five-point scale with response options ranging from 1 = "None of the time" to 5 = "All of the time." The index is the total mean of all item scores; it can vary between 1 and 5. Higher scores indicate better social support. The instrument has been validated in English (51).

The QDR36 was used to measure the quality of the couple relationship. It contains 36 questions divided into five different dimensions: consensus, cohesion, satisfaction, sensuality, and sexuality. Every item is scored on a six-point scale from 1 = "Never" to 6 = "Always." The index is the total sum of all five dimensions' mean scores, ranging from 5 to 30, with higher scores indicating better quality in the dyadic relationship (134). The QDR36 is based on the Dyadic Adjustment Scale, which has been validated in English (135), and the QDR36 has been validated in Swedish (134).

The PSOC was used to measure parenting sense of competence. It comprises 16 items divided into two dimensions: parental satisfaction and parental efficacy. Each item is scored on a six-point scale in which 1 = "strongly agree" and 6 = "strongly disagree." Total scores ranged from 9 to 54 for the satisfaction items, with higher scores indicating a greater sense of satisfaction. Total scores ranged from 7 to 42 for the efficacy items; higher scores indicate a greater sense of efficacy (105). The PSOC has been validated in English (105) and is available in Swedish and Somali (136).

The PPC was used to measure coparenting; it measures parents' abilities to cooperate regarding child-rearing issues. It is a 16-item binary scale with "yes" (1) and "no" (0) response options. The total score ranges from 0 to 16, with a clinical cut-off of ≥ 5 , which indicates problems in coparenting (137). The PPC has been validated in English (137) and is available in Swedish (102).

Table 3: Overview of the number of questions and instruments at the different time points.

	1 month after discharge	6 months after discharge	1 year post-partum	3 years post-partum
Number of questions in total	143 (NICU) 138 (MU)	109	128	142
Background questions	62 (NICU) 57 (MU)	29	30	30
Mental health	RAND-36 EPDS	RAND-36 EPDS	RAND-36 EPDS	RAND-36 EPDS
Relationships				
– Partner	QDR36	QDR36	QDR36	QDR36
– Social support	MOS-SSS	MOS-SSS	MOS-SSS	MOS-SSS
Parenting			PSOC	PSOC PPC

NICU = neonatal intensive care unit; MU = maternity unit; RAND-36 = The Research ANd Development 36-item health survey (1 item); EPDS = Edinburgh Postnatal Depression Scale (10 items); QDR36 = Quality of Dyadic Relationship (36 items); MOS-SSS = Medical Outcomes Study Social Support Survey (19 items); PSOC = Parenting Sense of Competence scale (16 items); PPC = Parenting Problem Checklist (16 items)

Data collection, Study 2

Interviews with the NICU parents were conducted between October 2020 and February 2024 when their infants were between 8 months and 3 years old. Due to COVID-19 restrictions and long travel times to participants' homes, all interviews were conducted through Zoom (Zoom Video Communications, Inc. San Jose, California). Audio was recorded through a recorder, saved on a secure server, and transcribed verbatim. The interviews lasted between 31 and 61 minutes (mean = 47 minutes). During and after all interviews, memos were written that captured thoughts that emerged; these memos concerned eventual codes and categories, links between experiences, or ideas about further questions. To gain an understanding of how and why hospitalization in the NICU might have influenced parents' couple relationship after discharge, the interviews began with questions about the couple's history together, followed by questions regarding the experiences of giving birth and their time in the NICU. The main focus of the interviews was the couple relationship after discharge, but questions also concerned relationships with significant others and support needs. The interview guide featured open questions such as "How do you feel

when thinking of the time in the NICU?” “How do you think the time in the NICU has affected you and your partner as a couple after discharge?”, and “How do you receive support today?” The interview guide was revised several times to focus more on the time after discharge and to further explore the processes of how and why NICU experiences might have influenced the parents. Parents with diverse characteristics were included in the interviews to more fully explore tentative categories and their properties in the studied population, in line with constructivist grounded theory.

According to Charmaz (123), in interviews, the researcher should have an open mind and be ready to hear what the participants say, and the questions that appear from analyses should guide the next step in collecting data in upcoming interviews. Unlike classical grounded theory, categories do not “emerge” but are constructed and interpreted by the researcher. One strategy of showing reflexivity in how interpretations are made is using participants’ quotes when writing the results (123, 138).

Data analysis

Study 1, statistical analyses

The required sample size was calculated based on the hypothesis that NICU parents are more likely to experience distress and problems in parental relationships 6 months after discharge, as indicated by lower scores on the QDR36 compared to parents from MUs. With alpha set at 0.025 (two-tailed) and power at 0.80, we needed to include parents of 393 infants per group (NICU and MU) to detect a small effect size ($d = 0.2$). IBM SPSS Statistics 28 was used in all papers, and R 4.3.0 (R Foundation for Statistical Computing, Vienna, Austria) was used for the linear mixed-effect model analysis in paper II. The rate of missing data was low throughout the study period. Missing completely at random (MCAR) tests were performed to evaluate whether missing data were completely random for the outcome variables and for the predicted associated variables. All data were assumed to be missing at random, with the PPC having the highest missing data rate (5%; MCAR $p = 0.390$), and no multiple imputations were performed. Cases with missing data were excluded from the analyses (139).

Descriptive statistics are given as frequencies, percentages, means with standard deviations, or medians with interquartile ranges. The groups (NICU mothers/fathers versus MU mothers/fathers) were compared through bivariate analyses using independent samples *t*-tests or Pearson’s chi-square tests.

In paper I, differences between NICU mothers and MU mothers (and NICU fathers and MU fathers) regarding the outcome of the RAND-36 and the EPDS

were analyzed using Pearson's chi-square tests for cut-offs and optimal pooled t-tests for differences in means. Optimal pooled t-tests were chosen because of partially paired samples (couples who just experienced the birth of their infant together) (140). A multivariate logistic regression analysis was performed to test the relationship between traumatic birth experiences in a NICU or MU (independent variables) and EPDS score ≥ 13 (dependent variable).

In paper II, a linear mixed-effect model was used to analyze the trajectory of the QDR36 index and its five dimensions at three time points (1 month, 6 months, 1 year) for four groups (NICU mothers, NICU fathers, MU mothers, MU fathers) and compare the groups (NICU mothers versus MU mothers and NICU fathers versus MU fathers). A generalized linear model was used to analyze which factors (independent variables) were associated with the couple relationship (dependent variable). Only participants who answered the 1-year questionnaire were included in the analyses.

In paper III, independent samples t-tests were used to compare parental PSOC satisfaction and efficacy between NICU parents and MU parents, and a chi-square test was used to compare the PPC scores (cut-off ≥ 5) between the parental groups. A linear mixed-effect model was performed to analyze parental satisfaction and efficacy when the infant was 1 year and 3 years old, and to evaluate factors predicted to be associated with the PSOC outcomes satisfaction and efficacy. An adjusted multiple regression was performed to examine which factors (independent variables) were associated with coparenting, measured by the PPC score (dependent variable), among NICU parents. In addition, univariable analyses were conducted for each of the covariates included in the multivariable logistic regression models. Only participants who answered the 3-year questionnaire were included in the analyses.

Study 2, qualitative analysis, constructed grounded theory

In accordance with CGT, interviews were analyzed by reading the transcribed interviews, conducting initial and focused coding, and constantly comparing constructed codes, memos, categories, and relations between them. CGT involves theoretical sampling, which is done with the aim of further exploring the codes, categories, and relations between them. To conduct theoretical sampling, analyses were performed between interviews. After the first three transcribed interviews were coded and compared, it was clear that the parents mainly focused on their time in the NICU. Thus, the interview guide was revised according to theoretical sampling to focus more on exploring and illuminating experiences after discharge. The interviews, analyses, and memo-writing were conducted in parallel, and the interview guide was revised

several times during this process to gain a deeper understanding of experiences, feelings, and processes occurring after discharge.

Three researchers were involved in the analysis of the interviews; all three researchers fully read the transcribed interviews, and two researchers performed initial coding of the interviews individually and then compared the coding and memos. Further memos were written during reading, coding, and constant comparison. The memos were discussed by all researchers and included in the analyses. The initial coding focused on different events, actions, and feelings that parents had experienced. During focused coding, the two researchers worked together to constantly compare and discuss initial codes, new data, interpretations, and constructed categories. More interviews were conducted to further explore and saturate each category and the relationships between categories. Data analyses and discussions about coding and categories continued between the three authors until new data did not change the constructed categories and subcategories, and data saturation was reached.

Ethical considerations

Research should have benefits for the people it concerns. Therefore, parents of NICU infants were involved in these studies from the beginning, discussing the aim and design of the studies, as well as the design of the questionnaires.

Since the aim of the research was to describe and explore families' situations after discharge, it was not necessary to recruit participants at the hospitals. Discussions with the advisory board of parents resulted in the decision to recruit parents 1 month after discharge so they had the opportunity to settle in at home. However, during hospitalization, they received information about the study and that more information about the study would be sent to them after discharge. The parents were informed that the entire study was voluntary and that they could withdraw their participation whenever they wished to do so, without having to explain their decision. To ensure that parents' confidentiality was maintained, all data are presented on a group level. To include non-Swedish-speaking parents, all information, the consent form, and questionnaires were available in four languages: Swedish, English, Arabic, and Somali.

The studies comprise sensitive information about the participants and their families; they shared information about their own and their infant's health, their relationships with each other, and their relationships with other family members and friends. All questions and instruments were reviewed by the parent advisory board and by other parents, which was highly valuable for the ethical considerations made. For example, some instruments regarding the parent-infant relationship and parenting were discarded due to how items were phrased. Parents were instructed to fill in the questionnaires individually because their own experiences were considered important. However, answering questions about the couple's relationship and parenting could result in related discussions between parents, which hypothetically could lead to negative or positive outcomes in their relationship. Similarly, answering questions about symptoms of depression might lead to increased awareness of having these symptoms, which could make parents seek help or cause feelings of guilt over having these negative feelings after becoming a parent. All participants were instructed to write their phone numbers at the end of the questionnaire if they wanted the researcher to call them. They were also provided with a phone number to the researcher if they wished to make contact themselves. If

someone had called, the researcher would, if needed, have guided them to contact adequate support for the issue addressed by the parents.

Parents who agreed to be interviewed received additional written and oral information before they gave written consent. This information conveyed the aim of the interviews; that the researcher conducting the interview was a pediatric nurse and doctoral student working half-time in an NICU; that the interviews would be recorded (sound only; no video), transcribed, and stored at a secure server; that they could choose to be interviewed individually or together as a couple according to their own wishes; and that they could stop the interview whenever they wanted.

As an NICU nurse and as the researcher conducting the interviews, I had to be reflexive about how my occupation might influence the interviews. My background as an NICU nurse could be beneficial since I understood the medical environment the parents experienced; this benefit was even expressed by parents during interviews. However, there was a risk that parents could perceive an imbalance in roles or power, since I was a representative of the environment they were talking about. To reduce this risk, no parents whom I had cared for during their hospitalization were interviewed. There was also a risk that the interviews might have triggered unwanted memories for the parent/couple. However, telling one's story to someone who has insight into neonatal care and is interested in listening can be considered beneficial for processing such experiences. The benefits of understanding what experiences influence NICU parents' family life after discharge were considered to outweigh the potential risks.

All data handling was conducted in accordance with the General Data Protection Regulation and the regulations of Dalarna University. The head managers of the maternity clinics and the pediatric clinics consented to the units' participation. These studies aimed to collect personal and sensitive information, and, therefore, ethical approval was needed. Ethical approval was obtained from the ethical review board in Uppsala (dnr: 2019-04367) with a supplementary application (2019-04367).

Results

The main results from Study 1 (papers I, II, and III) and from Study 2 (paper IV) are presented separately.

Study 1

Study 1 aimed to describe parents' health, couple relationships, and parenting competence in a Swedish context, comparing parents whose infants needed neonatal care to parents of term and healthy infants from discharge up until 3 years postpartum. Parents from six NICUs and four MUs answered questionnaires at four time points during their first 3 years at home.

Characteristics of participants

Parents from NICUs and MUs who participated 1 month after discharge were very similar in their characteristics. Over 60% of the mothers and 40% of the fathers had higher education. Approximately 90% of all parents were working or studying at the time and were born in Sweden. About 60% had been a couple for at least 5 years. NICU parents were significantly more likely to be first-time parents (55% versus 43%), and they were more likely to room-in at the hospital with their partner and infant compared to MU parents (66% versus 58%). In total, 2.8% of respondents answered the first questionnaire in a language other than Swedish (English, $n = 11$; Arabic, $n = 12$; and Somali, $n = 3$). There were significant differences between infants at NICUs and those at MUs. In NICUs, infants were born in earlier gw and had a longer duration in the hospital (Table 4). In addition, in NICUs, there were more instrumental births ($p < 0.001$), such as vacuum extractions and cesarean sections, there were more multiple births ($p < 0.001$), the parents had less SSC immediately after birth ($p < 0.001$), and the infants had lower birth weights ($p < 0.001$).

Three years later, when parents answered the 3-year questionnaire, more parents who had higher education, were born in Sweden, and had more children at home participated. Many of the first-time parents at 1 month now had another infant (NICU parents: $n = 106$; MU parents: $n = 89$). A comparison of

the characteristics of participating parents between the 1-month questionnaire and the 3-year questionnaire showed that parents who were more likely to drop out of the study were younger, had lower education, were born outside Sweden, or had two children at home when answering the first questionnaire (Table 5).

Mental health

Results from paper I, which aimed to compare mental health between NICU parents and MU parents before birth and up to 1 month after discharge, showed that NICU mothers rated their overall experiences of the birth lower and experienced significantly more psychologically traumatic births, compared to MU mothers. They rated their own general health lower in the first week after delivery than MU mothers. Compared to the fathers, more mothers from both NICUs and MUs rated their general health (RAND-36, one item) worse 1 month after discharge, compared to 1 year ago (Table 6). NICU fathers also rated the overall birth experience lower, experienced more traumatic births, and rated their own general health lower in the first week after delivery compared to MU fathers. However, fathers from NICUs experienced better emotional support during hospitalization compared to MU fathers.

There was no difference between the NICU and MU groups regarding symptoms of postpartum depression 1 month after discharge. An EPDS score ≥ 13 for mothers and ≥ 10 for fathers indicates symptoms of depression. The percentage of NICU parents who had symptoms of depression at 1 month after discharge was 8% for the mothers and 9% for the fathers (Table 6).

Experiencing a traumatic birth was not related to an increased risk of depression symptoms (EPDS ≥ 13) for mothers in NICUs 1 month after discharge. In contrast, the risk of depression increased for MU mothers who had experienced a traumatic birth.

At 1 year and 3 years, EPDS scores were presented as background data and analyzed as associated factors for outcomes of quality of the couple relationship (paper II) and parenting (paper III). At 1 year postpartum, 6% of NICU mothers and 13% of NICU fathers had symptoms of depression, and 15% of the mothers and 6% of the fathers had been treated for mental health issues in the previous 6 months (paper II). At 3 years postpartum, the percentages of NICU mothers and NICU fathers with symptoms of depression was 15% for mothers and 12% for fathers (paper III), and 14% of the mothers and 4% of the fathers had been treated for mental health issues in the previous 6 months (not presented in any paper).

Table 4: Parent and infant self-reported characteristics in NICUs (parents: n = 439; infants: n = 255) and MUs (parents: n = 484; infants: n = 269). Analyzed with t-tests for comparing categorical variables and with chi-square tests for comparing means. Results presented with frequencies (n), percentages (%), means, SDs, and p-values.

	NICU		MU		NICU vs. MU	
	Mothers (n = 234) n (%)	Fathers (n = 205) n (%)	Mothers (n = 265) n (%)	Fathers (n = 219) n (%)	Mothers p-value	Fathers p-value
Educational level					0.693	0.401
Compulsory school or less	3 (1)	10 (5)	6 (2)	6 (3)		
Upper secondary school	85 (36)	104 (51)	98 (37)	121 (55)		
Higher education	146 (62)	91 (44)	161 (61)	92 (42)		
Difficulties paying household expenses					0.815	0.476
Yes	9 (4)	7 (3)	9 (3)	11 (5)		
No	225 (96)	198 (97)	254 (96)	208 (95)		
Age, mean, (SD), range	31 (±4.3) 21–42	34 (±5.8) 23–54	31 (±4.6) 19–44	34 (±5.9) 19–62	0.748	0.692
Born in Sweden					0.479	1.000
Yes	205 (88)	184 (90)	238 (90)	197 (90)		
No	29 (12)	21 (10)	27 (10)	22 (10)		
Duration as a couple					0.300	
≤5 years		169 (38)		211 (44)		
>5 years		266 (61)		272 (56)		
First-time parents					0.040	0.015
Yes	129 (55)	115 (56)	111 (42)	97 (44)		
No	105 (45)	89 (43)	154 (58)	122 (56)		
Number of previous children					0.592	0.342
1	70 (67)	56 (63)	110 (71)	84 (69)		
≥2	35 (33)	33 (37)	44 (29)	38 (31)		
Gestational age at birth, weeks					<0.001	
22+0–31+6		20 (8)		0 (0)		
32+0–36+6		102 (40)		4 (2)		
37+0–43		132 (52)		262 (97)		
Infant's care needs during hospitalization						N/A
Minor (e.g., monitoring, nutrition)		106 (42)				
Phototherapy		95 (37)				
Antibiotics		75 (29)				
CPAP		130 (51)				
Major (e.g., ventilation /cooling)		28 (11)				
Duration in hospital					<0.001	
1–6 days (0–6 days for MU parents)		98 (38)		264 (98)		
7–14 days		72 (28)		2 (1)		
≥15 days		84 (32)				
Parents rooming-in with each other and the infant					0.009	
Yes		290 (66)		279 (58)		
No		138 (32)		192 (40)		
Missing		11 (3)		13 (3)		

NICU = neonatal intensive care unit; MU = maternity unit; SD = standard deviation; CPAP = continuous positive airway pressure

Table 5: Characteristics of participating parents answering the 3 year questionnaire compared to the first questionnaire at 1-month. Analyzed with t-tests. P-values show if there were significant differences in characteristics between the first and last questionnaire.

	NICU parents		MU parents		All parents		p-values	
	1 month	3 years	1 month	3 years	1 month	3 years	1 month	3 years
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Parent								
Mother	234 (100)	150 (64)	265 (100)	161 (61)	499 (100)	311 (62)	0.46	0.31
Father	205 (100)	125 (61)	219 (100)	125 (57)	424 (100)	250 (59)		
Educational level when giving birth								
Upper secondary school or less	202 (100)	117 (58)	231 (100)	117 (51)	433 (100)	234 (54)		
Higher education	237 (100)	158 (67)	253 (100)	169 (67)	490 (100)	327 (67)		
Born in Sweden								
Yes	389 (100)	254 (65)	435 (100)	262 (60)	824 (100)	516 (63)	0.17	0.001
No	50 (100)	21 (42)	49 (100)	24 (49)	99 (100)	45 (45)		
Age when giving birth								
≤28 years	98 (100)	52 (53)	113 (100)	60 (53)	211 (100)	112 (53)	0.14	0.008
29–34 years	214 (100)	144 (67)	230 (100)	144 (63)	444 (100)	288 (65)		
≥35 years	127 (100)	79 (62)	137 (100)	82 (60)	265 (100)	161 (61)		
Number of births								
Singelton	405 (100)	255 (63)	480 (100)	286 (60)	885 (100)	541 (61)	0.03	0.21
Multiple	32 (100)	18 (56)	4 (100)	0 (0)	36 (100)	18 (50)		

Number of children in the household at 1 month									
1 child	212 (100)	128 (60)	<0.001	184 (100)	131 (71)	<0.001	396 (100)	259 (65)	<0.001
2 children	124 (100)	65 (52)		201 (100)	100 (50)		325 (100)	165 (51)	
≥3 children	102 (100)	82 (82)		96 (100)	52 (54)		198 (100)	134 (68)	
Duration as a couple when giving birth									
1–5 years	169 (100)	104 (61)	0.68	211 (100)	127 (60)	0.71	380 (100)	231 (61)	0.95
>5 years	266 (100)	170 (64)		272 (100)	159 (58)		538 (100)	329 (61)	
Experienced birth as traumatic									
Yes	226 (100)	136 (60)	0.28	162 (100)	101 (62)	0.33	388 (100)	324 (61)	0.89
No	213 (100)	139 (65)		322 (100)	185 (57)		535 (100)	237 (61)	

NICU = neonatal intensive care unit; MU = maternity unit

Table 6: Parents' self-reported health before delivery, during delivery, after birth, and at 1 month after discharge. Questionnaire answered 1 month after discharge. Analyzed with t-tests for comparing categorical variables and with chi-square tests for comparing means. Results presented with frequencies (n), percentages (%), means, SDs, and p-values.

	NICU parents		MU parents		NICU vs. MU parents	
	Mothers (n = 234) n (%)	Fathers (n = 205) n (%)	Mothers (n = 265) n (%)	Fathers (n = 219) n (%)	Mothers p-values	Fathers p-values
Overall experience of delivery						
0–10, mean, (SD)	5.7 (±2.7)	5.6 (±2.6)	6.7 (±2.5)	7.0 (±2.3)	0.017	0.002
Traumatic birth, fear of serious injury						
Yes	48 (21)	51 (25)	24 (9)	25 (11)	0.452	≤0.001
No	185 (79)	154 (75)	237 (89)	194 (89)		
Traumatic birth, fear of death						
Yes	37 (16)	33 (16)	22 (8)	8 (4)	0.037	≤0.001
No	196 (84)	172 (84)	239 (90)	211 (96)		
Traumatic birth, intense negative feelings						
Yes	112 (48)	100 (49)	85 (32)	66 (30)	0.693	≤0.001
No	122 (52)	105 (51)	179 (68)	153 (70)		
General health first week after delivery						
Excellent	22 (9)	48 (23)	40 (15)	79 (36)	≤0.001	≤0.001
Very good	52 (22)	51 (25)	82 (31)	89 (41)		
Good	59 (25)	68 (33)	74 (28)	41 (19)		
Fair	60 (26)	27 (13)	45 (17)	6 (3)		
Poor	40 (17)	10 (5)	22 (8)	4 (2)		
Emotional support by hospital staff after delivery						
Good	188 (80)	158 (77)	194 (73)	128 (58)	0.072	≤0.001
Bad/no support	46 (20)	45 (22)	71 (27)	90 (41)		

Emotional support by CHS							
Excellent	56 (24)	46 (23)	108 (41)	70 (32)	0.081	≤0.001	0.162
Very good	77 (33)	59 (29)	97 (37)	60 (27)			
Good	65 (28)	58 (28)	41 (15)	49 (22)			
Fair	24 (10)	10 (5)	14 (5)	14 (6)			
Poor	3 (1)	3 (1)	3 (1)	1 (1)			
Missing	9 (4)	29 (14)	2 (1)	25 (11)			
RAND-36 general health					0.011	0.297	0.079
Much better	26 (11)	13 (6)	32 (12)	21 (10)			
Better	25 (11)	23 (11)	41 (15)	43 (20)			
Same	111 (47)	132 (64)	119 (45)	121 (55)			
Worse	57 (24)	34 (17)	64 (24)	31 (14)			
Much worse	14 (6)	3 (1)	8 (3)	2 (1)			
EPDS							
Mean (SD)	6.1 (±4.4)	4.4 (±4.0)	6.3 (±4.6)	4.6 (±3.9)	≤0.001	0.799	0.687
Cut off ≥13	18 (8)	9 (4)	27 (10)	9 (4)	0.014	0.434	1.000
Cut off ≥10	47 (20)	18 (9)	59 (22)	21 (10)	≤0.001	0.661	0.867

NICU = neonatal intensive care unit; MU = maternity unit; CHS = child health services; EPDS = Edinburgh Postnatal Depression Scale

Parents' couple relationship

Results from paper II, which aimed to describe factors associated with NICU parents' quality of couple relationship (QDR36) 1 year after birth, showed that factors both during hospitalization and after discharge were associated with the outcomes of the QDR36. In NICU mothers, the following factors were associated with a higher quality of the couple relationship: being younger, being born outside Sweden, having better social support, and a hospital stay of 7–14 days in the NICU compared to 1–6 days. Risk factors for a lower quality of the couple relationship included not rooming-in with the infant and father for the whole or most of the hospital stay, as well as performing most of the household tasks. In NICU fathers, being younger was associated with a higher quality of the couple relationship, and risk factors for having a lower quality of the couple relationship included having symptoms of depression (EPDS scores ≥ 10) and multiple births (Table 7).

Furthermore, the aim of paper II was to describe the trajectory of the quality of the couple relationship in NICU parents during the first year after birth compared to MU parents. The results showed no significant differences in QDR36 scores between parents from NICUs and parents from MUs. All parents' QDR36 scores slightly decreased from 1 month after hospital discharge until the infants were 1 year old. The decrease in the QDR36 score was 0.8 for NICU mothers and 0.7 for NICU fathers. For the comparison group of parents from MUs, the QDR36 scores decreased by 0.9 points for both mothers and fathers.

Table 7: Factors associated with NICU parents' Quality of Dyadic Relationship (QDR36) index when the infant is 1 year old, analyzed with a generalized linear model (scale response linear). Results are presented with the change of mean QDR36 score (B), 95% confidence interval (95% CI), and p-value for each factor.

	NICU Mothers (n = 160)		NICU Fathers (n = 123)	
	B (95% CI)	p-value	B (95% CI)	p-value
Educational level				
Upper secondary school or less	0.48 (-0.27–1.22)	0.21	-0.29 (-1.18–0.61)	0.53
Higher education	ref		ref	
Born in Sweden				
No	1.77 (0.28–3.25)	0.02	0.75 (-0.90–2.40)	0.37
Yes	ref		ref	
Age				
21–28 years	1.64 (0.56–2.72)	0.003	2.06 (0.57–3.55)	0.007
29–34 years	0.76 (-0.18–1.70)	0.11	1.09 (0.15–2.04)	0.023
35–42 years	ref		ref	
First child				
No	-0.25 (-1.04–0.53)	0.52	-0.20 (-1.18–0.77)	0.68
Yes	ref		ref	
Number of births				
Multiple	-0.62 (-2.06–0.82)	0.40	-1.49 (-3.00–0.15)	0.05
One	ref		ref	
EPDS ≥13 at 1 year				
Yes	-0.98 (-2.54–0.58)	0.22	n/a	
No	ref		n/a	
EPDS ≥10 at 1 year				
Yes	n/a		-3.52 (-4.91 to -2.13)	<0.001
No	n/a		ref	
Length of hospital stay after birth				
31–150 days	0.91 (-0.27–2.09)	0.13	-0.92 (-2.34–0.51)	0.21
15–30 days	-0.35 (-1.36–0.66)	0.50	0.61 (-0.66–1.89)	0.34
7–14 days	0.91 (0.05–1.78)	0.04	0.68 (-0.44–1.81)	0.23
1–6 days	ref		ref	
Rooming-in with partner and infant, whole or part of the NICU hospitalization				
No	-0.82 (-1.61 to -0.03)	0.04	-0.28 (-1.30–0.75)	0.60
Yes	ref		ref	
Parents doing household duties				
Often or always	-1.58 (-2.38 to -0.78)	<0.001	-0.57 (-1.56–0.42)	0.26
Sometimes or never	-1.30 (-2.87–0.27)	0.10	-1.28 (-2.72–0.16)	0.08
Half of the time	ref		ref	
Social support, MOS-SSS score	0.56 (0.11–1.01)	0.01	0.44 (-0.18–1.07)	0.16

NICU = neonatal intensive care unit; EPDS = Edinburgh Postnatal Depression Scale; QDR36 = Quality of Dyadic Relationship; GLM = generalized linear model; B = change of mean; CI = confidence interval; MOS-SSS = Medical Outcomes Study Social Support Survey; m = mean; SD = standard deviation.

Parenting sense of competence and coparenting

Results from paper III, which aimed to compare parenting sense of competence and coparenting between NICU parents who had opportunities to room-in and MU parents 3 years postpartum, showed no differences in parental satisfaction or efficacy. There were also no differences in PPC scores between NICU and MU parents. A PPC score ≥ 5 indicates problems in coparenting (Table 8).

Table 8: NICU and MU parents' PSOC satisfaction and efficacy, and PPC at 3 years, analyzed with independent samples t-tests and chi-square test. Presented with percentages (%), means, standard deviations (SDs), and p-values.

	NICU Mothers	MU mothers		NICU Fathers	MU fathers	
PSOC satisfaction	mean \pm SD	mean \pm SD	p-value	mean \pm SD	mean \pm SD	p-value
	40.38 \pm 6.84	39.85 \pm 7.36	0.51	40.00 \pm 6.83	39.29 \pm 6.79	0.41
PSOC efficacy	mean \pm SD	mean \pm SD		mean \pm SD	mean \pm SD	
	31.01 \pm 5.25	30.66 \pm 6.09	0.59	31.06 \pm 5.34	30.93 \pm 5.94	0.85
PPC cut-off ≥ 5	n (%)	n (%)		n (%)	n (%)	
	32 (23)	21 (15)	0.07	16 (14)	16 (14)	1.00

NICU = neonatal intensive care unit; MU = maternity unit; PSOC = Parenting Sense of Competence scale; PPC = Parenting Problem Checklist; SD = standard deviation

This study also aimed to identify factors that may influence NICU parents' sense of competence and coparenting. In both NICU mothers and NICU fathers, their parental satisfaction and efficacy were better if they rated their couple relationship quality better. Both mothers and fathers also had more problems in coparenting if they rated their couple relationship lower.

NICU mothers' efficacy decreased between 1 and 3 years postpartum. Their satisfaction was higher if they did not experience a traumatic birth, and they experienced more problems in coparenting if they had a hospital stay of 7–14 days compared to 1–6 days.

NICU fathers did not have a decrease in satisfaction or efficacy between 1 and 3 years postpartum. Their satisfaction was higher if they did not have symptoms of depression (EPDS score ≥ 10). Their efficacy was higher if they had a longer couple relationship, better social support, and a hospital stay of 1–6 days compared to more than 14 days; their efficacy was also higher if they had roomed-in with their partner and infant during most of the hospital stay.

Fathers also experienced more problems in coparenting if they rated their social support lower.

Study 2

Characteristics of participants

A purposeful sampling of the 143 parents who had consented to participate in the interviews was performed to include participants with as varied characteristics as possible. To fulfill the aim of exploring experiences during the first years at home, the interviews were conducted when the infants were of various ages, ranging from 8 months to 3 years old (median 16 months old). The infants were born between gw 26 and 40 (median: 34 gw), and the length of time in the hospital varied from 6 days to 3 months (median: 3 weeks). All parents were born in Sweden and cohabited with the other parent. The group of parents consisted of 14 mothers and 6 fathers; 16 parents had been in the couple relationship for more than five years, and 4 parents had been in the couple relationship for less than five years. Before the current infant, two of the couples had lost infants in late pregnancies, and one couple lost a twin during their NICU hospitalization. Nine of the mothers and four of the fathers were first-time parents, and two of the mothers and none of the fathers had twins. The mothers were between 27 and 42 years old, with a mean age of 33 years, and 10 had higher education. The fathers were between 30 and 39 years old, with a mean age of 35 years, and three had higher education. The parents chose if they wanted to be interviewed individually or together, resulting in 16 individual interviews and 2 couple interviews.

Theory of how couples' relational resilience is influenced by experiences in the NICU and after discharge

This inductive study aimed to explore how parents of NICU infants experienced their first years at home after NICU hospitalization, with a focus on their relationship with their partner (paper IV). However, the parents' focus during the interviews was on the NICU experience and their mental well-being before and during hospitalization and after discharge. Therefore, the first and second categories in the constructed theory (Fig. 2) relate to experiences before and during NICU hospitalization. The main categories represent three phases, each of which influences the next ones: 1) their own carried trauma, 2) an uncertain or safe journey in the NICU, and 3) at home—with a backpack.

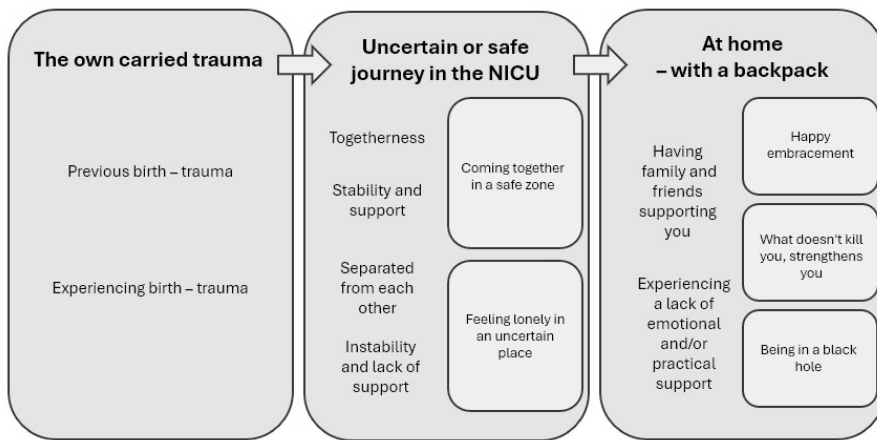


Figure 2: A model of how couples' resilience is influenced by experiences in the NICU and after discharge.

The first phase represents the traumatic embodied perinatal experiences parents carried with them both in the NICU and prolonged after discharge. Most parents had experienced a traumatic birth, and some had also experienced traumas in previous pregnancies. Fathers were worried about the health of both the mother and the infant, while mothers were primarily concerned about the infant. Directly after the birth of the sick or preterm infant, the parents experienced separation from each other and/or from the infant. The father and infant were taken to the NICU, and the mother was left in uncertainty without her family until she was stable enough to visit them in the NICU.

Such situations are where most NICU parents began their parental journeys; experiencing a traumatic birth, being separated, not being able to support each other, and carrying diverse experiences and feelings into the NICU. Parents who had time to visit the NICU before giving birth and receive information from doctors and nurses felt more prepared, which lessened their worries.

After the first traumatic birth experiences, parents often continued to experience traumatic events in the NICU. Such traumas included the infant's poor health, transportation to another hospital, and separation from the infant. These events exacerbated earlier experienced traumatic birth events and thus created a compilation of unprocessed embodied traumas and emotional burdens.

The second phase represents the parents' experiences of their journey in the NICU: coming together in a "safe zone" or feeling lonely in an uncertain place. All parents were mostly in one of these "places," but they could move

to the other place if circumstances changed. Most parents began their journey feeling lonely in an uncertain place due to being initially separated from each other, arriving at an unfamiliar NICU environment, and experiencing instability. Instability regarding infants' health, staff continuity, and not having their own private space reduced the likelihood of feeling safe and receiving adequate support during hospitalization. One mother of a full-term infant with hyperbilirubinemia, who had to change units several times, and whose husband had been at home with their older children, narrated:

I was truly afraid and worried. You don't know anything, and you're with a newborn who is ill. So that was hard being alone. I wished that our son and daughter could visit, that there was an opportunity to get an extra bed, so you would not have to be alone. // It was hard not to feel safe anywhere, that you had to change units. You are worried anyway, and then you must go 7 miles any second day. (Mother 15)

Being separated, not feeling safe, and a lack of support led to a process of lower likelihood of experiencing relational resilience, decreased well-being, and strain on the couple relationship. Parents who were able to be together, support each other, have their own private space without being moved around, have continuity regarding staff they trusted, and receive support and information experienced that they were coming together in a safe zone. The experiences of togetherness, stability, and support in the NICU led to increased relational resilience, better well-being, and a strengthened couple relationship. A mother described how their time together as a family in the NICU made her feel even more secure with her partner:

He took care of her when I couldn't; it was amazing to see. He grew in my eyes, and I felt 100% safe that he could take care of her, and at the same time, he supported me and was there for me. He grew in my eyes, which made me feel even more secure with him, as a partner and as a dad. (Mother 12)

The third phase, "At home—with a backpack," represents how the process of carrying and coping with trauma in NICU influenced the parents' relational resilience, well-being, and couple relationship months to years after discharge. If they came from "coming together in a safe zone" in NICU and had adequate support after discharge, they had strong relational resilience and felt a "happy embracement" at home. If they came from "feeling lonely in an uncertain place" in NICU but received adequate practical and emotional support after discharge, their relational resilience could increase, and they could experience posttraumatic growth, described as "what doesn't kill you strengthens you." However, without support after discharge, they did not achieve relational resilience and felt as if they were "in a black hole" with decreased well-being

and/or a struggling situation due to the infant's needs, causing strain on the couple's relationship. A mother to three children, with the youngest two being born extremely preterm, described that they, as parents, were still in a hole 1 year after discharge:

Weekends are almost the worst, because then we have three children at home, and it is the same routine as Mondays to Fridays. Therefore, there is nothing to look forward to, not the Friday evening, not the weekend, not the Tuesday. When you don't have a good start, you are not feeling well; then, you start from the bottom of a hole and try to be a good parent and a good partner in this hole. (Mother 9)

Discussion

The overall aim of this thesis was to describe mental health, couple relationships, and parenting outcomes in parents who initiated their parenthood in a NICU, compared to parents of term and healthy infants, up until 3 years of the infant's age, and to explore NICU parents' experiences of family relationships after discharge.

The findings in this thesis showed no differences between NICU parents and MU parents regarding symptoms of depression 1 month after discharge (paper I), couple relationships 1 year postpartum (II), or parenting outcomes 3 years postpartum (III), even though NICU parents reported more psychologically traumatic births, lower ratings of the birth experience, and poorer self-rated general health in the first week after delivery compared to MU parents. NICU parents had, in general, better possibilities of rooming in together during hospitalization and might therefore have had better opportunities of receiving support from both each other and staff, compared to MU parents. Both rooming-in together and receiving social support had a positive association with well-being (IV), the couple relationship (II and IV), and parenting outcomes (III) in NICU parents. The constructed theory (IV) provides a deeper understanding of how and why parents' experiences of togetherness/separation, stability/instability, and support/lack of support during birth and NICU hospitalization influence their relational resilience, well-being, and couple relationship in the long term.

The importance of rooming-in together during hospitalization, social support in the NICU and after discharge, and mental health will be further discussed in relation to previous research, the Bowen Family System Theory (BFST), and the ecological model of coparenting.

Family togetherness and the couple relationship

The study results indicate that NICU parents' opportunities for rooming-in together during hospitalization are an important factor in promoting long-term family well-being through a strengthened couple relationship and increased confidence in parenting. Mothers rated their couple relationship better one year postpartum (II), and fathers rated their parenting efficacy higher three

years postpartum (III) if they had been rooming-in together with their partner and the infant during hospitalization. However, this should not necessarily be interpreted as a causal relationship, as parents in stable relationships might be more likely to want to be together, and parents with children at home might not have the opportunity to stay together in the NICU. Nevertheless, the NICU parents' narratives provided evidence of the importance of being together in the NICU for improved well-being and a stronger couple relationship (IV). Indeed, previous research has shown that one of the most important risk factors for developing postpartum depression is a lack of support from one's partner (141). Family togetherness increases the opportunities for parents to support each other and be close to their infant, and it facilitates receiving support from hospital staff for both parents. It is well established that social support plays a crucial role in enhancing relational resilience (142-145) and preventing depressive symptoms (26, 78). Relational resilience and mental health are correlated (146). Resilience after trauma is defined as adaptation and recovery after a traumatic event which protects against prolonged psychological distress (142); it may even lead to improved personal strength and interpersonal relationships, a phenomenon known as posttraumatic growth (143-145). Relational resilience depends on both the specific context and the support the person receives through relationships with others within that context (142, 144, 146-149). NICU parents' better opportunities of togetherness and to receive support during hospitalization may therefore explain why MU mothers' experiences of trauma were associated with symptoms of depression 1 month after discharge, while NICU mothers' traumatic experiences were not (I).

Furthermore, NICU parents' togetherness and their opportunities to support each other may have helped them to maintain or even increase their relational resilience, thus promoting improved well-being and strengthening the quality of their couple relationship, despite the stressful events they faced at the beginning of their parenthood (I, II, and IV). The BFST describes the family as an emotional unit in which individual family members' feelings and behaviors affect the others in the unit. The theory provides further understanding of why family members' togetherness and individuality are important for the ability to give each other support and increase family well-being. The individuals in the unit are dependent on and reactive to one another, which is described as a chain of reactions occurring between them (121). For families exposed to stressful events such as a traumatic birth, NICU hospitalization, or health issues, the resulting chain of reactions within their emotional unit may be a great source of stress. Thus, if one parent experiences decreased well-being, the other parent may become focused on that person and even be in symbiosis with their negative feelings. This can result in decreased well-being for both

parents and subsequently strain their relationship. However, if they each have a strong sense of individuality, they can manage to provide each other with adequate support without incorporating the other person's negative feelings, thereby increasing each other's well-being. Individuality and togetherness must therefore be in balance to establish healthy relationships; such a balance may even strengthen the relationship (121). The findings in this thesis are in line with the BFST since the parents described the process of how and why traumatic birth and NICU events influenced their well-being and subsequently their couple relationships. Parents' well-being and couple relationships were strengthened in the long term by togetherness, stability, and support during hospitalization. On the other hand, separation, instability, and a lack of support in the NICU led to decreased well-being and could subsequently influence the couple's relationship negatively (IV).

Regarding the analysis of factors associated with parenting outcomes in the NICU population (III), the results showed that higher ratings of the couple relationship were associated with higher parenting sense of competence (satisfaction and efficacy), and lower ratings of the couple relationship were associated with more problems in coparenting in both NICU mothers and NICU fathers 3 years after discharge. Fathers who roomed-in during hospitalization in the NICU rated their parenting efficacy higher compared to fathers who did not room-in. The fathers who roomed-in were more likely to have had better opportunities to be involved in caring for their infants, which might have strengthened their parenting efficacy. To optimize the development of NICU infants, it is important to understand what influences their parents' sense of competence and cooperation in parenting. Previous studies on NICU parents' sense of competence are scarce (116-118). Such studies have shown that symptoms of depression, low social support, and low income are negatively associated with parenting competence (116), while receiving support from the NICU during the transition to home and a longer period of time at home after discharge are positively associated with parental sense of competence (117, 118). However, these studies examined parents of preterm infants in contexts with fewer opportunities for parents to stay together with each other and the infant. In a general population of parents, studies have shown that the parents' couple relationship influences parenting sense of competence and coparenting (100, 150). The results from the studies in this thesis, as well as previous research, highlight that togetherness is important for the couple relationship, mental health, and parenting outcomes.

The power of social support

In the general population of parents, social support is positively associated with better mental health (151, 152), increased satisfaction and efficacy in parenting (153), and stronger parent-child relationships (151, 153). Mautner et al. (154) highlighted that the most important sources of support for enhancing resilience and well-being among NICU mothers include not only their partners but also their family and friends being involved in care for and spending time with the infant. Although other research has confirmed the importance of support from family and friends for NICU families (54, 55), NICUs often lack guidelines and routines for integrating them into care (7, 54, 155). In fact, there may even be restrictions on family and friends visiting (7).

Both the quantitative and qualitative results of this thesis show that supportive relationships with family and friends are beneficial for NICU parents' family outcomes, including quality of the couple relationship (II and IV), efficacy in parenting and coparenting (III), and well-being (IV). Mothers with better social support rated their couple relationship higher 1 year postpartum (II). Three years postpartum, fathers with better social support rated their parenting efficacy higher, while fathers with less social support experienced more problems in coparenting (III).

The constructed theory of how couples' relational resilience is influenced by experiences in the NICU and after discharge demonstrates why social support is important both during and after hospitalization, even years after discharge. The results showed that support from family and friends improved relational resilience, which led to better well-being and, subsequently, a strengthened couple relationship. Parents who carried embodied traumatic experiences with them and had decreased mental health after discharge could still increase their well-being and strengthen their couple relationship through social support and increased relational resilience (IV). Relational resilience is dependent on social support, since it is achieved through relationships (142-144, 146-149), and relational resilience is in turn known to influence mental health (142, 146).

The findings regarding support are also in line with both Feinberg's model of coparenting, which notes that social support is positively associated with coparenting (100), and BFST, which states that supportive family and friends can be stabilizing for the nuclear family (121). With adequate emotional and practical support in the NICU and after discharge, parents can boost their mental well-being, improve their parenting skills, spend more time with each other, and strengthen their couple relationship. A stronger couple relationship, in turn, increases the likelihood of improved parenting competence and better coparenting in both NICU mothers and NICU fathers (III).

Previous research and theories have highlighted that family and friends are an important source of support for both parents in the general population and NICU parents. Still, NICUs may have visiting restrictions or may lack guidelines on including family and friends. Findings from the studies included in this thesis further strengthen the evidence that it is important to acknowledge that relationships outside the nuclear family are important sources of support for NICU families, even in the long term. However, family and friends may find it difficult to understand what kind of support NICU families need. To understand parents' needs for support, family and friends may also need information and support from staff (7, 54, 55). Hence, NICUs can improve care by incorporating the support of family and friends and providing them with supportive information regarding how they may support the NICU family.

Mental health and its influence on family outcomes

It is known that negative birth experiences and preterm birth are related to an increased risk of postpartum depression in mothers (141). Studies have shown that symptoms of depression among NICU mothers are higher compared to mothers of term and healthy infants (20, 73, 74) and that such symptoms may persist for years (75). Therefore, the results from Study 1 are unique in this regard since there were no differences in depression symptoms between NICU and MU parents, even though the NICU parents had experienced more traumatic events at the beginning of their parenthood.

Previous research has suggested that there is an increased risk of depression in NICU parents due to the experiences of trauma and that this depression may cause long-term negative effects on the couple's relationship if the parents do not manage to support each other adequately (96, 97). On the other hand, it has been suggested that parents of preterm infants who manage to support one another during hospitalization may experience a strengthened couple relationship (94). In this thesis, symptoms of depression among fathers were associated with lower ratings of the quality of their couple relationship compared to fathers with no symptoms of depression (II). One explanation for this association in line with BFST, is that partners struggle to support each other when they are in poorly balanced relationships in which they incorporate each other's decreased well-being; subsequently, this lack of support negatively influences their relationship. The findings show that NICU parents may struggle with decreased well-being and symptoms of depression after discharge, which negatively influenced their couple relationship. Some parents even sought out private psychologists to cope with their depressive symptoms (IV). Both individual and couple counselling during hospitalization and after discharge could

be important in strengthening individual well-being and a balanced couple relationship, both of which would be beneficial for the whole family.

It is well known that both mental health and quality of the couple relationship are associated with parenting outcomes such as coparenting and parenting competence in the general population, as described in Feinberg's ecological model of coparenting (100). In Study 1, fathers without symptoms of depression rated their parenting sense of competence (satisfaction) higher than those with such symptoms (III), which is in line with the ecological model of coparenting (100). The mothers having symptoms of depression in Study 1 had about two points lower scores in both parenting efficacy and satisfaction, although not significant. Traumatic birth experiences increase the risk of developing postpartum depression (156), and decreased mental health is known to influence parenting negatively (100, 113). In addition, NICU mothers who did not experience a traumatic birth rated their parenting sense of competence (satisfaction) higher (III). There is a lack of research regarding traumatic birth and parenting outcomes. It can be discussed if it is the association between traumatic birth and decreased mental health seen in other studies (156) that also subsequently influenced the parenting outcomes in the results of this thesis, since mental health is known to influence parenting (100, 113). Parenting outcomes are important since they affect the developmental and emotional outcomes of children (100, 101, 113, 115).

The results thus further emphasize the importance of preventing NICU parents from experiencing decreased mental health, as their mental health influences their parenting (III) and subsequently their infant. Other studies have found an association between a more family-centered approach in NICUs and fewer symptoms of depression among parents of preterm infants (26, 40, 78). In this study, FCC approaches and infant developmental care were not evaluated. However, some elements of IFCDC (35) were measured, including family access/rooming-in and support from staff (I). Rooming-in was found to be positively associated with both quality of the couple relationship (II) and parenting outcomes (III). NICU fathers rated the support from staff during hospitalization as higher compared to MU fathers. NICU parents' narratives clearly highlighted the importance of being together as a family in the NICU (IV). In all NICUs in these studies, both parents had 24/7 access to their infant. Moreover, NICU fathers rated the support from staff better than MU fathers. NICU parents' togetherness and support during hospitalization may have positively influenced their well-being, protecting them from symptoms of depression after discharge despite their traumatic birth experiences.

Length of the hospital stay

Parents of NICU infants begin their parenthood in an unfamiliar, highly technical and medical environment with a large number of staff members. Depending on the prematurity and illness of the infant, their hospital stays can greatly vary, ranging from hours to several months (3). The findings in these studies showed that the length of hospital stay was associated with outcomes regarding both the couple relationship and parenting. A hospital stay of 7–14 days compared to 1–6 days was associated with higher ratings of NICU mothers' couple relationships (II). This may be because a longer hospital stay increases the opportunities for parents to incorporate parenthood in togetherness and support each other. As previously mentioned, partner support is the most important form of support for mothers during NICU hospitalization (154). The opportunity for parents to room-in together and support each other for a longer time might therefore have influenced how NICU mothers rated their couple relationship with their partner.

The results showed conflicting findings regarding mothers' and fathers' length of hospitalization and parenting outcomes; 3 years postpartum, mothers with a hospital stay of 7–14 days (compared to 1–6 days) rated their coparenting with their partner better, while fathers with a hospital stay of 1–6 days (compared to >14 days) rated their parenting competence (efficacy) higher (III). In a previous study, mothers who stayed ≥ 14 days in a NICU had higher parenting competence at 1 year postpartum compared to MU parents (118). A longer hospital stay may facilitate prolonged support delivered by hospital staff to the parents. However, such support must target both parents equally to strengthen their sense of parenting competence and coparenting (157). Previous studies (157) and narratives from fathers in paper IV show that staff tend to turn to the mother when talking to the parents. An explanation for the conflicting findings may therefore be that fathers may not feel equally important as the mother because of experiences such as staff talking to the mother when something rears the infant.

Methodological considerations

This doctoral project was designed in collaboration with a parental advisory board. The inclusion of individuals from the group intended to be studied strengthens the studies validity as discussed below. Another strength is that the studies included parents of infants at all gw, rather than premature infants alone. Moreover, unlike most other NICU studies, which have included mothers only, these studies included both parents.

A limitation of the studies is that they were conducted during the COVID-19 pandemic, which imposed unique challenges. For example, both NICU and MU families faced strict restrictions regarding visits from family and friends. In addition, couples at some MUs had fewer opportunities to be together as a family during hospitalization due to visiting restrictions for fathers. These circumstances may have negatively influenced some of the assessed outcomes, particularly for MU parents, who experienced more frequent separation than NICU parents. These contextual factors should be considered when interpreting the findings.

Strengths and limitations of Study 1

Study 1 has several strengths. One is that the aim, design, and methods were developed together with the parental advisory board consisting of parents whose infants had been in NICUs. Other parents whose infants had been in NICUs participated in focus groups and discussed life circumstances that influenced their couple relationships after discharge. The purpose of these discussions was to determine which elements should be included in the questionnaires. Then, the parental advisory board tested different instruments and discussed their relevance in targeting the elements of mental health, the couple relationship, social support, and parenting in a Swedish context. Furthermore, other parents from NICUs and MUs tested the entire questionnaire to evaluate its feasibility. This rigorous process of involving parents in developing the aim, design, and methods and testing the questionnaires increases the study's relevance and validity.

Another strength is the intention to include non-Swedish-speaking parents, since those who do not speak a context's native language are often excluded from studies. Parents received information about the study from several different sources in four languages (Swedish, English, Somali, and Arabic). All questionnaires were also translated into the languages included in the study. However, a limitation in this regard is that it was not possible to validate all instruments culturally and contextually due to limited time and resources. Nevertheless, the questionnaire was still translated back and forth and discussed with NICU staff and lecturers who were fluent in Swedish, English, Somali, and Arabic, which facilitated the participation of non-Swedish-speaking parents. In the end, few non-Swedish speaking parents participated which can be seen as a limitation.

The NICU parents and MU parents did not differ significantly in their general characteristics, such as age, education, and time as a couple. Therefore, we assumed that the two groups' results are comparable. A strength of the

linear mixed-effect model used is that it takes eventual missing data and potential confounders into account as fixed effects.

An additional limitation is that the units were not asked if they used certain care frameworks or philosophies, such as FCC approaches, the Neonatal Individualized Developmental Care and Assessment Program – NIDCAP, or Family and Infant Neurodevelopmental Education – FINE. To evaluate the potential association between these frameworks or philosophies and NICU parents' outcomes, a much more comprehensive questionnaire about care routines could have been sent to the units. Alternatively, observations could have been conducted to evaluate staff compliance with these frameworks or philosophies.

Another limitation is the low participation rate for the first questionnaire. Only 20–22% of invited parents consented to participate in this questionnaire, and we obtained no information about nonrespondents. The participating parents had a higher level of education than the general population; over 60% of mothers and over 40% of fathers had a higher level of education. By contrast, in Sweden, in 2020, when parents in these studies gave birth to their infants, 45% of people aged between 25 and 64 years had a higher education (158). Previous studies have indicated that people with a higher level of education, women, and older people more commonly respond to questionnaires (159). People who choose not to participate tend to have a lower level of education, which is known to negatively affect income, parental well-being, family relationships, and parenting (160). Since we have no information about the parents who did not participate, we cannot generalize the study results to all groups of parents. It can be argued that the sample being skewed toward a well-educated population might have positively influenced the studied outcomes. It is also possible that highly educated participants have higher expectations regarding care and support and therefore tend to be less satisfied with the care provided during hospitalization. The results of Study 1 showed no significant association between level of education (upper secondary school versus higher education) and the couple relationship or parenting outcomes. The groups of parents with a lower education level than upper secondary school or with difficulties paying household expenses were too small to be included separately in the analyses, so any associations between a lower education level or a lower income level and the studied outcomes could not be revealed.

In addition, nonresponse bias is more likely to occur in studies targeting specific groups (e.g., those with health problems). Among participants with mental health issues, those with more severe problems are more likely to decline participation (159). Therefore, it is possible that parents with more severe mental health issues did not answer the questionnaires. Including additional participants might have resulted in nonsignificant results becoming

significant, particularly for the outcomes of the PSOC and the PPC. NICU mothers without symptoms of depression scored approximately two points higher on the PSOC compared to mothers with symptoms of depression. Furthermore, 23% of mothers in NICUs experienced problems in coparenting compared to 15% among MU mothers, another result that did not reach significance. When interpreting the results of Study 1, therefore, the risk of non-response bias must be considered.

Finally, another limitation of this study is its focus on NICUs in Sweden only. Parents in other contexts might encounter additional challenges due to less favorable social welfare systems and fewer opportunities to stay at the NICU, and they also might have more difficulties related to lower education levels, lower incomes, and decreased well-being. The results, therefore, cannot be generalized to all NICU parents in every NICU context.

Strengths and limitations of Study 2

A strength of Study 2 is the use of CGT, which acknowledges that the researcher has preconceived knowledge that is used when conducting interviews and interpreting the results. In this framework, the researcher must be aware and reflexive regarding their preconceived knowledge and how it may affect the results. I, as an interviewer, was interviewed about my preknowledge regarding the studied topics before conducting the interviews to ensure that I was aware of this knowledge during data collection and analysis. All three researchers discussed interpretations, coding, memos, and categories regularly to make sure that the interpretations stayed close to the participants' narratives. When conducting the interviews, it appeared to be beneficial that I was a pediatric nurse working in an NICU, since I understood the NICU environment and what medical challenges the infants and parents faced. Because of my occupation and preunderstanding regarding the NICU environment, it is possible that the parents opened up about their experiences more easily.

The study aimed to explore family relationships after discharge, and according to the parents' narratives, their NICU experiences influenced their mental well-being and subsequently their couple relationships. The participants' focus on the NICU hospitalization period was probably because this period was particularly important and not fully processed by them. Whether the parents' memories of the birth and their time in the NICU were accurate may be debatable, since several years had passed for some of the parents. However, during the interviews, they remembered details very well, which further strengthens the idea that their period in the NICU was highly important. This effective remembering of details from the NICU is consistent with previous research, which has described NICU parents as remembering

details well (161). Thus, the participants' inductive narratives were in focus, which strengthens the credibility of the constructed theory that described how NICU parents' experiences during hospitalization influenced well-being and couple relationships after discharge.

As a result of theoretical sampling, the interview guide was changed several times to further focus on experiences, events, and processes arising from the analyses conducted between the interviews. New parents were contacted for further interviews to obtain as varied a sample of parents as possible, further increasing the credibility of the results. The same participants could have been interviewed again, and member checking could have been performed to increase trustworthiness. However, based on CGT and theoretical sampling, interviewing additional participants and analyzing data continued until data saturation was reached, no new data changed the constructed categories or the relationships between them, and the theory seemed robust.

Quotations from the parents have been presented in the results section to show how the data were interpreted to form the constructed theory, further strengthening the confirmability. The constructed theory is based on the specific context of Swedish NICUs, which allow parents and infants to be together during hospitalization. However, Swedish NICU parents still experience trauma, separation, instability, and a lack of support, which may influence their relational resilience, well-being, and couple relationship negatively for years. The theory is thus transferable to NICUs within similar contexts. It can be used to increase knowledge about how traumatic birth and NICU events influence parents, why they are affected in the way that they are, and (most importantly) how to prevent traumatic experiences from negatively influencing parents in the long term. The theory can also be used to improve NICU facilities for families internationally, as currently, parents in other countries' NICUs may have fewer opportunities to stay together with each other and their infants.

Conclusion

The results showed that there were no differences between NICU and MU parents' symptoms of depression 1 month after discharge (I), ratings of the quality of the couple relationship 1 year postpartum (II) or parenting competence and coparenting 3 years postpartum (III), in a context where most NICU parents roomed-in together with their partner and infant during the hospital stay.

Further, the results showed that rooming-in as parents with the infant during hospitalization and social support were positively associated with the quality of the couple relationship (II) and parenting sense of competence (III). The couple relationship was, in turn, associated with both parenting sense of competence and coparenting (III). Having symptoms of depression was negatively associated with both the quality of the couple relationship (II) and parenting sense of competence (III).

The studies also provide a deeper understanding of how and why parents are affected by their NICU experiences. The constructed theory describes a process in which parents' experiences of togetherness/separation, stability/instability, and support/lack of support during birth and NICU hospitalization influence their relational resilience, well-being, and couple relationship in the long term. Relational resilience is dependent on relationships and social support and is important for adaptation and recovery after a traumatic experience. The results showed that stability and adequate support during hospitalization made parents feel as if they were in a "safe zone," which resulted in them carrying a "light backpack" home and feeling stronger as a couple. Parents who had been separated from each other during the NICU stay and who experienced instability and a lack of support from staff carried a "heavier backpack" of embodied trauma and emotional burden home, which led to decreased well-being and strain on the couple relationship. If they also lacked emotional and practical support after discharge, they felt as if they were "in a black hole."

In a NICU context in which parents can be together with each other and their infant during hospitalization, these parents' outcomes regarding symptoms of depression, quality of the couple relationship, and parenting do not differ compared to parents from MUs. However, NICU parents are affected by their NICU experiences in various ways for years. To optimize parents'

well-being, couple relationships, and parenting in the long term, the togetherness of parents and infants, and support from staff, family, and friends should be prioritized during hospitalization. Furthermore, there is a need to provide better emotional and practical support after discharge for NICU parents who are at risk for decreased well-being, strained couple relationships, and parenting difficulties.

Implications for practice

This thesis demonstrates that NICU parents' outcomes regarding symptoms of depression, the couple relationship, parenting sense of competence, and coparenting did not differ from MU parents' outcomes in a context in which NICU parents had a higher likelihood of staying together compared to the MU parents (due to different COVID-19 restrictions for the two groups). The couple relationship was, in turn, associated with both parenting sense of competence and coparenting. Thus, all units should allow and facilitate for parents to stay together during hospitalization, since togetherness seems to influence parenting even 3 years after discharge, and parenting is crucial for children's development. To be able to stay at a unit together, parents also require financial support in the form of temporary parental leave for both parents, as well as practical support from family and friends.

Furthermore, as the constructed theory indicates, to promote parents' relational resilience, well-being, and couple relationships, it is important to facilitate togetherness, stability, and support during NICU hospitalization. Many parents are already carrying traumatic events with them into the NICU and may continue to face traumatic events during hospitalization. To cope with these experiences, it is important that the parents can be together and support each other both emotionally and practically. Parents also require adequate support from NICU staff and from counsellors or psychologists. To identify parents at risk for decreased mental health, EPDS screening could be provided already in the NICU if the family is still there at the time at which EPDS screening is usually done.

Parents want stability and not to be moved around. They also want staff continuity and want to feel that the staff are competent and can be trusted. Staff continuity and competency facilitate feelings of stability and safety, which appeared to influence parents' relational resilience and well-being.

Parents who carry traumatic events with them home and do not have adequate support after discharge may experience decreased mental health and strain on their couple relationship (IV). In Study 2, several parents received private counselling after discharge due to their symptoms of depression; they needed and wanted better support. No NICUs in Sweden provide any routine psychological support for parents after discharge, and many NICUs do not

even have a psychologist employed. Parents are intended to be supported by CHS, but the results show that the NICU mothers were less satisfied with CHS support compared with the MU mothers (I).

To promote NICU parents' well-being, the quality of their couple relationship, and parenting outcomes, NICUs should do the following:

- Facilitate family togetherness.
- Provide stability and safety through staff continuity and competence.
- Provide emotional and practical/informational support to both parents.
- Welcome family and friends into the NICU if the parents want their support.
- Identify parents who are at risk for decreased well-being (separation, instability, and lack of support).
- Employ psychologists who can provide additional targeted support.
- Strengthen the support for NICU parents after discharge.

Future research

In this thesis, I did not study or assess parents' resilience as an independent factor for the outcomes, which would have been valuable for further identification of parents with an increased risk of decreased mental health, a strained couple relationship, and lower parenting competence. More research is also needed regarding parents' relationships with their infants after a NICU stay in a context where they were together during hospitalization.

The findings clearly show that parents both desire and need targeted individual support, potentially during hospitalization but certainly after discharge. Hence, there is a need to develop and evaluate feasible interventions aiming to support and improve NICU parents' well-being and family outcomes after hospitalization.

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Svensk sammanfattning (Swedish summary)

Bakgrund

Att få barn innebär för de flesta par en stor glädje, men för en del blir inte början av föräldraskapet som man har tänkt sig utan en tid med mycket oro; att få barn för tidigt eller få ett barn som föds sjukt upplevs oftast traumatiskt. I Sverige behöver cirka 10% av alla nyfödda barn neonatalvård, vilket motsvarar drygt 10.000 barn per år. Vårdtiden kan variera stort, från en dag till flera månader beroende på vilken graviditetsvecka barnet föds i samt hur sjukt barnet är. Under de senaste decennierna har det skett stora medicinska framgångar i att rädda för tidigt födda och sjuka barn. Även i omvårdnaden av barnen har det skett stora förbättringar där föräldrarna inkluderas mer i vården. Sverige och de nordiska länderna är i framkant i implementeringen av en mer familjecentrerad vård; ungefär hälften av de svenska föräldrarna kan bo tillsammans med barnet på neonatalavdelningen under vårdtiden.

Tidigare forskning har visat att föräldrar på neonatalavdelning kan ha svårt att hitta sin föräldraroll och stötta varandra i den medicinsk-tekniska miljön med mycket personal. Många upplever också traumatiska händelser och har symtom på depression under vårdtiden, symtom som riskerar att bli kvarstående under flera år. Studier har visat att symtomen kan minskas om vården är mer familjecentrerad där föräldrarna inkluderas i vården av sina för tidigt födda barn samt om de får adekvat känslomässigt stöd under vårdtiden. Det är känt att psykisk hälsa påverkar både parrelationen och föräldraskapet i en generell population av föräldrar. Det finns ett fåtal studier om parrelationen hos föräldrar till för tidigt födda barn där resultaten visar att parrelationen kan stärkas av att föräldrarna går igenom något traumatiskt ihop, men också att parrelationen riskerar att försämrats på grund av vad de tvingats gå igenom. Studier visar också att föräldrar till för tidigt födda barn upplever mer föräldrastress, har ett större kontrollbehov och har sämre samspel med sina barn. Studier om föräldrakompetens och samarbete är få men tyder på att symtom på depression och brist på socialt stöd påverkar föräldrakompetens negativt samt att bättre stöd under övergången till hemmet påverkade kompetensen positivt.

Få studier har undersökt föräldrars välbefinnande, parrelation och föräldraskap efter att deras barn har vårdats på neonatalavdelning. De studier som finns har oftast fokuserat på tiden på neonatalavdelningen eller månaderna

efter utskrivning och i en kontext där föräldrarna inte har haft samma möjligheter att bo kvar på avdelningen. Dessutom har många studier endast inkluderat mammor till för tidigt födda barn. Således, med en förändrad neonatalvård och goda möjligheter att bo tillsammans med partner och barn under vårdtiden uppstår ett ökat behov av studier i en sådan kontext som Sverige.

Syfte och metod

Syftet med denna avhandling var att beskriva psykisk hälsa, parrelation och föräldraskap hos föräldrar som påbörjat sitt föräldraskap på en neonatalavdelning, jämfört med föräldrar till fullgångna och friska barn, till dess att barnen fyllt 3 år. Syftet var också att utforska föräldrars upplevelser av familjerelationer efter utskrivning från neonatalavdelning. Detta i en kontext där majoriteten av föräldrarna hade möjlighet att vara tillsammans med partner och barn under vårdtiden på neonatalavdelningen.

Avhandlingen består av två studier där den första är en enkätstudie där både föräldrar från neonatalavdelningar och föräldrar från BB-avdelningar har svarat på fyra enkäter under de första tre åren efter utskrivningen: vid 1 månad och 6 månader efter utskrivning samt då barnet var 1 år och 3 år. Enkäterna innehöll bakgrundsfrågor och olika instrument avseende symtom på depression, parrelation, socialt stöd, föräldrakompetens och föräldrasamarbete. Föräldrarna som var med i dessa studier fick barn då det rådde olika COVID-19-restriktioner på neonatalavdelningar och BB-avdelningar. BB hade striktare restriktioner där många pappor inte fick stanna kvar med familjen på BB. Totalt inkluderades över 900 föräldrar från 6 olika neonatal- och 4 olika BB-avdelningar. Resultaten från Studie 1 presenteras i tre olika artiklar (I–III). Studie 2 (IV) är en intervjustudie med konstruktivistiskt grounded theory design där 20 föräldrar intervjuades en gång när barnen var mellan 8 månader och 3 år gamla. Fokus för intervjuerna var främst parrelationen, men också andra familjerelationer och vilket stöd familjen erhöll eller saknade efter utskrivningen.

Resultat

Resultaten från Studie 1 visade att föräldrar till neonatalt vårdade barn (härefter: neo-föräldrar) upplevde förlossningen som mer traumatisk och de skattade sin egen hälsa sämre under den första veckan efter förlossningen jämfört med föräldrar vars barn endast hade vårdats på BB (härefter: BB-föräldrar). Neomammor som hade upplevt en traumatisk förlossning hade ingen ökad risk för symtom på depression en månad efter utskrivningen till skillnad från BB-mammor som hade en ökad risk för symtom på depression.

Studiens resultat visade att det inte fanns några skillnader i symtom på depression en månad efter utskrivning, i kvalitén på parrelationen ett år efter utskrivning, eller i föräldrakompetens och föräldrasamarbete tre år efter utskrivning mellan neo-föräldrar och BB-föräldrar.

I studie 1 analyserades också samband mellan olika faktorer och parrelationen och föräldraskapet hos neo-föräldrar. Resultaten visade att föräldrar som var tillsammans med varandra och barnet under vårdtiden och föräldrar som hade bättre socialt stöd skattade både sin parrelation och sitt föräldraskap bättre. Parrelationen hade i sin tur ett samband med föräldraskapet; en bättre parrelation hade ett samband med högre föräldrakompetens och en sämre parrelation hade ett samband med fler problem i föräldrasamarbetet. Symtom på depression hade ett negativt samband med både parrelation och föräldraskap.

Resultaten från intervjustudien beskriver hur upplevelser av att vara tillsammans/separerade, stabilitet/instabilitet och stöd/brist på stöd på neonatalavdelningen och hemma kan påverka föräldrars relationella motståndskraft (resiliens), psykiska välbefinnande och parrelation flera år efter utskrivning. Denna teori beskriver hur föräldrarnas upplevelser av att få vara tillsammans i en trygg och stabil miljö med adekvat stöd ökade deras relationella motståndskraft, välbefinnande och stärkte parrelationen. Dessa föräldrar kände tacksamhet för att ha fått vara på neonatalavdelningen och de upplevde sig starkare som par. Samtidigt visade teorin också hur separation från varandra, känslor av ensamhet, otrygghet och brist på stöd påverkade den relationella motståndskraften negativt med ett sämre mående och en negativ påverkan på parrelationen. Om dessa föräldrar fick ett bra socialt stöd efter utskrivningen upplevde de att ”det som inte dödar, stärker”. För dem som inte fick ett bra emotionellt och praktiskt stöd från samhället, vänner och familj efter utskrivning var känslan att befinna sig i ett ”svart hål”.

Diskussion

Studie 1, genomförd i en kontext där neo-föräldrar hade bra möjligheter att bo tillsammans under vårdtiden, visar på unika resultat där det inte fanns några skillnader mellan neo- och BB-föräldrars symtom på depression, kvalitet i parrelationen eller skattning av föräldraskapet efter utskrivning. Dessa resultat skiljer sig från andra studier som till exempel har visat på högre risk för symtom på depression hos mammor till för tidigt födda barn. Få studier har undersökt parrelation och föräldraskap efter utskrivning från neonatalvården. Resultaten i denna studie visar att få vara tillsammans under vårdtiden, socialt stöd och symtom på depression har samband med kvaliteten i parrelationen och föräldraskapet efter utskrivning.

Att bo tillsammans under vårdtiden möjliggör att kunna stötta varandra både praktiskt och känslomässigt, vilket också kan stärka parrelationen. En starkare parrelation har i sin tur ett positivt samband med föräldraskapet, både i denna studie och i tidigare studier. Tidigare studier har visat att det viktigaste stödet under vårdtiden på neonatalavdelningen kommer från partnern, men även att stöd från personalen och socialt stöd från övrig familj och vänner är viktigt. Detta visar även resultaten från studie 2 där föräldrar som fått vara tillsammans i en stabil och trygg miljö under vårdtiden, där de fått bra stöd av personal samt av familj och vänner, beskrev ett starkt välbefinnande och en starkt parrelation efter utskrivning. Föräldrarna i studie 2 som däremot upplevde separation från varandra, instabilitet och brist på stöd under vårdtiden riskerade ett sämre välbefinnande och negativ påverkan på parrelationen om de inte fick bra stöd efter utskrivning. För att främja neo-föräldrars välbefinnande, parrelation och föräldraskap långsiktigt så ska neonatalvården undvika separation och möjliggöra för familjer att bo tillsammans under vårdtiden. Föräldrarna behöver känna stabilitet och trygghet genom personalkontinuitet och få bra känslomässigt och praktiskt stöd från personal samt få socialt stöd genom att välkomna övrig familj och vänner. Idag finns inget annat rutinemässigt stöd än det generella stödet på BVC för föräldrar efter utskrivning från neonatalvården, så stödet för dessa föräldrar borde stärkas.

Studien har både styrkor och svagheter. Studien är relevant för den studerade gruppen eftersom studien designades tillsammans med ett föräldraråd bestående av föräldrar som haft barn på neonatalavdelningar. Enkäterna fanns på fyra olika språk för att även kunna inkludera föräldrar som inte talar svenska. En svaghet är den initiala svarsfrekvensen på 21% och att det inte finns någon information om dem som inte ville delta. Således finns det en risk för bias. De föräldrar som svarat på enkäterna är mer högutbildade än befolkningen i Sverige generellt och det behöver tas i beaktande då utbildning kan påverka hur man svarar. Dock verkar de två grupperna av BB- och neo-föräldrar i studien vara jämförbara då till exempel deras utbildningsnivå, ålder och antal år de varit ett par inte skiljer sig åt.

Slutsats

Sammanfattningsvis, i en miljö där neo-föräldrar kan vara tillsammans med varandra och barnet under vårdtiden så har föräldrar inte fler symtom på depression och de skattar sin parrelation och sitt föräldraskap lika bra som föräldrar till barn födda i fullgången tid och som är friska vid födseln. Dock kan neo-föräldrar som inte får vara tillsammans under vårdtiden och som känner en otrygghet och brist på stöd påverkas negativt av sina upplevelser under flera år. Föräldrar som riskerar ett försämrat mående på grund av

traumatiska upplevelser, separation, instabilitet/otrygghet och brist på stöd under vårdtiden bör identifieras för att få ett utökat stöd både under och efter utskrivningen.

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