

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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## **SUMMARY**

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Focus in neonatal care giving has shifted to a more individualized and family-centered approach. In the 1980's Heidelise Als introduced individualized developmental care, which is based on the Synactive Theory of Development. This theory looks at the infant's individual behavior in specific circumstances and looks at the infant's emotional state transition, developmental stage and efforts at self-regulation and interaction through observed approach and avoidance behavior. This theory has led to some basic developmental care based recommendations for neonatal care such as reduced activity, light and sound levels in the infant's environment (for example by using incubator covers) and the support of the infant's (flexed) positioning (for example by the use of standardized nests).

The Newborn Individualized Developmental Care and Assessment Program (NIDCAP) is an intervention which uses a standardized observation tool. Nursing and (para)medical staff need special training to use this tool. The observation and recommendations are discussed with parents and other caregivers and parents are stimulated to become more actively involved in the caregiving process. Studies in the USA and Sweden have shown promising results but reviews on developmental care call for more large randomized controlled trials in multiple settings. Because of the labor intensive and costly characteristics of the NIDCAP, hospitals often implement the basic non-individualized recommendations of developmental care (reduced activity, light and sound and positioning support) as a first step before training personnel.

This thesis described the outcomes of two consecutive randomized controlled trials (inclusion period from 2000-2004: first trial included 192 infants and the second trial included 168 infants) in a Dutch level III NICU at two locations (Leiden and The Hague). The first trial explored the effect of basic developmental care (the use of standardized incubator covers and standardized nests) compared to standard care. The second trial explored the effect of the more individualized NIDCAP intervention compared to basic

developmental care. This thesis focused on the effects of these two interventions on the infant's behavior and health-related quality of live and the experiences of their parents and the nursing and (para)medical staff.

Chapter 2 of this thesis described the effect of basic developmental care, and the more individualized NIDCAP intervention on parental stress, confidence and perceived nursing support during the admission of the infant (completed questionnaires: RCT1=133 and RCT2=150). The NIDCAP intervention tended to increase paternal stress (decrease of the higher stress levels of mother versus father, p=.03), possibly as a result of increased involvement of fathers. No effects were found of both interventions on the overall stress level, confidence and perceived nurse support of mother and father.

The effect of basic developmental care and the NIDCAP intervention on the infant's Health-Related Quality of Life (HRQoL) at 1 year of the infant's age, corrected for prematurity, was described in **chapter 3**. HRQoL scores were good to optimal for most infants (completed questionnaires RCT1=136, RCT2=128). Neither basic developmental care nor the NIDCAP intervention improved HRQoL of very preterm infants at 1 year, as reported by parents.

In **chapter 4** we explored the effect of basic Developmental Care on the behavior of very preterm infants and parental stress at 1 and 2 years of corrected age (completed questionnaires at 1 year = 139 and at 2 years = 133), compared to standard care. We found a significant positive effect on the infant's competence behavior at 1 year (p=.009), especially on mastery motivation (p=.002) related competence behavior. No significant effects were found on parental stress and problem behavior. We therefore concluded that the basic elements of developmental care have a positive influence on the child's competence behavior at 1 year of age.

**Chapter 5** described the effects of the more individualized NIDCAP intervention, compared to basic developmental care, on parental stress and infant behavior (completed questionnaires = 128) and temperament (completed questionnaires = 134) during the first year. The NIDCAP tended to improve social relatedness behavior at 1 year (p=.011), especially when the

duration of admission in the NICU where the study took place was longer (duration of the intervention > 1.5 months, p=.006). Parents overall indicated positive effects on their own experiences and the well-being of their infant during admission but this did not significantly improve the infant's temperament or parental stress at 1 year.

An evaluation of the opinions of the (para)medical and nursing staff regarding the NIDCAP implementation during the two RCT's in the Neonatal Intensive Care Unit in Leiden and The Hague was described in **chapter 6**. We concluded that, in general, staff members (N=124) were positive with regards to NIDCAP. Staff reported observing improvement in the infants' well-being as a result of the NIDCAP caregiving. However, the NIDCAP was considered to be time-consuming and might worsen some job conditions. Respondents furthermore indicated a need for ongoing information and guidance. The nursing staff seemed to be more positive about NIDCAP, compared to the medical staff (p=.004). These findings led to the following recommendations with regards to the implementation of NIDCAP: easy access to continuous and up to date information about NIDCAP related issues and research, continuous clinical lessons and practical guidance, a multi-disciplinary approach and a multi-disciplinary NIDCAP team, possibilities to improve and discuss NIDCAP related job conditions and possibilities to review improving (time)efficiency.

Chapter 7 discussed the implications for future research and the implementation of developmental care in the light of the results described in this thesis. We only found small effects on infant behavior in a Dutch setting on the outcomes discussed in this thesis. However, both parents and staff report positive effect on the comfort and well-being of the infant during admission. A study on the effects of NIDCAP with a longer duration and possibly home visits in the Dutch setting would be an interesting sequel of the current study. Before decisions can be made with regards to the implementation of the NIDCAP, other outcomes (medical and (neuro)developmental) in other settings and a thorough cost-benefit analysis should demonstrate if future positive outcomes outweigh the costs. Until then, it seems advisable to implement the less intensive basic elements of

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developmental care and to formulate other basic recommendations for care giving and for the training of personnel, based on the NIDCAP observational tool and the synactive theory of infant development.