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Kangaroo Mother Care

Parents' experiences and patterns of application in two Swedish neonatal intensive care units

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Abstract
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Kangaroo Mother Care (KMC) is an alternative model of care that prevents parent-infant separation when preterm infants need neonatal intensive care by skin-to-skin contact between infants and their parents. KMC is also a strategy that involves parents in their infants' care and enables them to assume the responsibility for the care. Furthermore, KMC promotes parent-infant bonding and attachment.

The overall aim of this thesis was to gain a deeper understanding and knowledge about parents' capacity, willingness, and experiences of KMC and to which extent parents choose to use KMC throughout their infants' hospital stay. These studies were conducted in the NICUs at two Swedish university hospitals (NICU A and NICU B).

Mothers of infants cared for at NICU A (n=17) answered a questionnaire about their experiences of KMC (Paper I). Twenty parents of infants cared for at NICU A recorded the duration of each KMC session during a period of 24 hours and the identity the KMC provider (Paper II). Seven fathers were interviewed about their experiences of KMC (Paper III) and 76 mothers and 74 fathers completed a questionnaire about what facilitated or rendered it difficult to perform KMC (Paper IV). The time of initiation of KMC and duration in minutes, and the identity of the KMC providers was recorded continuously during the infants' (n=104) hospital stay: 83 mothers and 80 fathers also completed a questionnaire during their infants' hospital stay (Paper V).

This thesis provides new knowledge about parents' practice of KMC, also continuously day and night, in a high tech NICU in an affluent society, with good resources for infant care in an incubator by trained staff. The accuracy of parents' records of KMC were comparable to nurses' records. The results indicate that parents want to be together with their infant in the NICU and be actively involved in the infants' care. Although parents may experience KMC as exhausting and uncomfortable, they still prefer KMC to conventional neonatal intensive care as it supports their parental role. Early initiation of KMC after birth appears to result in a longer total duration of KMC during the infants' hospital stay.

Keywords: Kangaroo Mother Care, Neonatal intensive care unit, Preterm infant, Nursing, Parenting

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Baby in a world without pity
Do you think what I'm askin's too much?
I just want to feel you in my arms
And share a little of that human touch

Bruce Springsteen

List of Papers

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

I Blomqvist YT, Nyqvist KH. Swedish mothers' experience of continuous Kangaroo Mother Care. *Journal of Clinical Nursing.* 2011 20(9-10): 1472-1480. Epub 2010 Nov 30.

II Blomqvist YT, Rubertsson C, Nyqvist KH. Parent-infant skin-to-skin contact; How do parent records compare to nurse records? *Acta Paediatrica.* 2011 100(5): 773-775.

III Blomqvist YT, Rubertsson C, Kylberg E, Jöreskog K, Nyqvist KH. Kangaroo Mother Care helps fathers of preterm infants gain confidence in the paternal role. *Journal of Advanced Nursing.* 2012 68(9): 1988-1996.

IV Blomqvist YT, Frölund L, Rubertsson C, Nyqvist KH. Provision of Kangaroo Mother Care: supportive factors and barriers perceived by parents. *Scandinavian Journal of Caring Sciences.* 2012 Jul 22. [Epub ahead of print]

V Blomqvist YT, Ewald U, Gradin M, Nyqvist KH, Rubertsson C. Kangaroo Mother Care in two Swedish NICUs. Submitted

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Abbreviations

CPAP	Continuous Positive Airway Pressure
CA	Corrected age; the age of the infant calculated from the expected date of delivery.
GA	Gestational Age; the time elapsed between the first day of the last menstrual period and the day of delivery.
KMC	Kangaroo Mother Care
LBW	Low Birth Weight < 2500 g
NICU	Neonatal Intensive Care Unit
PNA	Postnatal Age in days
PMA	Postmenstrual Age. Gestational Age plus the time elapsed after birth.
Preterm	Born before 37 + 0 gestational weeks
WHO	World Health Organisation

Introduction

Neonatal care has changed over the decades, both in terms of medical, psychological and nursing care of the infants and their families [1]. In the late 1890s, the first incubators were introduced for care of preterm and/or low-birth weight infants in Europe, and then later all over the world. Initially, the mothers were allowed to participate in the care of their infants in incubators, but soon infant care was only performed by trained nurses, and it was not until during the 1950s the discussion commenced about parents' rights to be together with and visit their infants at the NICU [2]. However, around the world, separation is commonplace in NICUs, where the infant is generally physically separated from the parents, and often the parent's presence is restricted by the rules and routines in the neonatal intensive care environment. The NICU is a complex, highly sophisticated environment that is structured to maintain and support the infant for achieving the desired outcome and quality of sustaining life. The focus of the care is often medical, technological, and procedural [3, 4].

Born premature

Rapid socio-economic development and improved maternal health combined with improved technological and medical care has led to a higher rate of infant survival and quality of life [5]. Preterm births are those occurring before a gestational age of 37 weeks and are a significant perinatal health problem globally, in terms of associated mortality, long- and short-term morbidity, and financial implications for the health-care systems [6]. In Europe, preterm deliveries comprise 5-12% of all births [7], and accounts for about 75% of perinatal mortality and more than half of long-term morbidity [8]. Moderately preterm infants (born between 30 and 34 gestational weeks) occupy almost half the beds in an NICU [9].

The reasons for preterm birth are mainly spontaneous labour with intact membranes, followed by premature rupture of membranes, or delivery due to maternal or foetal illness, either induced or by caesarean section [8]. Globally, the single most common cause of spontaneous preterm labour is infectious disease [10]. Preterm infants are especially vulnerable to temperature instability, and risk of having low blood sugar and feeding problems, infec-

tions, and breathing difficulties. Saving lives and preventing disability from preterm birth can be achieved through a wide range of care procedures from simple care, such as warmth and breastfeeding, up to full intensive care [7]. Appropriate thermal control of the preterm infant, such as the use of an incubator or skin-to-skin contact, decreases neonatal morbidity and neonatal mortality [11].

Becoming a parent of a preterm infant

The healthy growth and psychological well-being of an infant are dependent on her (for simplicity, in this thesis, the infants are entitled "she") relationship with a significant caregiver, such as the mother and/or father [12], and a loving relationship between a parent and the infant promotes emotional wellbeing in both [13]. However, there is confusion about the concepts of 'infant attachment', 'bonding' and 'parental (mother/father) attachment', and these terms are sometimes used interchangeable [13, 14]. Often the term 'attachment' is used to describe the relationship in both directions from and to the infant. In this thesis, the conventional definitions are used [15]. Attachment is used when the direction is from the infant to her parents and bonding when the direction is from the parents to the infant.

Attachment

The term 'attachment' is used to describe the emotional tie emerging between an infant and its parents: it is about the infant's need to receive care and parents' willingness to provide the care [16]. The central role of parenting is that the parents are a "secure base" from which the child can venture into the outside world. The parents are the infants' "safe haven" to which she can return, knowing she will be welcomed when she returns, for example receiving physical and emotional contact and being soothed when needed. It is essential that parents are available, ready to respond, encourage, and perhaps assist. The parent's role as a secure base and a safe haven is mainly about waiting and being there, but this is still vitally important [16].

Bonding

The term 'bonding' is used to describe the emotional preoccupation with the infant by a parent who is expecting or just had an infant. Bonding can be facilitated by the infant giving feedback to the parents, such as looking at them, and by the parents' possibility to spent time alone with their infant [17]. Parents' bonding to their infant is a process that occurs over time, and begins during pregnancy, or even before, and increases shortly after birth through the influence of several factors, including the parents' experiences

from their own childhood, experiences during pregnancy, childbirth, the period immediately after birth, and the first months of the infant's life [18]. The first hours after birth appear to be an especially valuable time in the bonding process [17, 19]. The parents' bonding to their infant is attributed as being one of the strongest and most important among human behaviours [18]. The power of this bonding is so great that it enables the parents to make many sacrifices for the infant, such as protecting the infant from danger and providing food in the middle of the night, despite their own desperate need for sleep [17].

Human physical contact is a powerful contributor to health and wellbeing, and it is in the arms of her caregiver that an infant begins to develop her capacity for human connection and meaning [12]. Physical contact and touch are the most important communication tools parents use to interact with their infant [13]. Early and extensive contact between the infant and the parents enables the parents to get to know their infant. Care-giving activities such as feeding, rocking, and embracing maintain prolonged contact that allows the parent to interact with their infant [13]. Physical proximity is required to develop bonds between the parent and infant, and the amount and timing of contact may explain why parents of preterm infants experience the early bonding process differently to parents of term infants [20]. Mothers of preterm infants who are deprived contact with their infants may inhibit physical stimulation and therefore delay the bonding process [3, 20]. Thus, separation between a parent and their infant affects the bonding process [3].

Separation in the NICU

Parent-infant separation occurs when an infant is placed in, for example, an incubator, as the incubator can be perceived as the optimal and normal place for the preterm infant. The parents, in turn, could interpret the situation as meaning the "infant does not need them". Through this separation, the parents' bonding to their infant and the infant's attachment to her parents can be unnecessarily delayed [21, 22]. The incubator has been described as the main barrier between parents and their infants in the NICU [23]. This period of separation leads the mother through a particular transition to parenthood, which is different from parents with a healthy, full term, infant [24]. Furthermore, for the preterm infant it may be difficult to interact with her parents in the same way as a healthy infant [4]. Separation from the infant is one of the most stressful aspects for parents of infants who need care at a NICU [25-27], and being unable to hold the infant is a separation experience that is especially stressful [25, 28]. Whatever the circumstances, mothers of an infant in an NICU want be close to their infant [29].

Separation or not in the delivery room

There is evidence for numerous benefits of skin-to-skin contact between a healthy term infant and her mother/father immediately after birth. Early skin-to-skin contact alleviates the “stress of being born”, as the mother’s touch, body heat and odour decrease the infant’s sympathetic tone [19]. In the early 1970s, Klaus and Kennel and co-workers [30] found mothers of full-term infants who had extended contact with their newborn infants were more reluctant to leave their infants with someone else, and usually stood and watched during examinations, showed more soothing behaviour and engaged in more eye-to-eye contact and fondling. Early and extended contact by the human mother may have powerful effects on her interaction with her infant, and subsequently, on the infant’s later development [30].

Full-term infants who are separated from their mothers often cry and then stop crying when they are reunited with their mother [31]. This is humanity’s "separation distress call", a genetic response in young infants to separation from their caregivers. When full-term, healthy infants born by caesarean section are cared for skin-to-skin by their fathers they are more quiet and cry less than infants cared for in a crib next to their fathers [32].

Furthermore, mothers and infants who experience early skin-to-skin contact are more likely to establish a successful breastfeeding during the early post-partum period: there has been shown s a dose-response relationship between early skin-to-skin contact and exclusive breastfeeding [33, 34]. Early skin-to-skin contact between a healthy newborn infant and her mother improves maternal-infant bonding [33], and infants cared for skin-to-skin with a parent have shorter crying bouts, better blood glucose levels, and can maintain physiological parameters better. No significant negative effects of early skin-to-skin contact have been identified [33].

Healthy term infants may benefit from skin-to-skin contact for a limited period during the day and for a limited number of days, as long as the infant and parents accept this contact [35]. The term application model of skin-to-skin contact is used for healthy term infants as they do not need skin-to-skin contact or another source of heat in the same way as a preterm/LBW infants do.

Parenting in the NICU

A majority of all studies investigating parenting in a NICU are performed under the circumstances of parent-infant separation. A mother’s new identity starts at some point during the pregnancy, emerges after the infant’s birth, and then attains full development after several months of caring for the in-

fant at home. When the infant is born preterm, the mother's motherhood mindset is also premature and psychologically fragile [36]. Therefore, a preterm birth will not only produce a preterm infant but also parents not really prepared to be parents [37]. The mother can have feelings of being a mother who is unable to fulfil a pregnancy and become a "real mother". These feelings can be reinforced by physical separation from the infant [37]. When an infant is in an NICU, the mothers' and fathers' needs are similar [38]: the need for assurance and information is high, for example, the parents want to have knowledge and information about the infant's care, treatment and expected outcome [38-40].

A sense of lack of control and a struggle to gain control is common among fathers with an infant in an NICU [41, 42]. Fathers feel in control when they are included in the infant's care, and attribute the loss of control and stronger feelings of stress to not being involved in the care or having to leave the infant at the NICU [20, 42]. Fathers gain paternal feelings [23] and increasing confidence in their paternal role [43] when they are active in their infant's care. Mothers of infants in the NICU expend commitment and energy in getting to know both their infant and the staff and understanding and anticipating their activities [44]. Mothers separated from their infants develop feelings of guilt that they had abandoned their infant, and describe a need to be together with their infant as much as possible [29]. Spending time with and being close to the infant allows feelings of motherhood to grow [27].

Parental participation in the care of preterm infants has changed over time, and the parents have moved from being left outside to being partners in the care of their infants [1]. A Swedish study reported parents consider themselves more capable than nurses may assume; some parents expressed the opinion parents should be offered the opportunity to take over certain intensive care procedures [45]. In another Swedish study, the provision of facilities for parents of preterm infants enabled them to stay with their infant in the NICU from admission to discharge, and their involvement reduced the infants' total length of hospital stay [46].

One intervention for empowering parents and strengthening their role in the infants' care in the NICU are, for example, Family-Centred Neonatal Care which aims to encourage the infants' family (mother, father, siblings, and extended family) to participate in the caring of and decision-making for their hospitalised infants [47-49]. The infants' family should be involved in caregiving activities and it is essential to support unrestricted family presence in the NICU. A Swedish randomised, controlled trial found that infants that received family centred care (these infant had at least one parent with them 24 hours a day during the entire hospital stay) had a reduced total length of hospital stay by 5,3 days [46]. The importance of the physical environment

at the NICU for family centred care has received increasing attention, for example, private-rooms/single-family rooms for preterm infants reduce infections and medical mistakes, promotes family-centred care, and increase parents' participation in their infants' care [50]. The provision of parental bed spaces at a paediatric intensive care unit allows continual parental presence and reduces the parental stress [51].

Kangaroo Mother Care

Kangaroo Mother Care is defined as early, prolonged and continuous (or as much as the circumstances permit) skin-to-skin contact between the LBW infant and its mother, or a substitute for her, such as the father or a relative [52]. KMC starts in hospital and, if necessary, continues at home, for as long as the infant needs it for temperature control, which can be up to term age. Ideally, the infant should, have breast milk as nutrition, be cared for by the mother or relatives at home after early discharge, and be followed up in an appropriate manner.

Kangaroo Mother Care facilitating LBW infants' transition from intra- to extra-uterine life and for supporting the parental role in neonatal care [53]. KMC provides an alternative to incubator care, without separating the infant from the mother (parents) [54]: the separation is prevented by the skin-to-skin contact. KMC is also a strategy that involves the parents in the infant's care and enables them to take over the responsibility for the infant's care.

KMC was originally developed to prevent hypothermia in infants, to promote exclusive breastfeeding and to strengthen the mother-infant bond, and was first described in the scientific literature in the mid 1980s [55]. In 1979, two neonatologists, Rey and Martinez, introduced a home care programme for LBW infants at the overcrowded San Juan de Dios Hospital, Bogota, Columbia, and included care of the infant skin-to-skin between the mothers' breasts in a head-up position. The reason for this new care model was a constant lack of staff and equipment, many infants being abandoned by their mothers, and a high frequency of cross-infections among the infants [56].

Parental proximity through KMC involves the parents' physical presence in its entirety and includes a range of interconnected stimuli: parental body heat, smell, touch, voice, skin texture, movement, physiological rhythms and the parents unique social and emotional style [57].

In both literature and practice, there is a variety of terms for KMC, such as Kangaroo Care, Skin-to-skin contact, Skin contact. In this thesis, the term

Kangaroo Mother Care (KMC) is used because the method is more than merely skin-to-skin contact, both for the infant and her parents.

Practical application of KMC

According to the WHO guidelines for KMC [58], the naked infant should be positioned upright between the mother's breasts or on the father's chest, under their clothes, wearing only a nappy and a cap. The skin-to-skin contact should ideally start as early as possible, preferably in the delivery room, or immediately on admission to the neonatal unit. The infant should be placed, either in a frontal, vertical position on the upper part of the parents' chest with flexed arms and legs and the head turned sideways (the kangaroo position) [21] or placed on the parents' chest lying in a side-lying position [59, 60]. It is important that as much as possible infant skin surface is in direct contact with the parent's skin [21]. The infant needs adequate support of the head with straight trunk and neck in order to safeguard patent airways. The infant's position should be controlled frequently to prevent a 'slumped-together' position. In order to prevent water and heat loss, all parts of the infant's body not in contact with the parent's skin should be adequately covered with one or more blankets and the head covered with a cap. The parents should be informed about how to hold the infant in an optimal position with still hands and that each KMC session length should be as long as possible, as it is the transfer to and from the parent that could be problematic for the infant [21].

To facilitate breastfeeding, the infant should be positioned at the breast as early as possible to stimulate lactation, even if latching on or sucking does not always occur [35]. If preterm infants receive sufficient time and support, they can commence breastfeeding, even when they are very preterm [61, 62]; full breastfeeding can be attained as early as 32 postmenstrual weeks. Mothers should be supported to start breastfeeding as soon as possible, without any unjustified limitations. The mother needs to know how preterm infant show signs of interest in breastfeeding, and know the characteristics of preterm infants' nursing behaviour. Furthermore, during the initial phase of breastfeeding, the mother needs counselling about how to position her infant at the breast and be encouraged to continue to put the infant to the breast often, irrespective of the infant's current postmenstrual, postnatal age or weight. In neonatal care, breastfeeding is commonly considered mainly asan aspect of nutrition and separate from the mother's relationship building with the infant, however, it is important to consider the relationship (between the infant and her mother and between the mother and the NICU staff) as essential in the breastfeeding process [63].

KMC can assist the infants' neurobehavioral development [64]. For instance, KMC minimises the infants' purposeless movements and offers parental proximity for interaction and attention periods. Parents need guidance on observing and interpreting the infants behavioural signs of stability or instability and how they can assist their infant [53].

KMC can be applied in two main ways:

- *Continuous KMC* - providing a LBW or sick newborn infant with continuous skin-to-skin contact, 24 hours a day, is an alternative option to incubator care [65].
- *Intermittent KMC* - when KMC around the clock is not possible, skin-to-skin contact for limited periods, such as one or two hours per day, is an appropriate care strategy for strengthening the mother, improving bonding and facilitating lactation and breastfeeding [53].

In low income countries, regulation of temperature and maintenance of lactation together with skin-to-skin contact, i.e. KMC, is lifesaving for the infant [66, 67]. In developed countries, KMC assists mothers and fathers in overcoming feelings of guilt after separation and feelings of inadequacy during the NICU stay [53]. If KMC is performed continuously, or as much as possible, it will provide the preterm infant with a location of care that protects the continuity in her sensory experiences from foetal life to life after birth, which may counteract the detrimental effects of the NICU environment [21].

Extent and initiation of KMC

Studies of KMC as an intervention differ considerably with respect to the length of time when the infant receives KMC, both in terms of the duration and initiation of KMC. The extent of KMC can vary from 20 minutes per day [68] to one hour per day [69], occasional one hour sessions [70], or up to 24 hours per day [71, 72]. Application of KMC also varies regarding when the parent initiates KMC, such as directly after birth [54] or after stabilisation of the infant [69]. A recently performed Swedish study showed that extremely preterm infants experienced their first skin-to-skin contact at a median of six postnatal days, however with a wide range: 0–44 days.

Few studies present information about the exact extent of the infants and parents exposure to KMC contact. In the majority of these studies, the number of minutes of KMC is presented without further explanation of how this was measured or recorded. However, there are some exceptions, for example, in one study [73], the mothers were given a "Kangaroo Mother Care chart" for recording the duration of skin-to-skin contact : if the mother was unable to fulfil this task, a close family member took over. In two studies [74, 75], the duration of KMC was recorded by two instruments, a "contact

log" and the Index of Mother-Infant Separation: these instruments were used to document the time, frequency, and duration of skin-to-skin contact and the identity of the person providing the contact. In a study by Whitelaw et al. [76], a record was completed each time the mother visited, with information on the duration of the visit and whether the contact was "normal" (defined as "clothed"), or skin-to-skin. Rojas et al. [77] asked the parents to complete a self-assessment questionnaire after each KMC session, where they recorded the duration of the session and any problems encountered during the procedure. Boo and Jamli [69] provided mothers with charts for documenting each KMC session. If the intervention was KMC 24 hours a day, no documentation of the time is needed [71, 72, 78].

Evaluation of KMC from the infant's perspective

Advantages

In low-income countries, LBW infants treated with KMC have lower rates of neonatal mortality and morbidity than infants cared for with conventional care [66, 67]. Low birth weight infants who received KMC are more physiologically stable than infants cared for in an incubator [54], and during and after KMC, infants have lower and more stable heart rate and more stable oxygen saturation [79].

In conventional neonatal care, the infant is mostly cared for in an incubator, however, KMC can shorten the infant's length of hospital stay [80, 81]. Kangaroo Mother Care decreases the infant's need for incubator treatment and reduces the risk of hypothermia [54]. Even extremely preterm infants are able to maintain their body temperature during skin-to-skin contact [59, 82]. Karlsson et al. [59] studied extremely preterm infants before, during and after skin-to-skin contact and found infants maintained a normal body temperature during the skin-to-skin session. During the transfer from and to the parent, there was a drop in skin temperature, which increased soon again, when the infant was skin-to-skin. Although there is an increased water loss during the time the infant is cared for skin-to-skin, this is so small that it should not affect the infant's fluid balance [59].

Furthermore, KMC may contribute to improved head growth [73] and better weight gain [73, 81]. KMC infants, compared with infants cared with conventional care, are breastfed more and often exclusively at discharge [75, 83]. KMC initiated directly after birth has positive effects on exclusive breast-feeding at 6 months age, compared with KMC started after approximately 24 hours [84]. KMC has a positive effect on the infant's perceptual, cognitive, emotional and physical development [57, 85], and improve the infants sleep organisation, including a more mature sleep [86]. The infant's

body temperature is maintained both when mothers and fathers perform KMC [87], and pain from invasive procedures, such as heel lance [88, 89] and vein puncture [90], diminishes when the infant is cared for skin-to-skin during the procedure.

Disadvantages

A few studies describe disadvantages of KMC. One study found that infants born before a GA of 30 weeks had difficulties in maintaining body temperature during KMC [79]. Infants born between a GA of 24-31 weeks can have more bradycardia and desaturation during KMC than when they are in the incubator [91, 92]; this highlights the importance of adequate monitoring of extremely preterm infants when they were being cared for skin-to-skin. Nagai et al. [93] found an 'earlier' (within 24 h postbirth) start to continuous KMC for relatively stable LBW babies in a resource-limited country was associated with a higher, but not statistically significant higher, mortality in the first 28 days post birth, and suggest more research of 'earlier' continuous KMC is needed to examine its effectiveness.

Evaluation of KMC from the parents' perspective

KMC empowers the parents through gradually transferring the responsibility and skills for becoming the infants' primary caregiver and for meeting the infants' every emotional and physical needs [35]. In developing countries, temperature regulation and maintenance of lactation through KMC are life-saving for the preterm infant. In developed countries, KMC is not always an alternative to intensive care for life-treating illness, but through emphasising physical contact, it can help parents to overcome at least some of the psychological difficulties that frequently accompany preterm delivery [94, 95]. Kangaroo Mother Care facilitates parent-infant bonding [72, 96], and even when KMC is intermittent, parents feel that they are doing something for their infant and some of their worries about the infant disappear [95]. Parents, who experience holding their infant skin-to-skin, describe this as an emotional, important and positive experience and is an important part of becoming a parent and getting to know their infant [97].

Mothers who care for their infants with KMC are less depressed, have lower cortisol in saliva, perceive themselves as more competent, feel stronger in the maternal role, have a more positive mood, and perceive their infants as more normal than mothers who are separated from their infants [72, 85, 98-100].

KMC mothers showed concern for their infants by picking them up more frequently when they cried and spent more time with their babies beyond the routine care taking activities [101]. Mothers feel KMC is safe, and prefer

KMC to conventional care as it does not separate them from their infants [102]. Mothers who care for their infants with KMC report confidence in their abilities, for example, they feel they know and can monitor their infants better than nurses or technology [86, 103], KMC improves bonding and the mothers feel good, satisfied and happy they can do something for the infant [104]. Before the first time mothers hold their infants skin-to-skin, they can feel ambivalence and be nervous and/or stressed [98, 105, 106], but when they hold the infant skin-to-skin, the stress decreases and their mood improves [98].

In one study, mothers expressed a desire to be relieved from KMC during the second week of caring for their infant with KMC in the NICU, as they felt tired and stressed [107], and decided to take a day off from KMC. Although KMC does not appear to physiologically disadvantage the mother, Tessier et al. [72] noted some mothers who practised continuous KMC felt more isolated and lonely than mothers whose infants received conventional neonatal care, and was more common among mothers whose infants spent a longer time in hospital. Tessier et al. [72] suggest the infants of these mothers' infants did not gain enough weight or were sick, which rendered the mothers overwhelmed by the responsibility of taking care of their infants and in need of more social support [72].

Kangaroo Mother Care may induce the father's participation in his infant's care, enhance active fatherhood during the infant's first year of life [108], and make him feel that he has a parenting role [109]. Fathers describe KMC as an extraordinary emotional experience when they could hold their infant skin-to-skin [110] and emphasise the importance of being close to the infant [42]. Fathers' involvement can be strengthened by a positive skin-to-skin holding experiences [20]. Holding or having visual contact with their preterm infants give fathers a sense of reality, and realisation that the infant is real, his own baby [23]. Through skin-to-skin contact or touching the infant, fathers feel important participants in the infant's care [20].

Evaluation of KMC from NICU staff's perspective

Despite ample research supporting the use of KMC, there are concerns among NICU staff about its safety and suitability [111]. Engler et al. [112] found nurses from NICU practising KMC appear to have positive perceptions of KMC, its appropriateness and advantages, but conclude KMC is an example of nursing practice that is based on perceptions rather than scientific evidence. However, NICU nurses have identified difficulties related to KMC, in the time required for preparing the infant, supporting the parents and monitoring the infant during KMC [113], which is considered problematic during periods with staff shortage. Other aggravating circumstances

regarding KMC is the NICU environment with lack of space and privacy, and nurses' concerns about the safety and stability of the infant [113]. Similarly, Engler et al. [112] found the barriers stated by nurses to the practice of KMC are concerns for the infants' safety and reluctance by nurses, physicians and families to initiate KMC. Despite nurses' perceptions about KMC being positive, their knowledge about its use and benefits and experience of the method are moderate [112]. NICU staff consider KMC improves bonding between the mother and her infant and the mother feels more satisfied when performing KMC [104], and highlight the advantages of KMC in promoting parent-infant attachment, improving the parents' confidence in handling their infant and participating in the infant's care [113]. Nurses with longer experience of working in a NICU are more likely to implement KMC [114], although another barrier for implementing KMC is the definition of required clinical stability for considering an infant ready for KMC [115], as this definition can vary among NICUs.

Theoretical knowledge about KMC alone does not change practice, and NICU staff's attitudes and beliefs strongly influence their encouragement or discouragement of KMC [111, 112]. If NICU staff personally notice KMC can improve the wellbeing of both infant and parents and that KMC facilitates their professional satisfaction, this influences their attitude to the method and makes them more open-minded and positive regarding the criteria for introduction of KMC [112, 113, 116].

Impetus for this thesis

Despite increasing evidence about the safety and positive effects of KMC and the Swedish national parental and health insurance, in Swedish NICUs, the KMC method is mainly applied as intermittent and late KMC for limited periods. Possible reasons for this restricted application may be insufficient knowledge among staff about KMC and its practical application, a predominant focus on the medical and technical aspects of care, and confusion regarding the parental and staff role division at the NICU. The physical environment at the NICU can also be considered an obstacle to the implementation of extended KMC. This, put together, can have influence on parents' opportunities to fully be involved in their infants' care at the NICU, and also to perform KMC to the extent they wanted to do.

Thus, the focus for this thesis was to study KMC in a high income setting in a high tech NICU through exploring parents' experiences of caring for their infants with KMC, and to study the extent of time parents spent with their infants with KMC during their stay at the NICU.

Overall and specific aims

The overall aim of this thesis was to gain a deeper understanding and knowledge about parents' capacity, willingness and experiences of Kangaroo Mother Care, and to which extent parents choose to use KMC throughout their infants' hospital stay.

The specific aims were to:

- Investigate aspects of the practical application of KMC and to explore mothers' experiences of this model of care (Paper I).
- Investigate whether parents of infants at an NICU were able to document KMC time and the identity of the KMC provider with sufficient reliability to achieve complete and accurate records, comparable to nurses (Paper II).
- Describe fathers' experiences of providing their preterm infants with KMC (Paper III).
- Identify factors parents perceived as supportive factors or barriers for their performance of KMC, and explore the timing of and reasons why, parents discontinued caring for their preterm infants with KMC (Paper IV).
- Describe when parents initiated KMC and the extent of KMC application during the infants' hospital stay (Paper V).

Methods

Setting

The studies included in this thesis were conducted at the NICUs in two Swedish University hospitals (Table 1). NICU A consisted of three intensive care rooms with four care spaces each. Every care-space included an adult bed and privacy screens to allow parents to be present close to their infant 24 hours/day. The unit also had nine single family rooms, where both parents could stay together with their infant and provide the infant's care, supported by nurses. In these rooms, siblings could stay with the parents and infant. All parents had access to a parent's kitchen and lounge where they could prepare meals, eat, and socialise, and the unit had play areas for siblings. There were no visiting restrictions for parents, siblings, or relatives. Both parents could stay with the infant at the NICU 24 hours/day free of charge. With some exceptions, mothers could stay with her infant 24 hours/day at the NICU and the nursing staff from the maternity ward came to her to provide postnatal care.

NICU B had one intensive care room and two intermediate care rooms with care-spaces for five infants each. Each care space included one or two arm chairs/recliners with footstools, where parents could sit holding their infant. There were three parent rooms, where one or both parents could room-in, free of charge, with their infant a few nights before discharge, depending on the current patient census at the NICU. The parents could be together with their infants as much as they wished during daytime. There were no visiting restrictions for parents' visits, but visits from siblings and relatives were restricted.

In both NICUs the parents were encouraged to be together with their infant, to participate in their infant's care, and to care for their infant with KMC as much as they wanted to and found possible. Both NICUs applied a care strategy that involved early discharge, which could occur from a PMA of about 34-35 weeks.

The parents' presence at the NICU was facilitated through the Swedish national insurance system, which allows both parents to share parental benefit for 480 days per child in order to take care of their children [117]. In addi-

tion, both parents of an infant requiring neonatal intensive care are entitled to "temporary parental benefit" until the infant is discharged. This means that during the infant's entire NICU stay both parents have the legal right to be together with their infant at the NICU. In Sweden, hospital care for all children is free of charge.

Study sample

Paper I

A purposive sample consisting of mother-infant pairs who had experienced continuous KMC from birth to discharge at NICU A, after introduction of clinical guidelines which allowed all infants to have at least one parent present 24 hours per day and to perform KMC as much as the circumstances permitted, during the period November 2004 to May 2006. Twenty-three infants were identified and 17 of the 23 mothers (74%) completed a questionnaire: 10 of these mothers responded to the open-ended question in the questionnaire.

The infants, 7 girls and 16 boys, were born at a GA between 31+2 and 41+0, with birth weights between 1715 and 3820 g. The infants' length of hospital stay ranged from 1 to 33 days, with a mean of 13 days. One infant required a short period of ventilator therapy followed by CPAP and two infants required CPAP for limited periods.

Paper II

The participants consisted of a convenience sample of parents of 20 infants cared for at NICU A. during the period April to September 2008

The infants included were born at gestational ages ranging from 22 to 40 weeks, with birth weights between 516 and 4500 g. All infants had been cared for with KMC during at least three days (3-45 days) before the study was undertaken. At the time of the study, the infants' weight ranged between 546 and 4757 g and the infants had reached a postmenstrual age between 26 and 42 weeks.

Paper III - V

A consecutive sample of parents of infants born between 1 October 2008 and 30 September 2010 at GA ranging from 28+0 to 33+6 (weeks + days) was recruited as a part of a longitudinal project investigating KMC at two Swedish University hospitals (Figure 1). Of 244 eligible infants, 121 infants did not meet the inclusion criteria, which were the infant should be cared for at the same NICU from birth to discharge, the parents mastered the Swedish

language, and the infant should be a singleton without any life-threatening illness. Of the 123 infants fulfilling the inclusion criteria, 19 were excluded because the parents declined participation or they were recruited too late to obtain the initial data required. The final sample for the main project was 104 infants and their parents.

In Paper III, the first twelve fathers who marked willingness to participate in an interview in a questionnaire, during their infants' NICU stay, were approached by mail, followed by a phone call, and asked if they would participate: the fathers decided the time and place for the interview. At the time of the interview, the infants had reached the corrected age of four months ± 2 weeks. Seven fathers, aged between 25 and 36 years, whose infants born preterm had been cared for in either NICU A or B, participated in the interview study. Four fathers had their first skin-to-skin contact with their infant on the day the infant was born, two on the infants' second day, and one on the infant's fifth day of life. The infants, one girl and six boys, were born at a GA between 29 and 33 weeks, with birth weights between 1315 and 2500 g. The infants' length of hospital stay ranged from 15 to 53 days, with a mean of 27 days.

In Paper IV, 76 mothers and 74 fathers completed a questionnaire developed to meet the aim of this study. The 76 infants were born at a GA between 28 and 33 weeks and had birth weights ranging from 740 to 2920 g. The infants' length of hospital stay ranged from 13 to 76 days, with a mean of 32 days.

In Paper V, the initiation time and duration in minutes, and by whom the 104 infants were cared for with KMC was recorded continuously in the infants' medical charts during their hospital stay, either by the infant's parents or by the NICU staff. Eighty-three mothers and 80 fathers completed a questionnaire during their infants' hospital stay.

Table 1. An overview of the studies included in this thesis.

Paper	Design	Setting	Study sample	Data collection	Data analysis
I	Descriptive, quantitative and qualitative	NICU A	Twenty-three mother–infant pairs, who had experienced continuous KMC from birth to discharge	Review of patient charts and medical records and a questionnaire	Descriptive statistics and qualitative content analysis
II	Comparative and quantitative	NICU A	Parents of 20 infants	Records, completed by staff and parents, of KMC duration during a 24 hours period	Descriptive statistics
III	Qualitative	In the fathers' homes. The infants had previously been cared for at either NICU A or B	Seven fathers of preterm infants	Individual semi-structured interviews and a questionnaire during the infants' hospital stay	Qualitative content analysis
IV	Descriptive, quantitative and qualitative	Parents of infants that had previously been care for at either NICU A or B	Seventy-six mothers and 74 fathers	Review of patient charts and medical records and a questionnaire	Qualitative content analysis and descriptive statistics
V	Descriptive and quantitative	NICU A and NICU B	104 preterm infants and their parents	Review of patient charts and medical records and a questionnaire.	The Chi-square test, Mann-Whitney U-test, Wilcoxon signed rank test and Pearson's correlation.

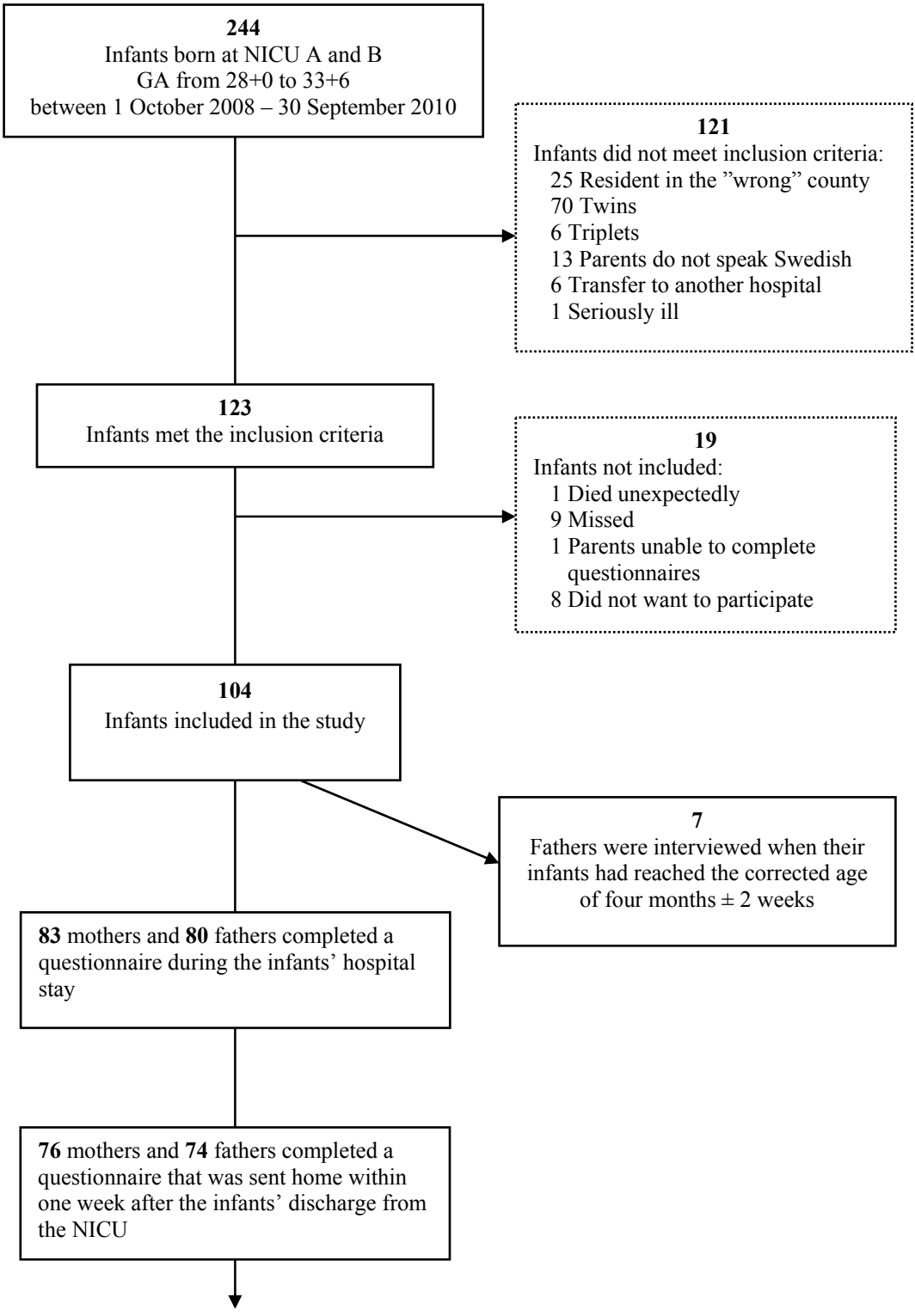

Figure 1. Flow chart of the included and not included infants in Paper III – V.

Data collection and instruments

Paper I

Relevant background data on the infants' medical status, such as birth weight, diagnoses, medical treatment, number of days at the NICU and breastfeeding at discharge were obtained from the infants' medical records.

A questionnaire, consisting of 24 closed questions (Appendix I), with positive or negative wording, was designed for this study, based on relevant research [52, 56, 72, 116] and the authors' clinical experience. The mothers were asked to rank their response as 'Agree completely', 'Agree partly', 'Disagree partly', or 'Do not agree at all'. The questions addressed the mothers' experience of and attitudes towards continuous KMC with respect to mother-infant contact; maternal stress, anxiety and fear related to KMC; KMC and the role of the nursing staff; and the KMC method itself. One open-ended question was included inviting the mothers to give spontaneous comments about KMC and the care provided at the NICU. Content validity was tested through peer review by two experienced registered nurses who read the questionnaire for critical appraisal. Four mothers and one father of infants currently being treated in the unit participated in a pilot study in which they gave their opinions about the content and design of the questionnaire by responding to the questionnaire and providing their comments during a face-to-face session. Subsequent minor linguistic changes were made.

The questionnaires, together with a letter of invitation to participate in the study, signed by the authors, were mailed to the mothers' home addresses in June 2006. The mothers were asked to complete the questionnaire and return it in an attached stamped response envelope. A reminder was sent to all mothers in September 2006 with the aim of achieving an optimal response rate.

Paper II

The parents were asked to record the duration of each KMC session during a period of 24 hours, from the exact starting time (infant placed in kangaroo position) to the time of termination, in hours and minutes (for example 8.10-14.45), and the identity of the KMC provider (mother or father). The records were a blank chart, identical to that used by the nurses for their regular daily documentation and the chart had columns with the hours as headings. After completing the chart, the parents placed it in an envelope and gave it to the nursing staff. In order to maintain a naturalistic data setting, the nurses were not informed this study was being conducted.

Paper III – V

A member of the research team asked the parents about participation before the infant's birth or within three days after birth. The purpose of the project was explained to the parents both orally and in writing, and the parents who chose to participate signed a consent form. Infant data, such as GA, birth weight, diagnoses, medical treatment and length of hospital stay, were obtained by review of the infants' medical charts and the Swedish PeriNatal Quality register (PNQ; MedSciNet AB, Sweden), a national register to which both NICU report all inpatients continuously. Maternal and paternal socio-demographic factors, such as level of education, marital status, siblings and smoking, were collected in a questionnaire completed by the parents individually during the infants' stay at the NICU.

In Paper III, the fathers were invited to participate in an interview by marking their acceptance to participate in a questionnaire completed during the infant's stay at the NICU. The first twelve fathers of infants cared for at either NICU A or B who marked acceptance were approached by mail, and later by a phone call, and asked about participation, and a time and place for the interview were reserved. Individual semi-structured interviews were conducted and recorded digitally in the fathers' homes in 2009 by a member in the research group who was unknown to the fathers. An interview guide (Appendix II) based on the research group members' clinical experience and the literature [53, 118] was used as a memento of topic focus. The initial question was a broad question about how the fathers had experienced their time at the NICU. Then, the interview focused on the fathers' experiences of KMC. The interviews varied in length from 15 to 60 minutes.

In Paper IV, the mothers and the fathers completed a questionnaire after the infants' discharge from the neonatal unit. The questionnaire included four survey questions (Appendix III) designed by the authors to fulfil the aim of the study. The questions, which were based on scientific literature and the researchers' clinical experience, were about which factors the parents felt facilitated and rendered it difficult to provide the infant with KMC to the extent they desired. And also about when they did discontinue KMC to the extent they used it during the infant's NICU stay, and why they did discontinue performance of KMC. Two questions were open-ended, and two had fixed response alternatives together with the opportunity for the parents to provide answers and comments in free text. The questionnaire, along with a pre-paid return envelope, was sent home to the 104 infants' mothers and fathers within one week after the infant's discharge from the NICU. If no reply was returned within one week, text messages and E-mail reminders were sent to both the mother and father. If no response was received after

two weeks, a letter of reminder, a new questionnaire, and a pre-paid return envelope were sent to the parents.

In Paper V, the time the infants were cared for with KMC was recorded continuously in the infants' medical charts in minutes every day and night during the infants' hospital stay, either by the infant's parents or by the NICU staff.

Data analyses

Quantitative analysis

In Paper I, data from the infants' medical records and the quantitative questions were analysed with descriptive statistics in the Statistical Package for Social Sciences (SPSS) version 15.0 for Windows.

In Paper II, the nurses' and parents' KMC recordings were analysed with descriptive statistics in the Statistical Package for Social Sciences (SPSS) version 15.0 for Windows. The sessions where the mother and father took turns were treated as one session. In cases when the exact time was not recorded, but only illustrated with a drawn line, the distance in millimetres between the ends of the line was converted into minutes.

In Paper IV, data from the infants' medical records and the fixed response alternatives in questions 3 and 4 were analysed by descriptive statistics in the Statistical Package for Social Sciences (SPSS) version 18.0 for Windows.

In Paper V, data were analysed in the Statistical Package for the Social Sciences (SPSS) version 20.0. The Chi-square test and Mann-Whitney U-test were used for comparison of independent samples, and the Wilcoxon signed rank test for related samples [119]. Pearson's correlation was used for correlation analyses. A p-value of less than 0.05 was considered significant.

Qualitative content analysis

The mothers' spontaneous responses to the open-ended question (Paper I), the verbatim transcribed interviews with the fathers (Paper III), and the parents' responses to the open-ended questions and the free text answers to questions (Paper IV) were analysed by qualitative content analysis [120], according to Graneheim and Lundman [121]. This method of analysis included the several steps: first, the text (the interviews) was listened to and read through to obtain an understanding of its content, and meaning units were then identified. The meaning units were coded according to their content and these codes were grouped into subcategories. The subcategories

were then merged into main categories to summarise the data. In Paper III, one theme was also identified. A theme is a thread of meaning running through condensed meaning units and codes on an interpretative level [121]. The research group met several times during the analysis processes to discuss and reflect on the preliminary results until consensus was reached.

In Paper IV, all responses from the parents were analysed and reported as one dataset. The specific responses from the mother or father are only described separately for topics relating to their specific roles, such as fathers' responses about returning to work after discharge, and mothers' statements about breast milk expression and breastfeeding.

Ethical considerations

Permission to perform Paper I was obtained from the medical director of NICU A. After reconstruction of NICU A, in combination with introduction of new evidence based guidelines for KMC [21, 118], it was considered important to evaluate mothers' acceptance of and opinions about KMC for quality assurance. To ensure the mothers' anonymity, the questionnaires were not encoded. The mothers were informed that their participation was voluntary and their responses would be anonymous.

Ethical approval for Paper II - V was obtained from the Regional Ethical Review Board in Uppsala, Sweden. The parents were informed that their participation was voluntary and they could withdraw from the study at any time without having to give any explanation, and non-participation would not have affect their infants' care and treatment. Confidentiality was protected by de-identification of data and the list with the infants' names was kept in a locked office. The parents and infants' names were not included in any of the transcripts or manuscripts.

Summary of findings

Paper I

Practical application of KMC

According to the mothers' responses to the questionnaire (n = 17), nine infants were positioned on the mother's breast with KMC directly after birth. The other eight infants commenced contact with the mother's chest within four hours after birth, seven of these were first positioned on the father's chest with KMC directly after birth and were then transferred to the mother. Seventeen mothers and 16 fathers provided KMC during the infants' stay at the NICU. None of the 17 mothers slept at home during the infants' hospital stay.

Mothers' experience and perceptions of KMC

The mothers were generally satisfied with their contact with the infant and liked having close contact with their infant: none of the mothers would have chosen not to provide KMC or preferred to sleep at home instead of being together with the infant in hospital. The question with the lowest level of agreement concerned whether the mother had slept well during the nights with the infant in the kangaroo position. The mothers generally felt safe when they were providing KMC and did not feel stressed or apprehensive during KMC. No mother felt compelled to be at the hospital with the baby or wanted to discontinue KMC earlier than she actually did. There was moderate agreement regarding the positive effects of KMC on breastfeeding.

The lowest level of satisfaction reported by the mothers was about the nursing care and the role of the staff. Information received about the KMC method and the option of asking other people to participate in the provision of KMC at the NICU was rated as inadequate, as was the sensitivity shown by the staff to the mother's personal needs and wishes regarding KMC.

Mothers' suggestions about continuous KMC

Providing KMC: All comments about KMC were positive: it was good to be close, a fantastic method, it was a positive experience, it was safe, it felt natural, and it gave the infant a good start in life.

Nursery environment: All comments regarding the NICU environment were negative. In the intensive care nurseries, there was too much technical equipment, the family rooms were considered too small, and the bed-settee was uncomfortable for sleeping.

Role of the family: Comments from individual mothers concerned disappointment about being separated from the infant because of her own illness, and lack of a routine for the postpartum care of mothers rooming-in at the NICU.

Role of the nurses: The mothers wanted more advice and assistance, and experienced stress and exhaustion relating to breast and cup feeding. Only one mother was satisfied with the breastfeeding support. The mothers' complained about inadequate information and unsatisfactory communication between the staff. During the night, there were problems encountering a large number of nurses, some nurses lacked experience, and a difference in routines and attitudes to the daytime staff. A few mothers found the responsibility for the infant's care during the night exhausting and considered nurses' assistance during the night a relief.

Paper II

The nurses documented 41 records of KMC sessions and the parents documented 45 sessions (Table 2). According to the parents' documentation, the infants experienced a mean of 2.25 KMC sessions during 24 hours (range 1-4); the corresponding mean number calculated from the nurses' records was 2.05 (range 1-3).

For all documented KMC sessions, the agreement between the parents and the nurses' documentation, for both KMC duration and the starting and termination times, was 18 out of 45 (40%). The mean difference between parents and nurses' documentation for the 41 KMC sessions for which both parents and nurses had provided records was 3.17 minutes (with a range from -60 to +55 minutes). For 38 of the 41 documented sessions, the differences against the mean for parents' and nurses' records of the sessions remained within ±2 SD. Parents provided complete documentation on the identity of KMC providers, whereas, the nurses only provided this information for 31/41 (76%) of the sessions.

Table 2. Parents and nurses' documentation of duration of KMC (20 infants).

KMC	m	SD	Range
Minutes per session:			
Parents (45 sessions)	138	94	35-640
Nurses (41 sessions)	149	94	15-630
Total duration in 24 h, minutes:			
Parents (45 sessions)	310	178	100-845
Nurses (41 sessions)	305	176	105-840

Paper III

The constant theme for all categories was the fathers' opportunities for being close to their infants facilitated attainment of their paternal role in the NICU. Paternal experiences not apparently associated with KMC still affected the fathers during their provision of KMC.

Handling the unexpected situation

Helping each other: The parents shared care-giving activities with each other, for example KMC and feeding the infant. Parents who slept together with the infant at the NICU considered it necessary to take turns in order to maintain enough strength to act as a caregiver.

It might have been different: When the fathers compared their own situation at the NICU with others parents, the fathers interpreted their own situation as not too bad; it could have been much worse. For example, it would have been harder if there were older siblings at home to take care of, if only one parent was allowed or able to be with the infant at the NICU, or if the infant was more seriously ill. However, the opposite was also mentioned: their baby could have been a full-term healthy baby, "a normal baby".

Feelings related to becoming a father

Feelings related to KMC: Providing KMC was something the fathers did voluntarily, and they expressed satisfaction with the method; it was safe, convenient, and not difficult., They felt safe with the infant close and knew the infant was all right; the infant was well taken care of, thanks to KMC. The infants displayed clear signs of preference for this model of care, and the fathers were convinced KMC made the infants feel secure. The provision of KMC gave the fathers an obvious role in the infant's care, which made them feel important and involved.

Feelings about and for the infant: The fathers did not feel anxious about the infant during the NICU stay and spoke about their infants with respect and

pride. The fathers who did not stay overnight at the NICU would have preferred to remain together with their infants' from when they were born.

Paternal feelings; The NICU was described as a completely different world, where you are disconnected from everything else and everything focuses on the infant. Active involvement during the infant's birth and in the infant's care enhanced the feeling of having become a father. The fathers described steps in the process of becoming a father: in the beginning, it felt strange, some sensed paternal feelings immediately at the birth, whereas, it took others one or a few days, weeks, or even months before they felt like a father. Providing KMC reinforced the feeling of actually having become a father.

The fathers' experience of the division of roles between them and the NICU staff

Fathers' experience of their role: The majority of the fathers were unprepared for a preterm birth. Even if everything was new, the fathers accepted the situation and did not feel compelled to be in the hospital with the infant. Spending time together with their infants and taking care of them at the NICU made them feel in control over the infant and their care. The fathers considered it important to be involved in the infant's care directly from birth, and to be a person who knew and understood the infant better than the staff. When staff gave conflicting information and when no clear routines were conveyed for what the fathers were allowed to do or what was expected from them, the fathers found it difficult to have control over the infant and to feel safe with the situation.

Fathers' experience of the role of the NICU staff: The fathers' were positive about the staff and described them as supportive; the parents received the desired assistance and felt safe when providing the infant's care. Even when fathers expressed dissatisfaction with the staff, they simultaneously justified the dissatisfaction by stating staff was busy and there were many critically ill infants at the NICU at that time, and it was probably not pleasant working night shifts. They commented staff members made conflicting statements and displayed conflicting behaviour, and there were different approaches among different shifts.

Practical aspects

Practical application of KMC; The majority of fathers expressed the opinion there were no real difficulties at all with KMC, except it could be difficult to eat and sleep with the infant skin-to-skin. The fathers tried to have their infants skin-to-skin as much as they could and the situation permitted.

Accommodation: The fathers who stayed at the NICU during the infant's entire hospital stay experienced the beds as uncomfortable and difficult to

sleep in, and some developed backache. When the fathers provided KMC, they spent both the nights and days in the bed, semi-reclining with the infant.

The fathers who were unable to stay overnight during the entire hospital stay found the commuting between the hospital and the home hard; life did not feel right until they could stay with their infant. Many parents received assistance from relatives and friends in managing their life at home, buying food, and having meals delivered to the NICU. The fathers described the provision of their infant's care as a full-time job. Some fathers got bored and restless after some time and felt time passed slowly, but being able to do something else while providing KMC, such as watching TV, relieved these feelings.

Paper IV

Factors perceived by parents as supportive for their performance of KMC

Parent-related factors: Through encouraging one another and by taking turns the parents supported each other and "shared the job" of performing KMC. Furthermore, support from significant others was an important facilitating factor for their opportunity to perform KMC. The NICU staff provided information and practical advice about KMC, assisted and encouraged the parents to take the infant out of the incubator, brought parents something to drink: the parents considered this was valuable. Further, the parents mentioned the government as a supportive factor, as it provided both parents with temporary parental benefit during the infants' entire NICU stay.

Time: At the NICU, it was possible to disregard everyday chores and focus only on the infant. Some parents appreciated the opportunity to perform KMC without limitation, whereas, others stated there was nothing else to do.

Infant-related factors: One way of getting to know and being close to the infant was through KMC. The parents' conviction KMC was beneficial for the infant increased their willingness and motivation and promoted their use of KMC. The parents found it easier to perform KMC, if the infant required it for maintaining normal body temperature.

The NICU environment: The extent of parents' use of KMC was facilitated by access to a private space, a quiet atmosphere, and being able to shut out staff and other parents with privacy screens in the nursery and in a family room, and the opportunity to stay overnight at the NICU.

Factors perceived by parents as barriers for their performance of KMC

A notable part of the parents stated there were no problems with providing their infants with KMC, either in hospital or at home.

Parent-related factors: There were NICU routines that restricted parents' opportunities for performing KMC to the extent they desired. For example, one NICU had a routine that did not permit parents to be present with the infant during medical rounds. A further obstacle to KMC was lack of information about KMC, and its use in practice.

Staff attitudes could be a barrier to KMC, for example, some staff members were noisy and disturbed parents when they performed KMC without asking for permission or without a justified reason. Sometimes staff did not have sufficient time to help to position the infant on a parent's chest, which resulted in delayed and shorter KMC sessions.

Parents' own physical limitations sometimes rendered KMC difficult, such as mothers' pain after a caesarean section and backache, everyday needs, both at home and at the NICU, such as eating, going to the toilet, taking a shower and resting, limited the time spent with KMC.

Time: Although lack of time was perceived as a barrier for KMC, there was more time for KMC at the NICU than at home. Some parents felt divided between the infant at the NICU and the family; they wanted to be at the NICU with the infant and at home with the rest of the family at the same time. The parents who were unable to stay overnight at the NICU felt commuting between the home and the NICU deprived them of the time they would rather have spent together with the infant.

Infant-related factors: The infants' feeding process could be an obstacle to KMC for the mothers, as feeding, breastfeeding and breast milk expression interrupted the skin-to-skin contact. Furthermore, sleeping with the infant skin-to-skin in the same position throughout the night could be difficult, as an uncomfortable sleeping position caused insufficient sleep.

NICU and home environment: Limited facilities for the parents at the NICU hampered the extent of KMC. There were too few single rooms where parents could stay overnight together with their infant and some parents were never offered the opportunity to stay overnight with the infant at the NICU.

In the intensive care nurseries with several infants in the same room, it could be difficult to rest, as the sound level could be high, especially when several infants cried at the same time. Lack of privacy was perceived as an obstacle

to KMC, as there was limited available space and an inadequate number of screens to provide sufficient privacy when the parents had the infant skin-to-skin. Inappropriate furniture at the NICU made it difficult to perform KMC and several parents missed comfortable armchairs and beds: uncomfortable beds caused physical problems such as backache.

Discontinuation of KMC

A majority of parents continued caring for their infant with KMC to some extent after discharge, but some discontinued KMC as soon as they came home. A few parents reported they stopped using KMC before discharge. Among parents who continued performing KMC after discharge, a majority provided KMC at times that suited them and when they enjoyed it. For example, some performed KMC only during the night, whereas, others only did so during daytime. Few parents reported performance of KMC around the clock at home.

Reasons for discontinued performance of KMC

One reason for discontinuation of KMC could be the parents' perception the infant did not need KMC any more. Some parents stopped with KMC because the infant did not want it any more, others because the infant was too warm. When the fathers returned to work after the infant's discharge from the NICU, they did not have time for KMC. Several mothers described KMC as uncomfortable and unpractical to continue at home. At home, both mothers and fathers felt it was difficult to find sufficient time to perform KMC: siblings could be jealous and demand attention, household chores took time, and breastfeeding took a lot of time. Those who did not completely discontinue KMC, stated it was easier to perform KMC during the evenings and nights, because everything that needed to be done at home was done during the daytime. Many parents felt they could be close to the infant without KMC at home and had their infant lying on their chest, wearing baby clothes.

Paper V

Identity of person providing KMC

Fifty-four of the infants had their first KMC session with the mother, 48 with the father, and one infant with a maternal aunt: information was missing for one infant. There was a difference in which parent performed KMC first related to hospital of birth: at NICU A, the father was the first person to provide KMC for a higher number of infants (33 of 49 infants) than at NICU B (15 of 55 infants, $p < 0.001$).

Both mothers and fathers of all infants were involved in KMC. However, the infants spent more time with KMC per day with their mothers than with their fathers, except during the infants' first three days of life when there was no difference. During the hospital stay, 10 of the 104 infants were occasionally cared for with KMC by a significant other, such as the maternal grandmother, the infant's older siblings, and the maternal aunt.

Initiation of KMC

Three infants experienced KMC directly after birth, 34 within one hour, and 85 within 24 hours. For the remaining 19 infants, KMC was initiated at 24-78 hours post birth. For one infant, the exact time of initiation of KMC was not recorded. The infants' first experience of KMC occurred at a median (range) age of 344 (0 - 4680) minutes after birth. Seventy-six of the infants were born during the day (6 am to before 10 pm) and 28 during the night (10 pm to before 6 am); however, time of birth (i.e. during the day or night) did not affect the infants' age at initiation of KMC. Similarly, mode of delivery did not affect the infants' age at initiation of KMC: 56 infants were born by caesarean section and 48 vaginally.

Infants whose first KMC contact was with their father, commenced KMC earlier in life, median age of 50 minutes (range 0 - 1823) than infants who started with their mother, median age of 50 minutes (range 0 - 4680: $p<0.001$). Infants with higher gestational age at birth ($r=0.415$, $p<0.001$) and infants higher birth weight ($r=0.376$, $p< 0.001$) were exposed to KMC earlier.

KMC commenced later for infants with respiratory distress (n=68), median age of 463 minutes (range 0 - 4680) than for infants without this diagnosis (n=36), median age of 62 minutes (range 0 - 2654: $p<0.014$). Infants who had at least one infection period in hospital (n=15) had their first skin-to-skin contact later, median 825 minutes (range 46 - 4680) than infants who did not have any infection, median 205 minutes (range 0 - 2654: $p<0.008$). The infants' age at introduction of KMC was dependent on birth hospital. At NICU A, the infants' care skin-to-skin commenced earlier, median age of 55 minutes (range 0 - 2033) than at NICU B, median age of 639 minutes (range 0 - 4680: $p<0.001$). There were no differences in prevalence of respiratory distress or incidence of infection periods between the two hospitals.

KMC during the infants' hospital stay

There was a wide range in the time the infants spent with KMC. Fourteen infants spent 1440 minutes with KMC over a few days, i.e. around the clock, during their hospital stay. All these infants were cared for at NICU A. The time spent on KMC for all infants was a median of 403 minutes (range 67-1284) per day during their whole hospital stay.

The earlier KMC was initiated, the more the infant was cared for with KMC per day during his/her hospital stay ($r=0.444$, $p<0.001$).

Those infants whose first experience of KMC was with their fathers (n=48) spent more minutes with KMC during their hospital stay, median of 697 minutes (range 148 - 1284) than infants who started with their mothers (n=54), median of 346 minutes (range 67 - 1189: $p<0.001$). Infants with higher birth weight were cared for more with KMC per day during the hospital stay ($p<0.028$). In contrast, infants with respiratory distress (n=68) experienced fewer minutes with skin-to-skin contact per day during their hospital stay, median of 371 minutes (range 67 - 1228) than infants without this diagnosis (n=36), median of 502 minutes (range 174 - 1284: $p<0.013$).

Infants born at NICU A (n=49) spent more time skin-to-skin per day, median of 894 minutes (range 101 - 1284) than infants at NICU B (n=53), median of 345 minutes (range 67 - 778: $p<0.001$).

Discussion

"Life holds one great but quite commonplace mystery. Though shared by each of us and known to all, it seldom rates a second thought. That mystery, which most of us takes for granted and never think twice about, is time. Calendars and clocks exist to measure time, but that signifies little because we all know that an hour can seem an eternity or pass in a flash, according to how we spend it. Time is life itself, and life resides in the human heart."

Momo - Michael Ende

The studies included in this thesis must be interpreted with appropriate consideration of the context. These studies were performed in Sweden, a country with an insurance system including parental benefits that allows both parents to be together with their infant at the NICU instead of working [117]. This means that parents have an option (to some extent): to choose to be in the NICU with their infant, or, at home with siblings, or at work. However, is it really appropriate to consider this as an option without psychological and ethical implications; shouldn't parents always take care of their children, even in the NICU (as long as this does not involve any hazards for the infant)? Furthermore, the idea of an option is problematic, because who has the authority to decide parents' right to be with their infants in the NICU, and to decide infants' right to be together with their parents?

Since the NICU environment has a long history of separating infants from their parents and the fact that infants can easily be cared for by other persons, continued survival of this separation is not so astonishing. However, in order to put a stop to all unjustified parent-infant separation, it is important to define the criteria for justified separation; when such criteria are absent, separation should not occur. But it is just as problematic to define criteria for what constitutes criteria for justified parent- infant separation as to define criteria for a clinically "stable" infant [115] (in connection with guidelines for use of KMC). Is there an objective way of describing this, considering that it depends on who's perspective is taken as the starting point? A parent may feel close to her/his infant, even when the infant is lying in an incubator, because the parent can look at the infant through the incubator glass walls. One staff member may consider the separation necessary, another may

not do so. Indeed, this must be regarded as a situation of pure arbitrariness. From the infants' perspective the separation is most likely a fact when she lacks tangible physical contact with a parent. This assessment is based on what would have been normal: for a fetus to constantly sense the touch of the amniotic sac and fluid, and for the newborn baby to feel the mother/father hold and touch her, in addition to hearing and seeing the parent, and sensing the parent's odour. It is logically unimaginable that the infant is aware of a parent's presence when she/he is just sitting at the side of the incubator. To solve this conflict of opinions, it is necessary to continue open discussions about this issue, and consider ways of providing infants' care in a NICU with adequate security without separating them from their parents, and with maximum parental involvement in their infants' care, without unjustified delays after the infant's birth.

However, in these two NICU settings, parents were generally allowed to take an active part in the care of their infants; they could be together with their infants and were allowed to perform many care giving activities. Parents' experiences can vary depending on the extent of separation from their infants, and the division of roles between nurses or parents in the provision of the infant's care. In the two NICUs studied, there were differences both in the physical NICU environment and in the NICU staff's experiences of KMC. The results of these studies should be assessed based on all these aspects.

Furthermore, the incubator is sometimes considered as the golden standard for an optimal environment for a preterm infant, but it is important to remember that the incubator was established in comparison with treatment of infants in an unheated crib [50], not with infants cared for skin-to-skin.

Practical aspects of KMC

One finding that deserves consideration was that the same aspects of the care could act as both a support and a barrier for parents' performance of KMC.

Routines and staff attitudes at the NICUs

In Paper I, both the mothers' responses to statements and their comments revealed dissatisfaction with the amount of information provided about the practical aspects of KMC and about the option of inviting members of their social network to participate in KMC. Information to parents about the possibility of sharing the task of performing KMC with others is important, as this provides opportunity to rest and alleviate fatigue. Mothers appreciate timely information about issues they consider important when their infant is being cared for in an NICU [40]. Mothers with infants in a neonatal unit who

do not receive the information they consider essential feel a lack of control over the situation and that they are entirely in the hands of the staff [29]. In Paper IV, parents defined NICU staff support as positive, through encouragement, information and practical assistance. Continuous information to parents and making sure that parents receive the type of information they need is important [40]. It is essential staff understand and confirm the mother's individual needs [122], as mothers find it is easier to voice what they desire when they perceive they are understood and "seen" by staff [29].

In accordance with an Australian study [44], the fathers in Paper III strived both to take care of the infant and to learn the routines and rules at the NICU. The fathers were grateful for their time at the NICU, and when they complained about the care or the nursing staff, they simultaneously defended them, criticising and justifying at the same time: similar findings are also presented by others [123].

However, Paper IV revealed NICU staffs' attitude and behaviour in the infant's care space could also hamper KMC, for example, when staff were loud and disturbed the parents when they had the infant skin-to-skin. This finding supported results from another study reporting mothers of preterm infants perceive a lack of privacy in the NICU [124]. Moreover, the parents in Paper IV were sometimes disturbed by noise and personal conversations among the staff at the NICU. As long as the infant is stable, it is important for the family to be together without unjustified disturbance [27].

Parents in Paper IV noticed differences in opinions among NICU staff members and between NICU staff and maternity ward staff about the encouragement of closeness between the infant and the parents. The parents perceived this as a factor that hindered them from applying KMC. Negative staff attitudes to parent-infant closeness are contrary to parents' preference, as parents have a strong desire to be close to their infants and perceive separation from the infant as stressful [27, 29]. Nurses at a NICU that practised KMC had positive perceptions of the appropriateness and advantages of KMC, but considered KMC an example of nursing practice based on individual perceptions rather than scientific evidence [112]. Similarly, in an Irish study [111], nurses voiced concerns whether KMC is appropriate and safe for some preterm infants, despite the evidence supporting the application of KMC in preterm infants. A further aspect regarding the role of the NICU staff is the initiation of KMC, as the staff decides when the initiation of KMC should take place. As long as concerns about the safety and applicability of KMC exist among NICU staff, there will be differences regarding the initiation and duration of KMC, both between hospitals and among infants with various medical diagnoses and treatments [111].

Initiation and extent of KMC

When KMC was initiated early after birth, the infant was cared for longer with KMC per day during her hospital stay (Paper V). Surprisingly the infant and parental characteristics did not exert any major influence on the time (post birth) when the parents initiated KMC, or the total time spent with KMC during the infants' hospital stay. The differences between the two NICUs, suggested it was the parents' exposure to KMC soon after the birth (early initiation in NICU A) that determined the continued use of the method. This means the earlier the staff members involve the parents in the infant's care through actively encouraging them to perform KMC, as part of the NICU routine, the earlier parents will feel confident in this model of care, and consequently, perform KMC more during the infant's hospital stay.

There were differences both in time of initiation of KMC and duration of KMC between the two NICUs: similar results are presented in a survey of Swedish regional hospitals [125]. However, the reasons for these differences can only be speculated. A plausible explanation could be the differences between the NICUs in family centred care in terms of the physical environment and routines for KMC initiation. NICU A had parent beds in each infant's care-space, which allowed at least one parent the opportunity for being together with the infant around the clock. In addition, the staff at NICU A had a longer previous and more frequent experience of KMC. However, the mere acquisition of theoretical knowledge about KMC does not change practice and attitudes and beliefs among NICU staff strongly influence their encouragement or discouragement of KMC [111, 112]. If NICU staff members experience KMC can improve the wellbeing of both infant and parents, and realise KMC can be perceived as professionally gratifying, this will influence their attitude and make them more open-minded and positive regarding KMC [112, 116].

Another explanation for the hesitation about KMC among NICU staff is that many staff members have extensive experience of caring for preterm infants in incubators and are comfortable with the capacity of an incubator to maintain infants' temperature in a reasonably stable fashion in the thermo-neutral zone [50]. However, when these professionals gain more experience of caring for infants in the kangaroo position, they are likely to feel just as comfortable with this model of care. Consequently, the infants are likely to spend more time skin-to-skin on their parents than with a conventional incubator care. Thus, a desirable goal is that all NICU staff acquires the knowledge, motivation and capacity to advocate, promote and assist parents in caring for their infants with KMC early after birth, and - in environments with sufficient resources for providing conventional high technology incubator care - reduce the separation time between the preterm infants and their parents.

The infants' medical condition does influence their experience of KMC. The timing of initiation of KMC occurred later for infants with respiratory distress than for infants without this diagnosis and they were granted less time with KMC during their hospital stay (Paper V). Infants who had at least one infection period during their hospital stay also commenced KMC later than infants without any infection did. Other researchers [125] have found an association between the number of days with ventilator treatment and a delay in infants' first skin-to-skin contact. At the same time, Bergman et al. [54] found that infants cared for skin-to-skin from birth were more stable than those cared in an incubator. It should be noted that inclusion criteria in their study was birth weight between 1200 and 2199 gram and an Apgar score at least 6 at 5 minutes. However, currently, there is not enough evidence to support conclusions about any cause and effect association between early KMC and infant stability.

The physical NICU environment

The design of the NICU environment was crucial for the parents' presence and opportunities for performing KMC to that extent they wanted (Paper I, III and IV). The parents stated the extent of their use of KMC was facilitated by access to a private space, family rooms, and the opportunity to stay overnight at the NICU; this supported similar findings by Neu [105]. Single-family rooms allow infants to be cared for in an environment where they are protected from stimuli emanating from care giving and social activities occurring in adjacent care spaces [50]. Therefore, single rooms, when available, are preferable, as they allow privacy for the whole family, including siblings, and provide parents with optimal opportunities for becoming their infant's primary caregivers, without unfounded delay. At the same time it should be noted that successful application of continuous KMC is also possible in settings with limited resources regarding private space for families [84, 93]. If the NICU environment emits signals, both verbal and non-verbal, that invites and facilitates parents' unrestricted presence and participation in their infants' care, this can be expected to enhance their willingness to use KMC and feel comfortable doing so, even in a high technology NICU.

Infant and parental factors

The infant's care and the parents' presence at the NICU affected family life (Paper I, III and IV). Some parents perceived a lack of time, as they felt torn between the family at home and the infant at the NICU, and it was stressful for both parents to have older siblings at home. Others have also found that mothers wanted to be both at home with older siblings and at the same time at the NICU with the infant [27]. The duration of KMC was not affected by the presence of siblings (Paper V), although this contrasted to the findings of Flacking et al. [126], possibly because the parents shared the task of performing KMC, and the other parent could be with the siblings.

Some fathers were exhausted and/or developed backache (Paper III), similar findings are also described by others [109]. Fathers were clear about the sacrifices they were making when performing KMC, such as spending day and night in an uncomfortable bed. However, this was not expressed as a complaint, just a sharing of experiences with the interviewer. This could be interpreted as a high level of motivation; they wanted to do this, and were proud of having done it.

For the mothers, a negative aspect of KMC was the procedures surrounding the infant's feeding, as they intervened with KMC (Paper IV). For example, mothers discontinued KMC in connection with breast milk expression. If mothers perceived breast milk expression or breastfeeding did not work, was stressful or complicated; this might aggravate other existing barriers to performing KMC. This is unfortunate, as Sweden is a country where breastfeeding is the norm, and many mothers connect breastfeeding with good motherhood [127].

Several parents continued the practice of KMC at home to some extent, often timing KMC when it suited them (Paper IV). This indicated parents did not perceive KMC as an obligation to perform in hospital but as an enjoyable way of being close to their baby.

Emotional aspects of KMC

A study of KMC necessitates acquisition of data on the duration spent with KMC and parents' experience of this time. The perception of time is a human experience and perception of time represents the mental status of the individual person [128]. The individual's subjective well-being strongly influences how time is experienced. Time speeds up when you are involved in pleasant activities, but drags during periods of boredom. In accordance, time intervals are judged longer when more attention is paid to time and when the load of varying experiences stored in memory is higher. Therefore, from the studies in this thesis, it would be inappropriate to assess if parents' experiences of more or less time KMC was better or worse, or to define a minimal time that should be recommended to parents. However, there was sufficient data to support providing the opportunity and support for parents to have their infant skin-to-skin early and as much as circumstances allowed so they felt empowered and had the sense they had control over their situation.

Although the infants' perceptive was not studied in this thesis, in the literature there is sufficient data that as much time with KMC as possible is preferred. Although it is difficult to know how an infant experiences time and

their existence, infants probably know their own experience at the moment and all time appears significant for them [129].

Some mothers would have liked to commence KMC earlier than they did (Paper I), even if this was only a matter of a few hours. This illustrated the importance of preventing mother (parent)-infant separation as far as possible, no matter how brief. Mothers want to be close to their infant, regardless of the reason for the separation [29] and the most stressful aspect of having an infant admitted to an NICU is the involuntary separation from the infant [27]. KMC promotes emotional ties and parent-infant bonding [72], despite the mothers did not appear to be convinced KMC strengthened their love for the infant or made it easier for them to become acquainted with the infant (Paper I). A probable explanation for this result was the statements in the questionnaire being hypothetical and difficult to answer, as the mothers, with just one exception, were unable to make a comparison with any other type of neonatal care.

Tessier et al. [72] found some mothers who practise continuous KMC experience isolation and a feeling of too much responsibility. However, this was not evident in Paper I or IV, possibly because the parents had the opportunity of sharing KMC with the other parent, and that both study NICUs had generous visiting guidelines, which allowed the parents to receive visitors while they were at the NICU with the infant and performed KMC. Some mothers report disliking KMC as they cannot see their infant's face and eyes when performing KMC [74]. However, no parent mentioned this, probably because in both NICU parents were routinely offered hand mirrors to use during KMC so they could see their infant's face.

According to the definition of KMC, the father is a substitute for the mother [52]. However, the fathers were more than merely substitutes, they participated in the infant's care just as much as the mother (with the exception of capacity for breastfeeding), and the parents helped each other to manage the situation (Paper III). Fathers took KMC for granted and could not see how they would have done otherwise, and accepted the opportunity to act as caregiver as a 'matter of course'. Kangaroo Mother Care meant more than merely skin-to-skin contact, it gave the fathers increased responsibility for the infant and the infant's care. Being the person, together with the mother, who kept the infant warm and knew the infant best made them feel in control over the infant and the situation and was positive for the infant. In a Canadian study [41], fathers maintained a sense of control through engagement in various activities away from the NICU, such as work and physical exercise, as having an infant in the NICU was associated with a feeling the situation was "out of my control". However, the fathers in Paper III felt in control when they were together with their infant and performed KMC and they

perceived themselves as one of the people who knew the infant best. In contrast to this, a Swedish study [43] reports fathers sometimes feel compelled to take over certain components of their infants' care. The fathers in Paper III continued performing KMC and participating in the infants care although it meant hard work and exhaustion; however, unless they had shared this care with the mother, it would have been almost impossible; providing KMC, changing nappies, tube feeding and so on was described as a fulltime job, not just a 'one-man show'. Similar findings are presented in a Norwegian study [20] where parents also shared the responsibility for the infant's care.

Infants who commenced KMC with their fathers had their first experience of KMC earlier in life and had a longer total duration of KMC during their hospital stay than infants who started with their mother (Paper V). Separation from the infant is one of the most significant stressors reported by fathers of preterm infants [26] and fathers feelings of love for their infants coincide with the time they first hold their infant [130]. Fathers of preterm infants describe a desire to take an active part in their infants' care [23] and KMC increases the fathers' involvement in their infants' daily routine care at home after discharge [108]. Thus, it is important to involve both parents in the infant's care immediately after birth. If the mother, for some reason, is unable to have the infant skin-to-skin after the delivery, the father is the best alternative to offer his infant KMC: similar recommendations are made by Tessier et al. [108]. One explanation for the results in Paper V could be fathers felt more involved in their infants' care and gained more confidence in their paternal role (Paper III) after performing KMC. Their participation in the infant's care commenced directly after birth, which made them feel more connected and responsible for the infant, and consequently, they applied KMC more during the infants' subsequent period of hospitalisation.

Methodological considerations

One limitation of the papers included in this thesis was that the samples consisted of parents at high technology NICUs in a Western country with a widespread breastfeeding culture and opportunity for both parents to be with their infant at the NICU. Therefore, parts of the results can only be generalised to similar settings; although it could be assumed that parent's willingness and motivation to be with and close to their infant at the NICU is probably similar in most parts of the world. However, the sample in Paper IV and V was consecutive and relatively large, and data collection was prospective and occurred during two years, which supported generalisation of the results. Nevertheless, differences between Sweden and other countries in terms of provision for parental leave and maternal/parental benefit after an

infant's birth, and other socio-economic circumstances must also be considered in studies on parents' role in the care of their infants at the NICU and after discharge.

The possibility to study KMC

The reason for including both preterm infants and ill term infants in Paper I was that the focus of the investigation was the mothers' experiences of continuous KMC, irrespective of the infants' diagnoses. This inevitably reflected the experience of becoming a mother when the infant was treated in a neonatal unit. Therefore, it is possible that some results were attributed to a combination of both the skin-to-skin component in the KMC method and that these infants were never separated from their parents.

Paper I was performed retrospectively, however, an ideal design would be a prospective study with an in-depth qualitative design that comprised interviews instead of questionnaires to obtain a deeper understanding of the practice of KMC. Nevertheless, the results in Paper I indicated neonatal care without infant-parent separation was possible and parents might be willing to perform continuous KMC in an affluent society. Moreover, Paper I was the stepping-stone for this thesis, as it provided the knowledge KMC was accepted in this type of NICU setting.

Assessment of the quality of records of KMC

The comparison of the duration of KMC reported by both parents and nurses (Paper II) tightens the methodology used in research about the application and effects of KMC; if parents are capable of performing this component in data collection, the validity of the results is likely to increase.

The magnitude of the differences in recorded time between the parents and the nurses could be regarded clinically insignificant considering the total duration of KMC they experienced (Paper II). However, the quality of the parental records was superior to that of the nurses on the completeness of data identifying the KMC providers. One explanation for the discrepancies may be differences in perspective, in that staff mainly focused on medical data and might not regard KMC as medical treatment. With such an approach, the staff would not document KMC in the same way as the medical aspects of the infants' care. Another possible explanation for the difference in the KMC time measured by parents and nurses was that the nurses spent a limited time at the infants' bedside, as the infants were cared for most of the time by their parents and behind privacy screens. This supported the trustworthiness of parents for recording the use of KMC during 24 hours, both for clinical and research purposes. However, the documentation of skin-to-skin contact time during 24 hours is a different matter to documenting KMC during the entire hospital stay. The documentation can be an additional bur-

den for parents already in a difficult situation [131], in terms of finding the time to document the duration of KMC and measuring the amount of time spent on KMC, or not, which can be experienced as stressful. However, it can also have an opposite effect in that it is one way for the parents to have control over the situation and stresses the value of KMC in optimizing the infant's wellbeing. Therefore, it is important parents are offered the opportunity to document the amount and duration of KMC: if parents do not want to perform this documentation, it is the responsibility of the NICU staff.

As the aim (in Paper II) was to obtain naturalistic data from the nurses' routine documentation, without reminding them about recording KMC, staff were not informed about the study. If the study had continued for a longer period, the nurses would have noticed the study charts in the infants' care spaces, which would have influenced the results.

A limitation of Paper II was the small sample size. Future research should address parent's willingness to record KMC throughout the infant's first few days of life when the parents may be in shock, and during a long hospital stay. Another limitation was reliability, as an objective measure was lacking; neither the parents' nor the nurses' records could be regarded as objective and accurate. Fully objective data would require continuous video recording.

Paper V was based on data documented in medical charts and from a parental questionnaire. The outcome measure of time in minutes that the infants were cared for with KMC was documented by the staff or the parents; however, depending on the circumstances at the NICU and the infants' medical status, it could be assumed that the parents either over- or underestimated the time they spent with KMC.

Appropriate design and data collection methods for studying KMC

Although these studies generated new knowledge about KMC, which is gaining increasing attention in the modern western type of NICU, they also had several limitations; they were all descriptive and explorative in nature. For satisfactory investigation of the effects of KMC, randomised, controlled studies would be preferable for identifying different patterns of application of KMC that could be supported for achieving optimal effects on infants' health. However, randomised controlled trials studying KMC within these NICUs would not be possible due to contamination between parents and between staff, and that the parents practise KMC to the extent they want and the circumstances allow, thus, the results cannot be generalised. Further, the KMC method *per se* is difficult to study in the randomised control trial model, as the different components in KMC (skin-to-skin contact, breastfeeding, and parent participation in the infant's care) are aspects subject to individual preference and cannot be controlled. Therefore, the use of a ran-

domised control trial design was considered unethical in a setting that already encourages parents' unrestricted use of KMC.

In a qualitative study, an appropriate sample size can be defined as one that adequately answers the research question [132]. Similarly, the trustworthiness of a qualitative study should evaluated through the richness of each interview rather than by the sample size [133]. The limited sample size in Paper I should be considered in context, as the study was conducted during the initial phase of implementation of continuous KMC when the guidelines were initially applied as longer periods of KMC rather than continuous KMC. Therefore, a plausible explanation for the reason why few infants received continuous KMC during the study period was the reluctance from staff to change their care-giving practices from conventional incubator/cot care to KMC, particularly during the admission of newborn infants and during the night. During the implementation period, the staff gradually began to modify their care-giving activities to adhere to the new principles of care. Contrarily, the seven interviews with fathers in Paper III contained rich information about their experiences of KMC.

Creditability and dependability are used to describe aspects of trustworthiness in qualitative research [121]. During the analytical process in these studies, the research group involved met several times to discuss the preliminary results until consensus was reached: this strengthened the trustworthiness of the results. In order to allow the reader to judge the authenticity and credibility of the studies, relevant quotations are included in the published papers along with the findings. Credibility relates to the focus of the research, and refers to how well the data and the processes of analysis address the intended focus. The focus of these studies was on KMC, but KMC meant much more than merely skin-to-skin contact, both for the parents and for the NICU staff. Thus, experiences and perceptions not apparently associated with KMC still affected the provision of KMC. Dependability refers to changes over time in data and the researchers' decisions; thus, the same author conducted all interviews in Paper III.

In Paper IV, parents' responses were combined into one dataset, as the aim was to describe what parents perceived as supportive factors or barriers regarding their performance of KMC, not to compare the parents' statements. The use of a mixed methods approach (Paper I and IV) allowed the research to be conducted from both a descriptive and an explanatory perspective, and combined both qualitative and quantitative aspects. This type of approach enhances the strengths and minimises the weakness of both qualitative and quantitative studies, and can generate important research questions [134]. In NICU environments, quantitative measures alone sometimes miss the complexity of the phenomena occurring, whereas, qualitative methods can allow

for a deeper understanding of the NICU complexity [135]. Therefore, the integration of these two approaches is preferable to considering then as opposing and separate research strategies.

Further research

In this thesis, some questions have been answered, but many new questions arose along the way. Further research within this area, both of qualitative and quantitative nature are needed, aimed to identify practical and clinically useful ways and strategies for reducing all unnecessary separation between an infant at an NICU and its parents. This would include studying the NICU environment, the role division between the NICU staff and the parents, and ways of empowering parents early to give them a sense of power and control over their and their infant's situation at the NICU.

Further, studying non-separation between the infant and her parents at a NICU, from the infants', the parents' and the NICU staff perspectives are also desirable research focuses to give priority to.

Conclusions and clinical implications

This thesis provides new knowledge about parents' practice of KMC in an affluent NICU setting, where the possibility existed for the infant to be cared for in an incubator by trained staff. The results from this thesis indicate that parents want to be with their infant at the NICU and be actively involved in the infants' care and care-giving activities. Although KMC can be experienced as tough, parents want to perform KMC. Early initiation of KMC after birth appears to result in longer duration of KMC during the infants' whole hospital stay.

Conclusions and clinical implications of the results from this thesis are:

- As early initiation of KMC seemed to have an effect on the total time the infants spent skin-to-skin during their NICU stay, parents should be given the opportunity to start KMC, be involved in their infants' care, and to stay with their infant around the clock as soon as possible after the infants' birth (Paper I, III and V).

- The NICU environment should be improved to become as family-centred as possible, and provide both verbal and non-verbal messages that invite parents to stay with their infant around the clock and perform KMC and other care-giving activities as much as they wish and the infants' condition allows (Paper I, III and IV).

- Parents should be provided with adequate, repeated information about the KMC method and be supported in their performance of KMC (Paper I, III and IV).

- As it can be exhausting for parents to undertake the care of a small infant around the clock, NICU staff should actively offer parents the assistance they need by performing components in the infant's care, especially during the night, so that the parents have sufficient sleep and rest (Paper I and III)

- The NICU staff are important for parents' use of KMC and their involvement in their infants care. Therefore, staff should have

sufficient knowledge about the advantages of KMC and practical skills to be able to assist and support parents in performing KMC to the extent that they desire (Paper I, III, IV and V).

- Parents should been given the opportunity to be involved in the documentation of KMC for both clinical and research purposes (Paper II).

- Even though the infants in this thesis were cared for with KMC to a relatively high extent there is a potential for extended use of KMC for reducing unjustifiable separation between the parent and the infant (Paper II and V).

Sammanfattning på Svenska

Det övergripande syftet med denna avhandling har varit att inhämta ökad kunskap om föräldrars möjlighet, vilja och upplevelse av att vårda sitt förtidigt födda barn eller sjuka nyfödda barn hud mot hud enligt kängurumetoden.

I delstudie I var syftet att undersöka kängurumetodens praktiska tillämpning samt att beskriva mammors erfarenheter av att känguruvårda sitt barn kontinuerligt. Mammor till 23 barn som vårdats på en neonatalavdelning fick en enkät hemskickad, 17 besvarade denna enkät. Data analyserades med beskrivande statistik samt kvalitativ innehållsanalys. Resultatet visade att mammorna var positiva till att vårda sina barn enligt kängurumetoden. Däremot var alla kommentarer som gällde vårdmiljön negativa: Rummen ansågs vara för små, bäddsofforna var obekväma att sova i och det för mycket teknisk utrustning. Dessa mammor ville och kunde känguruvårda sina barn en stor del av dygnet, tillsammans med barnets pappa, förutsatt att de fick den hjälp, det stöd samt den information från vårdpersonalen de ansåg att de behövde.

I delstudie II var syftet att undersöka föräldrars möjlighet att journalföra den exakta tiden samt vem som vårdat barnet enligt kängurumetoden, på ett tillförlitligt sätt. Tjugo föräldrapar vars barn vårdades på en neonatal intensivvårdsavdelning dokumenterade under 24 timmar all tid de vårdade sitt barn enligt kängurumetoden. Därefter jämfördes föräldrarnas dokumentation med personalens. Föräldrarna dokumenterade mer noggrant än personalen, de skrev klockslagen noggrannare och skrev alltid upp vem som vårdat barnet enligt kängurumetoden.

I delstudie III var syftet var att beskriva pappors upplevelser av att vårda sitt underburna barn enligt kängurumetoden. Sju pappor vars underburna barn vårdats på två svenska neonatalavdelningar intervjuades när deras barn var fyra månader gamla. Intervjuerna analyserades med kvalitativ innehållsanalys. Resultatet visade att dessa pappors möjlighet att vårda sitt barn enligt kängurumetoden underlättade för dem att tidigt finna sin roll som pappor. Genom att vara tillsammans med sitt barn kände papporna att de hade kontroll över situationen och upplevde det som viktigt att få vara delaktig i vården av barnet. Det var först då de fick vårda barnet enligt kängurumetoden som de verkligen kände de sig som pappor.

I delstudie IV var syftet att identifiera faktorer som underlättar eller hindrar för föräldrar att vårda sitt barn enligt kängurumetoden, samt att ta reda på när och varför föräldrar slutar att vårda sitt barn enligt kängurumetoden. En enkät skickades hem till 104 underburna barns mammor och pappor inom en vecka efter utskrivning från neonatalavdelningen. Sjuttiosex mammor och 74 pappor besvarade denna enkät. Data analyserades med beskrivande statistik samt kvalitativ innehållsanalys. Resultatet visade att vad dessa föräldrar upplevde som underlättade för dem att vårda sitt barn enligt kängurumetoden var att de fick stöd från sin partner, stöd från personalen, stöd från anhöriga samt stöd från samhället i form av tillfällig föräldrapenning som innebar att de hade ekonomisk och laglig möjlighet att vara med sitt barn på sjukhuset i stället för att arbeta. Något som upplevdes försvårande var om föräldrarna hade äldre barn hemma. Rutiner på neonatalavdelningen samt personalens attityder kunde försvåra föräldrarnas möjlighet att vårda sitt barn hud mot hud. En majoritet av båda mammorna och papporna fortsatte att vårda sina barn hud mot hud hemma i någon utsträckning.

I den femte och sista delstudien var syftet att beskriva i vilken utsträckning föräldrar vårdar sina underburna barn enligt kängurumetoden under tiden på neonatalavdelning, samt att beskriva när barnen började vårdas hud mot hud och vilka det var som vårdade barnen hud mot hud. Materialet bestod av 104 underburna barn vårdade på två svenska neonatalavdelningar. Tiden barnen vårdades hud mot hud registrerades. Resultatet visade att både barnens mammor och pappor vårdade barnet hud mot hud. De barn som började vårdas hud mot hud av sin pappa hade sin första hudkontakt signifikant kortare tid efter födelsen än de som började hos mamman, dessutom vårdades dessa barn mer hud mot hud under hela sin vårdtid än de som började vårdas hud mot hud av sin mamma. Desto tidigare efter födseln ett barn började vårdas hud mot hud, desto längre var den totala tiden det sedan vårdades hud mot hud under hela vårdtiden.

Sammanfattningsvis visar denna avhandling att dessa föräldrar i Sverige ville vara delaktiga i sina barns vård under tiden de vårdades på neonatalavdelning. De ville vårda sina barn hud mot hud enligt kängurumetoden och var väldigt motiverade till att göra så, trots att det ibland kunde upplevas som jobbigt. Desto tidigare efter barnets födelse föräldrarna fick börja vårda sitt barn enligt kängurumetoden, desto mer vårdades barnet hud mot hud under hela vårdtiden.

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"Jag är ingen soldat,
jag har inga vapen att ta till,
inga korståg jag vill gå,
ställ mig inte i ett led,
du får mig aldrig att stå still,
jag fungerar inte då,
jag är ingen soldat,
jag tänker inte så."

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References

1. Thomas, L.M., *The changing role of parents in neonatal care: a historical review.* Neonatal Netw, 2008. 27(2): p. 91-100.
2. Baker, J.P., *The incubator and the medical discovery of the premature infant.* J Perinatol, 2000. 20(5): p. 321-8.
3. Bialoskurski, M., C.L. Cox, and J.A. Hayes, *The nature of attachment in a neonatal intensive care unit.* J Perinat Neonatal Nurs, 1999. 13(1): p. 66-77.
4. Als, H., et al., *The Assessment of Preterm Infants' Behavior (APIB): furthering the understanding and measurement of neurodevelopmental competence in preterm and full-term infants.* Ment Retard Dev Disabil Res Rev, 2005. 11(1): p. 94-102.
5. Fellman, V., et al., *One-year survival of extremely preterm infants after active perinatal care in Sweden.* JAMA, 2009. 301(21): p. 2225-33.
6. Beck, S., et al., *The worldwide incidence of preterm birth: a systematic review of maternal mortality and morbidity.* Bull World Health Organ, 2010. 88(1): p. 31-8.
7. WHO, *Born too soon: the global action report on preterm birth.* 2012(http://whqlibdoc.who.int/publications/2012/9789241503433_eng.pdf).
8. Goldenberg, R.L., et al., *Epidemiology and causes of preterm birth.* Lancet, 2008. 371(9606): p. 75-84.
9. Altman, M., et al., *Shorter hospital stay for moderately preterm infants.* Acta Paediatr, 2006. 95(10): p. 1228-33.
10. Steer, P., *The epidemiology of preterm labour.* BJOG, 2005. 112 Suppl 1: p. 1-3.
11. Pio, A., B.R. Kirkwood, and S. Gove, *Avoiding hypothermia, an intervention to prevent morbidity and mortality from pneumonia in young children.* Pediatr Infect Dis J, 2010. 29(2): p. 153-9.
12. Duhn, L., *The importance of touch in the development of attachment.* Adv Neonatal Care, 2010. 10(6): p. 294-300.
13. Goulet, C., et al., *A concept analysis of parent-infant attachment.* J Adv Nurs, 1998. 28(5): p. 1071-81.
14. Walsh, J., *Definitions matter: if maternal-fetal relationships are not attachment, what are they?* Arch Womens Ment Health, 2010. 13(5): p. 449-51.
15. Kennell, J. and S. McGrath, *Starting the process of mother-infant bonding.* Acta Paediatr, 2005. 94(6): p. 775-7.

16. Bowlby, J., *A Secure Base: Clinical Applications of the Attachment Theory.* 1994, Routledge. p. 17-80, 149-169.
17. Kennell, J. and M. Klaus, *Bonding: Recent Observations That Alter Perinatal Care.* Pediatr Rev, 1998. 19: p. 4-12.
18. Klaus, M., J. Kennell, and M. Klaus, *Bonding. Building the Foundations of Secure Attachment and Independence.* 1996, Addison-Wesley Publishing Company, Inc. p. 59-92, 128-167.
19. Bystrova, K., et al., *Skin-to-skin contact may reduce negative consequences of "the stress of being born": a study on temperature in newborn infants, subjected to different ward routines in St. Petersburg.* Acta Paediatr, 2003. 92(3): p. 320-6.
20. Fegran, L., S. Helseth, and M.S. Fagermoen, *A comparison of mothers' and fathers' experiences of the attachment process in a neonatal intensive care unit.* J Clin Nurs, 2008. 17(6): p. 810-6.
21. Nyqvist, K.H. and A. Heinemann, *Kangaroo mother care: optimal support of preterm infant´s transition to extra-uterine life in the high tech NICU environment.* Curr Womens Health Rev, 2011. 7: p. 278-87.
22. Flacking, R., et al., *Trustful bonds: a key to "becoming a mother" and to reciprocal breastfeeding. Stories of mothers of very preterm infants at a neonatal unit.* Soc Sci Med, 2006. 62(1): p. 70-80.
23. Lundqvist, P., L.H. Westas, and I. Hallstrom, *From distance toward proximity: fathers lived experience of caring for their preterm infants.* J Pediatr Nurs, 2007. 22(6): p. 490-7.
24. Shin, H. and R. White-Traut, *The conceptual structure of transition to motherhood in the neonatal intensive care unit.* J Adv Nurs, 2007. 58(1): p. 90-8.
25. Affonso, D.D., et al., *Stressors reported by mothers of hospitalized premature infants.* Neonatal Netw, 1992. 11(6): p. 63-70.
26. Joseph, R.A., et al., *Stress in fathers of surgical neonatal intensive care unit babies.* Adv Neonatal Care, 2007. 7(6): p. 321-5.
27. Lindberg, B. and K. Ohrling, *Experiences of having a prematurely born infant from the perspective of mothers in northern Sweden.* International Journal Circumpolar Health, 2008. 67(5): p. 461-471.
28. Shaw, R.J., et al., *Acute stress disorder among parents of infants in the neonatal intensive care nursery.* Psychosomatics, 2006. 47(3): p. 206-12.
29. Erlandsson, K. and I. Fagerberg, *Mothers' lived experiences of co-care and part-care after birth, and their strong desire to be close to their baby.* Midwifery, 2005. 21(2): p. 131-8.
30. Klaus, M.H., et al., *Maternal attachment. Importance of the first post-partum days.* N Engl J Med, 1972. 286(9): p. 460-3.
31. Christensson, K., et al., *Separation distress call in the human neonate in the absence of maternal body contact.* Acta Paediatr, 1995. 84(5): p. 468-73.

32. Erlandsson, K., et al., *Skin-to-skin care with the father after cesarean birth and its effect on newborn crying and prefeeding behavior.* Birth, 2007. 34(2): p. 105-14.
33. Moore, E.R., et al., *Early skin-to-skin contact for mothers and their healthy newborn infants (Review).* Cochrane Database Syst Rev, 2012(5): p. CD003519.
34. Bramson, L., et al., *Effect of early skin-to-skin mother--infant contact during the first 3 hours following birth on exclusive breastfeeding during the maternity hospital stay.* J Hum Lact, 2010. 26(2): p. 130-7.
35. Nyqvist, K.H., et al., *Towards universal Kangaroo Mother Care: recommendations and report from the First European conference and Seventh International Workshop on Kangaroo Mother Care.* Acta Paediatr, 2010. 99(6): p. 820-6.
36. Stern, D.N. and N. Bruschweiler-Stern, *The birth of a mother*, in *Basic Books*. 1998: United States of America. p. 3-55, 93-109, 214-230.
37. Bruschweiler Stern, N., *Early emotional care for mothers and infants.* Pediatrics, 1998. 102(5 Suppl E): p. 1278-81.
38. Mundy, C.A., *Assessment of family needs in neonatal intensive care units.* Am J Crit Care, 2010. 19(2): p. 156-63.
39. Ward, K., *Perceived needs of parents of critically ill infants in a neonatal intensive care unit (NICU).* Pediatr Nurs, 2001. 27(3): p. 281-6.
40. De Rouck, S. and M. Leys, *Information needs of parents of children admitted to a neonatal intensive care unit A review of the literature (1990-2008).* Patient Educ Couns, 2009. 76(2): p. 159-73.
41. Arockiasamy, V., L. Holsti, and S. Albersheim, *Fathers' experiences in the neonatal intensive care unit: a search for control.* Pediatrics, 2008. 121(2): p. e215-22.
42. Lindberg, B., K. Axelsson, and K. Öhrling, *The birth of premature infants: Experiences from the fathers perspective.* J Neonatal Nurs, 2007. 13: p. 142-9.
43. Lindberg, B., K. Axelsson, and K. Ohrling, *Adjusting to being a father to an infant born prematurely: experiences from Swedish fathers.* Scand J Caring Sci, 2008. 22(1): p. 79-85.
44. Fenwick, J., L. Barclay, and V. Schmied, *Craving closeness: a grounded theory analysis of women's experiences of mothering in the Special Care Nursery.* Women Birth, 2008. 21(2): p. 71-85.
45. Nyqvist, K.H. and G. Engvall, *Parents as their infant's primary caregivers in a neonatal intensive care unit.* J Pediatr Nurs, 2009. 24(2): p. 153-63.
46. Ortenstrand, A., et al., *The Stockholm Neonatal Family Centered Care Study: effects on length of stay and infant morbidity.* Pediatrics, 2010. 125(2): p. e278-85.
47. Harrison, H., *The principles for family-centered neonatal care.* Pediatrics, 1993. 92(5): p. 643-50.

48. Griffin, T., *Family-centered care in the NICU.* J Perinat Neonatal Nurs, 2006. 20(1): p. 98-102.
49. Gooding, J.S., et al., *Family support and family-centered care in the neonatal intensive care unit: origins, advances, impact.* Semin Perinatol, 2011. 35(1): p. 20-8.
50. White, R.D., *The newborn intensive care unit environment of care: how we got here, where we're headed, and why.* Semin Perinatol, 2011. 35(1): p. 2-7.
51. Smith, A.B., G.C. Hefley, and K.J. Anand, *Parent bed spaces in the PICU: effect on parental stress.* Pediatr Nurs, 2007. 33(3): p. 215-21.
52. Cattaneo, A., et al., *Recommendations for the implementation of Kangaroo Mother Care for low birthweight infants. International Network on Kangaroo Mother Care.* Acta Paediatr, 1998. 87(4): p. 440-5.
53. Nyqvist, K.H., et al., *State of the art and recommendations. Kangaroo mother care: application in a high-tech environment.* Acta Paediatr, 2010. 99(6): p. 812-9.
54. Bergman, N.J., L.L. Linley, and S.R. Fawcus, *Randomized controlled trial of skin-to-skin contact from birth versus conventional incubator for physiological stabilization in 1200- to 2199-gram newborns.* Acta Paediatr, 2004. 93(6): p. 779-85.
55. Whitelaw, A. and K. Sleath, *Myth of the marsupial mother: home care of very low birth weight babies in Bogota, Colombia.* Lancet, 1985. 1(8439): p. 1206-8.
56. Martinez, G., S. Rey, and C. Marquette, *The mother kangaroo programme.* Int Child Health, 1992. 3: p. 55-67.
57. Feldman, R., et al., *Skin-to-Skin contact (Kangaroo care) promotes self-regulation in premature infants: sleep-wake cyclicity, arousal modulation, and sustained exploration.* Dev Psychol, 2002. 38(2): p. 194-207.
58. WHO. *Kangaroo mother care: A practical guide. Department of Reproductive Health and Research. http://www.who.int/reproductive-health/publications/kmc/text.pdf.* 2003.
59. Karlsson, V., et al., *Early Skin-to-Skin Care in Extremely Preterm Infants: Thermal Balance and Care Environment.* J Pediatr, 2012. 161(3): p. 422-6.
60. Barradas, J., et al., *Relationship between positioning of premature infants in Kangaroo Mother Care and early neuromotor development.* J Pediatr (Rio J), 2006. 82(6): p. 475-80.
61. Nyqvist, K.H., *Early attainment of breastfeeding competence in very preterm infants.* Acta Paediatr, 2008. 97(6): p. 776-81.
62. Nyqvist, K.H., P.O. Sjoden, and U. Ewald, *The development of preterm infants' breastfeeding behavior.* Early Hum Dev, 1999. 55(3): p. 247-64.

63. Dykes, F. and R. Flacking, *Encouraging breastfeeding: A relational perspective.* Early Hum Dev, 2010. 86(11): p. 733-6.
64. Ludington-Hoe, S.M. and J.Y. Swinth, *Developmental aspects of kangaroo care.* J Obstet Gynecol Neonatal Nurs, 1996. 25(8): p. 691-703.
65. Charpak, N., et al., *Kangaroo Mother Care: 25 years after.* Acta Paediatr, 2005. 94(5): p. 514-22.
66. Lawn, J.E., et al., *Kangaroo mother care' to prevent neonatal deaths due to preterm birth complications.* Int J Epidemiol, 2010. 39(Suppl 1): p. i144-54.
67. Conde-Agudelo, A., J.M. Belizan, and J. Diaz-Rossello, *Kangaroo mother care to reduce morbidity and mortality in low birthweight infants.* Cochrane Database Syst Rev, 2011. 3: p. CD002771.
68. Miles, R., et al., *A controlled trial of skin-to-skin contact in extremely preterm infants.* Early Hum Dev, 2006. 82(7): p. 447-55.
69. Boo, N.Y. and F.M. Jamli, *Short duration of skin-to-skin contact: effects on growth and breastfeeding.* J Paediatr Child Health, 2007. 43(12): p. 831-6.
70. Tornhage, C.J., et al., *First week kangaroo care in sick very preterm infants.* Acta Paediatr, 1999. 88(12): p. 1402-4.
71. Charpak, N., J.G. Ruiz-Pelaez, and Y. Charpak, *Rey-Martinez Kangaroo Mother Program: an alternative way of caring for low birth weight infants? One year mortality in a two cohort study.* Pediatrics, 1994. 94(6 Pt 1): p. 804-10.
72. Tessier, R., et al., *Kangaroo mother care and the bonding hypothesis.* Pediatrics, 1998. 102(2): p. e17.
73. Suman, R.P., R. Udani, and R. Nanavati, *Kangaroo mother care for low birth weight infants: a randomized controlled trial.* Indian Pediatr, 2008. 45(1): p. 17-23.
74. Anderson, G.C., et al., *Mother-newborn contact in a randomized trial of kangaroo (skin-to-skin) care.* J Obstet Gynecol Neonatal Nurs, 2003. 32(5): p. 604-11.
75. Hake-Brooks, S.J. and G.C. Anderson, *Kangaroo care and breastfeeding of mother-preterm infant dyads 0-18 months: a randomized, controlled trial.* Neonatal Netw, 2008. 27(3): p. 151-9.
76. Whitelaw, A., et al., *Skin to skin contact for very low birthweight infants and their mothers.* Arch Dis Child, 1988. 63(11): p. 1377-81.
77. Rojas, M.A., et al., *Somatic growth of preterm infants during skin-to-skin care versus traditional holding: a randomized, controlled trial.* J Dev Behav Pediatr, 2003. 24(3): p. 163-8.
78. Charpak, N., et al., *Kangaroo mother versus traditional care for newborn infants </=2000 grams: a randomized, controlled trial.* Pediatrics, 1997. 100(4): p. 682-8.
79. van Zanten, H., et al., *The kangaroo method is safe for premature infants under 30 weeks of gestation during ventilatory support.* J Neonatal Nurs, 2007. 13: p. 186-90.

80. Charpak, N., et al., *A randomized, controlled trial of kangaroo mother care: results of follow-up at 1 year of corrected age.* Pediatrics, 2001. 108(5): p. 1072-9.
81. Cattaneo, A., et al., *Kangaroo mother care for low birthweight infants: a randomized controlled trial in different settings.* Acta Paediatr, 1998. 87(9): p. 976-85.
82. Maastrup, R. and G. Greisen, *Extremely preterm infants tolerate skin-to-skin contact during the first weeks of life.* Acta Paediatr, 2010. 99(8): p. 1145-9.
83. Hurst, N.M., et al., *Skin-to-skin holding in the neonatal intensive care unit influences maternal milk volume.* J Perinatol, 1997. 17(3): p. 213-7.
84. Nagai, S., et al., *Long-term effects of earlier initiated continuous Kangaroo Mother Care (KMC) for low-birth-weight (LBW) infants in Madagascar.* Acta Paediatr, 2011. 100(12): p. e241-7.
85. Feldman, R., et al., *Comparison of skin-to-skin (kangaroo) and traditional care: parenting outcomes and preterm infant development.* Pediatrics, 2002. 110(1 Pt 1): p. 16-26.
86. Ludington-Hoe, S.M., et al., *Neurophysiologic assessment of neonatal sleep organization: preliminary results of a randomized, controlled trial of skin contact with preterm infants.* Pediatrics, 2006. 117(5): p. e909-23.
87. Ludington-Hoe, S.M., et al., *Selected physiologic measures and behavior during paternal skin contact with Colombian preterm infants.* J Dev Physiol, 1992. 18(5): p. 223-32.
88. Johnston, C.C., et al., *Kangaroo mother care diminishes pain from heel lance in very preterm neonates: a crossover trial.* BMC Pediatr, 2008. 24;8: p. 13.
89. Cong, X., et al., *Effects of Skin-to-Skin Contact on Autonomic Pain Responses in Preterm Infants.* J Pain, 2012. 13(7): p. 636-45.
90. Akcan, E., R. Yigit, and A. Atici, *The effect of kangaroo care on pain in premature infants during invasive procedures.* Turk J Pediatr, 2009. 51(1): p. 14-8.
91. Bohnhorst, B., et al., *Skin-to-skin (kangaroo) care, respiratory control, and thermoregulation.* J Pediatr, 2001. 138(2): p. 193-7.
92. Bohnhorst, B., et al., *Bradycardia and desaturation during skin-to-skin care: no relationship to hyperthermia.* J Pediatr, 2004. 145(4): p. 499-502.
93. Nagai, S., et al., *Earlier versus later continuous Kangaroo Mother Care (KMC) for stable low-birth-weight infants: a randomized controlled trial.* Acta Paediatr, 2010. 99(6): p. 827-35.
94. Whitelaw, A., *Kangaroo baby care: just a nice experience or an important advance for preterm infants?* Pediatrics, 1990. 85(4): p. 604-5.
95. Tallandini, M. and C. Scalembra, *Kangaroo mother care and mother-premature infant dyadic interaction.* Infant Ment Health J, 2006. 27: p. 251-75.

96. Roller, C., *Getting to Know You; Mother´s Experiences of Kangaroo Care.* J Obstet Gynecol Neonatal Nurs, 2005. 34: p. 210-7.
97. Fransson, E., *Preterm birth - Parents' experiences, affect, stress and inflammatory markers*, in *Thesis from Karolinska Institutet, Stockholm, Sweden. http://publications.ki.se/jspui/bitstream/10616/40885/1/Emma%20Fransson_thesis.pdf*. 2012. p. 37-43.
98. Morelius, E., E. Theodorsson, and N. Nelson, *Salivary cortisol and mood and pain profiles during skin-to-skin care for an unselected group of mothers and infants in neonatal intensive care.* Pediatrics, 2005. 116(5): p. 1105-13.
99. de Macedo, E.C., et al., *The mood variation in mothers of preterm infants in Kangaroo mother care and conventional incubator care.* J Trop Pediatr, 2007. 53(5): p. 344-6.
100. de Alencar, A.E., et al., *Effect of kangaroo mother care on postpartum depression.* J Trop Pediatr, 2009. 55(1): p. 36-8.
101. Gathwala, G., B. Singh, and B. Balhara, *KMC facilitates mother baby attachment in low birth weight infants.* Indian J Pediatr, 2008. 75(1): p. 43-7.
102. Ibe, O.E., et al., *A comparison of kangaroo mother care and conventional incubator care for thermal regulation of infants < 2000 g in Nigeria using continuous ambulatory temperature monitoring.* Ann Trop Paediatr, 2004. 24(3): p. 245-51.
103. Affonso, D., V. Wahlberg, and B. Persson, *Exploration of mothers' reactions to the kangaroo method of prematurity care.* Neonatal Netw, 1989. 7(6): p. 43-51.
104. Nirmala, P., S. Rekha, and M. Washington, *Kangaroo Mother Care: Effect and perception of mothers and health personnel.* J Neonatal Nurs, 2006. 12: p. 177-84.
105. Neu, M., *Parents' perception of skin-to-skin care with their preterm infants requiring assisted ventilation.* J Obstet Gynecol Neonatal Nurs, 1999. 28(2): p. 157-64.
106. Johnson, A.N., *The maternal experience of kangaroo holding.* J Obstet Gynecol Neonatal Nurs, 2007. 36(6): p. 568-73.
107. Affonso, D., et al., *Reconciliation and healing for mothers through skin-to-skin contact provided in an American tertiary level intensive care nursery.* Neonatal Netw, 1993. 12(3): p. 25-32.
108. Tessier, R., et al., *Kangaroo Mother Care, home environment and father involvement in the first year of life: a randomized controlled study.* Acta Paediatr, 2009. 98(9): p. 1444-50.
109. Leonard, A. and P. Mayers, *Parents´ lived experience of providing kangaroo care to their preterm infants.* Health SA Gesondheid, 2008. 13: p. 16-28.
110. Danerek, M. and A.K. Dykes, *A theoretical model of parents' experiences of threat of preterm birth in Sweden.* Midwifery, 2008. 24(4): p. 416-24.

111. Flynn, A. and P. Leahy-Warren, *Neonatalnurses' knowledge and beliefs regarding kangaroo care with preterm infants in an Irish neonatal unit.* J Neonatal Nurs, 2010. 16(5): p. 221-8.
112. Engler, A.J., et al., *Kangaroo care: national survey of practice, knowledge, barriers, and perceptions.* MCN Am J Matern Child Nurs, 2002. 27(3): p. 146-53.
113. Chia, P., K. Sellick, and S. Gan, *The attitudes and practices of neonatal nurses in the use of kangaroo care.* Aust J Adv Nurs, 2006. 23(4): p. 20-7.
114. Johnson, A.N., *Factors influencing implementation of kangaroo holding in a Special Care Nursery.* MCN Am J Matern Child Nurs, 2007. 32(1): p. 25-9.
115. Lee, H.C., S. Martin-Anderson, and R.A. Dudley, *Clinician Perspectives on Barriers to and Opportunities for Skin-to-Skin Contact for Premature Infants in Neonatal Intensive Care Units.* Breastfeed Med, 2012. 7: p. 79-84.
116. Wallin, L., A. Rudberg, and L. Gunningberg, *Staff experiences in implementing guidelines for Kangaroo Mother Care--a qualitative study.* Int J Nurs Stud, 2005. 42(1): p. 61-73.
117. Forsakringskassan, *The Swedish Social Insurance Agency. Information retrived from www.forsakringskassan.se on 27 May 2010.* 2010.
118. Nyqvist, K.H., *How can kangaroo mother care and high technology care be compatible?* J Hum Lact, 2004. 20(1): p. 72-4.
119. Pallant, J., *SPSS Survival Manual*. 4th edition ed. 2010, Berkshire, England: Open University Press.
120. Krippendorf, K., *Content Analysis. An introduction to its methodology*. 2004, SAGE Publications. p. 3-17, 81-96.
121. Graneheim, U.H. and B. Lundman, *Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness.* Nurse Educ Today, 2004. 24(2): p. 105-12.
122. Wigert, H., et al., *Mothers' experiences of having their newborn child in a neonatal intensive care unit.* Scand J Caring Sci, 2006. 20(1): p. 35-41.
123. Gavey, J., *Parental perceptions of neonatal care.* J Neonatal Nurs, 2007. 13(5): p. 199-206.
124. Neu, M., *Kangaroo care: is it for everyone?* Neonatal Netw, 2004. 23(5): p. 47-54.
125. Morelius, E., et al., *Time of initiation of skin-to-skin contact in extremely preterm infants in Sweden.* Acta Paediatr, 2012. 101(1): p. 14-8.
126. Flacking, R., U. Ewald, and L. Wallin, *Positive effect of kangaroo mother care on long-term breastfeeding in very preterm infants.* J Obstet Gynecol Neonatal Nurs, 2011. 40(2): p. 190-7.
127. Flacking, R., U. Ewald, and B. Starrin, *"I wanted to do a good job": experiences of 'becoming a mother' and breastfeeding in mothers of very preterm infants after discharge from a neonatal unit.* Soc Sci Med, 2007. 64(12): p. 2405-16.

128. Wittmann, M., *The inner experience of time.* Philos Trans R Soc Lond B Biol Sci, 2009. 364(1525): p. 1955-67.
129. Burton, R., *The experience of time in the very young.* Avaible from http://www.phenomenologyonline.com/sources/textorium/burton-rod-the-experience-of-time-in-the-very-young/, 2002.
130. Sullivan, J.R., *Development of father-infant attachment in fathers of preterm infants.* Neonatal Netw, 1999. 18(7): p. 33-9.
131. Prevéus, M., *Ett barn på neo och två barn hemma (One infant at NICU at two at home).* Kontakt, 2011. 3: p. 14-5.
132. Marshall, M.N., *Sampling for qualitative research.* Fam Pract, 1996. 13(6): p. 522-5.
133. Sandelowski, M., *Sample size in qualitative research.* Res Nurs Health, 1995. 18(2): p. 179-83.
134. Johnson, R.B., A.J. Onwuegbuzie, and L.A. Turner, *Toward a Definition of Mixed Methods Research.* J Mix Methods Res, 2007. 1(2): p. 112-33.
135. Pierrat, V., et al., *How can we evaluate developmental care practices prior to their implementation in a neonatal intensive care unit?* Early Hum Dev, 2007. 83(7): p. 415-8.

Appendix I

Questionnaire Paper I

1. I did not really like to have my baby near me, with KMC
2. I would have preferred not to have my baby near me, with KMC
3. It was cosy to have my baby near me with KMC
4. To have my baby near me, with KMC, made me feel happy
5. I felt like a failure when I did not have the energy to have my baby near me, with KMC, all the time
6. To hold my baby, with KMC, made it easier to get to know her
7. I wish I could have had my baby near me, with KMC, earlier than I did
8. I felt that my love for my baby grew stronger through KMC
9. I slept well when I had my baby near me during the night
10. It felt safe to have my baby near me, with KMC
11. I was afraid that something would happen to my baby when I provided KMC
12. I became stressed by providing my baby with KMC
13. It happened that I felt forced to be at the hospital with my baby
14. I had wished that my baby would sleep sometimes in the nursery during the night
15. I didn't get the help and relief I needed by the staff when I provided kangaroo care
16. The staff was responsive to my needs and desires when it came to caring for my baby whit the kangaroo mother care method
17. I got the information about the kangaroo mother care method that I felt that I needed
18. I received enough information about the possibility of asking other family members and relatives to come to the NICU and provide kangaroo mother care
19. I had wanted to stop caring for my baby with KMC earlier than I did
20. It happened that I felt forced to have my baby skin to skin
21. KMC make me feel as an important person in my baby' care
22. If I would give birth to a preterm or/ sick baby again, I would not provide KMC
23. It felt better to sleep in the hospital with my baby, than too sleep at home without her/him)
24. I believe that KMC helped us establish breast feeding earlier than we would have done otherwise

Appendix II

Interview guide Paper III

Introduction
How did you experience the time your baby spent as a patient in the NICU?

Key words
- Expectations
- Becoming a parent: mother/father
- The professionals' role - the parents' role
- Support from your relatives and social network
- Participation in your baby's care: Voluntary – forced to…
- Skin-to-skin - incubator
- Breastfeeding/feeding and nutrition
- Possibilities/difficulties
- Start skin-to-skin care… How? Feelings? Can you tell me about it.
- Stop skin-to-skin care… How, why? Can you tell me about it.

Important themes that should be included
EXPERIENCE OF/ OPINIONS ABOUT KMC
- How did you experience use of kangaroo mother care?
- Which advantages do you see in parents' use of kangaroo mother care?
- Which disadvantages do you see in parents' use of kangaroo mother care?
- What made it difficult or easier for you to use kangaroo mother care?

EXPERIENCE OF THE PARENTAL ROLE/THE PROFESSIONALS' ROLE
- When did you sense that having become X's mother/father was a reality?
- How did that feel?
- What did you perceive as obstacles to/support of your sense of having become X's parent?
- How did you perceive the professionals' approach to you and expectations on you as a parent?
- Any difficulties your experienced in relation to professionals – can you tell me about them?
- Anything you think should have been different, can you tell me about it?

Appendix III

Questions Paper IV

1. Which factors (in your family and social network and at the NICU) facilitated your provision of KMC to the extent you desired?
2. Which factors (in your family and social network and at the NICU) rendered it difficult for you to provide your infant with KMC to the extent you desired?
3. When did you discontinue KMC to the extent you used it during your infant's NICU stay?
4. Why did you discontinue performance of KMC?

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