The Leiden developmental care project : effects of developmental care on behavior and quality of life of very preterm infants and parental and staff experiences

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CHAPTER 1

Introduction

Preterm birth: infants and their parents

Advances in neonatal caregiving have decreased the mortality of infants born very preterm [1,2]. When an infant is born preterm this also has a major long-lasting impact on both the family and the individual infant. Parents of preterm infants report more stress [3,4] and experience more maladaptation and need for support during the first year after delivery [5] than parents of infants born at term. Furthermore, mothers of high-risk preterm infants have reported that they experience symptoms of post-traumatic stress [6].

Very preterm infants have lower health-related quality of life (HRQoL) compared to children born at term [7-10], as reported by their parents, especially regarding stomach, lungs and eating problems [9]. Health-related quality of life is defined as the functioning of the child on four dimensions (physical functioning, social functioning, cognitive functioning and emotional functioning), weighted by the emotional evaluation of the problems [11,12]. Preterm infants also show more problem behavior compared to infants born at term. A meta-analysis [13] found more externalizing and internalizing problem behavior in preterm infants in 13 out of 16 studies (81%) and more Attention Deficit and Hyperactivity Disorder (ADHD) symptom behavior in 10 out of 15 studies (67%).

Parental stress and infant behavior problems are interrelated in which increased maternal stress and depression at 4 months and parents' post traumatic stress reactions were correlated with increased problem behavior at 36 months [14] and increased risk of the child developing sleeping and eating problems [15].

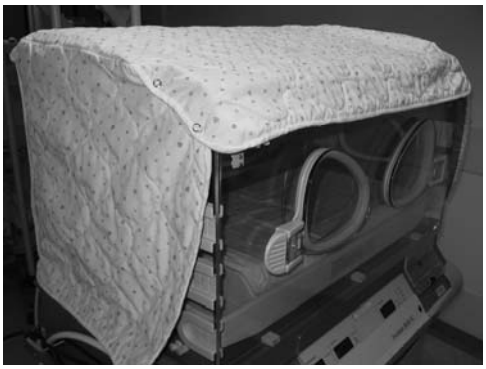
The NIDCAP intervention

Because of the advances in neonatal caregiving and the decrease in the mortality of infants born preterm [1,2], focus in neonatal caregiving has shifted to a more individualized and family-centered approach. In this context the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) [16], introduced by dr. Heidelise Als in the 1980's, seems very promising. This program is based on the Synactive Theory of Development [17] where the infant's behavior is observed along four channels of communication: the autonomic system (skin color, respiration etc.), the motor system (posture, tone and movements), the state organization system (type and range of states available to the infant from asleep to aroused and state transition) and the attention and interaction system (the infant's ability to come to an alert, attentive state and to utilize this state to handle stimuli from the environment). The infant's efforts at self-regulation and interaction are observed through approach and avoidance behaviors [17,18]. The infant's behavior is observed before, during and after caregiving by a NIDCAP trained developmental specialist. A narrative of the observation is written with recommendations to modify the infant's environment and caregiving, based on the infant's individual behavior. Examples of recommendations are: time-outs during caregiving when the infant becomes stressed, giving the infant something to hold on to or to suck on (whatever comforts the infant most) and placing the caregiver's hands around the infant's body to support flexed position and to provide comforting boundaries (containing). Furthermore, parents are guided in observing and responding to the infant's behavioral cues during caregiving and kangaroo care is encouraged (placing the infant on the parent's chest to support bonding and provide the infant with familiar odours, sounds and warmth). The observations and recommendations are discussed with parents

and other caregivers and parents are stimulated to become more actively involved in the caregiving process [16,19].

The results of NIDCAP intervention studies in the United States and Sweden revealed improved infant outcomes, such as improved short term medical outcomes (fewer ventilation days, shorter duration of parenteral feeding and lower incidence of necrotizing enterocolitis) [20-22], better behavioral performance as measured with the Assessment of Preterm Behavior (APIB) [20,21,23-25], improved cognitive developmental outcome [18,21,23,26], lower hospital charges [26], improved brain function and altered brain structure [23] and a positive impact on behavior [27]. In addition, less parental stress was reported [20]. However, a recent review regarding Developmental Care [28] concluded that although overall limited benefits and no major harmful effects were found, the significant effects were mainly based on studies with small sample sizes and that several of these findings were not supported in other settings.

Basic Developmental Care



The NIDCAP observations have resulted in basic recommendations for the Neonatal Intensive Care Unit (NICU) such as the use of standardized nests (to support the children's posture) and standardized incubator covers (to decrease the light level in the incubator). The guidance by a NIDCAP trained developmental specialist, the NIDCAP training and the individual observations are (labor) intensive and costly to implement. In this context the implementation of the basic recommendations of Developmental Care can be seen as a first step before deciding to officially train staff members. Previous research has only focused

on the implementation of the complete NIDCAP observations. A comparison of the basic elements of Developmental Care with the complete and more intensive NIDCAP intervention would provide information about the additional value of the individualized aspects of the NIDCAP observations and guidance by a NIDCAP trained developmental specialist.

Implementation of NIDCAP in a Dutch setting

The implementation of NIDCAP in a NICU is very intensive and requires changes in the NICU environment and care as well as changes in medical and nursing staff's attitudes. Als and Gilkerson [19] stated that because NIDCAP is relationship-based, system-orientated, process-guided and not procedure-based, it can be difficult to implement NIDCAP in an acute care environment like the NICU, which focuses on medical protocols and caregiving routines [19].

A study of NIDCAP in a Swedish setting examined staff experiences and opinions regarding the implementation of NIDCAP. This study concluded that NIDCAP was well-received by nursing staff, neonatologists and parents [29,30]. Staff indicated improvements with regards to their ability to assess the infant, the infant's well-being and the opportunities for, and quality of, parental attachment. Because the implementation phase can influence the acceptance of NIDCAP in the unit it is important to monitor and evaluate NIDCAP implementation. The evaluation of NIDCAP implementation can result in recommendations for future implementation in different settings.

Study design

The study described in this thesis consists of two consecutive randomized controlled trails (RCT) evaluating the effects of NIDCAP in two stages (basic and complete Developmental Care) in a Dutch Neonatal Center at two locations (Leiden and The Hague). In addition, the nursing and (para)medical

staff's experience with NIDCAP and attitudes at both locations were evaluated. The Neonatal Center encompasses 8 Intensive Care beds and 8 High Care beds in the level III unit in the Leiden University Medical Center (LUMC) and 4 Intensive Care beds and 9 High Care beds in the level III unit in the Juliana Children's Hospital in The Hague. Usually, infants admitted to the LUMC remain there until they are stable and are transferred to a medium care unit in a regional hospital, where they remain until they are discharged to go home. Infants admitted to the Juliana Children's Hospital usually remain in the unit until they are discharged to go home.

During the first RCT (inclusion period: April 2000 – March 2002) we evaluated the effect of the basic elements of Developmental Care (DC). The intervention was based on the reduction of light and sound through the use of standardized incubator covers and the support of motor development and physiological stability by positioning the infant in ways that encourage flexion and containment through the use of standardized nests. The control group received standard care without incubator covers or forms of nesting.

During the second RCT (inclusion period: July 2002- August 2004) we evaluated the additional effect of individual care plans and guidance through the use of the NIDCAP behavioral and observation tool [16,19]. The intervention in the second trial consisted of NIDCAP observations of the infant before, during and after caregiving [16] every 7 to 10 days by a NIDCAP-trained developmental specialist. The trained developmental specialist wrote reports and discussed recommendations with parents and other caregivers and supported them in giving care to the infant. The first observation was done within 48 hours after birth. The control group in the second trial received the basic elements of DC as described in the first trial.

The parents were given questionnaires measuring parental stress, confidence and perceived nurse support after 1 week of their infant's birth. Parents also received a set of questionnaires, measuring parental stress, the child's health-related quality of life and child behavior at the follow-up appointments with

the neonatologist at 1 and 2 years of their child's corrected age (age corrected for gestational age at birth, thus time interval from term date). During the second RCT an additional questionnaire measuring infant temperament was send to the home addresses of parents at 9 months of corrected age. A summary of the questionnaires and outcome measures described in this thesis is shown in Table 1.

The NIDCAP was implemented in the course of the two RCT's. After the two RCT's (2 years implementation of basic DC and 2 years implementation of NIDCAP), a questionnaire was given to the nursing and (para)medical personnel in both hospitals to evaluate their opinions regarding the implementation of NIDCAP.

We developed this study design to explore the effects of two forms of developmental care (basic DC and the NIDCAP observations and guidance) on parental stress and infant behavior and health-related quality of life. We furthermore wanted to report the parents' and nursing and (para)medical staff's experiences with NIDCAP. We expected the basic elements of developmental care to positively affect parental stress and infant behavior and health-related quality of life. Furthermore we expected the more individualized NIDCAP intervention to further increase the positive effect of the basic elements of developmental care, especially on parental stress, confidence and perceived nurse support and the infant's self-regulatory behavior.

	Questionnaire	Measuring	N RCT 1*	N RCT 2*	Ch.
After 1 week	Parental Stressor Scale - NICU	Parental stress	133	150	2
admission	Nurse Parent Support Tool	Nurse support	133	150	2
	Mothers and Baby Scale - 2 scales	Parental confidence	133	150	2
9 months corr. age	Infant Behavior Questionnaire - Revised	Infant temperament	Not given	134	5
1 year corr. age	TNO-AZL Preschool Quality of Life	Health related quality of life	136	128	3
	Infant-Toddler Social & Emotional Assessment	Infant behavior	139	128	4/5
	NOSIK, Nijmegen Parental Stress Index - short	Parental stress	139	128	4/5
2 years corr. age	Child Behavior Checklist 2-3 yrs	Infant problem behavior	133		4
	NOSI, Nijmegen Parental Stress Index	Parental stress	133		4
After both RCT's	Questionnaire NIDCAP Implementation	Staff attitudes (N=124)			6

Table 1. Questionnaires given during both RCT's

* Number of infants whose parents completed the questionnaire.

RCT 1: standard care - basic elements of Developmental Care, inclusion period: April 2000 – March 2002, 192 infants included.

RCT 2: basic elements of Developmental Care – NIDCAP (Newborn Individualized Developmental Care and Assessment Program), inclusion period: July 2002- August 2004, 168 infants included.

Outline of the thesis

The objective of this thesis was to measure the effect of the basic elements of developmental care and the complete NIDCAP on several parent and infant outcomes during admission and at 1 and 2 years of age. This thesis furthermore aims to report staff's attitudes after NIDCAP implementation in a Dutch NICU.

Chapter 2 describes the effect of the basic elements of developmental care (the use of standardized nests and covers) and the more individualized NIDCAP intervention on parental stress, confidence and perceived nurse support while the child is admitted to the neonatal intensive care unit.

Chapter 3 reports on the effect of both the basic developmental care and the NIDCAP intervention on the infant's health-related quality of life at 1 year of corrected age.

Chapter 4 describes the effect of the basic elements of developmental care, compared to standard care, on parental stress and child behavior at 1 and 2 years of corrected age.

Chapter 5 reports on the effect of the complete NIDCAP intervention, compared to basic developmental care, on parental stress, child behavior and temperament and parent's opinions during the infant's first year of life.

Chapter 6 evaluates the nursing and (para)medical staff's attitudes towards the implementation of NIDCAP after the two RCT's.

In conclusion, **Chapter 7** discusses the results of both trials and the implementation evaluation and discusses the conclusions and implications that can be derived from these outcomes.

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