Stress and discomfort in the care of preterm infants: A study of the Comfort Scale and the Newborn Individualized Developmental Care and Assessment Program (NIDCAP®) in a Dutch level III NICU
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Chapter 1

Introduction
The last few decades perinatal and neonatal care has changed. Technological and pharmacological possibilities of treatment increased and existing treatments improved. The importance of these changes for preterm and critically ill infants and the impact on their clinical outcome and development has become a concern for the professional caretakers, neonatal nurses as well as neonatologists.

Epidemiology

In 2003, 13,547 of the 189,899 alive newborn infants (>24 weeks gestational age) were born prematurely (<37 weeks gestational age) of which 1904 infants were born very preterm (<32 weeks gestational age) in the Netherlands. The Neonatal Intensive Care Unit (NICU) of the Emma Children’s Hospital / Academic Medical Center is a referral unit for critically ill preterm and term infants. This NICU has also a regional function for older more stable preterm infants. In 2003 558 infants admitted to this unit needed intensive care treatment, 167 infants were born preterm and 186 very preterm.

Neonatal mortality (0-28 days) rates for very preterm infants in our NICU was 11% in 2003. This is comparable with the overall neonatal mortality rate in the Netherlands in 2003 (14%). In 1983 the overall neonatal mortality rate for this age group in the Netherlands was 31%, and in 1993 it decreased to 17%. The decreasing mortality rates in the Netherlands are also seen in other European countries as well as in countries overseas.

The most common disorder in (very) preterm infants is Respiratory Distress Syndrome (RDS). The incidence of RDS is higher when infants are more preterm or have a low birth weight (<1500 gram). Treatment of RDS has resulted in the use of advanced ventilation techniques and pharmacological interventions (surfactant, steroids). Despite improvement of care the incidence of the most important pulmonary morbidity, chronic lung disease (CLD) have remained unchanged at about 22% of surviving preterm infants. Infants with very low birth weight (501 to 750 grams) have a higher incidence of CLD compared to infants with low birth weight (1251-1500 grams), respectively 46% (range 25-81%) and 6% (range 2-23%).

Another problem in the care of (very) preterm infants is the occurrence of intraventricular haemorrhage (IVH) and periventricular leucomalacia (PVL). Both occur more frequently in infants born below 1500 grams birth weight. The incidence of IVH overall determined by ultrasonography is approximately 27%, and 12% restricted to grades III and IV. The incidence of PVL based upon ultrasonographic findings range from 1 to 5%. Preterm infants are at an increased risk for having infections during the hospital stay. Overall, the risk is the greatest after the first week of life. Around 21% of very preterm infants develop a culture-proven sepsis, over 50% is treated for clinical or proven sepsis at least once during hospital stay. A small number of infants develop meningitis (5%) and/or necrotizing enterocolitis (10%).
A major problem in the care of preterm infants is instability of blood pressure; high and low blood pressure occurs frequently and is associated with cranial haemorrhages and periventricular leucomalacia, while the preterm brain is still immaturity developed and vulnerable. Hypertension can be induced by activities such as crying, body movement, feeding, and therapeutic interventions, including endotracheal intubation or suctioning. Hypotension is often seen during severe infection or sepsis. Fluctuations in systemic blood pressure during mechanical ventilation have been associated with the occurrence of IVH and PVL.

Neonatal morbidity, as a result of pulmonary immaturity, intracranial events and infections in the preterm infant consequently affects morbidity later on in live. Almost 10% of all very preterm infants are diagnosed with severe handicaps before the age of five. This percentage remains unchanged since 1960-1970. Around 50% of all preterm infants develop disabilities or impairments, measured at school age. Comparison with healthy term peers results in a six times higher chance on impairments. Initially it was thought that these infants would overcome their developmental problems when aging. However this appeared not to be the case. These infants demonstrate difficulties with attention, behaviour, visual-motor integration, language performance and/or academic skills. Overall optimal development and performance is seen in 31% of children born in 1983 of <32 weeks gestational age and in 41% of children born in 1993.

Neonatal intensive care

Neonatal intensive care treatment and the environment of the neonatal unit have a major impact on the infants and hence their development. Intensive care treatment and caregiving activities cause a lot of pain and (di)stress apart from environmental disturbances like noise and light. This results in periods without rest and undisturbed sleep for preterm infants. Handling a preterm infant for more than 200 times per 24 hours is not uncommon. Three out of four hypoxemic episodes are associated with caregiving itself. Mechanical ventilation, a common treatment in the majority of these infants, is accompanied by a lot of potential stressful interventions like (re)intubation, endotracheal suctioning, punctures, skin lesions, and the use of adhesive materials. A-synchronized spontaneous breathing known as “fighting the ventilator” is a known phenomenon, therefore, the mechanical ventilation period can be described as a very stressful and uncomfortable period.

Excessive handling is also a factor that encroaches upon the vulnerability of the brain. PVL and IVH are the result of impaired cerebral vascular auto regulation, which is needed to maintain adequate cerebral blood pressure when systemic blood pressure varies. The number of invasive procedures infants undergo while in the NICU is staggering. A case described an infant born at 23 weeks gestation underwent 488 painful procedures during the NICU stay. Other reports on invasive procedures mention between two and
ten procedures per day as well as an average of 53 moments of handling, lasting an average of 2.7 hours per day.\textsuperscript{52,53}

Stress and discomfort caused by treatment and caregiving interventions are experienced during the long period of hospitalization of preterm infants. Although more immature in their responses, preterm infants are more sensitive to pain (stress) than older infants.\textsuperscript{54-57}

Experiences of repeated and long lasting exposure to pain have been proven to result not only in acute physiological responses, but also changes in the structure and function of the brain.\textsuperscript{58} One study has shown how developing pain circuitry depends on non-noxious sensory activity, and how early injury can alter pain processing permanently.\textsuperscript{59}

Besides, sensory input affects the synaptogenesis of neuronal networks and therefore the ability of the functioning of these networks.\textsuperscript{36} Sensory input may easily over-stimulate very preterm infants during a critical period of extraordinarily rapid brain development. Stressful situations and repetitive stress in an early stage of life are a serious threat to the immature brain and consequently for later development of these vulnerable preterm infants.\textsuperscript{50,58,60-63}

Development of the brain

Neural multiplication and migration in the germinal zone has largely been completed at 30 weeks of gestation. Astrocytes, however, are still being formed and migrating to upper cortical layers. During the same period myelinisation begins and naturally occurring apoptotic neuronal death is more frequent than at any other time of brain development. Up to 70\% of the neurons in the human cortex undergo apoptosis between the 28\textsuperscript{th} and 40\textsuperscript{th} week of gestation.\textsuperscript{64-66} The volume of the cortical grey matter normally increases almost four-fold from the 30\textsuperscript{th} and 40\textsuperscript{th} week of gestation.\textsuperscript{64,67} The synaptogenesis of neuronal circuits is regulated by endogenous factors on one side and by sensory input and experience the other side.\textsuperscript{68} Therefore, it is not surprising that the brain will be negatively influenced by preterm birth and all the consequences of undergoing intensive care treatment. Als described in a study that neonatal intensive care experiences before term age, influence brain development.\textsuperscript{69} Early prolonged exposure to pain and stress is proposed as one of the contributing factors to later difficulties with self regulation and attention span in very preterm infants.\textsuperscript{57,62,70,71} Self regulation, being a marker of neurobehavioral organization may predict later developmental outcome.

Stress

Stress, (di)stress and non acute pain are often used interchangeable in clinical practise as well as in literature. Stress can be described as the reactions of the body or mind to forces of a deleterious nature, and various abnormal states that tend to disturb the normal physiological or mental equilibrium (homeostasis). Stress, distress and (non acute) pain can result in discomfort. It is hard to decide when observing an ‘uncomfortable’ infant
whether the behavioural discomfort is caused by stress or pain. But it is clear that ‘all pain is stressful, but not all stress is painful’.72

Management and evaluation of stress and discomfort as well as anticipation during the neonatal period are important components in the care of preterm infants.47,50,73,74 Stress and discomfort is also of major concern to parents.75 Neonatal pain assessment has received increased attention over the past two decades.76,77 Although a number of pain assessment scales for preterm infants exist and have been tested as research tools, yet no perfect clinical scoring system exists. Up to now there was no objective way to differentiate between pain and (di)stress of preterm infants. For older infants and children the Comfort scale has been developed, an instrument to measure distress during the period of mechanical ventilation.78

As advances in neonatal care lead to a better survival of smaller and sicker preterm infants, attention has shifted towards neuroprotective care strategies and neurodevelopmental support, in an effort to improve developmental outcome.

Cue-based individualized care can enhance the preterm infants’ potential for normal development, and reduce the negative effect of their stay in NICU. How to identify preterm infants behaviour becomes a very important challenge for NICU caregivers to learn. Preterm infants can not communicate verbally with caregivers, but communicate their needs and status through behavioural cues that may indicate wellbeing or stress. Changes in preterm infant behaviour can be used to identify pain and stress.79-81

In this context, developmental care interventions have been designed in order to create a NICU environment that minimizes stress experienced by the infant. Preterm infants need to be as comfortable and as free of pain (stress) as possible to grow and develop to their full potential.

Developmental care

Developmental care was introduced in the early 1980’s and is described as a group of interventions designed to modify the NICU environment, so as to minimize the stress experienced by the preterm infant. A number of elements are included in developmental care such as modification of external stimuli (vestibular, auditory, visual, tactile), clustering of nursing care activities and positioning and swaddling of the preterm infant to provide containment similar to the intrauterine experience and to support the infant-family relationship.

Research has been performed on the influence of separate developmental care interventions on neurodevelopmental outcome such as kangaroo care, oral stimulation and non nutritive sucking and vestibular, auditory and visual stimulation and positioning. But also on outcomes such as weight gain, length of mechanical ventilation, physiological stress (heart rate, oxygen saturation), and length of hospital stay.82-108
The NIDCAP

In 1986 the first publication on a complete model of developmental care, called the Newborn Individualized Developmental Care and Assessment Program (NIDCAP®), was presented. This model is based on the Synactive Theory of Development. The theory describes the infant as a system consisting of five subsystems: autonomic, motor, state, attention/interaction and self regulatory system. The subsystems develop independently in each phase of development but are in constant interaction with each other and with the environment (including the family). Each infant has its own specific way of being interactive which can be observed as behaviour with the Naturalistic Observation of Newborn Behavior (NONB). Prior to the NONB information on infants’ location, bed, clothing, and bed space, ratings of nursery room sound, light and activity levels will be obtained. After the observation, information on the medical history and current status are collected. The observation measures the organization of behaviour and self regulation in a given environmental setting and a set of caregiving situations. The observation visualizes the way the preterm infant communicates with its environment. A NIDCAP trained person observes the infant for a 60-90 minute period. This includes a 10 minute pre-activity observation and at least a 20 minute post-activity observation period, during which the observer has no interaction with the infant. A caretaking interaction

Table I Naturalistic Observation of Newborn Behavior (N=85 items)

<table>
<thead>
<tr>
<th>Autonomic Behavior (N=25)</th>
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<tbody>
<tr>
<td>Respiratory: regular, irregular, slow, fast, short pause, AA (long pause)</td>
</tr>
<tr>
<td>Color: jaundice, pink, pale, web, dusky, blue</td>
</tr>
<tr>
<td>Neurologic: tremor, startle, twitch face, twitch body, twitch extremities</td>
</tr>
<tr>
<td>Visceral/respiratory: spit up, gag, burp, hiccough, bowel movement grunt, sounds, sigh, gasp</td>
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<tr>
<th>Motor Behavior (N=36)</th>
</tr>
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<tbody>
<tr>
<td>Limb and/or trunk movement: flaccid arm(s), flaccid leg(s), active flexed arm(s), postured flexed arm(s), active flexed leg(s), postured flexed leg(s), active extended arm(s), posture extended arm(s), active extended leg(s), posture extended leg(s), smooth movements arms, smooth movements legs, smooth movements trunk, stretch down, diffuse squirm, arch, tuck trunk, leg brace</td>
</tr>
<tr>
<td>Face: tongue extension, hand on face, gape face, grimace, smile, mouthing, suck search, sucking</td>
</tr>
<tr>
<td>Extremity specific: finger splay, airplane, salute, sitting on air, hand clasp, foot clasp, hand to mouth, grasping, holding on, fistng</td>
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</tbody>
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<tr>
<th>State Behavior (N=13)</th>
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</thead>
<tbody>
<tr>
<td>States: disorganized deep sleep, quiet sleep, drowsy, alert, active awake and sleep, organized deep sleep, quiet sleep, drowsy, alert, active awake and sleep</td>
</tr>
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</table>

<table>
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<tr>
<th>Attention and Interaction (N=11)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fuss, yawn, sneeze, face open, eye floating, aver, frown, ooh face, locking, cooing, speech movement</td>
</tr>
</tbody>
</table>
is observed like suctioning, diaper change, feeding session or blood sampling. The observation sheet is set up as a set of 85 items of behaviour which can be observed. This allows the continuous observation of the behaviour of the infant (Table I). Not the period of time a specific behaviour is shown but the frequency of appearance of a certain type of behaviour is noted. The observed behaviour can be subdivided into the five subsystems: autonomic, motor, state, attention/interaction and self regulatory system. Each system is divided in subcategories consisting of several items. Additional information on the posture of the infant, the kind of intervention or manipulation performed and vital parameters, such as heart rate, respiratory rate and oxygen level is noted. Following the observation, a case report is written assessing the infants’ current ability to organize and modulate the five subsystems. The case report consists of several standard parts: introduction, description of the nursery environment, the behaviour of the child before, during and after caregiving interaction. The infants’ behaviour described as, approach towards or avoidance of stimuli, enables the observer the possibility to assess how the infant strives to cope with the caregiving and the environment in order to continue its development. The observations provide information concerning the infants’ strengths and weaknesses. Next a summary is written consisting of the medical history, the last 24 hours and the present behavioural functioning. Finally, current goals and caregiving recommendations to support the individual infants’ development are formulated. Caregiving recommendations are then used by parents as well as professional caregivers to diminish stress and to support the infants’ competence to overcome stress and discomfort (Figure I). This results in longer periods of restfulness and calm breathing, a well-functioning digestive tract, a well-modulated tone of the extremities, trunk and face, and a comfortable restful position. The tempo of caregiving procedures is individualized, slowed and adjusted in timing and well-supported relaxation periods are provided.

The information provided by the observation is used to individualize care and environment to the needs of the specific infant. In this way, after modification of external stimuli, clustering of care activities and positioning, individualization of care and family support is added as a fifth dimension to developmental care.

NIDCAP is believed to support the infants’ development, with the structuring of the appropriate physical environment in the NICU for the infant and the family, the timing and organizing of nursing care and medical interventions appropriate to the individuality of the infant and the family, supporting and facilitating the parents’ confidence in caring for their infants physical and developmental needs.

In the years following the first publications on the NIDCAP model several promising research publications on this new model appeared.\textsuperscript{107,108,112-120} Some studies showed significant results in the outcome parameters, in favour of infants cared for by NIDCAP such as reduction in ventilation days\textsuperscript{112,113}, less IVH\textsuperscript{113}, increased weight gain\textsuperscript{108,113}, decreased days of parenteral feeding\textsuperscript{112,114,116}, better physiological stability\textsuperscript{118} and behavioural organization\textsuperscript{107,112-114}, less complications\textsuperscript{108,113,114} and decreased length of
hospital stay as well as a better mental and psychomotor development up to the age of 12 months. However, other studies were not able to show differences between infants cared for by NIDCAP or in a conventional way.
Introduction

Two systematic reviews were performed on NIDCAP.\textsuperscript{121,122} Both reviews showed limited evidence of NIDCAP on moderate-severe chronic lung disease, necrotizing enterocolitis and family outcome (stress and perception). There was also very limited evidence for long-term effects on behaviour and motor outcome at five years and no benefits on cognition. The cost of intervention was considerable. The meta-analyses illustrated the large variation in outcomes and limited numbers of randomized control trials that were included in each outcome. The reviewers addressed a number of design limitations. Because of the nature of the intervention blinding was not possible, sample sizes were small, contamination of the intervention by existing developmental care practices and differences in gestational age of the infants included. The reviewers called for more (multi-center) trials with larger sample sizes to study the effects of NIDCAP. Recently, a group from Edmonton presented preliminary short-term outcome from a large NIDCAP randomized controlled trial on very low birth weight infants that confirms findings of significantly less mechanical ventilation, lower incidence of chronic lung disease and shorter hospitalization, as noted in the earlier smaller trials included in the systematic reviews.\textsuperscript{123}

Despite the conflicting study results up to now, for the NICU of the Emma Children’s Hospital / Academic Medical Center, with a long history of being interested in the humanization of the highly advanced technological care and a traditional interest in preventing stress and discomfort for newborn infants as well as in the parental involvement in the care and decision making process it was just a logical consequence to be interested in implementing such a practice in care.

Objectives of the study

In this thesis stress and discomfort and new ways of reducing stress and discomfort for preterm infants in the NICU, including consequences in infant outcome and the satisfaction of parents and nursing staff related to the care was subject of study. In more detail we studied the next objectives:

1. The Comfort scale can be validated to assess stress and discomfort of preterm infants.
2. The Comfort scale is useful in studying stress during different techniques of mechanical ventilation.
3. Care according to NIDCAP improves the clinical outcome during NICU stay of very preterm infants.
4. Care according to NIDCAP during the NICU period improves growth and developmental outcome during the first two years of life of very preterm infants.
5. NIDCAP increases the satisfaction rates of parents of very preterm infants.
6. NIDCAP improves the job satisfaction of nursing staff caring for very preterm infants.
Outline of this thesis

Chapter 1 of this thesis presents a general introduction including the objectives of the study.

In chapter 2 one of the major problems in the NICU, namely stress is described. Validating the Comfort scale to measure stress of ventilated preterm infants is presented.

Chapter 3 focuses on conventional and high frequency ventilation modes in the care of preterm infants and the consequences for the amount of stress experienced.

Chapter 4 describes the current status of developmental care and NIDCAP in Dutch speaking NICU’s in the Netherlands and Flanders.

Chapter 5 compares the NIDCAP as a new model of care of preterm infants in the NICU with the conventional care model and evaluates its effects on medical outcome during hospital stay.

Chapter 6 describes the results of infants cared for with NIDCAP compared to conventional care on developmental outcome and growth in the first two years of life.

Chapter 7 presents the levels of satisfaction of the parents of infants cared for in the NICU in the NIDCAP way or the conventional way.

Chapter 8 outlines the job satisfaction of the nursing staff with the introduction of NIDCAP in the unit.

Finally, in chapter 9 and 10, a general discussion, conclusions and the summary of the main results of this thesis are provided.
REFERENCES


Introduction


82. Brandon DH, Holditch-Davis D, Belyea M. Preterm infants born at less than 31 weeks’ gestation have improved growth in cycled light compared with continuous near darkness. J Pediatr 2000; 140: 92-199.


Introduction


