

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

Pal, S.M. van der

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2

CHAPTER

Parental experiences during the admission of their very preterm infant after two Developmental Care interventions

Sylvia M. van der Pal Celeste M. Maguire Saskia le Cessie Jan Maarten Wit Frans J. Walther Jeanet Bruil

Abstract

Aim:

To explore the effect of two developmental care interventions on parental stress, confidence and perceived nursing support.

Methods:

Two consecutive randomized controlled trials comparing 1) standard care versus basic developmental care (standardized nests and incubator covers) (n=133) and 2) basic developmental care versus the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) (n=150). Parents of infants born < 32 weeks gestational age completed questionnaires after the first week of admission.

Results:

No significant differences were found on parental stress, confidence or perceived nursing support. The difference in stress between mother and father tended to be less in the NIDCAP intervention group (p=.03).

Conclusion:

Both developmental care interventions had little effect on parental experiences during admission. As a result of increased paternal stress, the NIDCAP intervention tended to decrease the difference in stress levels of fathers and mothers, possibly because of the increased involvement of father during the NIDCAP intervention.

Introduction

The preterm birth of an infant is in most cases unexpected and overwhelming for parents. Parents of preterm infants report more stress ^{1,2} and experience more maladaptation and need for support during the first year after delivery ³ than parents of infants born at term. Mothers of high-risk preterm infants may furthermore experience symptoms of post-traumatic stress syndrome ⁴. High parental distress, anxiety and posttraumatic stress is related to poorer parental and infant outcomes, such as: behavior, sleeping and eating problems, poorer developmental outcomes and less effective parental coping strategies ⁵⁻⁸.

Neonatal care has become more family-centered over the past years. The Newborn Individualized Developmental Care and Assessment Program (NIDCAP) ⁹ is an intervention based on the individuality of preterm infants and their families and was developed by Heidelise Als in the 1980's. This program is based on the Synactive Theory of Infant Development in which the infant's behavior is observed along four channels of communication: being the autonomic (color, respiration patterns, etc.), motor (posture, tone and movements), state organization (type and range of sleep and wake states available to the infant from asleep to aroused and state transition) and 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 before, during and after caregiving by a trained developmental specialist. A narrative of the observation is written and discussed with parents and other caregivers as a guide for caregiving and for modifying the infant's environment ⁹.

The results of NIDCAP intervention studies in the United States and Sweden show positive infant outcomes ¹⁰⁻¹⁵. The effect of NIDCAP on parental stress has been studied in Sweden ¹⁶ and in a three-center study in the USA ¹¹. In the three-center study, mothers of infants that had received NIDCAP indicated less parental stress and described their infant as being more independent when completing the Mother's View of the Child (MVC) compared to controls, two weeks after the expected date of confinement ¹¹. Recently, the effects of

various developmental-care-based interventions were reviewed ¹⁷. The interventions ranged from basic interventions, focused on positioning and modification of external stimuli, to more individualized developmental care interventions, such as the NIDCAP program. The authors concluded that overall limited benefits and no major harmful effects were found, but that the significant effects were mainly based on studies with small sample sizes and several of these findings were not supported in other settings.

The current study aims to explore the effect of a basic and less intensive form of developmental care (the use of standardized covers and nests) and the effect of the more intensive and individualized NIDCAP intervention (with individual behavior observations and guidance) on parental experiences during admission. Our hypothesis was that the basic elements of developmental care would reduce parental stress because infants may appear more comfortable to parents because of the incubator covers and nests. The more individualized NIDCAP intervention was thought to further reduce parental stress and increase parental confidence and the nurse support parents perceived. Previous studies have shown that mothers of preterm infants report more stress in comparison with fathers ^{18,19}. Our secondary hypothesis was that NIDCAP would decrease the difference in maternal and paternal stress levels because of the active inclusion of both parents in the caregiving process.

Methods

Developmental care interventions

Two consecutive randomized controlled trials (RCT's) at a tertiary NICU with two locations in the Netherlands were carried out to measure the effect of two Developmental Care interventions. The first randomized controlled trial (inclusion: April 2000 to May 2002) studied the effect of the basic elements of developmental care. The basic developmental care intervention consisted of the reduction of light and sound through the use of standardized incubator covers, which shielded the incubator on the top and three sides. Motor development and physiological stability were supported by using

standardized nests and positioning aids to support a flexed position with boundaries. The control group received the standard care prior to the beginning of this research project, when no covers or nests were used.

The second randomized controlled trial (inclusion: July 2002 to August 2004) studied the additional effect of NIDCAP compared to the basic elements of developmental care. The intervention in the second trial consisted of NIDCAP observations of the infant's behavior before, during and after caregiving every 7 to 10 days by a NIDCAP-trained developmental specialist ⁹. A psychologist and 5 nurses were trained to use the NIDCAP observational tool ⁹. These trained developmental specialists wrote behavioral reports and discussed individualized 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. A nursing team that had received clinical lessons in the NIDCAP approach cared for the infants in the NIDCAP intervention group. The control group in the second trial received nests to support positioning and incubator covers (basic developmental care). Parents in both groups received the support of social workers when needed, which is part of the normal protocol. The Medical Ethics Committees of both locations approved this study.

Subjects

Infants born at a gestational age (GA) below 32 weeks were randomly assigned to a control or intervention group within 48 hours after birth by using sealed envelops. Exclusion criteria were: infants of drug-addicted mothers and infants with congenital heart disease or other major birth anomalies. According to protocol, all infants admitted for less then 5 days were excluded from follow-up and analysis because the duration of the basic DC intervention was expected not to be long enough to detect an effect. A sample size power calculation showed that 140 infants (70 control, 70 intervention) were needed per RCT to show a significant difference with a power of 80%, based on the expected difference of half a standard deviation on the primary outcome of the two RCT's (developmental tests at follow up). After parental informed consent was obtained, both parents were given a questionnaire to complete at home one week after their infant's birth (after

one week of admission). Infant and parent characteristics were obtained from the medical records and the questionnaire.

Measures

Infant and parent characteristics:

The infant and parent characteristics used to describe and compare the groups were: gender, gestational age (GA) at birth, birth weight, Clinical Risk Index for Babies (CRIB) score, infant's age when parents completed the questionnaire (days after birth), duration of admission to the intervention NICU, parental age, parental educational level and whether parents were living together or not. The CRIB score ²⁰ 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.

Mothers and Baby Scale (MABS):

Two scales of the Mothers and Baby Scale 21 were used and translated into Dutch, being the Confidence in Caregiving (CC) scale (α =0.93; 13 items) and the Global Confidence (GC) scale (α =0.78; 3 items). Some items were slightly altered to make them more appropriate for the NICU setting. For example, the item "I've been afraid I might drop my baby" was changed into "I've been afraid that I might accidentally pull one of the lines or tubes loose". The reliability of the scales was reasonable in the present study (CC mother/father α =0.80/0.78, GC mother/father α =0.63/0.60). Items were recoded before analysis so that all item categories were on a 6-point Likert scale ranging from 0 (very insecure) to 5 (very confident) with a higher score corresponding with higher parental confidence.

Nurse Parent Support Tool (NPST):

The Nurse Parent Support Tool 22 , consists of 21 descriptions of nurse support on a 5-point Likert scale ranging from 1 (almost never seen) to 5 (almost always seen) and a total nurse support scale (α =0.95) measuring the amount of nurse support parents perceive. Examples of items are: "The nursing staff at this hospital in general has: ...Taught me how to take care of my child" or "...Made me feel important as the parent". A higher score corresponded with

higher perceived nurse support. The Cronbach's alpha of this translated Dutch version was 0.90 (for mothers) and 0.92 (for fathers).

Parental Stressor Scale-NICU (PSS-NICU):

The Parental Stressor Scale-NICU 23 includes 44 descriptions of NICU related stressors and 1 item concerning the overall stress of parents, all on a 5point Likert scale ranging from 1 (not stressful) to 5 (very stressful). There is an extra answer possibility for parents to indicate that they did not experience the stressor (not applicable), which was assigned a score of 1 (not stressful). The questionnaire consists of five subscales measuring parental stress on: infant's appearance, parent role alterations, sights and sounds, staff behavior and communication and a total score. The infant's appearance scale includes stressors such as; "tubes and equipment on or near my baby" and "when my baby seemed to be in pain". The parent role alterations scale includes stressors such as; "being separated from my baby", "not being able to hold my baby when I want" and "feeling helpless about how to help my baby". A higher score corresponded with a higher stress level. Alpha reliability scores ranged from 0.73 to 0.96 ²³⁻²⁵. In the present study, using the Dutch translation, the alpha scale reliability for the total score scale was 0.93 (alpha scores for the scales ranged from 0.72 to 0.89).

Analysis

For statistical analysis SPSS 11.0 for Windows was used. Average scale scores were calculated if the scale contained no more than 30% missing items. To test whether the infant and parent characteristics at birth were comparable between groups, the Chi square test, the Chi-square test for trend, the two-sample t-test or the non-parametric Mann-Whitney test were applied where appropriate.

To measure effect size between groups a covariance analysis was carried out in which some of the infant and parent characteristics (the infant's gender, GA at birth, CRIB score, parental age, parental educational level and the infant's age when parents completed the questionnaire) were included as covariates. This was done to obtain a more precise estimation of the differences between the intervention and control groups. The differences

between mother and father per infant were also compared between groups with a covariance analysis. Because of multiple testing a p-value of below 0.01 was chosen to indicate significance on all outcomes.

Results

Subjects

The loss to follow-up and return rates of both RCT's are shown in Figure 1. The loss to follow-up in this figure also includes infants transferred within 5 days of admission.

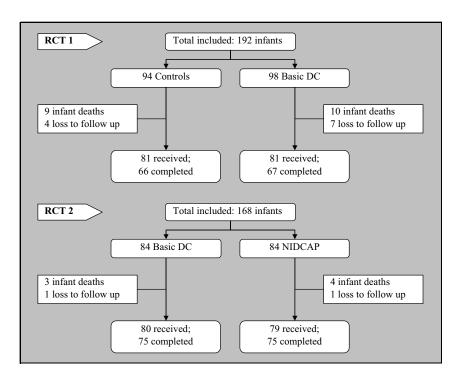


Figure 1. Loss to follow up and returned questionnaires.

During the first RCT, 133 questionnaires were returned (82% of the 162 sets of parents that were given the questionnaire and 77% of all included infants minus deaths). One mother and 6 fathers in the standard care control group

and 1 mother and 3 fathers in the basic DC intervention group did not complete the questionnaires while their spouse did.

During the second RCT 150 questionnaires were returned (94% of 159 parents that received the questionnaire and 93% of all included infants minus deaths). Two mothers and 2 fathers in the basic DC control group and 7 fathers in the NIDCAP intervention group in the second trial did not complete the questionnaires while their spouse did.

The two groups in the first RCT were comparable regarding the parent characteristics (Table 1). The two groups in the second RCT were comparable regarding the child characteristics but mothers in the NIDCAP group tended to be younger (p=.02). This variable was included as one of the covariates in the covariance analysis. The infants in both groups during both trials whose parents did not receive (because of loss or death) or complete the questionnaire, were also comparable concerning gender, gestational age at birth and birth weight (data not shown).

		Controls (N=66)	Basic DC (N=67)	Basic DC (N=75)	NIDCAP (N=75)
		mean(sd) or n(%) ^			
Gender (male), n(%)		42 (64%)	32 (48%)	37 (49%)	43 (57%)
Gestational age at birth (weeks)		28.9 (1.9)	29.0 (1.7)	29.3 (1.6)	29.6 (1.7)
Birth weight (grams)		1185 (341)	1193 (329)	1247 (344)	1239 (319)
CRIB score ²		4.1 (3.0)	4.0 (3.8)	2.8 (3.0)	2.9 (2.8)
Both parents caucasian, n(%)		52 (84%)	49 (75%)	59 (82%)	56 (78%)
Parents not living together, n(%)		4 (6%)	4 (6%)	4 (5%)	9 (12%)
Maternal age (years), n(%)	<25	7 (11%)	13 (19%)	4 (5%)*	11 (15%)*
	25-35	47 (71%)	38 (57%)	47 (63%)	49 (65%)
	>35	12 (18%)	16 (24%)	24 (32%)	15 (20%)
Maternal educational level	Low	18 (27%)	24 (36%)	18 (24%)	26 (36%)
n(%)	Interm.	31 (47%)	27 (41%)	25 (34%)	25 (35%)
	High	17 (26%)	15 (23%)	31 (42%)	21 (29%)
Paternal age (years), n(%)	<25	5 (8%)	4 (6%)	4 (5%)	4 (5%)
	25-35	31 (47%)	35 (53%)	39 (53%)	52 (69%)
	>35	30 (46%)	27 (41%)	31 (42%)	19 (25%)
Paternal educational level	Low	20 (30%)	22 (33%)	15 (21%)	19 (28%)
n(%)	Interm.	26 (39%)	25 (38%)	31 (43%)	22 (32%)
	High	20 (30%)	19 (29%)	27 (37%)	28 (41%)
Infant's age completion questionnaire (days) #	lays) #	10 (6-29)	11 (6-67)	14 (4-85)	14 (6-88)
Admission duration (days) #		34 (5-105)	40 (6-142)	30 (5-128)	38 (6-160)

 Table I.
 Comparison of infant and parent characteristics of returned questionnaire.

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 sion p-value < 05</td>

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sign. p-value < .05 educational level: low (vocational training) / intermediate (high school) / high (college education/ university) Clinical Risk Index for Babies (CRIB), ²⁰ statistical Risk used: chi-square test (for linear trend), n(%) / two-sample t-test, mean(sd) non parametric Mann-Whitney test, median (range).

Effect of basic developmental care and NIDCAP

No significant differences were found on mother's confidence, perceived nursing support and stress scores in both trials (Table 2). The expected decrease in maternal stress in both trials and increase in maternal confidence and perceived nurse support of the mothers in the NIDCAP group in the second trial were not found. Mothers in the basic DC intervention group during the first trial tended to show more stress on the subscale staff behavior and communication (p=.05), compared to the standard care controls.

The scores of fathers in both RCT's also did not show significant differences and the expected effects were not observed (Table 2). Fathers in the NIDCAP intervention group in the second trial reported more stress on the subscale staff behavior and communication, but this difference was not significant (p=.046). In the first trial the fathers in the basic DC intervention group also tended to experience more stress compared to the standard care control group (NS).

In both trials, overall mean parental confidence scores were approximately 3.50, which corresponds with being moderately confident. Mean nurse support scores were approximately 4.30, which corresponds with nursing staff showing much support. Mean stressor scores were approximately 2.00, which corresponds with NICU stressors being a little stressful.

Effect on difference between father and mother

Overall, the largest differences in stress level between mother and father were on the PSS-NICU subscale parent role alterations. No significant effects of the two interventions were found on the difference of mothers and fathers regarding parental confidence, perceived nurse support and parental stress in both trials (Table 3). The difference in total stress levels of mothers (higher) compared to fathers tended to be lower in the NIDCAP intervention group in the second RCT (p=.034).

	Controls	Basic DC	RCT 1	Basic DC	NIDCAP	RCT 2
Mother Total scales ∼	Mean (sd)	Mean (sd)	Diff (99%CI)#	Mean (sd)	Mean (sd)	Diff (99%CI)#
Confidence caregiving	3.46 (.72)	3.41 (.75)	.09 (27;.44)	3.34 (.76)	3.43 (.65)	09 (42;.23)
Global confidence	3.42 (.86)	3.41 (.94)	.03 (40;.46)	3.39 (.80)	3.49 (.78)	.01 (35;.36)
Nurse support	4.19 (.54)	4.18 (.52)	.04 (21;.29)	4.14 (.51)	4.26 (.53)	14 (37;.10)
Total stressor score	2.09 (.55)	2.16 (.58)	12 (38;.15)	2.25 (.60)	2.16 (.54)	.09 (18;.36)
Father Total scales ~	Mean (sd)	Mean (sd)	Diff (99%CI)#	Mean (sd)	Mean (sd)	Diff (99%CI)#
Confidence caregiving	3.46 (.62)	3.43 (.69)	.06 (27;.39)	3.51 (.70)	3.45 (.65)	.05 (27;.36)
Global confidence	3.73 (.80)	3.67 (.93)	.05 (37;.46)	3.79 (.73)	3.67 (.77)	.10 (24;.44)
Nurse support	4.10 (.57)	4.21 (.56)	10 (37;.18)	4.17 (.48)	4.23 (.58)	07 (30;.17)
Total stressor score	1.88 (.45)	1.98 (.59)	11 (37;.15)	1.85 (.55)	2.05 (.57)	15 (40;.10)
PSS stressor subscale:						
Staff behav & comm.	1.42 (.57)	1.56 (.66)	10 (41;.21)	1.34 (.59)	1.55 (.77)	25 (56;.07)*

Table 2. Effect of basic elements of developmental care on parental stress, confidence and perceived nurse support.

p-value < .05

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higher mean score represents: higher confidence, higher nurse support, higher stress levels

differences (C-DC and DC-NIDCAP) after adjusting for covariates (infant and parent characteristics being; gender, GA at birth, CRIB score, day of completing the questionnaire, parental age and parental educational level). Min N on total scales C1; mother=61, father=58, I1; mother=60,

father=60, C2; mother=66, father=67, I2; mother=68, father=63

	Controls	Basic DC	RCT 1	Basic DC	NIDCAP	RCT 2
	Mean (sd)	Mean (sd)	Diff (99%CI)#	Mean (sd)	Mean (sd)	Diff (99%CI)#
Confidence caregiving	.052 (.67)	002 (.68)	.11 (23;.46)	161 (.77)	.012 (.56)	16 (49;.18)
Global confidence	328 (.74)	280 (.85)	.04 (35;.43)	376 (.93)	211 (1.01)	09 (57;.39)
Nurse support	.103 (.51)	020 (.48)	.17 (08;.42)	024 (.51)	006 (.52)	01 (26;.25)
Total stressor score	.199 (.60)	.183 (.56)	04 (33;.25)	.410 (.57)	.142 (.57)	.23 (05;.50)*
PSS stressor subscales:						
Sights and sounds	.305 (.74)	.118 (.77)	.17 (21;.54)	.379 (.68)	(17.) 651.	.18 (15;.51)
Infant's appearance	.174 (.89)	.163 (.81)	09 (51;.33)	.447 (.76)	.184 (.66)	.23 (11;.57)
Parent role alterations	.438 (.76)	.374 (.73)	.04 (35;.42)	.621 (.78)	.331 (.96)	.24 (18;.65)
Staff behav & comm.	088 (.46)	.033 (.70)	17 (47;.14)	.172 (.76)	061 (.70)	.21 (16;58)

Table 3. Difference between mother and father (if both completed the questionnaire).

p-value < .05, paired t-test

I1=59, C2=65, I2=62

differences (C-DC and DC-NIDCAP) after adjusting for covariates (infant and parent characteristics being, gender, GA at birth, CRIB score, day of completing the questionnaire, parental age and parental educational level). Min N on total scales C1=56,

Discussion

During two randomized controlled trials, measuring first the effect of the basics elements of developmental care compared to standard care and secondly the effect of NIDCAP compared to basic DC, no effects were found of developmental care and NIDCAP on parental confidence, perceived nurse support and parental stress of mothers and fathers of very preterm infants during admission. The differences found between groups were mostly small in both trials.

Overall, mothers in this study reported more stress compared to fathers. This difference tended to decrease in the NIDCAP intervention group in the second trial, but this was mainly caused by a higher stress level of the fathers in the NIDCAP intervention group. A higher parental stress level of mothers compared to fathers, as found in the current study, has previously been found and explored in other studies ^{18,19,26,27}. Miles et al. suggested that because mothers score highest on "parent role alteration" stressors, they are more affected by the loss of the caretaking role ²⁷. This large difference in stress between mother and father on parent role alterations was also found in the current study. Jackson et al. 26 examined the difference in experiences of both father and mother more extensively. Mothers felt a need to participate more in the caregiving of their infant and some mothers felt they were "borrowing their child from the staff" leading to feelings of insecurity. Fathers expressed the feeling of being an outsider because of the preterm delivery, but some had difficulty getting leave from work and had no choice but to leave the care to the staff ²⁶.

In the current study, the difference in stress levels of mothers compared to fathers was lower (but not significantly) in the NIDCAP intervention group compared to the basic developmental care control group. Studies up to date have mainly focused on maternal stress. The effect of increased paternal stress on the preterm infant and the family due to the effects of NIDCAP on the stress levels of fathers have not been studied yet, to our knowledge. Pierrehumbert et al. ⁷ found that both maternal and paternal post-traumatic reactions increased infant sleeping and eating problems reported by parents.

The lower difference of maternal and parental stress levels in the NIDCAP group, although non-significant, might be caused by a more active involvement of fathers during the NIDCAP guidance. This might result in paternal stress levels that are more comparable with maternal stress levels. This study shows that future research exploring the effects of early intervention in the neonatal intensive care unit needs to focus on the involvement and stress levels of fathers.

The effect of the NIDCAP intervention on parents has previously been examined in a three-center RCT by Als et al. 11. This study found less parental stress on the total child and parent domain scales and the total score of the Parent Stress Index (PSI) at two weeks after the expected date of confinement following the NIDCAP intervention with infants born < 28 weeks of gestation and weighing < 1250 grams. Furthermore, mothers perceived their children as more independent individuals on the Mother's View of the Child (MVC) 11. A recent NIDCAP study with 20 mothers by Kleberg et al. 16 concluded that although mothers in the NIDCAP group perceived more nurse support and closeness to their infant, they also expressed more anxiety. The authors suggested that higher anxiety might be a sign of early bonding ¹⁶. A recent Dutch study ²⁸ concluded that parents of infants born <30 weeks of gestation receiving NIDCAP were significantly more satisfied with the caregiving and parents indicated more nurse support on the NPST questionnaire but, as in the current study, this difference was not significant. Other intervention studies, mainly based on coping and stress of parents of preterm born infants, used the parental PSS-NICU questionnaire and did show positive results ^{29,30}.

Parents in this study indicated little stress (an average score of 2) on the stressors stated in the PSS-NICU. In other studies the stress scores appeared to be somewhat higher, with mean values of 2.5 to 3.0 ^{25,27,30}. Two recent studies ^{24,29} also found mean total scores of approximately 2. Parental age and infant birth weight and gestation in these studies were comparable to the present study. Mean perceived nurse support scores ranged from 4.13 to 4.27, which indicated that parents are in general satisfied with the support shown by the nursing staff. In a previous Dutch NIDCAP study ²⁸ NPST scores were comparable (mean score of 4.10 for controls and 4.26 for the NIDCAP

intervention group). These scores do not leave much of a window of opportunity to decrease parental stress and improve nurse support. Furthermore, prenatal and neonatal care and the support from social workers in the Netherlands is equally available for all people from different social economic backgrounds, which might lead to moderate stress levels and relatively high perceived nurse support in general.

The questionnaires were given after one week of admission because some children were already transferred to a regional hospital by then. In the Netherlands, infants receive intensive care at an academic unit and are transferred to a regional hospital once they become more stable. The questionnaires were on average completed in the second week of admission (Table 1). One or two weeks of intervention might not be an adequate amount of time to already measure effect on parents' experiences at the unit. In the second trial on average only one or two NIDCAP observations were done when parents completed the questionnaire. However, at that moment, parents were experiencing strong emotions regarding the preterm birth and the sudden admission of their infant in the intensive care unit. They might feel the need for guidance most during the first weeks of admission and the outcomes measured (parental stressors in the unit and perceived nurse support) related to parental experiences during the admission of their infant in the unit. Furthermore, the intervention already started within 48 hours after birth.

The return rates of this study were good, which implies that the research sample provided a good representation of all infants below 32 weeks admitted to a Dutch NICU. Other outcome variables of this study, related to the infant's medical condition and outcomes at follow-up, will be presented in the future.

In conclusion, both basic developmental care and the complete NIDCAP care program with individual observations and guidance had no significant effect on perceived nurse support, parental stress and parental confidence. The expected effect of a decrease in parental stress of both interventions and the expected positive effect of the NIDCAP intervention on parental confidence and perceived nurse support was not observed. As a result of increased

paternal stress, the NIDCAP intervention tended to decrease the difference in stress levels of fathers and mothers. The NIDCAP program may therefore lead to increased involvement of fathers, compared to a basic form of developmental care, leading to more comparable stress levels of fathers and mothers.

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