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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

4

Very preterm infant's behavior at 1 and 2 years of age and parental stress following basic Developmental Care

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Abstract

Objectives

To explore the effects of basic Developmental Care (DC) on the behavior of very preterm infants and parental stress at 1 and 2 years of corrected age.

Methods

Randomized Controlled Trial comparing basic DC (standardized nests and incubator covers) and controls (standard care). Parents of infants born < 32 weeks of gestation completed questionnaires measuring child behavior and parental stress at 1 year (n=139) and 2 years (n=133) of the child's age. Parental stress was measured using the Nijmegen Parenting Stress Index and child behavior was measured using the Infant-Toddler Social and Emotional Assessment and the Child Behavior Checklist 2-3.

Results

At 1 year of age children in the basic DC group had significantly higher behavior scores on the total competence domain ($p=0.009$) and the competence subscale mastery motivation ($p=0.002$), meaning that the infants showed more curiosity, persistence, obedience and enjoyment with small accomplishments. No significant effects were found on problem behavior or parenting stress.

Conclusion

Introducing a basic form of developmental care in the neonatal intensive care unit has a positive influence on the child's competence behavior at 1 year of age.

Introduction

Preterm infants show increased problem behavior compared to infants born at term. A meta-analysis¹ showed more externalizing and internalizing problem behavior in preterm infants in 13 out of 16 studies (81%) and more attention deficit hyperactivity disorder symptom behavior in 10 out of 15 studies (67%). In addition, parents of preterm infants report more stress^{2,3} and experience more maladaptation and need for support during the first year after delivery⁴ than parents of infants born at term. Holditch-Davis and colleagues⁵ found that mothers of high-risk preterm infants experienced at least one of three symptoms of post-traumatic stress disorder (re-experiencing, avoidance and increased arousal), which might relate to their overall stress levels.

Parental or post-traumatic stress and infant behavior problems seem interrelated. In a study by Miceli and colleagues⁶, the development and problem behavior of very preterm born infants at 36 months were related to maternal stress and depression at 4 months. Furthermore, the intensity of posttraumatic stress reactions after the preterm birth of parents of preterm infants correlates with the risk of the child developing sleeping and eating problems⁷.

Advances in neonatology have decreased the mortality of infants born preterm^{8,9}. To reduce morbidity and to support parents, neonatal caregiving in the neonatal intensive care unit (NICU) has shifted to a more individualized approach. In this context the Newborn Individualized Developmental Care and Assessment Program (NIDCAP)^{10,11} was introduced in the 1980's. This program is based on individual observations of preterm infant behavior during caregiving that result in individual recommendations for caregiving.

A three-center NIDCAP intervention study in the United States showed positive outcomes on parental stress and infant behavior, such as improved self-regulation (motor and autonomic system) and less required facilitation on the Assessment of Preterm Infants' Behavior (APIB) at 2 weeks after the

expected due date¹². A study in Sweden found improved behavior after NIDCAP, as reported by parents at 3 years of age¹³.

General developmental care based recommendations are reduced light, sound and activity levels in the NICU and the use of nests to support the infant's posture and incubator covers to decrease the light and sound level inside the incubator to provide an environment more comparable to the circumstances in the womb. The guidance by a NIDCAP-trained developmental specialist is intensive and costly. The implementation of the basic recommendations of developmental care is therefore often seen as a first step when implementing NIDCAP, before deciding to train staff members. In this context information needs to be provided about the effects of this basic form of developmental care.

The randomized controlled trial in the current study was designed to measure whether providing only basic developmental care (the use of standardized nests and covers) would have a positive long-term effect on very preterm infants' behavioral problems and their parents' stress at 1 and 2 years of age. We hypothesized that the protective characteristics of the nests and covers would allow the infants to rest and sleep more and become more alert and calm. The protective characteristics of the nests and covers might therefore improve the infant's self-regulation and behavior. Improved infant behavior and the sight of their infant being more comfortable in the nests and under the incubator covers was thought to reduce parental stress.

Methods

Subjects

Infants born with a gestational age (GA) below 32 weeks admitted to a NICU at two locations in the Netherlands (inclusion April 2000 – May 2002) were randomly assigned, by using sealed envelopes, to a control or intervention group within 48 hours after birth.

Exclusion criteria were: infants of drug-addicted mothers and infants with congenital heart disease or other major birth anomalies. According to protocol, infants in both groups who were admitted for less than 5 days were excluded from follow-up because the duration of the basic DC intervention was hypothesized not to be long enough to measure effects. Based on the primary outcome of this study, the developmental tests at follow up, a sample size power calculation showed that 140 infants (70 controls, 70 intervention) were needed to show a significant difference with a power of 80%, based on the expected difference of half a standard deviation. We included more infants (a total of 192 infants) after parental informed consent was obtained, because of anticipated loss to follow up. The Medical Ethics Committees of both locations approved this study.

Basic Developmental Care Intervention

The basic developmental care (DC) intervention consisted of the reduction of light and sound inside the incubator through the use of standardized incubator covers. Standardized nests were used to support motor development and physiological stability by positioning the infant in ways that encourage flexion and containment. The control group received standard care prior to the beginning of this study when no incubator covers or forms of nesting were used. All infants were cared for in the same unit with the same light, sound and activity levels. Therefore, the only difference between the groups was the use of standardized incubator covers and nests. The nurses could not be blinded because of the visual aspects of the intervention. They received a clinical lesson about the use of the standardized materials.

Outcome Measures

All ages mentioned hereafter are corrected for prematurity (age corrected for gestational age at birth, thus time interval from term date). At 1 and 2 years of age the children were seen for follow-up by the neonatologist and parents were asked to complete a set of questionnaires.

Parent and child characteristics:

Demographic variables were obtained from the questionnaires and included parental age, educational level and country of birth (the Netherlands/other).

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Infant characteristics at birth were obtained from the medical records and included gender, gestational age, birth weight and the Clinical Risk Index for Babies (CRIB) score. The CRIB score¹⁴ assesses initial neonatal risk by scoring birth weight, gestational age, congenital malformation, maximal base excess in the first 12 hours and minimum and maximal oxygen requirements in the first 12 hours after birth.

Child behavior:

At 1 year of the infant's age, parents completed a Dutch translation of the Infant-Toddler Social and Emotional Assessment (ITSEA)¹⁵. This questionnaire was translated into Dutch and some items were deleted from the original questionnaire because of the young age of the infants. The following subscales were excluded from the original ITSEA: peer aggression, general anxiety (i.e. "worries about own body"), prosocial peer relations and the maladaptive scale. The modified questionnaire consisted of 15 behavior subscales, divided over 5 main factor domains: externalizing (activity/impulsivity and aggression/defiance), internalizing (depression/withdrawal, separation distress and inhibition to novelty), dysregulation (sleep problems, negative emotionality, eating problems, sensory sensitivity), competence (compliance, attention, imitation/play, mastery motivation, empathy) and social relatedness.

Other than the above described deleted subscales, zero to three items were removed from the remaining subscales in each domain. The modified questionnaire used in this study consisted of 107 items with answers on a 3 point Likert scale (0=not true/rarely, 1=somewhat true/sometimes, 2=very true/often). In a previous study the original questionnaire was validated¹⁵. In the current study alpha's ranged from 0.78 to 0.87 for all domains of the Dutch translated questionnaire, which is comparable to the Cronbach alpha's, ranging from 0.80 to 0.90 (and alpha of 0.56 for social relatedness), found for the domains of the original ITSEA¹⁵. The mean domain scores ranged from 0 to 2 and a higher score represented more problem or competence behavior.

At 2 years of age parents received the Child Behavior Checklist 2-3 yrs. (CBCL 2-3)¹⁶. The CBCL 2-3 includes 100 problem behavior items divided

into 5 domains; total internalizing (anxiety/depressed and withdrawn), sleep problems, somatic problems, total externalizing (aggressive behavior and destructive behavior) and a total behavior score. Domain scores were calculated by adding the item scores within a scale. Mean test-retest reliability (0.87) of the CBCL was good¹⁶ and in the current study Cronbach's alpha ranged from 0.57 (somatic problems) to 0.95. A higher total score (table 3 shows the range of total scores per scale) represented more problem or competence behavior.

Parenting Stress:

The Nijmegen Parenting Stress Index (NOSI)¹⁷ is a Dutch version of the Parenting Stress Index (PSI)¹⁸. At 1 year parents were asked to complete the short version, the NOSIK. The NOSIK consists of 25 parental-stress-related statements (the items that performed best in the NOSI complete version) with answers on a 5 point Likert scale ranging from 1 (totally disagree) to 5 (totally agree). The NOSIK has a total parenting stress scale and a parent and child domain. The Cronbach's alpha score of the total scale of the short version, NOSIK, was good ($\alpha=0.95$)¹⁷ and this was also true in the present study ($\alpha=0.92$).

The complete version, the NOSI, was given at two years of age and consists of 123 parental-stress-related statements with a total score and a child and parent domain. The parent domain contains the subscales: competence, parent role restriction, attachment, depression, health, isolation and spouse. The child domain contains the subscales: adaptability, mood, demandingness, distractibility/hyperactivity, reinforces parent and acceptability. Cronbach's alpha's of the domains (parent, child and total score) of the complete version, the NOSI, were good in earlier studies and ranged from 0.95 to 0.97¹⁷. In this study the Cronbach's alpha reliability scores of the domains ranged from 0.93 to 0.95. The mean scale scores on the NOSI(K) ranged from 0 to 5 and a higher score represented more parenting stress.

Analysis

Mean scores were calculated for the domains and subscales of the ITSEA and NOSI(K). Mean scores were calculated when less than 30% of the items

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within a domain or subscale were missing. The CBCL domain scores represented a sum of all items belonging to the domains.

For statistical analysis SPSS 11.0 for Windows was used. Child and parent characteristics were compared with the Chi-square test, the Chi-square test for trend, the two-sample t-test or the non-parametric Mann-Whitney test, where appropriate.

Mean and total scale scores between groups were compared using a covariate analysis in which the infant and parent characteristics (parental age, educational level and country of birth (the Netherlands/other) and the infant's gender, gestational age, birth weight and CRIB score) and the completion day (the number of days between the infant's age of 1 and 2 years, corrected for prematurity, and the date when the parents completed the questionnaire) were included as covariates for a more precise estimation of the difference between the intervention and control groups and to correct for possible confounders. Because of multiple testing a p-value of below 0.01 was chosen as significance level.

The percentages of infants scoring high (> 95/90th percentile, compared to the reference groups) on problem behavior or parental stress, were reported and compared between both groups using a Chi square test. The CBCL reference group consisted of the scores of Dutch girls from a study by Koot¹⁹ and the NOSI reference group was derived from the manual (scores of non-clinical Dutch mothers)¹⁷. The reference group of the ITSEA of 12-17 month old boys and girls in the USA as described in a study by Carte and colleagues¹⁵ was not used because a modified version of the ITSEA was used in the current study.

Results

Subjects

Figure 1 shows the loss to follow-up. The loss to follow-up in this figure also included infants transferred within 5 days of admission. One hundred and

ninety two infants were included in this study (Figure 1). At 1 year, 139 questionnaires were returned of 146 sets of parents who received the questionnaire (return rate: 95% of received questionnaires and 83% of all included infants minus infant deaths).

At 2 years 133 questionnaires were returned (Figure 1) of the 142 sets of parents that received the questionnaire (return rates: 94% and 80%). At 2 years 1 set of parents in the control group and 6 sets of parents in the DC group forgot to fill in the CBCL behavior questionnaire on the last pages of the set of questionnaires.

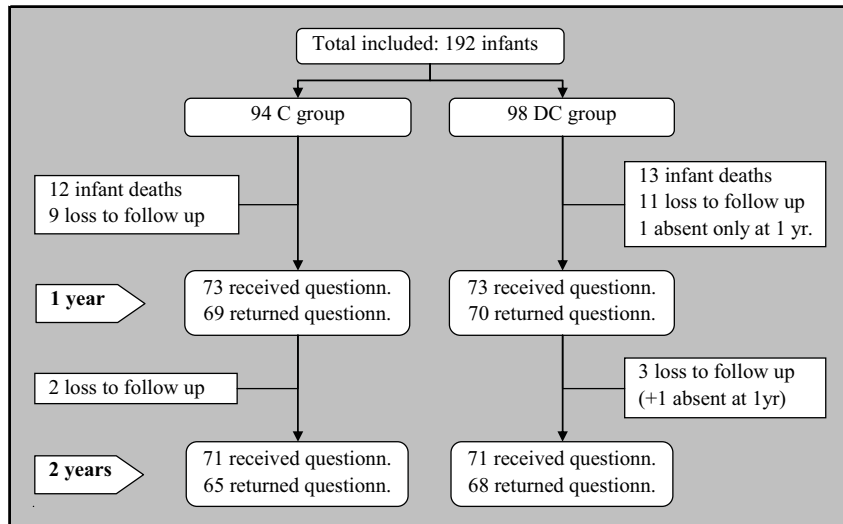


Figure 1. Loss to follow up and returned questionnaires.

The infant and parent characteristics were comparable between both groups within the returned questionnaires (Table 1), with the exception of the corrected age of the infant when completing the questionnaire at 2 years ($p=.008$). This variable was one of the covariates in the covariance analysis of the questionnaires.

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		DC	Control	Difference
		n(%) or mean(sd)	n(%) or mean(sd)	p-value [^]
Infant and parent characteristics		N= 70	N= 69	
Gender (male)		37 (53%)	46 (67%)	.10
Gestational age at infant's birth (weeks)		29.5 (1.6)	29.1 (2.0)	.22
Birth weight (grams)		1249 (341)	1237 (324)	.84
CRIB score 14		3.2 (3.0)	3.7 (3.0)	.37
Duration of admission in intervention hospitals (days; median/range)		36.5 (6;100)	35 (5;114)	.50 ^o
Maternal age at infant's birth (years)		30.2 (5.1)	30.5 (4.8)	.74
Maternal education level #	low	31 (44%)	22 (32%)	.25
	intermediate	23 (33%)	28 (41%)	
	high	16 (23%)	18 (27%)	
Country of birth mother (the Netherlands)		48 (69%)	53 (77%)	.28
Paternal age at birth infant (years)		33.1 (5.3)	33.8 (5.7)	.47
Paternal education level #	low	27 (39%)	16 (24%)	.12
	intermediate	25 (36%)	31 (46%)	
	high	17 (25%)	20 (30%)	
Country of birth father (the Netherlands)		52 (74%)	55 (80%)	.45
Completed by ...	mother	48 (70%)	48 (72%)	.81
	father	8 (12%)	9 (13%)	
	both	13 (19%)	10 (15%)	
Completing day after age 1 years (days; median/range)		15 (-12;95)	9.5 (-11;117)	.10 ^o
Completing day after age 2 years (days; median/range)		18 (-14;213)	9 (-13;112)	.008 * ^o

Table 1. Comparison of infant and parent characteristics of completed questionnaires at 1 year.

* p < .01

[^] Two sample t-test / Chi square test (for trend)

Low = vocational education, intermediate = high school, high = college education/ university

^o Non parametric Mann-Whitney test

There were no significant differences in gender, gestational age at birth and birth weight, within the infants whose parents did not receive or complete the questionnaire (non-responders: 1 year: controls N=25, basic DC N=28, 2 years: controls N=29, basic DC N=30, data not shown).

Behavior According to ITSEA and CBCL Parent Questionnaires

Table 2 shows that at 1 year of age (ITSEA) the mean scores of the total Competence domain were better in the DC group compared to the controls (difference (99%CI)= 0.15 (0.003;0.30), p=0.009). Within the subscales of the competence domain, children in the DC group had significantly better mastery motivation competence mean scores compared to the controls

(difference (99%CI)= 0.20 (0.03;0.37), p=0.002), which indicates that children in the DC group showed more curiosity, persistence and enjoyment with small accomplishments. Although mean scores on problem behavior at 1 year tended to be higher in the DC group, indicating more problem behavior, this difference did not reach statistical significance.

ITSEA	DC	C	DC-C
Domain scores (range 0-2)	N=70 (min n=67)	N=69 (min n=67)	Difference #
Problem behavior	Mean (sd)	Mean (sd)	Difference (99% CI) #
Externalizing	.50 (.30)	.38 (.28)	.06 (-.06;.19)
Internalizing	.52 (.26)	.44 (.26)	.05 (-.07;.17)
Dysregulation	.45 (.26)	.39 (.21)	.005 (-.10;.11)
Competence behavior	Mean (sd)	Mean (sd)	Diff (99% CI) #
Competence	1.16 (.29)	1.03 (.33)	.15 (.003;.30)*
Mastery Motivation ~	1.57 (.32)	1.41 (.37)	.20 (.03;.37)*
Social Relatedness	1.64 (.27)	1.60 (.29)	.08 (-.06;.21)

Table 2. Comparison DC and C on infant behavior at 1 year (ITSEA) of corrected age.

- * p < .01
- # Covariance analysis; difference (99% CI), corrected for the completion day after the age of 1 year, infant gender, gestational age, birth weight, CRIB and the age, educational level and country of birth of parents. Min N DC=62, C=65
- ~ Subscale of competence domain of ITSEA
- . For all ITSEA domains: higher mean score represents more behavior problems/competence

At 2 years of age no significant differences were found between the two groups on child behavior problems using the CBCL 2-3 (Table 3). The percentages of infants scoring non-optimal on problem behavior also did not differ between the two groups.

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CBCL 2 years	DC	C	DC-C	DC	C
Problem behavior	N=62	N=64	Difference #	% non optimal	% non optimal
Scale scores (range)	Mean(sd)	Mean(sd)	Diff (99% CI) #	%(n) ≥95 perc.	%(n) ≥95 perc.
Sleep Problems (0-14)	2.4 (2.3)	2.8 (2.9)	-38 (-1.62;86)	8.1 % (5)	7.8 % (5)
Somatic Problems (0-28)	2.7 (2.4)	3.1 (2.5)	-50 (-1.75;76)	6.5 % (4)	10.9 % (7)
				%(n) ≥90 perc.	%(n) ≥90 perc.
Internalizing (0-50)	5.1 (4.7)	5.7 (4.7)	-40 (-2.73;1.93)	8.1 % (5)	10.9 % (7)
Externalizing (0-52)	10.8 (7.3)	11.0 (8.1)	.20 (-3.41; 3.80)	11.3 % (7)	12.5 % (8)
Total Behavior (0-198)	27.2 (18.1)	29.0 (20.2)	-1.12 (-10.4;8.1)	9.7 % (6)	14.1 % (9)

Table 3. Comparison DC and C on infant behavior at 2 years (CBCL) of corrected age.

Covariance analysis; difference (99% CI), corrected for the completion day after the age of 2 years, infant gender, gestational age, birth weight, CRIB and the age, educational level and country of birth of parents. Min N DC=57, C=59

. For all CBCL scales: higher mean score represents more problem behavior

Parenting Stress

At 1 and 2 years of age no significant differences were found between the two groups on parenting stress (Table 4). Although parental stress at 2 years tended to be higher in the DC group, this difference was not statistically significant and the percentages of parents scoring non-optimal did not differ between the two groups.

	DC	C	DC-C	DC	C
	Mean(sd)	Mean(sd)	Difference #	% non optimal	% non optimal
NOSIK (short version) 1 year	N=70	N=69	diff.(99%CI) #	%(n) ≥90 perc.	%(n) ≥90 perc.
Total score Parent Domain	1.74 (.71)	1.70 (.67)	.03 (-.29;.35)		
Total score Child Domain	1.95 (.77)	1.78 (.76)	.11 (-.21;.43)		
Total Stress score	1.86 (.70)	1.75 (.68)	.08 (-.23;.38)	9 % (6)	3 % (2)
NOSI 2 years	N=67	N=65	diff.(99%CI) #	%(n) ≥90 perc.	%(n) ≥90 perc.
Total score Parent Domain	2.06 (.67)	1.85 (.64)	.22 (-.13;.56)	16 % (11)	15 % (10)
Total score Child Domain	2.08 (.52)	1.91 (.52)	.16 (-.10;.42)	12 % (8)	8 % (5)
Total Stress score	2.07 (.55)	1.89 (.53)	.19 (-.09;.46)	16 % (11)	8 % (5)

Table 4. Comparison DC and C on parenting stress at 1 year (NOSIK, short version) and 2 years (NOSI) of corrected age

Covariance analysis; difference (99% CI), corrected for the completion day after the age of 1 or 2 years, infant gender, gestational age, birth weight, CRIB and the age, educational level and country of birth of parents. Min N 1yr: DC=64, C=66, 2 yrs: DC=62, C=59

. For all NOSI(K) scales: higher mean score represents more parental stress (range 0-5)

Discussion

This randomized controlled trial demonstrated that very preterm infants who received basic elements of developmental care (standardized nests and incubator covers) showed more competence behavior at 1 year of age, especially regarding mastery motivation. Parents of children that received basic Developmental Care reported that their child showed more curiosity, persistence and enjoyment with small accomplishments and that they were more often well-behaved and obedient. While competence behavior at 1 year was improved in the basic DC group, parents also tended to report more problem behavior at 1 year, but this small difference had disappeared by 2 years of age. At 2 years of age we used the CBCL 2-3 because this questionnaire is often used in the Netherlands and in other intervention studies. This questionnaire only included problem behavior items and no competence behavior items and therefore it was not possible to test the continuation of improved competence behavior at 2 years of age.

Although parents in the DC group reported that their child showed more competence behavior, there were no significant differences between the groups in parental stress. The improved competence behavior found in this study therefore does not seem to be related to a decrease in parental stress as expected in the context of the correlation of parental stress and child behavior found in previous studies^{6,7}.

The children and parents in this study had problem behavior and stress scores comparable to reference groups from the normal population. A meta-analysis showed that previous studies found more behavior problem in preterm infants¹. Most behavioral impairment was found in studies with infants < 30 weeks of gestation¹, while the infants included in this study were < 32 weeks of gestation. A recent study with Dutch preterm infants < 32 weeks also showed that the prevalence of behavior problems was comparable to term infants using the CBCL 2-3 at 2 years of age²⁰.

Previous studies on the effect of the complete NIDCAP intervention with individual observations and guidance found positive effects on infant

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behavior and parental stress. These effects were mainly found around the expected due date, such as improved behavior on the Assessment of Preterm Infant Behavior (APIB) test at 2 weeks of age, corrected for prematurity^{12,21,22}, improved emotional regulation and motor quality on the BSID II Behavior Rating Scale at 9 months of corrected age²¹ and improved parental stress at 2 weeks corrected age, using the Parenting Stress Index¹². A Swedish study reported improved child behavior on the H  k-Cederblad Child Behaviour Interview and improved child communication on the Early Relational Assessment at 3 years of age¹³. At 5 years of age, a higher, however non-significant, percentage of survival without attention deficits was found in the NIDCAP group²³. The authors of the Swedish study call for caution in interpreting their results because of a small sample size. Kaaresen and colleagues²⁴ studied the effects of a modified version of the Mother-Infant Transaction Program with 8 sessions during admission and 4 home visits after discharge. They found a decrease on the total parental stress domain and on both the parent and child domains of the Parenting Stress Index questionnaire at 6 and 12 months of corrected age.

In the current study, no effects were found of a basic form of developmental care on parental stress or problem behavior during follow-up at 1 and 2 years of age. A more individualized approach, such as the individual behavior observation and recommendations and the guidance of parents of the complete NIDCAP intervention, might decrease parental stress and decrease problem behavior of the infants. Further research that explores the effects of a more individualized form of Developmental Care, such as the NIDCAP, on child behavior and parental stress in the first year after intervention is needed.

Two intervention studies regarding the Infant Health and Development Program, (IHDP; home visits, child development center services and parent group meetings until 3 years of age in the USA) and the Avon Premature Infant Project (APIP; two interventions consisting of weekly home visits up to 2 years of age, a developmental education program and a social support intervention in the UK) found less problem behavior on the CBCL after the intervention ended at respectively 3 and 2 years of age but no significant differences were found at follow up at 5 years^{25,26} and 8 years of age²⁷. An

intervention with weekly home visits for 8 weeks, resulted in improved competence behavior, such as better problem solving and activity, cooperation, general emotional tone and vocalization at 7 months of age²⁸. These studies on the effect of interventions with preterm infants show effects on child competence behavior but not on behavior problems at follow up. The current study also found no effects on problem behavior but did find an effect on competence behavior. There seems to exist an opportunity for interventions to positively influence competence behavior, which is also an important part of the behavioral spectrum. Future research on the effect of interventions at the NICU should, besides exploring effects on problem behavior, also focus on the child's competence behavior.

In conclusion, this study shows that basic developmental care (the use of standardized nests and covers) during the admission of very preterm infants does not have a significant effect on the child's problem behavior and parental stress at 1 and 2 years of age. However, problem behavior and parental stress scores in the current study did not seem to differ much from term reference groups. There appeared to be a window of opportunity to improve the child's competence behavior and this study found a significant effect of the basic elements of developmental care on competence (mastery motivation) behavior at 1 year of age. The effects of basic DC on the infant's growth and development will be described elsewhere and are also of importance before recommendations for implementation can be given. This study shows that basic developmental care has a positive effect on infant competence behavior at 1 year and this form of developmental care seems easy to implement.

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