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Promoting preterm infants’ development and mother child interaction
Newborn Individualized Developmental Care and Assessment Program

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Stockholm 2006
The behavior of the infant is its primary way to communicate

Heidelise Als
I would like to dedicate this thesis to all families, and to my family, Annamaria, Anders and Arne
ABSTRACT

Family-centred care according to Newborn Individualized Developmental Care and Assessment Program (NIDCAP) has been increasingly introduced in Europe since the 1990’s. The NIDCAP model provides a tool for observation and interpretation of preterm infant’s behavioural cues, and includes guidelines on how to support the preterm infant’s development and family.

The overall aim of the thesis was to investigate effects of NIDCAP as compared to conventional neonatal care on short and long-term outcomes of the preterm infant, on mother-child interaction, and on mothers’ experiences of the different care regimes. The thesis also aimed to test if a structured intervention based on NIDCAP reduces pain and distress during eye examination for retinopathy of prematurity.

Study I was performed at a county hospital in Sweden, and evaluated outcome at 3 years of age of two cohorts of infants with BW \( \leq 1500 \) gram who were subjected either to conventional care or to NIDCAP in a phase lag study design. Studies II, III and IV report outcomes from a randomized controlled trial performed at the level III NICU Karolinska University Hospital in Stockholm. Preterm inborn infants, with GA <32 weeks and need for ventilatory support at 24 hours of age were included. Study V was performed as a randomised cross-over study evaluating two eye examinations, one with a NIDCAP-intervention and one with conventional care. The study was performed at two level-III NICU’s, St Mary’s Hospital (London, UK) and University Hospital (Lund, Sweden).

The main short-term effects from NIDCAP care (paper II) was lower respiratory morbidity, including fewer days with CPAP and additional oxygen. At 36 weeks PMA, none of the 11 infants in the NIDCAP group displayed bronchopulmonary dysplasia in comparison to 8/11 infants in the control group. At 36 weeks PMA (paper III), when the infants were still in hospital, the mothers of the infants in the NIDCAP group perceived more feelings of closeness and eye contact with their infants. Furthermore, they tended to rate the staff’s ability to support them in their role as a mother somewhat higher, but at the same time they expressed more anxiety than did the mothers of the infants in the control group. At one year of age (paper IV), cognitive development was significantly higher for the children in the NIDCAP intervention group.

At three years of age (paper I) there were no significant differences in overall cognitive development between the two groups in the phase lag study. However, the NIDCAP-intervention group demonstrated significantly better language skills and higher scores for mother-child interaction. The mothers’ in the NIDCAP group also displayed more physical and visual contact with their children. In addition, the children cared for according to NIDCAP also demonstrated fewer behavioural problems and less internalizing problems, i.e. were more open and expressed their feelings more readily.

The NIDCAP-intervention was clearly associated with a quicker recovery of the infants, as measured by lower salivary cortisol levels one hour after the eye examination (paper V). Furthermore, after the first examination when infants were 1-2 weeks younger than at the second examination, significantly fewer infants needed additional oxygen after the NIDCAP intervention.

The studies reported in this thesis show different aspects on how a behaviourally sensitive, developmentally oriented, family-centred humane care supports and promotes short-term and long-term outcomes for preterm infants and their families, as well as reduces stress in connection with a painful procedure.
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LIST OF PUBLICATIONS

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


III. Agneta Kleberg, Lena Hellström-Westas, Ann-Marie Widström. Mothers’ perception of Newborn Individualized Developmental Care and Assessment Program (NIDCAP) as compared to conventional care. Accepted for publication in Early Human Development.


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# LIST OF ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ADHD</td>
<td>Attention deficit hyperactivity disorder</td>
</tr>
<tr>
<td>BPD</td>
<td>Bronchopulmonary dysplasia</td>
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<tr>
<td>CI</td>
<td>Confidence interval</td>
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<td>CLD</td>
<td>Chronic lung disease</td>
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<td>CRIB</td>
<td>Clinical risk index for babies</td>
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<tr>
<td>CPAP</td>
<td>Continuous positive airway pressure</td>
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<tr>
<td>ELBW</td>
<td>Extremely low birth weight, i.e. &lt;1000 g</td>
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<tr>
<td>ELGA</td>
<td>Extremely low gestational age, i.e. &lt;28 weeks</td>
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<tr>
<td>GA</td>
<td>Gestational age (completed weeks)</td>
</tr>
<tr>
<td>HR</td>
<td>Heart rate</td>
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<td>IRDS</td>
<td>Infant respiratory distress syndrome</td>
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<td>IVH</td>
<td>Intraventricular haemorrhage</td>
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<td>IQ</td>
<td>Intelligence quotient</td>
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<td>KMC</td>
<td>Kangaroo Mother Care</td>
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<td>NEC</td>
<td>Necrotizing enterocolitis</td>
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<td>NICU</td>
<td>Neonatal Intensive Care Unit</td>
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<td>NBAS</td>
<td>Neonatal Behavioral Assessment Scale</td>
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<td>NIDCAP</td>
<td>Newborn Individualized Developmental Care and Assessment Program</td>
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<tr>
<td>PIPP</td>
<td>Premature Infant Pain Profile</td>
</tr>
<tr>
<td>PVL</td>
<td>Periventricular leukomalacia</td>
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<tr>
<td>PCA</td>
<td>Postconceptional age</td>
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<td>PMA</td>
<td>Postmenstrual age</td>
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<tr>
<td>PNA</td>
<td>Postnatal age</td>
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<tr>
<td>RCT</td>
<td>Randomized Controlled Trial</td>
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<tr>
<td>ROP</td>
<td>Retinopathy of prematurity</td>
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<tr>
<td>SaO₂</td>
<td>Oxygen saturation</td>
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<tr>
<td>SSC</td>
<td>Skin-to-skin care</td>
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<tr>
<td>VLBW</td>
<td>Very low birth weight, i.e. &lt; 1500 g</td>
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BACKGROUND

Introduction
After ten years as an anaesthetic nurse I exchanged the operating theatre and adult intensive care environment for the neonatal intensive care unit. Although the intensive care environment felt familiar, the fragile preterm infant affected me and made me very concerned. I asked “Why do the infants twitch and squirm, stop breathing, become pale and why do they look unhappy and stressed”? The answers I received were the same - “Preterm babies always do”. I was not, however, satisfied with the answers. I could also see how stressed the parents were and that they sometimes felt like outsiders in the NICU-environment. My thoughts circled around the question “How can we better comfort the infants?”, “Does the behaviour of the infant contribute to the stress the parents express?”, and “How will this affect the infant – parent relationship?” The Newborn Individualized Development Care and Assessment Program (NIDCAP) gave me, as a neonatal nurse, a structured tool for how to better interpret and support the preterm infant and its parents. My attempt in this thesis, has been to work empirically, observing and interpreting preterm infants, according to NIDCAP, using the NIDCAP model as an early intervention during clinical work and testing hypotheses based on these experiences.

SURVIVAL AND DEVELOPMENT OF PRETERM INFANTS

Development in perinatal care, including administration of antenatal steroids and surfactant has lowered neonatal morbidity and increased survival in the most immature infants (1). The survival rate for very low birth weight (VLBW) infants has increased from around 50% in the late 1960’s to around 85% in the late 1990’s (1-5). During the last decade, a new group of NICU-survivors have emerged, the extremely low gestational age (ELGA) infants with gestational ages below 28 weeks. A Swedish national study of ELBW infants born 1990-92 reported survival rates of 8%, 30% and 60% at 23, 24 and 25 gestational weeks, respectively (6). A few years later (1995) the EPICure study reported survival rates for infants born in Great Britain to 39%, to 60% and 67% at 23, 24 and 25 gestational weeks, respectively (7). It is clear that an increasing number of these infants will survive with active perinatal management (8).

Neonatal morbidity is still significant in the extremely preterm infants although it has changed during the 1990’s with fewer infants developing pneumothorax and intraventricular hemorrhages (IVH). However, figures for bronchopulmonary dysplasia (BPD), necrotizing enterocolitis (NEC) and sepsis seem to remain largely unchanged (1). In the Swedish national ELBW study, including data from 633 live born (and 298 stillborn) infants born during the time period 1990-92, 8% suffered from IVH or periventricular leukomalacia PVL, 10% from retinopathy of prematurity (ROP), 22% from patent ductus arteriosus (PDA), 2% from NEC, and 28% were oxygen dependent at a time corresponding to 36 weeks of gestation (6). The increasing number of survivors does not seem to affect the overall prevalence of cerebral palsy, and around 2 out of 3 Swedish neonatologists now consider treatment at 24 weeks of gestation to be clearly beneficial (9, 10).

However, the proportion of VLBW survivors with disabilities is still high and several investigators have reported that around 15-25% of children born VLBW develop
disabilities, and approximately 40% also have behaviour problems or deficits in academic skills (11-16). In a recent study Hack et al reported school-age outcomes of a cohort of ELBW children born during the 1990’s (17). At 8 years of age, 14% had cerebral palsy, 38% had IQ below 85, 47% had poor motor skills, and 10% suffered from visual disability. In the Swedish ELBW study at 3 years of corrected age, 372 of the 633 live born infants had survived (59%). Fourteen percent, 10% and 3% of the children born at 23-24, 25-26 and ≥ 27 gestational weeks, respectively, had developed cerebral palsy. However, more than 90% of the ELBW children born at ≥ 25 completed gestational weeks were without handicap (18). In the EPICure study at six years of age, 22% and 24% of the children had severe and moderate disability, respectively (19).

Although Ment et al reported increasing verbal and IQ test scores in VLWB children without disability at 8 years, a majority of studies have not seen any improvement in outcome over time (19, 20). In a ten year follow-up study of children born before 29 gestational weeks, 38 % of the children performed below grade level at school, 32% had general behavioural problems and 20% had attention deficit hyperactivity disorder (ADHD) (16). In a longitudinal, population-based Canadian study of ELBW children born 1977-1982, 28% displayed neurosensory impairments when evaluated between 12 and 16 years of age (21). When followed-up at 22 to 25 years, 82% of the ELBW adolescents had graduated from high school, as compared to 87% in a control group (22). A higher proportion of the young ELBW adults were neither employed nor in school (26% versus 15%), as compared to the controls, but the difference did not persist when participants with disabilities were excluded. In a large follow up study of VLBW infants born between 1977 and 1979, an increased incidence of psychopathology in 20 years old adults was reported (23).

THE SENSORY ENVIRONMENT OF THE NICU

The normal setting for the foetus is the protective environment in the mother’s womb. The intrauterine environment is not quiet, but sounds and somatosensory input are muffled by the amniotic fluid. Differences in maternal activity during the day, and at night, contribute to development of circadian rhythms. When an infant is born preterm, the infant may become exposed to an excess of stimuli from noise, light, activity, odours, painful procedures, disturbed circadian rhythm and separation from the mother which may have long-term effects on the infant and on infant-parent bonding.

Brain development of the preterm infant

Als describes the sensory environment outside the womb as an “unexpected challenge” for the preterm infant during a very sensitive period of rapid brain growth and differentiation (24) (Figure 1). Foetal brain development is under genetical control but also dependent on neural activity for fine tuning of the networks (25, 26). Spontaneous neural activity in for example the retina seems to be of importance for the wiring and particularly the fine tuning of the neuronal circuits in the visual cortex. This has been demonstrated in ferret pups before they open their eyes. This normal spontaneous activity which probably also occurs in the human foetus may be changed or disturbed when the preterm infants open their eyes in the extrauterine environment. “Neurons which fire together wire together and those which don’t won’t” (27). Both animal and
human studies have documented how sensory inputs influence the structure and the function of the central nervous system, as well as the behaviour of the newborn (28-31).

During the last decades there has been a growing interest in how stimuli from the NICU environment affect the preterm infant. In the 1980’s, Long et al documented changes in heart rate and respiratory rate, transcutaneous oxygen tension, and intracranial pressure after exposing preterm infants to a burst of sound at ≥ 70dBA (32). The investigators noted that almost all high sound levels in the NICU were associated with activities of the staff, such as closing and opening of doors and drawers, garbage disposal, laughter, and conversations carried on across the room. The sound levels in the NICU did not decrease until the caregivers adjusted their behaviours. Als et al have shown that preterm infants at term are more likely to have more autonomic, motor, and state instability in response to auditory, visual, handling, and social interaction than full-term infants (33, 34). During light sleep, most healthy full-term infants habituate to repeated light or sound stimuli, whereas preterm infants have difficulties “shutting out” or habituating to repeated stimuli. The preterm infants are also more easily disturbed and may react with for example increased motor action, irregular breathing or apnoea. The differences in responses between term and preterm infants at term are probably, and at least partly, attributed to differences in sensory experience of the immature nervous system. Als hypothesized that the very early born infants find themselves in a “mismatch” between their immature brains’ expectations of sensory input and the input from the NICU environment (24).
Hearing, sound and noise

The frequencies of sound waves are measured in Hertz (Hz) and perceived as pitch. The higher the frequency, the higher is the pitch. The pressure of the sound waves is perceived as loudness and measured in decibel scale (dB). The decibel metric is a logarithmic scale that doubles with each 6 decibel increased. The A-weighted scale (dBA) is used to describe sound levels as they would be perceived by the human ear. The softest sound that humans can hear is between 0 dB and 20 dB and the threshold of pain is 120 dB (35). The intrauterine environment is not quiet, although extrauterine sound reaching the fetus is reduced, an extrauterine sound at 90 dB would be reduced to about 45 dB at the fetal cochlea (36). As a result of foetal hearing experience, the healthy term newborn infant recognizes its mother’s voice soon after birth (36).

Infants treated in NICU’s may become exposed to long periods of high sound levels. A typical home bedroom is about 30 to 40 dBA, while NICU’s may produce sound levels between 50 and 75 dBA with peaks of 105 dBA and frequent prolonged periods between 70 and 80 dBA (37, 38). To assure sleep for healthy term infants, it is recommended that the hourly median sound level should stay below 50 dBA most of the time. The percentage of disturbed or wakened infants rose sharply with each 5 dBA sound increase, at 55 dBA 5% of infants were affected and at 60 dBA 20% were disturbed (39).

Concerns have also been raised about the transmission of sound into the incubator (40). Robertson et al concluded that incubators reduce average sound exposure to levels near recommended levels for NICU’s (41). However, the sound from lower frequencies created by the incubator motor may be higher inside the incubator. In the survey of Robertson et al, sound measurements in the NICU outside the incubator averaged 56 dBA, and exceeded the recommended hourly L_{eq} (of 50 dBA with 6 dBA). Inside the incubator, the average sound level was 50.3 dBA with the motor on. Although the latest models of incubator are very quiet, the noise inside the incubator may exceed the recommended levels as soon as respiratory equipment is used. Incubator door latches or objects hitting the incubator may increase the sound level to be even higher inside than outside the incubator.

The healthy term newborn infant can within a few hours discriminate between his mother’s voice and that of an unfamiliar woman (36). With support in attaining an alert state, the term infant can orient visually to auditory signals by turning head and eyes to the sound (42, 43). In contrast, the preterm infant has difficulties in reaching an alert state and to attend, to stimuli and is more easily distracted (31, 33, 44, 45). The preterm infant also has difficulties turning towards and away from the stimuli, or coordinating motor response with auditory stimuli. The preterm infant experience the same or greater sleep disruption as do term infants to similar stimuli (33, 34, 46).

Concern has been raised regarding possible adverse effects of sound and noise on human brain development, especially for infants treated in NICU’s since this environment contrasts to the intrauterine environment where the auditory stimulation is better regulated as regards amount, type and timing (47). In a review of literature, Philbin recommended that clinicians measure and reduce noise levels in nurseries and incubators, and provide individualized, parental care for hospitalized infants (e.g. facilitating parents’ efforts to talk and sing to their own babies), and limit added sound stimulations (e.g. tape recording) to specific situations in order to improve the
conditions for the developing preterm infant (38). Programs to make hospital nurseries more quiet have included education for staff to self-correct noisy behaviour, day-night cycling of lights, quiet periods, blocking of sound at infants’ ear (ear muffs etc), installing acoustic ceiling materials, and increasing the space at the bedside. However, more research is needed in this area. Philbin and Klass provide a checklist for evaluating research on the effects of sound on infants (48).

Recommended Standards for Newborn ICU Design from 2003 give the following recommendation concerning noise control: “Infant bed areas and spaces opening onto them shall be designed to produce minimal background noise and to contain and absorb much of the transient noise that arises within the nursery. The combination of continues background sound and transient sound in any bed space or patient care area shall not exceed an hourly $L_{eq}$ of 50 dBA and an hourly $L_{10}$ of 55 dBA, both A-weighted slow response. The $L_{max}$ (transient sounds) shall not exceed 70 dBA, A-weighted slow response” (49, 50).

**Vision and light**

Based on a review of the literature, Graven concluded that high noise levels, bright light, sleep deprivation, and long-term sedation may affect the processes of early visual development (51). The early development of eye structures is under innate control and not dependent on light and vision during a normal pregnancy. Before 30 gestational weeks the fetus and preterm infant has only limited ability to reduce light into the eye as the eye lids are very thin and the pupillary constriction is not yet developed (52). Consequently, the eyes of the preterm infant are not fully developed while prematurely exposed to the environmental light in the NICU. The visual system is ready for light and visual stimulation only when the preterm infant approaches term, and at that time it is necessary for the postnatal functional maturation of vision.

Visual impairment is common in children who were born very preterm and include refraction errors, especially myopia (nearsightedness), squint and cerebral visual impairment (CVI) (52, 53). Retinopathy of prematurity is associated with visual impairment, and in very severe cases, even blindness. The aetiology to preterm visual impairment is multifactorial and includes oxygen, circulatory factors, nutrition and growth factors (54). Several trials have evaluated various interventions such as controlling for oxygen saturation, and reducing environmental light without clear improvement in visual outcomes (55, 56).

The foetus has active and quite periods suggesting periods with wakefulness and sleep, the foetus is not only protected from bright light, it is also exposed to the day and night rhythm of the mother. This will be partly disrupted if the infant is born preterm. Sleep state cyclicity is present also in extremely preterm infants in the NICU. Scher et al showed mean cycle duration of 68 minutes, with a range of 37 to 100 minutes in a group of extremely preterm infants (57). The day and night rhythm gradually develops during weeks and months after term.

Bright light has been very common in NICU’s. As early as 1986, Mann et al showed that cycled light in the NICU improved sleep in neonates even several months after discharge, later studies have shown similar results (58, 59). During the 1990’s, inspired
by the NIDCAP-method, dimmed lighting and incubator covers were introduced in many NICU’s. However, while some investigators failed to detect day-night differences in sleep patterns after introducing cycled light for preterm stable infants, others found that the regime induced a pattern of rest activity in these infants (58-60). Short-term use of incubator covers did not affect quiet sleep periods in stable preterm infants, although the duration of quiet sleep periods was more homogenous in NIDCAP-treated infants as compared to control (61, 62). However, Rivkees states that it is difficult to control for confounding factors when studying single sensory inputs, and more scientific evidence is still needed regarding the importance of adequately light (63).

Recommended Standards for Newborn ICU Design suggests that “Ambient lighting levels in newborn intensive care rooms shall be adjusted through a range of at least 10 to 600 lux (approximately 1- to 60-ft candles), as measured at each bedside (50). Both natural and electric light sources shall have controls that allow immediate darkening of any bed position sufficient from transillumination when necessary. Electric light sources shall have a colour rendering index of 80 or above, and shall avoid unnecessary ultraviolet or infrared radiation by the use of appropriate lamps, lens, or filters. No direct ambient lighting shall be permitted in the infant care space (as described in standard 3); this does not exclude direct procedure lighting, as described in standard 15. Any direct ambient lighting used outside the infants care area shall be located or framed so as to avoid any infant’s direct line of sight to the fixture. Lighting fixture shall be easily cleaned”.

**Pain and stress**

Preterm infants’ experience pain and discomfort caused by treatment and caregiving interventions during a long period of hospitalization. Although more immature in their responses they are more sensitive to pain than older infants (64, 65). Physiologic responses to painful stimuli include increased heart rate, increased blood pressure, raised intracranial pressure and decreased arterial oxygen saturation. Specific haemodynamic responses in the somatosensory cortical areas to tactile and painful stimuli from venipuncture and heel lance have recently been discovered (65, 66). Studies have reported that preterm infants in the NICU may be handled more than 200 times during a 24 hour period, and the earliest born infants can be exposed to a mean of over 10 painful procedures per day during the first days of life, and up to 700 invasive procedures during their hospital stay (67-70). Although not all interventions are painful many investigators have observed increased levels of stress hormones and physiological and behavioral responses during routine nursing procedures (70-74). Grunau et al found a positive correlation between exposure to pain in the neonatal period and higher baseline levels of stress hormone cortisol at eight months corrected age (75).

Experiences of repeated and long term exposure to pain have been proven to not only give acute physiologic responses, but also affect the structure and function of the brain (76). Als concluded that experiences before term may alter brain development significantly (31).

Management and evaluation of pain and stress during the neonatal period are important components in the care of preterm infants (77, 78). Pain is also a major concern of
parents (79). The PIPP (Premature Infant Pain Profile) is a validated and internationally acknowledged method for measuring procedural pain in preterm infants (80). This tool is combining physiological and behavioural cues and assesses the pain response 30 seconds following a painful procedure. A recent study showed that 25 behavioural signs according to NIDCAP were associated with acute pain in preterm infants (81). A conclusion from this study is that the NIDCAP tool does not only assess distress, but also pain.

**Olfaction**

The nasal chemoreceptive systems differentiate early during embryonic and foetal life. The amniotic fluid is in contact with the sensory cells in the upper part of the nasal cavity and on the nasal septum from the 22nd week of gestation (82). A growing body of evidence indicates that early infant behaviour is influenced by olfactory cues, many originating from the intrauterine environment (83-86). Newborns appear to be more attractive to amniotic fluid odour than to other odours, and to orient more to the odour of their own amniotic fluid. Amniotic fluid and maternal odours influence behaviour of the newborn infant including state modulation and emotional behaviour, and also seem to have soothing effects in newborn infants (82, 87). Sullivan and Toubas reported that newborn infants stopped crying when presented with maternal odours from a hospital gown, worn either by their own mother or another infant’s mother (88). Mouthing also increased when awake infants were presented with their own mother’s odour. Goubet et al also showed that preterm infants exposed to a familiar odour during venipuncture showed less pain responses (89). Infants also seem to prefer tastes that they were exposed to during foetal life through their pregnant mother’s diet (90-92).

**Kangaroo Mother Care and skin-to-skin contact**

Kangaroo Mother Care (KMC) was developed in Bogotá, Colombia as a way to care for preterm infants and as a result of lack of hospital resources and incubators (93, 94). The mother’s body and the skin-to-skin contact replaced the incubator and helped the infant maintain body temperature, and lowered the incidence of infections. The KMC also encouraged breastfeeding and promoted early attachment between mother and infant. A recent Cochrane review evaluates KMC for low birth weight infants, supporting the findings that KMC reduces infants’ morbidity without serious side effects (95). Furthermore, the mothers’ sense of competence was higher although their perception of social support according to infant stay in NICU was lower. There were no differences in infant mortality or psychomotor development at 12 months’ corrected age.

Skin-to-skin care (SSC) is often practiced in NICU’s in industrial countries and denotes a method when the infant is temporarily held skin-to-skin on a parent’s chest, as compared to KMC which includes 24 hour skin-to-skin contact. The SSC is commonly used as soon as the preterm infant is judged to be stable enough to be lifted out of the incubator and is associated with longer duration of breast-feeding and less crying (96). Mörelius et al assessed effects on both mothers and preterm infants during their first and fourth SSC session (97). The mothers’ heart rate, salivary cortisol and feelings of stress (as measured on a visual analog scale, VAS) decreased after the SSC session.
Maternal stress was more expressed before the first SSC. The duration of the SSC sessions was at least one hour. During the SSC, the infants’ heart rates and pain scores decreased, while their salivary cortisol levels both increased and decreased. From their results, Mörerus et al concluded that the “variable stress responses in preterm infants favor the need for individualized care” (97). Miles et al found in a randomised controlled study that 20 minutes of SSC once daily for four weeks resulted in neither benefits nor adverse consequences (98). On the other hand, Ludington-Hue et al demonstrated that preterm infants subjected to 2-3 hour SSC had fewer arousals and more mature sleep organization than a control group (99). When summarizing 25 years of experiences with KMC Charpak et al concluded that provision of 24-hour KMC, beginning soon after birth and with appropriate technological support, has not yet been “adequately tested, despite numerous reports during the past decade with respect to more mature preterm infants” (100).

PARENTING THE PREMATURE BABY

During the course of a full-term pregnancy, the pregnant woman becomes increasingly psychologically prepared to become a mother and to bond with her newly born infant. Stern et al describe three stages of the pregnancy, “the physical fetus is growing in your womb”, “the motherhood mindset developing in your psyche”, and “the imagined baby taking shape in your mind” (101). The father-to-be is also experiencing parallel psychological and emotional preparation. Rafael-Leff distinguish the pregnancy in three trimesters, where “the focus shifts from pregnancy, to fetus, to baby” (102). After a preterm birth “the baby needs the biorhythm and pulsations of the mother as well as her milk and the mother need the baby to complete her pregnancy” (102). The mother of a preterm infant will lose the last part of pregnancy, including the final psychological and emotional preparation of becoming a mother. The real baby arrives when she is still highly involved with the baby of her dreams and wishes. The importance of technical equipment and medical staff for the survival of her infant, may be associated with feelings of incompetence and the feeling that she is less special for her baby, which may prevent her from bonding (101).

Infant-parent attachment may become disturbed by several factors when an infant is born preterm. Incubators and medical care, necessary for the infant’s survival, is accompanied by physical separation between the preterm infant and his or her parents. The immature preterm infant is not able to interact with the parent in the same way as the healthy term infant, which includes sustained eye contact and auditory orientation to the parent’s voice (103). Furthermore, during the intensive care period the infant’s energy may become devoted to reacting to painful and other environmental stimuli, resulting in even less energy for parental interaction. The neonatal staff may also convey an impression to the parents that they understand the infant better than the parents. Under such circumstances the parents must begin to get acquainted with, and bond to their child. Several investigations have revealed that mothers’ experience of premature birth, and the NICU environment as very traumatic and stressful. These mothers often express feelings of anxiety, and fear that their infants will not survive or survive with disabilities, as well as guilt, anger and helplessness (104-107). Such feelings may also influence negatively on the process of bonding, and may be further enhanced by the preterm infant’s weaker signals and lower alertness and responsiveness.
It has been shown that the severity of the infant’s illness may influence the care-taking style of the parents. Mothers of seriously ill VLBW infants interact with their infants to a lesser extent than do mothers of healthy VLBW infants and continue to do so even after the infants’ recovery (108, 111).

Becoming a parent to a VLBW infant involves several stages, starting in an unfamiliar and intimidating environment in the NICU and continuing at home after discharge. Several studies using qualitative research methods have described mothers’ and fathers’ experiences of becoming a parent to a preterm infant. McHaffie identified six maternal emotional states, three while the mother was in the hospital (anticipatory grief, anxious waiting and positive anticipation) and three following discharge to home (anxious adjustment, exhausted accommodation and confident caring) (112). Heermann et al analyzed, how mothers developed from being an outsider to becoming an engaged mother. The transition occurred in four continual steps: from having the focus on technology and expertise of the nurses to focus her attention to her baby; from “the baby belongs to the nurses” to “claim the baby as her own”; from passive to active caregiver role; from silent observer role to advocacy (113). Jackson et al interviewed both mothers’ and fathers, they explained their experiences of having a premature infant as a synthesis of alienation, responsibility, confidence and familiarity (107). Both the mothers and fathers described concern for their child. A difference between the parents was that the mothers expressed a need for participation and control of care, while the fathers expressed more confidence in delegating the care to the neonatal staff. Somewhat contradictory results were found by Lundqvist and Jakobsson, where fathers’ expressed feelings of being outsiders and wanting to be active participants in the care of their infants (114). Lundqvist et al described fathers’ experiences as a process of feelings of distance towards feelings of proximity (115). A possible explanation of the different results could be that the latter investigators interviewed fathers separately, which may make them express their feelings without being loyal to their partner. Jackson et al concluded that parents’ identity in preterm birth was a process of integrating the unexpected start of parenthood into the parents’ sense of identity and their way of being (116). Important for this process, was support and acknowledgement as a parent from the health care staff as well as interaction with their infant.

**CARE STRATEGIES IN THE NICU**

**Conventional care**

Although performed with the infants’ best interest and security in mind, traditional caregiving in neonatal units can be described as based on routines and centred on timing and types of activities that are being performed. Feeding and caregiving interventions are performed according to set schedules. However, few clinical caregiving strategies have been formally investigated in randomised controlled trials (117). The preterm infant has often been cared for on flat surface in the incubator or in an open crib, in a hectic environment with high sound levels and strong direct light. The traditional neonatal care is organised from the staffs’ perspective and although parents
have participated in the caregiving, nurses have functioned as the infants primary caregivers.

Aspects of family-centred care and KMC have been introduced widely in NICU’s during the 1980’s and 1990’s, but KMC has often been practiced a routine once or twice a day for short periods of time (93, 94,118, 119). In Sweden the interest of developmental care according to NIDCAP increased during the 1990’s, in a many centers. Principles of developmental care were implemented such as dimmed lighting, reduced sound- and activity levels, incubator covers and standard bed support, without the individualized part of the program.

**Family-centred developmental care according to NIDCAP**

A primary challenge for health care professionals is not only to ensure infant survival, but to support and promote healthy development of the infant as well to support parent-infant relationship. Family-centred developmental care aims at optimizing conditions in the NICU for the immature infant by providing appropriate and individually supportive care and by adapting the physical and social environment for the infant and its family.

![Picture 1. Livia and her mother. Photo Ann-Cathrine Berg.](image)

*The synactive model*

In the 1970’s Brazelton developed the Neonatal Behavioral Assessment Scale (NBAS) for neurological and behavioural assessments of the full term newborn infant (42). An essential part of NBAS is to promote and show the infant’s best performance and behavioural competence. Als et al extended and refined the NBAS to be adjusted to the sensitive preterm infant and named it: “Assessment of Preterm Infants’ Behavior” (APIB) ((103, 120). In the synactive theory of development, a framework for structured assessment of preterm infant’s behavioural cues, Als describes the infant as an “organism” displaying subsystems in continuous interaction with the environment (121) (Figure 2).
The different subsystems in the synactive theory include:

- the autonomic system, which can be observed in the infant’s breathing pattern, skin colour fluctuations, temperature control, and visceral function;
- the motor system which can be observed from the infant’s muscle tone and movements of the face, trunk and extremities, respectively, and in extensor and flexor posture;
- the system for state regulation can be observed in an infant’s range of available states, their robustness and modulation, and in the pattern of transition from sleep to quiet awake, to active awake and aroused, and to upset and crying;
- the system for attention and interaction can be observed when the infant is able to reach a calm alert state;
- and the self-regulatory system observed in the context of the infant’s efforts at attaining stability through approach or avoidance behaviours.
All subsystems are described as interactive, with the functional state of one system profoundly influencing the others. Thus, stability in one of these subsystems affects the functions of other subsystems in a positive manner. For example, helping an infant to reduce his or her disorganised movements’ will result in stabilised autonomic function with improved breathing and oxygenation. This in turn promotes infant’s ability to reach an alert wakefulness and interact socially with the parent or caregiver. Another example, when a sleeping preterm baby is disturbed by sound or light, the sudden arousal may result in increased motor activity, which in turn affects the autonomic subsystem, leading to irregular breathing and a drop in oxygen saturation. If the infant does not successfully reorganise his or her motor system, the energy expenditure in these actions may lead to a loss in muscular tone and return to sleep by exhaustion. If a care-giver supports and calms the infant’s motor arousal, further disorganization will be prevented, which will help the infant to conserve energy.

**NIDCAP, a systematic observation tool and care program**

The synactive model provides the theoretical framework for the family-centred, developmental care in the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) (122, 123). The NIDCAP model focuses on the individuality and deep humane respect for the very tiny human being and its family. The major tool employed is repeated, formalized naturalistic observations of the infant, conducted weekly or biweekly, or as clinically indicated. A trained observer stands close to the infant, assesses and records at two-minute intervals, the infant’s current ability to organize and modulate the five interactive subsystems, in addition to recording respiration rate, heart rate, and oxygen level. The infant’s responses to environmental stimuli, and from caregiving is observed continuously for at least 10 minutes before caregiving interaction, during the whole session and at least 10 minutes after, e.g. nappy change and feeding, physical examinations, or blood sample collection etc. A descriptive narrative based on the observed behavioural communication between the infant and the caregiver, as well as on the infant’s reactions to environmental stimuli, is written after the observation. Detailed focus on the infant’s efforts of self-regulation, and responses, as well as the caregiver’s efforts to aid the infant is documented. Individual recommendations are then made, based on the information from the observations, on how to optimise the environment and care, derived from infant’s goals, including medical and family history and current medical status. The following aspects are considered: a quite and soothing environment; consistency of caregiving in form of a primary care team; structuring of the infant’s 24 hour day in order to assure the infant rest and to support growth; pacing of caregiving (the caregiver approach the infant and family in a calm manner); support during transitions between caregiving activities and when the infant awakens or makes efforts to sleep; appropriate positioning in form of support into a softly flexed and comfortable positioning during sleep, bathing and necessary procedures; individualized support during feeding; coregulation of the infant’s comfort and wellbeing during care and special examinations; opportunities for skin-to skin care and support of early family involvement in the care. A specially trained developmental care professional educates, and supports the neonatal staff, and serves as a resource in the implementation of developmental care.

According to NIDCAP, the infant is considered to be an active communicator and participant in its own development (103, 124). The caregiver has to watch closely for the infant’s own efforts and to offer just enough assistance to support the infant’s own developing capacities and next developmental step. Caregiving is not just the activity,
but the entire sequence of care before, during and after each intervention. When the caregiver observes, interprets and reflects during a caregiving interaction, it will be possible to respond to the individual infant’s expectations concerning environment and care. This way of caring will enhance the infant’s wellbeing, competence and development. The parents are guided and encouraged to learn how to interpret their infant’s signs and to participate in the care as early as possible.

The NIDCAP model was designed to create a relationship-based developmentally supportive care environment for the preterm infant and its family (125). It highlights the change from protocol-based to relationship-based support with the goal to ensure the family as the primary caregiver of the infant, decrease stressful environmental events, support the wellbeing of the preterm infant and to support early contact between the infant and his or her parents. This in turn will support early childhood development (31, 126-131). Early intervention, in the form of a sensitive, individualized care in a physically and socially adapted neonatal environment has been reported to be the most effective for the high risk group of preterm infants and may also contribute to optimising brain development in these high-risk infants (31, 132).

See appendix A for the observation sheet.
AIMS OF THE PRESENT STUDIES

The overall aim of the thesis was to investigate effects of family-centred individualized developmental supportive care according to NIDCAP versus conventional care on short- and long term outcomes of the preterm infant, on mother-child interaction, as well as to examine mothers’ experiences of the different care regimes. In addition, the thesis also aimed to test if a structured intervention based on the NIDCAP model reduces pain and distress during eye examination for retinopathy of prematurity. The aims of the investigations were:

I. To determine whether VLBW infants subjected to NIDCAP intervention demonstrate better motor and mental development, fewer behavioral problems and improved mother-child interaction at 3 years of age, compared to VLBW infants who have received conventional care.

II. To examine the effects of NIDCAP on the requirements for assisted ventilation, growth, and the period of hospitalization.

III. To investigate whether care according to NIDCAP, as compared to conventional care, affects how mothers of preterm infants experience their feelings of closeness to their infant, their role as a mother, and how they perceive the neonatal staff and the neonatal care.

IV. To compare the development, at one year corrected age, of two groups of infants born very prematurely who were involved during their neonatal period in a randomised controlled NIDCAP trial.

V. To compare “best standard care” and NIDCAP intervention on physiological, behavioral, pain and distress response during eye examination for retinopathy in preterm infants.
RESULTS

PAPER I

Aim
The aim of study I was to evaluate long-term effects of NIDCAP in a population of very preterm infants.

Design and subjects
Study I had a phase lag design, and was performed at the NICU at Falun county hospital in Sweden. The NIDCAP care model was clinically implemented during a one-year period in 1991. We studied two groups of consecutively born children who had been treated in the unit just before and after the implementation of NIDCAP. Inclusion criteria were inborn, singleton, BW <1500 gram, without malformations and with Swedish speaking parents. The control group, receiving conventional neonatal care, consisted of infants born during the time-period from January the 1 to December 31, 1990 (n=21). The NIDCAP intervention group comprised of 21 infants born between March 16, 1992 to April 30, 1993. In the NIDCAP group behavioural observations and care plans started within the first 72 postnatal hours, and were repeated every 10th day, until the infants’ reached a PMA of 36 weeks. Although the two groups were comparable regarding gestational age, birth weight and gender (Table 1), there were some significant differences between the two groups. Antenatal steroids were not given to any of the mothers in the comparison group, while it was administered to 7 of 21 mothers in the NIDCAP-group. Surfactant was provided to none of the infants in the comparison group but was given to 11 of 21 children in the intervention group. Short term outcome from the phase-lag NIDCAP study have been published by Westrup et al (133).

Table1. Characteristics of the two study groups (133).

<table>
<thead>
<tr>
<th></th>
<th>Control group n=21</th>
<th>NIDCAP group n=21</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother’s age at time of birth (y)</td>
<td>29 (22-45)</td>
<td>31 (22-38)</td>
</tr>
<tr>
<td>Maternal education level</td>
<td>4 (2-7)</td>
<td>4 (2-7)</td>
</tr>
<tr>
<td>Single mother</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Primipara</td>
<td>12</td>
<td>11</td>
</tr>
<tr>
<td>Gestational age (wk)</td>
<td>28.6 (23.4-31.4)</td>
<td>28.6 (23.9-33.3)</td>
</tr>
<tr>
<td>Birth weight (g)</td>
<td>1117 (660-1483)</td>
<td>1060 (700-1500)</td>
</tr>
<tr>
<td>Gender (male/female)</td>
<td>13/8</td>
<td>14/7</td>
</tr>
<tr>
<td>Severity of illness (CRIB)</td>
<td>4 (0-17)</td>
<td>2 (0-17)</td>
</tr>
</tbody>
</table>

The figures are median (ranges), there were no significant differences between the two groups. a according to Hollingshead: 2 = 9th grade, 3 = 10-11th grade, 4 = 12th grade, 5 = at least one year of college without degree, 6 = college degree, 7 = graduate studies (134); b Clinical Risk Index for Babies (135).

Methods
All surviving children, 18 of 21 in the control group and 15 of 21 in the NIDCAP group, were followed up at a mean (SD) corrected age of 36.4 (0.4) months, and 36.2 (0.6) months, respectively. All assessments were performed by the same follow-up
team, and in the presence of at least one parent. The study was approved by the hospital administration and informed consent was obtained from all families.

**Neurological assessment** was performed according to Amiel-Tison and Stewart (136) and employed the classification of impairment and disability suggested by the World Health Organisation (137). **Development** was assessed according to the Griffiths’ Developmental Scales II (138) translated into Swedish and standardised for Swedish conditions (111). The Griffiths’ test consists of six subscales, combined in order to obtain a total score, the Developmental Quotient (DQ). **Behaviour** was assessed on the basis of the Högk-Cederblad Child Behaviour Interview (139). The parents were asked questions concerning the child’s behaviour during the previous two months. This interview encompasses 43 different types of behaviour and the interviewer rates the parents’ responses in relation to operationally defined degrees of age-related normality or deviations. The results thus obtained are expressed as total problem scores and as scores for internalising and externalising factors. **Mother-child interaction** was assessed according to Parent-Child Early Relational Assessment (ERA) (140). Mother and child were videotaped during structured and free play, each segment lasting for 5 minutes. A psychologist certified in this method scored the videos “blind”, i.e. without knowing to which group the child belonged. The ERA includes 65 items grouped into 12 clusters, measuring parental-, child- and dyadic variables.

The continuous variables and clusters of categorical scores were compared statistically using the Mann-Whitney U-test. The chi-square, with exact P values and Fisher’s exact test were applied to the categorical values. The level of statistical significance was set at a p-value of \( \leq 0.05 \).

**Results**

One child in each group was classified as disabled, and data from these two children were excluded from subsequent analyses. Short-term outcome from the neonatal surviving infants are presented in Table 2.

<table>
<thead>
<tr>
<th></th>
<th>Control group n=18</th>
<th>NIDCAP group n=15</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mechanical ventilation (days)</td>
<td>3.3 (0-39)</td>
<td>0.5 (0-25)</td>
<td>Ns</td>
</tr>
<tr>
<td>CPAP (days)</td>
<td>5.3 (0-48)</td>
<td>5 (0-35)</td>
<td>Ns</td>
</tr>
<tr>
<td>Days of oxygen administration</td>
<td>4.9 (0-84)</td>
<td>1.3 (0-70)</td>
<td>Ns</td>
</tr>
<tr>
<td>IVH grade III-IV</td>
<td>1</td>
<td>3</td>
<td>Ns</td>
</tr>
<tr>
<td>BPD*</td>
<td>0</td>
<td>0</td>
<td>ns(^\text{e})</td>
</tr>
<tr>
<td>ROP ( \geq \text{stage 3} )</td>
<td>0</td>
<td>0</td>
<td>ns(^\text{e})</td>
</tr>
<tr>
<td>Weight gain(^\text{f}) (g/day)</td>
<td>20.2 (2.9)</td>
<td>21.4 (3.3)</td>
<td>Ns</td>
</tr>
<tr>
<td>PMA at discharge(^\text{e}) (wks)</td>
<td>39.7 (3.0)</td>
<td>38.7 (1.2)</td>
<td>Ns</td>
</tr>
<tr>
<td>Breast feeding at discharge</td>
<td>7/18</td>
<td>9/15</td>
<td>Ns</td>
</tr>
</tbody>
</table>

The figures are median (range); Mann-Whitney U test if not otherwise indicated. \(^\text{e}\)Fisher’s exact test; \(^*\)chest x-ray findings at 36 wks (PMA) (141); \(^\pm\)according to the international committee for the classification of ROP (142); \(^\text{f}\)mean (SD)
The median (range) developmental quotient was 108 (93-120) in the control group and 109 (94-122) in the intervention group (ns). The children in the intervention group performed significantly better on the subscale “hearing speech”; median (range) 119 (72-157) versus 108 (84-130) for the children in the control group (p=0.02).

On the Child Behaviour Symptom interview, the parents in the control group gave their children significantly higher problem scores than the parents of the children in the intervention group (p=0.03). Investigating the sub-scales, infants in the control group displayed more internalising symptoms than the children in the intervention group (p=0.02). No such difference was found for the groups according to the externalising sub-scales.

The results of the assessment of mother-child interaction, showed a significant difference in communication (visual contact, communicative competence and readability) in favour of the intervention group (p=0.03). In addition, and also favouring the intervention group, several items showed significant differences between the two groups including “parental quality and amount of physical contact” (p=0.03), “parental amount of visual contact with child” (p=0.05), and “child’s motoric competence and quality” (p=0.02).

**Comments**

This follow-up of two comparable cohorts of VLBWchildren, in the very beginning of implementing an individualized developmental supportive model, showed some interesting differences between the groups. However, since a historical control group was chosen the differences must also be interpreted with caution. At three years corrected age, the children in the intervention group exhibited better ability to communicate, displayed in form of better language skills and communication skills. In addition, they demonstrated fewer behavioural problems in form of less internalising problems, i.e. were more open and expressed their feelings more readily. The mothers of the children in the intervention group expressed more physical and visual contact to their children than did the mothers of the children in the comparison group.
PAPER II

Aim
The aim of the study was to evaluate effects of NIDCAP on the primary outcome variables assisted ventilation, growth, and hospitalisation.

Design and subjects
Randomized controlled trial performed at the level III NICU, Karolinska Hospital in Stockholm. During the period from September 1994 to April 1997, 41 preterm infants fulfilled the following criteria: inborn, singleton, GA <32 weeks, need for mechanical ventilation or CPAP at 24 hours of age, absence of major malformation, family residence in the hospital’s geographical catchment area, and Swedish speaking parents. Randomization and dropouts are presented in figure 3, and characteristics of the final study groups included at 24 hours are presented in table 3.

The infants assigned to the NIDCAP-intervention were transferred from the delivery room directly to a separate room at the NICU and cared for by specially trained nurses. Behavioural observations and care plans were performed within 3 days of life, and repeated weekly, until the infants’ reached 36 weeks’ PMA. The infants assigned to the control group were cared for in rooms where conventional neonatal care was practised.

Informed consent was obtained from all families. The study was approved by the Research Ethics Committee at the Karolinska University Hospital.

Figure 3. Subjects randomized to NIDCAP care and conventional care as well as dropouts.
Table 3. Characteristics of the final study groups included at 24 hours

<table>
<thead>
<tr>
<th></th>
<th>NIDCAP group n=12</th>
<th>Control group n=13</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother’s age at time of birth (y)</td>
<td>30.2 (24.2-36.3)</td>
<td>32.5 (18.3-39.4)</td>
</tr>
<tr>
<td>Maternal education level a &lt;12/12/13-14/≥15 (y)</td>
<td>0/6/1/5</td>
<td>3/6/2/2</td>
</tr>
<tr>
<td>Paternal education level a &lt;12/12/13-14/≥15 (y)</td>
<td>2/7/0/3</td>
<td>1/8/2/1</td>
</tr>
<tr>
<td>Single mother</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Primipara</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Prenatal steroids (none/&lt;24h/&gt;24h)</td>
<td>3/3/6</td>
<td>5/1/7</td>
</tr>
<tr>
<td>Gestational age (wk)</td>
<td>27.6 (24.0-28.7)</td>
<td>26.1 (23.9-30.3)</td>
</tr>
<tr>
<td>Birth weight (g)</td>
<td>1083 (630-1411)</td>
<td>840 (636-1939)</td>
</tr>
<tr>
<td>Head circumference (cm)</td>
<td>24.0 (22.3-26.5)</td>
<td>24.0 (21.1-30.0)</td>
</tr>
<tr>
<td>Gender (male/female)</td>
<td>9/3</td>
<td>8/5</td>
</tr>
<tr>
<td>Severity of illness (CRIB) b</td>
<td>4.0 (0-11)</td>
<td>6.0 (2-15)</td>
</tr>
</tbody>
</table>

a 12 years indicates high school degree; 15 years, college degree; b According to the International Neonatal Network (136). The figures are numbers, median (ranges). There were no significant differences between the two groups.

Methods

NIDCAP intervention
The infants in the intervention group were cared for according to NIDCAP (described in the Introduction section). Behavioural observations and individual care plans started within 72 hours of life, and were repeated thereafter every 7th day, until infants’ reached a PMA of 36 weeks.

Clinical outcome
The infant’s severity of illness was analyzed using the “Clinical Risk Index for Babies” (CRIB) (135). Need for respiratory support, i.e. days with mechanical ventilation, CPAP and supplementary oxygen, was recorded. Cranial ultrasound examination was performed and recorded according to Papile et al (143). Eye examinations were performed following the guidelines of the International Committee for the Classification of Retinopathy of Prematurity (144). Bronchopulmonary dysplasia (BPD) was diagnosed by chest radiograph according to a modified version of the recommendations of Toce et al. (141). Growth parameters were set at 35 weeks PMA to include infants discharged early from the hospital. Frequency of breast-feeding and lengths of hospital stay were recorded from the chart.
The continuous variables were compared statistically using the Mann-Whitney U-test. For categorical variables chi-square, with exact p values and Fisher’s exact test were used. The level of statistical significance was set at a p-value of ≤0.05.

Results

The infants in the NIDCAP group had significant fewer days with CPAP and supplementary oxygen, (Table 4). At 36 weeks PMA, six infants in the intervention group had mild radiographical signs of BPD but none required extra oxygen. In the control group, two infants suffered from mild, four from moderate and two from severe BPD, and all eight infants’ required additional oxygen. There were no significant differences between the two groups in severity of IVH, incidence of severe ROP, postnatal growth or PMA at discharge.

Table 4. Short-term outcomes for the two study groups.

<table>
<thead>
<tr>
<th></th>
<th>NIDCAP group</th>
<th>Control group</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>All subjects</td>
<td>n=12</td>
<td>n=13</td>
<td></td>
</tr>
<tr>
<td>IVH grade 0/I/II/III/IV</td>
<td>9/2/0/1/0</td>
<td>8/0/2/3/0</td>
<td>ns a</td>
</tr>
<tr>
<td>Neonatal survivors</td>
<td>n=11</td>
<td>n=10</td>
<td></td>
</tr>
<tr>
<td>Mechanical ventilation (d)</td>
<td>2.8 (0-36.7)</td>
<td>4.8 (0.1-29.8)</td>
<td>Ns</td>
</tr>
<tr>
<td>CPAP (d)</td>
<td>26.1 (6.9-52.0)</td>
<td>43.9 (5.0-65.1)</td>
<td>0.045</td>
</tr>
<tr>
<td>PMA at additional oxygen</td>
<td>33.0 (29.3-35.7)</td>
<td>38.1 (33.1-44.9)</td>
<td>0.007</td>
</tr>
<tr>
<td>withdrawal (wks)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BPD none-mild/moderate-severe</td>
<td>11/0</td>
<td>4/6</td>
<td>0.024</td>
</tr>
<tr>
<td>ROP ≥ stage 3 d</td>
<td>4/11</td>
<td>8/11 c</td>
<td>ns a</td>
</tr>
<tr>
<td>Daily weight gain up to 35</td>
<td>13.0 (6.7-21.0)</td>
<td>9.8 (6.8-16.6)</td>
<td>Ns</td>
</tr>
<tr>
<td>weeks of PMA (g)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weekly increase in head</td>
<td>0.73 (0.56-1.3)</td>
<td>0.63 (0.56-0.77)</td>
<td>Ns</td>
</tr>
<tr>
<td>circumference up to 35 wks</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PMA at discharge (wks)</td>
<td>38.3 (36.1-57-7)</td>
<td>41.0 (36.9-48.4)</td>
<td>Ns</td>
</tr>
</tbody>
</table>

Median (range); Mann-Whitney U test if not otherwise indicated; a Fisher’s exact test; b according to Papile (143); c chest x-ray findings at 36 weeks (PMA); d according to the International Committee of for the Classification of ROP (142); e including one infant who died at 37 weeks PMA
Comments
This RCT showed that NIDCAP-care is associated with a significantly shorter need for respiratory support (days with CPAP and additional oxygen), none of the 11 infants in the NIDCAP group required supplementary oxygen at 36 weeks (PMA) as compared to 8 of the 11 infants in the control group. Our interpretation of this is that NIDCAP skilled nurses become aware of the cues provided by the infants and could give support for the infants self-regulation, including the autonomic subsystem associated with respiratory regulation of the infant, as well as observe when the infant was capable of breath without mechanical support.

Many studies have reported association between BPD and neurodevelopment. BPD is a multifactorial disease where IRDS, perinatal inflammation, oxygen toxicity, and barotrauma from mechanical ventilation increase the risk (145). Many NIDCAP studies have reported effects in form of fewer days with mechanical ventilation and supplemented oxygen, thus, with lower incidence of infants displaying severe BDP (126-128, 131). A possible explanation for this effect could be that the NIDCAP trained caregivers observe the infants autonomic and behavioural cues continuously and closely and are more confident in terminating mechanical breathing support. In addition they have strategies, in form of supporting infant’s autonomic and motor regulation that prevents the infant from distress and requirements of supplemented oxygen.

To perform a RCT which includes an intervention that continuously lasts for weeks and months in the same NICU is a difficult achievement. During certain periods it was difficult to keep the different care teams separate. The nurses caring for the control group increasingly expressed feelings of discomfort for not being able to offer developmentally supportive care to their patients.
PAPER III

Aim
The aim of this study was to compare mothers’ feelings and experiences from two different care regimes, conventional neonatal care and NIDCAP.

Design and subjects
A questionnaire with an attitude scale was constructed for evaluating and comparing mothers’ attitudes towards different styles of neonatal care. The aim was to capture the mothers’ feelings of closeness to their infant, their role as a mother, and how they perceived the neonatal staff and the neonatal care.

Initially, 60 statements were created on the basis of interviews with neonatal nurses experienced in both conventional care and NIDCAP and review of previous studies evaluating parental stress and responses in the NICU. After validation of face validity and internal consistency, the 60 statements were reduced to a questionnaire containing 32 items. The 32 items were grouped into 9 subscales aimed at exploring different aspects of the mother’s perception of: the feeling of closeness between her and her infant; her own ability to interpret her infant’s physical signs and needs; her role as a mother; her reaction to the infant; her anxiety; the ability of the staff to interpret her infant’s signs and needs; the ability of the staff to support her in her role as a mother; the staff’s attitudes towards her; and the care her infant received.

The 32 items were either direct questions or statements that could be answered in four different ways: “Agree completely”; “Agree somewhat”; “Disagree somewhat”; “Do not agree at all”.

The subjects in this study were the mothers’ of surviving infants included in the NIDCAP-RCT that was performed at the NICU at Karolinska Hospital in Stockholm (Paper II). All mothers (except one from the NIDCAP intervention group) answered the questionnaire when the infants had reached 36 weeks PMA and still were in hospital. Informed consent was obtained from all families in the delivery room. The study was approved by the Research Ethics Committee at the Karolinska University Hospital.

Subscales were compared statistically using Mann-Whitney U test. Fisher’s exact test was applied for categorical variables. The level of statistical significance was set at a p-value of ≤0.05.

Results
The mothers in the two groups were comparable regarding age and education. The mothers in the NIDCAP-group rated “the feeling of closeness between her and her infant” significantly higher than mothers of infants treated with conventional care (p=0.022) (Table 5). Of the statements included in this subscale, there was a significant difference in the mothers’ attitudes towards the importance of eye contact, between the intervention group and the conventional care group (p=0.05). For the mothers of infants in the NIDCAP group no significant association between the mothers’ feeling of “closeness to her infant” and the infant’s gestational age, birth weight or severity of illness was found. In contrast, for the group receiving conventional care, the feeling of “closeness” was significantly, and negatively, correlated to the infant’s birth weight (p=0.036), and positively correlated with the infant’s severity of illness (p=0.02), but there was no significant correlation with gestational age detected.
The mothers in the NIDCAP group scored significantly higher on the subgroup “anxiety” (p=0.033), which contained statements about technical equipment and worries about survival and risks for later sequelae.

The mothers in the NIDCAP group tended to rate the ability of the staff to “support her in her role as a mother” more highly than the mothers in the conventional-care group (p=0.066). One of the statements in this subscale, “support in taking over the care of her own child” differed significantly (p= 0.003). Although not significant five mothers in the conventional care group as compared to only one in the NIDCAP group did not agree with the statement “I have received help from the staff to withdraw and spend time alone with my baby”. Four mothers from each group scored that they “agreed relatively well”, while four mothers from the NIDCAP-group and one from the conventional-care group “agreed completely”.
Table 5. Statistical comparison of the NIDCAP and conventional groups with respect to the different subscales and individual items concerning the mothers’ attitudes.

<table>
<thead>
<tr>
<th>The mothers perception of:</th>
<th>NIDCAP n=10</th>
<th>Conventional care n=10</th>
<th>z-value</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>The feeling of closeness between her and her infant</td>
<td>4 (3-4)</td>
<td>3.5 (2-4)</td>
<td>2.265</td>
<td>0.022</td>
</tr>
<tr>
<td>Her own ability to interpret her infant’s signals and needs</td>
<td>3.6 (2.5-3.8)</td>
<td>3.3 (1.5-3.8)</td>
<td>1.106</td>
<td>0.285</td>
</tr>
<tr>
<td>Her role as a mother</td>
<td>3.5 (2.7-4.0)</td>
<td>3.3 (1.7-4.0)</td>
<td>0.768</td>
<td>0.464</td>
</tr>
<tr>
<td>Her reaction to the infant:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling of being rejected by her infant;</td>
<td>4 (2-4)</td>
<td>4 (1-4)</td>
<td>1.07(3)‡</td>
<td>0.785£</td>
</tr>
<tr>
<td>Her infant’s state of Contentment</td>
<td>3 (2-4)</td>
<td>3 (3-4)</td>
<td>1.48(2)‡</td>
<td>0.650£</td>
</tr>
<tr>
<td>Her anxiety</td>
<td>3.2 (2.0-3.7)</td>
<td>2.5 (1.3-3.3)</td>
<td>2.133</td>
<td>0.033</td>
</tr>
<tr>
<td>The ability of the staff to interpret her infant’s signals and needs</td>
<td>3 (2-4)</td>
<td>3 (2-4)</td>
<td>0.44(2)‡</td>
<td>1.0£</td>
</tr>
<tr>
<td>The ability of the staff to support her in her role as a mother</td>
<td>3.5 (2.9-3.9)</td>
<td>3.2 (2.3-3.7)</td>
<td>1.872</td>
<td>0.066</td>
</tr>
<tr>
<td>The staffs’ attitudes towards her, positive or negative</td>
<td>1.3 (1.0-1.7)</td>
<td>1.3 (1.0-3.0)</td>
<td>1.201</td>
<td>0.251</td>
</tr>
<tr>
<td>The care her infant received</td>
<td>3.6 (2.9-4.0)</td>
<td>3.6 (3.1-4.0)</td>
<td>0.154</td>
<td>0.895</td>
</tr>
</tbody>
</table>

All values presented are medians (ranges). Unless otherwise indicated, the Mann-Whitney U-test was employed for statistical analysis. £ Fisher’s exact test was utilized for statistical analysis of subscales containing only one or two items, ‡ Chi² (df)

**Nutrition during the period of hospitalisation and at the time of discharge (unpublished data)**

Mother’s own milk was provided from birth to 36 weeks PMA to eight of 10 infants in the NIDCAP group and to seven of 10 infants in the control group. The other infants received human donor milk initially and later formula. The milk feedings to all infants.
were enriched with additional fat and proteins (Calogen® and Presemp®). At the time for discharge, six of the NIDCAP infants and two in the control group received their own mothers’ milk (were breast fed or received their mothers milk by bottle or gastric tube (ns).

Comments: The main findings in this study was that mothers to infants who were cared for according to NIDCAP scored higher on the subscale “feelings of closeness”, and on the individual item “eye contact” as compared to mothers in the control group. The NIDCAP model is seeing the parent as the primary caregiver which might have contributed to the result of higher scores of “closeness”. One aim of NIDCAP is to continuously support the infant’s autonomic and motor function, state stability, responsiveness and self-regulation which enhances infant’s capacity for calm wakefulness and, thus, increases the possibilities to have eye contact with its mother. An additional explanation that the mothers expressed more “eye contact” could be that the infants in the NIDCAP group required fewer days with CPAP and additional oxygen, thus, had fewer days with breathing devises or oxygen tubes fastened to the face.

The mothers in the intervention group also tended to rate the staffs’ ability to support her role as a mother more highly than did the mothers in the conventional care group. However, the mothers in the intervention group also expressed more anxiety. Although the infants in the NIDCAP group required less assisted respiratory assistance and exhibited better pulmonary function than did the infants in the conventional care group, their mothers were more frightened by all the equipments around their infants and were still afraid that their infant might be permanently injured as a result of its premature birth. The fact that the NIDCAP mothers felt closer to their infant could mean that they have progressed further in their emotional bonding and, consequently, felt more anxiety about something happening to their children and also experienced the medical equipment as being more threatening.
Paper IV

Aim
The aim of the study was to compare the neurodevelopment of two groups of infants born very prematurely and cared for with two different care regimes.

Design and subjects
The subjects in this study participated in the RCT evaluating care according to NIDCAP versus conventional neonatal care, as presented in paper II. The children were born and treated at the level III NICU at Karolinska Hospital between September 1994 and April 1997. Twenty five infants born at < 32 weeks of gestation, who fulfilled the definitive inclusion criteria at the age of 24 hour, were randomised to either receive care according to NIDCAP or conventional care. The background characteristics of the surviving infants are presented in paper II. At one year corrected age, all the neonatally surviving children in the NIDCAP intervention group were still alive, whereas one child in the control group died of Sudden Infants Death Syndrome at an age of 5 months corrected age. Thus, 11 children in the NIDCAP intervention group and 9 in the control group were eligible for the follow up.

Method
Neurodevelopment was assessed employing the Bayley Scales of Infant Development (BSID II) (146), which yield a Mental Development Index (MDI) and a Psychomotor Development Index (PDI) (both with a mean of 100 and a standard deviation of 15). Subnormal and abnormal development are defined as being present when the score is <85 (- 1S.D.) and <70 (-2S.D), respectively. In the current study we chose survival with MDI and PDI over 80 as an overall positive outcome. This level was chosen from a pragmatic point of view as the distribution of the results was expected to be skewed to the lower ranges. The assessor did not know to which of the two groups the child belonged.

MDI and PDI variables were compared for statistically significant differences using Mann-Whitney U-test and different subgroups compared using Fisher’s exact test. The level of statistical significance was set at a p-value of ≤0.05.

Results
The MDI was significantly higher for the children in the NIDCAP intervention group 88 (72-114) median (range) than for the children in the control group, 78 (50-82) (p=0.01). The PDI for the NIDCAP group was 85 (61-108) versus 69 (50-114) for the control group (ns). Abnormal MDI (<70) was observed in three of the nine children (33%) in the control group, but in none of the 11 (0%) children in the NIDCAP intervention group (p=0.07). Abnormal PDI (<70) was present in five of the nine (55%) children from the control group and three of the eleven (27%) children from the NIDCAP intervention group and (p=0.36).

There were no significant correlations between MDI and any of the background variables. When including gestational age, relative birth weight (birth weight/expected intrauterine weight) according to Marsal (147) and CRIB (severity of illness) in a logistic regression model, the odds ratio for survival with a MDI >80 was 18.6 (95% CI: 1.3-257.9) in favour for the NIDCAP intervention group. Birth weigh correlated
positively with PDI (correlation coefficient=0.47, p=0.04). The multiple regression analysis revealed a significant (p=0.02) negative impact on the PDI from the severity of BPD, although no such impact on the MDI was seen. There were no correlations between severity (grade) of IVH and MDI or PDI, respectively.

**Comments**
The median MDI and PDI, respectively, were well below 100 in both groups of preterm infants at one year corrected age, confirming that the included infants in the original NIDCAP-RCT consisted of a high-risk population for adverse future development. Nevertheless, this evaluation performed at one year corrected age showed that the children in the NIDCAP intervention group displayed better cognitive development (MDI) as compared to the children in the control group. However, there was no significant difference in motor development (PDI) between the two groups of children. The odds ratio for being alive with a MDI >80 was significantly associated with care according to NIDCAP, although due to the low number of infants the confidence intervals are large. However, the result is in agreement with other studies evaluating NIDCAP (31, 126).

We did not find any background variables that might explain the difference between the groups in MDI except for the NIDCAP intervention. In addition, the logistic regression with background variables did not eliminate the positive odds of being alive with MDI >80 in the NIDCAP group.
PAPER V

Aim
To investigate if a developmental care intervention based on NIDCAP during ROP-examination results in less behavioural, pain and stress responses during and after the examination, as compared to standard care.

Design and subjects
This randomized cross-over study was performed at two level-III NICU’s, St Mary’s Hospital (London, UK) and University Hospital (Lund, Sweden). The intervention started one hour before the eye examination, when the first eye drops were administered. Informed parental consent was obtained before each examination. The study was approved by the Research Ethics Committees at St Mary’s Hospital in London and University Hospital in Lund.

The groups at the two centers were comparable according to gestational age at birth. However, at the first examination London infants were slightly more mature. There were also differences in hemoglobin (Hb) levels, both between London and Lund, and between the two eye examinations (Table 6).

Table 6. Clinical data for included infants in London and Lund, respectively.

<table>
<thead>
<tr>
<th></th>
<th>London n=16</th>
<th>Lund n=20</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth weight, g</td>
<td>930 (650-1790)</td>
<td>823 (475-1500)</td>
<td>0.108</td>
</tr>
<tr>
<td>Gestational age, w</td>
<td>27.0 (23-31)</td>
<td>26.0 (23-30)</td>
<td>0.203</td>
</tr>
<tr>
<td>5-min Apgar score</td>
<td>8 (4-19)</td>
<td>8 (3-10)</td>
<td>0.813</td>
</tr>
<tr>
<td>Male, n (%)</td>
<td>13 (65)</td>
<td>10 (63)</td>
<td>0.877</td>
</tr>
<tr>
<td>Antenatal steroids, n (%)</td>
<td>12 (75)</td>
<td>19 (95)</td>
<td>0.167</td>
</tr>
<tr>
<td>Surfactant, n (%)</td>
<td>14 (88)</td>
<td>13 (65)</td>
<td>0.048</td>
</tr>
<tr>
<td>IVH grade &gt;2, n (%)</td>
<td>0</td>
<td>3 (15)</td>
<td>0.106</td>
</tr>
<tr>
<td>ROP 1-2, n (%)</td>
<td>3 (19)</td>
<td>4 (20)</td>
<td>0.147</td>
</tr>
<tr>
<td>ROP &gt;2, n (%)</td>
<td>2 (13)</td>
<td>3 (15)</td>
<td>0.829</td>
</tr>
</tbody>
</table>

Exam 1 n=16 Exam 2 n=18

<table>
<thead>
<tr>
<th></th>
<th>London</th>
<th>Lund</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental/standard</td>
<td>7/9</td>
<td>9/11</td>
<td>0.940</td>
</tr>
<tr>
<td>PMA, w</td>
<td>33 (30-36)</td>
<td>32 (31-33)</td>
<td>0.026</td>
</tr>
<tr>
<td>Mechanical ventilation, n</td>
<td>1</td>
<td>0</td>
<td>0.257</td>
</tr>
<tr>
<td>CPAP, n (%)</td>
<td>9 (56)</td>
<td>11 (55)</td>
<td>0.940</td>
</tr>
<tr>
<td>Supplementary oxygen, n</td>
<td>10 (63)</td>
<td>14 (70)</td>
<td>0.635</td>
</tr>
<tr>
<td>Caffeine/theophyll(am)ine, n</td>
<td>10 (63)</td>
<td>14 (70)</td>
<td>0.635</td>
</tr>
<tr>
<td>Hb, g/L</td>
<td>114 (81-122)</td>
<td>117 (101-148)</td>
<td>0.006</td>
</tr>
</tbody>
</table>

Exam 2 n=14 Exam 2 n=18

<table>
<thead>
<tr>
<th></th>
<th>London</th>
<th>Lund</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental/standard</td>
<td>8/6</td>
<td>11/7</td>
<td>0.821</td>
</tr>
<tr>
<td>PMA, w</td>
<td>34 (33-36)</td>
<td>34 (33-36)</td>
<td>0.809</td>
</tr>
<tr>
<td>CPAP, (%)</td>
<td>8 (57)</td>
<td>5 (28)</td>
<td>0.093</td>
</tr>
<tr>
<td>Supplementary oxygen, n</td>
<td>10</td>
<td>13</td>
<td>0.960</td>
</tr>
<tr>
<td>Caffeine/theophyll(am)ine, n</td>
<td>6 (42.9%)</td>
<td>4 (22.2%)</td>
<td>0.267</td>
</tr>
<tr>
<td>Hb, g/L</td>
<td>96 (82-111)</td>
<td>111 (85-132)</td>
<td>0.025</td>
</tr>
</tbody>
</table>

Median (range), numbers and percentages. *Mann-Whitney U-test, *Chi-square
Methods

Standard care during eye examination
Elements of developmental care according to NIDCAP were applied to all infants, at both sites.

Developmental care intervention during eye examination
The intervention during the eye examination was performed by a NIDCAP-certified observer, and aimed at performing the eye examination with a minimum of distress for the infant. The intervention consisted of general guidelines, with individual evaluation of the infant’s responses, including direct support to the infant, pacing of the eye examination, and modification of the environment.

Clinical assessment
Behavioural responses, including heart rate, respiratory rate and oxygenation of the infant and oxygen requirement were assessed as well as, procedural pain according to the Premature Infant Pain Profile (PIPP), and saliva cortisol analysed using a radioimmunoassay for cortisol was assessed (80, 148).

A protocol for quantitative evaluation of the support given to the infants was completed immediately after all eye examinations.

Continuous variables were compared statistically using Mann-Whitney U test. Chi-square was applied for categorical variables. The level of statistical significance was set at a p-value of ≤0.05.

Results
There were no significant differences in behavioural scores or PIPP-scores when the NIDCAP-interventions were compared with the standard care examinations, neither before nor after the eye examination. During eye examination the overall behavioural score was higher (i.e. better) for the intervention group. The PIPP score increased for both groups during the eye examinations but there were no differences between the care strategies. No significant differences were detected between the two care strategies in observed average heart rate, respiratory rate and oxygenation. Although not significant, there was a tendency that the oxygen requirement was increased more often after standard care. This difference was significant one hour after the first examination, when the infants were younger, than after the second examination (p=0.028).

Salivary cortisol increased from baseline values (before eye drops and before eye examination) to 30 and 60 minutes after the eye examination, and returned to baseline at 4 hours after the eye examination. Salivary cortisol was significantly lower after the NIDCAP-interventions at 60 minutes after the eye examination as compared to standard care (p= 0.016), (Figure 4). No significant correlations between any of the salivary cortisol measurements and the infants’ gestational age, postnatal age in days, postmenstrual age at the examination, or Hb-values was found.

The summary of the intervention score differed significantly between standard care and the NIDCAP-intervention (p<0.001). There was a change over time in the amount of support that was provided during standard care (p<0.001), the support increasing with increasing numbers of examinations and gradually approaching the level of the NIDCAP-intervention, which remained stable over time (Figure 5.).
Figure 4.
Salivary cortisol levels at the different measuring points for all examinations, and in relation to care strategy. Salivary cortisol levels differed significantly one hour after the eye examination between the two care strategies, and were lower for NIDCAP-interventions. Only Lund infants were evaluated at 4 hours after the eye examination. Values are medians and interquartiles.

Comparing London and Lund
Hemoglobin levels were lower in London (Table 6). Heart rate just before and during the eye examination was higher in London than in Lund (p=0.002 and p=0.034, respectively). The respiratory rate during the eye examination was also higher in London, than in Lund (p=0.027). The methods for eye examinations differed between the two hospitals, and PIPP-scores were evaluated slightly different during the eye examination, being higher in Lund than in London (p<0.001). Baseline salivary cortisol (before eye drops and before eye examination, respectively) was lower in Lund compared to London (p<0.001 and p=0.003, respectively). However, at 30 minutes after the eye examination there were no differences between the hospitals, but at 60 minutes after the examination salivary cortisol levels were lower in Lund (p=0.003). The differences were mainly present at the first examination when the infants were younger.
Comments
The main findings from this study show that a developmental care intervention according to NIDCAP in connection with eye examination for ROP reduces stress, as evaluated by higher (better) behavioural scores during eye examination and lower salivary cortisol at 60 minutes after the examination. In addition, during the first examination, when the infants were younger, the infants in the intervention group needed less additional oxygen. No difference between the two study groups was seen in PIPP. The support given to the infants during standard care changed significantly over time, and became closer to the level of support given to the intervention group (Figure 5).

Figure 5.
Intervention scores in relation to the order that the eye examination was performed in the study. Examinations performed on the same day were given the same order. There was a change over time in the intervention score during standard care ($r_s=0.663$, $p<0.000$) while the scores during the NIDCAP-interventions remained stable and did not change with increasing number of examinations ($r_s=0.199$, $p=0.259$).
There were differences between the two study populations in London and Lund that need further exploration in future studies. Systematic investigation of the background to such differences could lead to better understanding of infant’s stress and pain responses.

![A few minutes after an eye examination, the baby is protecting his face.](image)

**Picture 3.** A few minutes after an eye examination, the baby is protecting his face.

*Photo Ann-Cathrine Berg*
GENERAL DISCUSSION

The Newborn Individualized Developmental Care and Assessment Program (NIDCAP), provides the multidisciplinary neonatal care team with a tool that creates a shift from protocol-based care to process thinking, and from task-oriented to relationship-based care. The behaviourally sensitive approach to care views the infant both as a recipient of care, but also as an active and competent individual, who with increasing capacity participates in his or her care. The parents are regarded as the primary caregivers and the most important nurturers of their baby. Repeated systematic observations of the fragile infant’s behaviour guide the multidisciplinary team in evaluating and meeting the infant’s current needs in a highly technical and intensive care environment.

Short-term outcome

Effects from NIDCAP interventions on short-term outcomes and on maternal experiences were evaluated in papers II, III and V. In paper II, which was a RCT evaluating NIDCAP versus conventional care, from birth until discharge, positive short-term effects from the intervention were seen especially on respiratory morbidity. The infants in the NIDCAP intervention group needed fewer days with CPAP and additional oxygen could be withdrawn at an earlier age. The results are in agreement with other studies evaluating NIDCAP treatment and show a reduced need for ventilatory support, especially fewer days with mechanical ventilation and fewer infants with moderate-severe CLD (126-128, 131).

Why is NIDCAP-treatment so clearly associated with lower respiratory morbidity in preterm infants? In my experience, this is a direct result of the intervention which specifically adapts the care for the individual infant and also aims to give the infant opportunities to rest and recover between interactions that cause pain and distress. In study V we evaluated, in more detail, effects from a single NIDCAP-intervention during an eye examination for ROP. This important and clinically indicated investigation is aimed at preventing visual impairment but is associated with several adverse reactions in preterm infants (149-151). Study V was performed as a randomised cross-over study, evaluating two eye examinations, one with a NIDCAP-intervention and one with conventional care with the infants serving as their own controls. The NIDCAP-intervention was clearly associated with a quicker recovery in the infants, as measured by lower salivary cortisol levels one hour after the eye examination. Furthermore, after the first examination, when infants were 1-2 weeks younger than at the second examination, significantly fewer infants needed additional oxygen after the NIDCAP intervention. In another study, a single developmental-care intervention during a weighing procedure resulted in lower pain scores and lower heart rate (74). From the presented data, a hypothesis on how NIDCAP reduces respiratory morbidity can be made. It is well known that, during the NICU-period, very preterm infants may be subjected to several hundreds of clinically indicated but painful and distressing experiences (69, 70). The results from study V clearly indicate that especially the more immature infants recover more quickly and need less additional oxygen after a single NIDCAP-intervention. We hypothesise that repeated NIDCAP-interventions reduce stress and need for additional oxygen in a majority of invasive and stressful care procedures, and that this is one of the explanations for why continuously ongoing NIDCAP-care is associated with lower respiratory morbidity. In addition, the caregivers skilled in NIDCAP probably also become more sensitive when observing when the infants are
capable of breathing without mechanical support. However, with studies reporting that preterm infants can be handled over 200 times a day and exposed to up to 700 invasive procedures during their hospital stay, we should also focus on reducing, as much as possible, the number of painful and distressing events in order to prevent both negative short-term and long-term negative effects for the individual infant (67, 69, 70, 77).

The NIDCAP-intervention in study V did not reduce pain scores, and it must be stressed that also when applying NIDCAP, pharmacological pain relief should be given when necessary. Another experience from study V was that there is a need for validated pain scores for noxious procedures lasting over several minutes. We used the PIPP but found that it was difficult to score in relation to the duration of the eye examination. What we also learned was that we can use behavioural cues from the NIDCAP observation tool when assessing continuous pain/stress in preterm infants in accordance with what Holsti et al demonstrated (81). Furthermore, that muscle tone should also be added as an item for evaluation of pain and distress in preterm infants.

In paper II we did not find any differences as regards growth or age at discharge, which may be due to the relatively small study sample the study did not have enough power to show possible differences. Other NIDCAP-studies have shown such results but in the Cochrane analysis they were not evaluated as significant (126-128, 152-154).

The mothers’ attitudes and feelings towards the infants included in study II were evaluated in paper III. The mothers replied to a questionnaire when the infants were 36 weeks PMA and still in hospital. The questionnaire was specifically constructed for this purpose, and included 32 statements or questions related to possible differences in attitudes and experienced by being randomised to NIDCAP or conventional care. The mothers of the infants in the NIDCAP intervention group gave higher scores for feelings of closeness and eye contact with their infants, they also perceived that the neonatal staff better supported their role as a mother. These mothers also felt that they had been able to take responsibility for the care of their own baby. My interpretation of these results is that NIDCAP-trained staff more clearly communicate that the mother is the primary caregiver, and more sensitively guide her in how to interpret and respond to her infants’ signs and needs. This is turn leads to more opportunities for the baby to reach an alert state and calm wakefulness, which is necessary for interaction. In addition, the continuous observation and the support of infant’s physiological and motor balance helps the infant conserve energy that can be used for growth and maturation with increasing ability for interaction. The higher scores for “feeling of closeness” and competence among the mothers in the NIDCAP-group are comparable with data showing higher scores for bonding and competence in mothers practising KMC, for 24 hours a day, as compared to conventional care (155). However, the mothers in the NIDCAP-intervention group also expressed more anxiety related both to their infant’s survival and future health and to the technical equipment. A possible explanation for the expressed anxiety is that the mothers in the intervention group had bonded further to their baby.
Long-term outcome
The effects of NIDCAP on long-term outcome in two populations of infants were evaluated in studies I and IV. Study I evaluated a group of NIDCAP-treated prematurely born children at 3 years of corrected age, in relation to a comparable group of infants born at the same hospital 1-2 years before. The NIDCAP-treated infants received more antenatal steroids and surfactant, but there were no differences in short-term medical outcomes between the two groups (133). The NIDCAP-care was provided to all very preterm infants born at Falun county hospital in 1992-93 as a result of the data published by Als et al (152). At three years of age, there were no significant differences in cognitive development between the two groups. However, the NIDCAP-intervention group demonstrated significantly better language skills and higher scores for mother-child interaction, which indicated that the children in the intervention group had better communicative skills. The mothers’ in the NIDCAP group also displayed more physical and visual contact with their children, aspects that might have contributed to the better communication skills in their children. In addition, the NIDCAP-treated children also demonstrated fewer behavioural problems and less internalizing problems, i.e. were more open and expressed their feelings more readily. These results are clearly in line with the kind of effects that could be expected when applying NIDCAP. The core of the NIDCAP model is to guide the parents in “reading” their preterm infants cues and sensitively respond to them. This way of acting supports the mutuality between parent and infant during the newborn period and probably contributes to a lasting positive communicative pattern. Other NIDCAP trials have reported enhanced parental competence and better behavioural regulation in the children as a result of the NIDCAP-intervention (126, 128, 156).

Study IV evaluated the children included in the RCT (paper II and III) at one year corrected age. The neonatal outcomes for the two groups of infants differed for respiratory morbidity but not regarding incidence of IVH or PVL. At one year of age, cognitive development (MDI) was better in the NIDCAP intervention group. The lower incidence of BPD (paper II) and the stronger feelings of early bonding (paper III) seen in the NIDCAP group may have contributed to this findings. There were no correlations between cognitive development and any of the background variables. This indicates that the NIDCAP is likely to be the explaining factor for the difference in cognitive development. Other NIDCAP-trials have also shown positive developmental effects during the first year of life, and a recent study also indicates that “early experiences alter brain structure and function” by showing improved neurophysiological and morphological brain development in relation to NIDCAP (31). There are few studies evaluating long-term consequences in NIDCAP-treated children. When a repeated follow-up was performed on the infants in study II at five years of age, there was no difference in cognitive or motor development between the groups (157).

In study IV, the multiple regression analysis revealed a significant negative impact on the psychomotor development from the severity of BPD, but no such impact on the MDI was seen. My impression from a large amount of NIDCAP observations, although not specifically evaluated, is that infants with chronic lung problems have an increased motor arousal with difficulties in modulation and coordination of their motor behaviour. Such unbalanced motor behaviour could also affect the possibility of maintaining a state of alert wakefulness resulting in less interaction and eye contact with the mother. Furthermore, respiratory distress and unbalanced motor behaviour in the infant makes it more difficult to breastfeed which might have been the reason why
slightly more (but not significantly) mothers in the control group gave up breastfeeding/expressing milk before discharge (unpublished data).

Methodological considerations regarding the presented studies
Several methods have been used in this thesis, depending on both the clinical settings and the aims of the studies. It is difficult to conduct a “true experiment” in a clinical setting, and we found it difficult to choose a randomized design in our first NIDCAP study (study I presents the 3-year follow-up from this intervention). The neonatal unit was small and the risk for spillover effects was obvious. There was also a very large interest among the neonatal staff in implementing the NIDCAP-model, which was in accordance with the ongoing project to further develop family-centred care in the unit. Thus we decided to use a quasi-experimental approach, a phase lag design with historical controls when implementing NIDCAP-care at the unit. Although baseline data for the two groups were comparable, changes in neonatal care, e.g. increasing use of antenatal steroids and surfactant may have influenced the results even though later RCT’s have reported decreased need of respiratory support in association with NIDCAP (127,131).

The phase lag design is not optimal and for the second study we chose to perform a RCT (study II). At study II randomisation was done immediately after delivery and the infants admitted from the delivery room directly to either conventional care rooms or to the NIDCAP intervention room at the NICU. The two different care regimes started as soon as the infant entered the room. Power calculations, showing the number of required subjects in the study, in order to demonstrate the decided outcome variables, were performed before the trial started. However, the study had to be terminated before planned fulfilment because of significant drops in birth rate and politically decided economical down-sizing of the NICU. This also shows how sensitive well planned clinical research may be to factors outside the NICU. In spite of the relatively small study cohort we were able to demonstrate significant results on respiratory morbidity and on cognitive function at one year of age (paper IV).

In study II, the parents of six infants assigned to the control group, declined participation in the study. Four of the six infants were later transferred to another hospital, thus received different treatment from the rest of the control group. However, when including the background characteristics of the subject intended to treat in the analysis, there were still no significant differences in outcome between the two study groups (159). Since the infants intended to treat were comparable according to age, growth and severity of illness at birth I do not believe that the results of the medical outcomes would have changed between the groups if they had participated in the study (paper II).

For the purpose of performing study III, an entirely new questionnaire was created. We considered using several protocols but they were not validated for Swedish conditions and we did not find any instrument replying to the specific questions we put forward. When creating a new instrument it is difficult to compare results with other studies, although the current questionnaire can probably also be used for other NIDCAP-studies together with the current validated scale, PSS-NICU (158, 159). The mother’s age at birth of the infant, as well as education level did not differ significantly between the groups when all subjects intended to treat were included in the study. I do not believe that an alternative explanation for the difference in anxiety, expressed by the mothers,
could be that the most anxious mothers in the control group were among the six mothers who immediately denied participation. This would subsequently result in a control group with less anxious mothers which may have accounted for the group differences. However, my impression is that the mothers who denied participation in the original study did it to protect their infants from additional investigations without gaining the extra care provided by NIDCAP. To protect ones infant from anticipated distress may be a sign of innate maternal behaviour and could thus also be interpreted as a sign of strength instead of anxiety.

In paper V, we chose to evaluate a single intervention in more detail, with the hypothesis that a NIDCAP intervention was associated with less pain and stress during an eye examination. We used a validated pain score (PIPP) and repeated salivary cortisol measurements as well as clinical observations including notation of heart rate, respiratory rate, oxygen saturation and oxygen administration. For the purpose of the study we also created two protocols, one that quantified the type and amount of support that was given to the infant during the eye examination, and another based on NIDCAP-observations for quantifying infant behavioural responses. The study duration was short but rather complex in design. Two slightly different NICU’s were involved, which also made it possible to compare data and results from the two hospitals. A methodological reflection regarding the study is that development of new pain scores for procedures lasting some minutes are needed, and that such pain scores also should consider muscle tone in preterm infants.

During study II we noticed a spillover effect from the NIDCAP intervention to the infants in the control group. Due to the NICU-organization, it was difficult to keep the nursing team for the two different care regimes separated. Our concerns that NIDCAP had an impact on the clinical care to the infants cared for conventionally was confirmed in study V where we evaluated the level of intervention after each eye examination. The support given to the infants during standard care increased over time and became closer to the level of support given to the intervention group.

Methodological considerations for future studies
Developmental care has been vigorously challenged (154, 160), and even called a useless therapy during a Hot Topic meeting. It is a little difficult to understand the hostile attitudes towards developmental care. The basic feature of NIDCAP is to create an optimal physiological environment with regard to sensory input, daily rhythm and handling, and no adverse effects have ever been shown. No care intervention has been as thoroughly investigated as NIDCAP, and there are no alternative structured care programs aiming specifically at improving the clinical care of preterm infants treated in busy NICU’s for weeks and months. Do we really have to prove in RCT’s that humane care, systematic efforts to evaluate the well-being and structured gentle care to best support a fragile preterm infant and its’ family is better? I think it is as important to prove that a more aggressive and proactive care is better for the preterm infant than the more natural developmental care.

From my clinical experience during 15 years of implementing and scientifically testing the NIDCAP model, I question the necessity of spending more time and money in new studies to prove the importance of giving appropriate care to the preterm infant during a sensitive period of brain development. However, I am also aware of the methodological consideration from our previous studies. Although the issue of costs is true, my
experiences is that both infants and parents benefit from this care regime immediately in the form of better organisation of the infant and more competent and satisfied parents. When neonatal staff are introduced in the model, they ask for observations aimed at getting more information of the infants and to be able to support the parents in understanding their baby. This leads to better organised infants and more present parents, which frees up time from the neonatal staff. Concerns about not being able to apply all principles of the NIDCAP model to all infants and their parents were strongly pronounced by the neonatal staff in study II and it became an ethical dilemma whether to continue the study. Study V also showed that neonatal staff tend to incorporate methods of care from NIDCAP, when given the opportunity. This is already clear in many NICU’s using incubator covers and cycled light. However, study V also showed that even in NICU’s with partially implemented NIDCAP, the “real” NIDCAP performed by trained staff seems to have additional effects on stress responses in preterm infants. “The NICU’s choosing not to implement this form of therapy should have clear reasons and should consider their own randomized trial to attempt to disprove this work” (161).

In spite of my hesitance to perform new RCT’s there are still issues of developmental care that should be elucidated in future studies, among them are:

- A multicenter study should be carried out in Europe. The study should evaluate physiological and morphological changes in brain function (31), costs and also include scoring of level of interventions, and the care environment, as well as record the numbers of observations for each infant. In addition, assessments of behaviour, stress and pain responses as well as long-term effects on cognitive and motor development are warranted.

- To further increase the 24 hour continuity of NIDCAP for all infants and their parents, a parent support program, derived from the synactive model has been developed by Kleberg A (manuscript). This program needs to be systematically tested and validated.

- More detailed research should be performed regarding the association between developmental care and lower respiratory morbidity, and on the further association between the severity of BPD, child-parent interaction and psychomotor development.

- From our experiences performing the current studies, we also see the importance of developing and validating scales for assessment of continuous pain/stress.

Conclusions
The studies reported in this thesis show different aspects on how a behaviourally sensitive, developmentally oriented, family centred humane care supports and promotes improved short-term and long-term outcomes for preterm infants and their families. The strength of the model is the systematic naturalistic NIDCAP-observations tool and the 24 hour application used by the multidisciplinary team around the infant and his or her family. It requires time investment and agreement from the medical and nursing leadership to be successfully implemented. Developmental care, although developed in the US, fits well in the Scandinavian model of infant care promoting spontaneous breathing by CPAP, Kangaroo Mother Care and early breast feeding.
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## APPENDIX

### Appendix A. Observation sheet:

<table>
<thead>
<tr>
<th>Task Type</th>
<th>Action</th>
<th>Time (s)</th>
<th>Status</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Respiration</strong></td>
<td>Regular</td>
<td>0-2</td>
<td>1A</td>
<td>Breathe, chest rise and fall</td>
</tr>
<tr>
<td></td>
<td>Irregular</td>
<td>2-3</td>
<td>1B</td>
<td>Breathe, chest movement</td>
</tr>
<tr>
<td></td>
<td>Slow</td>
<td>3-4</td>
<td>2A</td>
<td>Breathe, chest rise and fall</td>
</tr>
<tr>
<td></td>
<td>Fast</td>
<td>4-5</td>
<td>2B</td>
<td>Breathe, chest movement</td>
</tr>
<tr>
<td></td>
<td>Pause</td>
<td>5-6</td>
<td>3A</td>
<td>No breathing</td>
</tr>
</tbody>
</table>

**Color:**
- Jaundice (1A), Yellow (1B), Pink (2A), Pale (2B), Web (3A), Red (3B), Dusty (4A), Blue (4B), Tremor (5A), Startle (5B), Twitch Face (5C), Twitch Body (5D), Twitch Extremities (5E)

**Vasovagal Reflex:**
- Sip (1A), Gag (1B), Burp (2A), Hiccup (2B), BM (3A), Lean (3B), Sounds (4A), Sigh (4B), Gasp (4C)

**Motor:**
- Flaccid Arms (1A), Flaccid Legs (1B), Flexed Arms Posture (2A), Flexed Legs Posture (2B), Tuck Legs Posture (3A), Extend Arms Posture (3B), Extend Legs Posture (4A), Smooth Mvmt Arms (4B), Smooth Mvmt Legs (5A), Smooth Mvmt Trunk (5B), Stretch/Drown (6A), Diffuse Squirm (6B), Arch (7A), Tuck Trunk (7B), Leg Brace (7C)

**Face:**
- Tongue Extension (1A), Hand on Face (1B), Gape Face (2A), Grimace (2B), Smile (2C)

**Posture:**
- Prone (1A), Supine (1B), Side (2A), Head (3A), Location (4A), Position (5A), Manipulation (6A), Heart Rate (7A), Respiration Rate (8A), TCPO2 (9A)
Appendix B.

Behavioural Observation

Introduction

Anna was observed in the intensive care nursery, room five during a bath and feeding by her nurse. The observation was done to learn about Anna to help us plan her care and took place on the 26th of May, between 7.30 to 8.40 am.

Nursery environment: Anna was lying in a bed close to her twin sister Emma. There were four more babies cared for in the room. The room was decorated with adhesive flowers on the window wall dividing the room from the adjacent care room. Morning daylight was shining through the window screens. Alarms from the monitors were heard now and then some of them rather high and lasting for about 15 seconds. Sounds were also heard from tap water and paper towels, cleaning of the room from outside and a baby crying as well. Five to six nurses were moving smoothly around the babies. They spoke with low voices. The room appeared very calm except for a few short moments when the sound and activity increased.

Anna bedsparse and bedding: Anna was lying on her back on a soft mattress in a nest, which gave her some support around her body and was covered tightly with a pink blanket. She had a tube through her mouth down to her stomach where she received milk. On one hand a light sensor was attached to register Anna heart rate and oxygen level in her bloodstream. On the side of the bed a picture of Anna’s and Emma’s elder sister was fastened.

Anna behaviour before interaction: Anna appeared to be on her way to wake up. She squirmed her body several times, arched backwards, stretched her arms and tucked them in again. She grimaced a lot, yawned and moved her mouth as if she wanted to suck. Sometimes she brought her hand close to her face which appeared to calm her for a moment. When she was active her skin became redder and when she rested it became pale red. For a brief moment Anna oxygen level dropped below 90% and increased at once. Anna breathed irregularly, changing between deep and shallow around 40 breaths per minute. She kept her heart rate around 170 beats per minute and her oxygen level in her bloodstream about 95%.

Anna behaviour during care: The nurse stepped to Anna’s bedside, greeted her with her voice, undressed her and disconnected the oxygen sensor. Anna extended her arms and legs into the air and splayed her fingers. She woke up and looked with a tensed glance that soon became a little dull. Anna yawned and sneezed several times and tried to pull her hands close to her mouth and then grasped her feeding tube. She raised and lowered her eyebrows intermittently and braced her legs as if she tried to find support for her feet. She trembled and twitched her body. Anna became briefly a little dusky around her eyes and continued to breathe irregularly.

The nurse took Anna hand and lifted her up in her arms and put Anna on the changing table. She took off the diaper and cleaned her buttocks. Anna reacted by stretching her arms and legs abruptly into the air. The nurse lifted up Anna from the table. Anna again stretched out arms and legs. She was positioned in the basin on a sheet and the nurse
washed her. Anna stayed awake and calm for a brief moment. She was lifted up from the bath to the table and got a towel around her body. The nurse dried Anna and removed the feeding tube while she supported her with the sheet. Anna tucked in her arms and legs, sometimes on her own and sometimes with the support of the nurse’s hands and the sheet. Anna kept her energy. She lay still with bent arms and legs. Her cheek became pale and a little dusky. Anna’s body trembled. She was lifted and positioned on the scale. Anna grasped her hair and stretched out her arms and legs again. She was lifted back to the table and the nurse dressed her. Anna arms again flew into the air and stayed there for a moment. She yawned and sneezed a lot, pulled her hand close to her mouth and once almost got her fingers in her mouth. The nurse positioned Anna on her side and introduced through her mouth a new tube for feeding down to her stomach. She supported Anna by her arm and hand. Anna gagged and grimaced a little, yet she kept still, she moved her mouth and appeared to try to suck on the tube. Her hair was combed and she was lifted up and held by the nurse while Anna bed was changed. Anna’s cheek regained pale red. The nurse smiled at Anna and said something nice to her. Anna continued to sneeze. She begun to hiccup and her skin became pale again. Anna stayed awake yet appeared tired. Her arms and legs were lying outstretched in the arms of the nurse. Anna moved her mouth a lot and appeared to search for something to suck on. The light sensor was attached; Anna heart rate was 150 and oxygen level 98%. Anna regained some energy; she pulled up her arms and legs closer to her body.

Anna was fed during almost 20 minutes, held in her nurse’s arms. Anna stopped hiccupping. During the first six minutes she sucked the bottle. She appeared as if she tried to look at the nurse and then slowly became drowsy. She breathed irregularly and it looked like that she lost some energy. Her arms and legs laid still. The nurse continued to stimulate Anna to suck. Anna increased her heart rate up to 195 and her oxygen level stayed above 95%. She remained pale red. Anna was lifted up on the shoulder of the nurse. Anna arms and legs lay outstretched and she appeared tired. Anna received the rest of her milk through the feeding tube. The nurse let Anna lay down on her arm again, and supported her arms and legs by her arm. Anna looked tired, her mouth was open. Sometimes she closed and moved it as if she wanted to gag. Her skin became paler and a little dusky around her eyes. Anna breathed irregularly sometimes with pauses. She kept her heart rate around 160 to 170 and the oxygen level above 92%. Anna seemed being asleep. The nurse ended the feeding, kept Anna in her arms for a few minutes before she laid her back in her bed on her side, facing the wall, and tucked her with the blanket. She then left the bed space to take care of another baby.

Anna behaviour after care: Anna looked drowsy. One eye was half open. She was holding onto her shirt and lying with her arms half tucked close to her body; she squirmed a little under the sheet. Her skin was pale. She breathed more regular around 50 breaths per minute and kept her heart beats around 170 and increased her oxygen level up above 95%. When the observation ended Anna seemed to sleep restfully.

Summary

Anna was born after 28 weeks and 3 days of gestation, delivered by caesarean section on the 26th of April 2005. She is the first born of a couple of twin sisters. She weighed
1185 grams, which shows that she had grown satisfactorily. A thin line was placed in a blood vessel where Anna received nutrition and medication. Anna needed breathing support for a few days in the beginning of her life (CPAP- a continuous airflow with some extra oxygen helped her lungs to expand). Anna has also been treated to break down the bilirubin that gave her yellow colouring (jaundice) by special light from a lamp. Today Anna is one month old. She is cared for and feed by her mothers milk every third hour. The last day she has been breathing irregularly, occasionally regularly, 40 to 70 breaths per minute, she has kept her heartbeats around 150 to 170 and her oxygen level in her blood above 90%.

From this observation Anna appeared to be a competent little girl. She showed her strengths by keeping her oxygen level and heart rate stable. She showed that she had developed a lot of strategies to regain or stay calm during care by pulling her arms and legs back close to her body or by pulling her hand to her mouth, grasping her hair or shirt, trying to search for something to suck on or searching for support for her feet. Anna was successful when there was support close to her. In the beginning of the care, thanks to the support offered by the nurse or the bed, she showed us smooth movements and the capability of keeping her energy. After being pale and limp she recovered by herself and from the support close to her. She also showed her strengths by changing from sleepiness to wakefulness smoothly and she stayed awake and kept her energy for a long period. To keep awake she opened and closed her face to manage keeping out the light from the room. For a brief moment she seemed to search for eye contact with her nurse. When Anna became awake she showed us that she wanted to suck. She managed to suck from the bottle part of her meal and stayed calm with stable breathing and colour and kept her energy for a short time.

Anna sensitivities were seen in her skin colour changing and dropping in oxygen level during her efforts to wake up. When trying to stay awake and interact with the nurse, Anna showed that it is still difficult for her to maintain herself in a stable awake state. During care and tube feeding she lost her colour and energy after having made a lot of effort to bring and keep her arms and legs back to her body. When the support disappeared Anna stretched out arms and legs and then she became pale and a little dark around her mouth and eyes. Anna also yawned, hiccoughed and sneezed after her own effort and strategies of getting back to rest.

**Anna’s current goals**

From this observation Anna appeared to be working towards:

- Becoming increasingly steady in her breathing and colour during care and feeding with support from the nest and the caregiver
- Becoming increasingly successful in developing strategies to tuck in herself to becoming restful and maintain her energy with support from the nest and caregiver
- Becoming increasingly successful in changing from sleep to awake and maintain her colour and oxygenation
- Becoming increasingly successful in sucking and eating bigger amounts of milk.
- While awake and calm interacting with her caregiver for a short moment with support
Recommendations

The following suggestions may help Anna to achieve her goals.

Nursery environment:
- Continue to talk with low voices and move smoothly in the care area and consider switching the alarms off as soon as possible. Think about decreasing the sound level of the monitors which will help Anna to stay restful, conserve energy and grow.
- Consider to close the door of the room to shut out the sound and activities from outside.
- Consider the opportunity to make the room as homelike as possible and ask Anna parents if they would like to bring personal items for Anna and Emma.
- Think about bringing a comfortable reclining chair for Anna’s and Emma’s parents to rest in with their daughters.

Bed space and bedding:
- Continue to use the nest in Anna bed. Consider the possibility to use a high support for her feet to brace into and a high support in her back while she is sleeping on her side. That will help Anna to keep her arms in midline and to be able to bring her hand to her mouth to suck on.
- Consider to cover Anna bed space with a canopy to help her sleep and wake up smoothly. Consider to adjust the light in the room so it will help Anna to open her eyes and stay with a relaxed view.

Care giving Interaction:
- Continue to care for Anna in a sensitive way.
- When possible organise the care of Anna according to her sleep and wake periods. Consider to use her signs of waking up and showing she would like to suck to start the feeding before she has used her energy on other caregiving activities.
- Continue to great Anna with your voice to make her aware of your presence. Consider to support her with your calm hands and give her time to wake up smoothly.
- Think about using Anna signals as a way for her to tell you when she needs a time out or rest before continuing the care. Anna shows you this by becoming pale, squirming or arching her body, moving her arms and legs abruptly into the air, splaying her fingers, sneezing, yawing and hiccupping and losing her tone/energy.
- Consider to lift Anna wrapped in a sheet to help her stay secure and calm with arms and legs tucked in close to her body.
- Consider to use a nest on the changing table and or put Anna close to your body, as Anna showed that she searched for support for her feet. That can help her stay calm and conserve energy.
- Consider to use a towel around Anna while you lift her into the bath and in the bath. Loose one piece at a time according to where you shall wash her. Consider using a tube filled with water, both strategies will help Anna to move smoothly during her bath. Engage her parents when they are by their daughters to bath.
and care for their little girls. Consider to arrange the bath during the time Anna’s and Emma’s parents are on the unit.

- Consider supporting Anna arms and legs when inserting the feeding tube and follow her movements of sucking to let the tube smoothly go down to her stomach. Consider to have Anna in your arms when you do this which use to be easy.
- Consider to put a nest on the scale to support Anna while she’s weighing.
- Consider to bottle feeding Anna in your arms while sitting on a comfortable chair; it would be easier to stay relaxed and becoming able to support Anna.
- Consider keeping the room calm during Anna bottle feeding and try to let her suck on the bottle pacing her own capability.
- Consider to take into account Anna’s signs indicating when she is available to interact. Consider to give Anna time for interaction when she shows she wants to.
- Ask Anna’s parents if they agree to let Anna suck on a pacifier during tube feeding.
- Consider to give Anna a pause as soon as she shows signs of disorganisation before continuing feeding or care.
- Consider to invite Anna and Emma’s parents in all care giving and feeding activities and show them ways to support their daughters’ strategies in becoming calm and restful.
- See Anna and her sister as active and competent involved in their own care and wellbeing.