

# Parental presence and activities on a Dutch NICU; an observational study

Name: Kim Kamphorst  
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Supervisor: AJ Brouwer, PhD  
Lecturer: IE Poslowsky, PhD  
Internship institution: Wilhelmina Children's Hospital,  
University Medical Centre Utrecht  
Master: Clinical Health Sciences, Nursing Sciences,  
Utrecht University

## Introduction

Each year, over 4000 infants are admitted to a Neonatal Intensive Care Unit (NICU) in the Netherlands.<sup>(1)</sup> Infants born before 32 weeks of gestation, and those above 32 weeks in need of neonatal intensive care, are admitted to NICUs to increase their chances of survival.<sup>(2)</sup> Preterm birth, and admission to a NICU, are stressful and traumatic events for both infants and their parents.<sup>(3)</sup>

The changes to parental role brought about through NICU admission are a high source of stress for both parents.<sup>(4,5)</sup> In addition, parents report higher levels of stress when infants are of lower gestational age (GA), lower birth weight, have more severe illness, and when they suffer from cardiovascular disorders.<sup>(6,7)</sup> Parents also experience increased stress when the length of NICU stay increases, and by less frequently visiting their infant.<sup>(8,9)</sup> However, it is unknown if these stress factors influence parental presence on the NICU and participation in the care of their infant.

Parents often struggle initially with the fear of becoming attached to their infant, given the threat of losing them.<sup>(10)</sup> In the early phase, parents sometimes avoid touching or holding their infant, because they are afraid they might transmit an infection or otherwise interfere with care.<sup>(11,12)</sup> Furthermore, parents are uncertain about performing the normal care-giving activities and feel unable to fulfill their desirable parental role.<sup>(6,8,9,11)</sup> Fathers of preterm infants describe the incubator as a barrier between them and their infant.<sup>(13)</sup>

The presence of parents on the NICU is extremely important. Infants whose parents are accommodated in the hospital have a lower sepsis incidence, require fewer medical procedures, gain more weight, have a lower gestational age at full enteral feeding, show better attention, and have less physiologic stress, hypertonicity, lethargy, and pain.<sup>(14)</sup> Furthermore, the length of hospital stay reduces for such infants, and their long-term cognitive development improves.<sup>(15,16)</sup>

It is therefore important to encourage parents to be present, and to take care of their infant in order to develop a solid relationship with them. It is recommended too for reducing the parental feelings of helplessness and inadequacy by empowering parents in their role, even with severely ill infants<sup>(17)</sup>. Empowerment can be developed through education, and by supporting parents to actively participate in daily care and decision-making.<sup>(9,18)</sup> Activities such as diaper change and 'kangaroo care' (skin to skin care) provide concrete skills and a feeling of intimacy with their

infant.<sup>(11,19)</sup> Through such increased participation, parents gain a sense of control, which reduces insecurity about their parental role, increases confidence in the care for, and bonding with, their infant, and potentially reduces their level of stress.<sup>(9-11,17,19)</sup> Through their involvement in care, parents are also better equipped for the care for their infant after discharge.<sup>(18)</sup>

In order to increase parental empowerment, the so-called VOICE (Valuable confidence, Opportunities in deliberation, Integration, Control, and Evaluation) program has been developed. VOICE is a structured communication program for parents from the point of admission of the infant to the first visit to the outpatient clinic. The program consists of five interdisciplinary meetings with parents, in line with the acronym VOICE, to inform and teach parents how to connect with, and take care of, their infant. The program aims to provide a complete partnership between parents and caregivers. By following the VOICE program, parents are encouraged to be more involved, better informed, and in greater control in the care of their infant. The VOICE program is not yet implemented in practice; however, it is expected that through it, parents will feel more in charge, more present on the NICU, more satisfied, and relieved of at least some of their fear and stress.

This study aims to gain insight into the current presence and activities of parents on the NICU, ahead of the implementation of the VOICE program. Through this baseline measurement, the effectiveness and potential improvement in care after the implementation of the VOICE program, can be assessed. Furthermore, it is currently not known if there are clinical characteristics of the infant or parents, which influence parental presence and participation. If there are influencing characteristics, these can be taken into account in the implementation of the VOICE program. Therefore, this observational study will measure the current presence and activities of parents with their infants on the NICU, in relation to characteristics of both the infants and parents.

### **Aim**

Identify the frequency and duration of parental presence, and their activities on the NICU, in relation to the characteristics of the infant and parents. The results from this study will be used, if necessary, to adjust the VOICE program and to evaluate its effectiveness.

## **Method**

### Study design

A quantitative observational descriptive study was performed. The natural occurrence of parental presence and activities was observed from January 4, 2016 until April 30, 2016 on a Dutch NICU. An observational design was chosen, in order to assess the current parental presence and activities, without actually disturbing this process.

### Setting and participants

All parents (both fathers and mothers) of infants admitted for at least 24 hours to the Wilhelmina Children's Hospital (WKZ) NICU, University Medical Centre Utrecht, the Netherlands, during the study period, were included. Biological parents of infants who opted to adopt were excluded from participation in this study. Information about infants who died during admission was collected, but only used in one sub analysis, since it was expected that these parents were more present and therefore do not present a reliable reflection of parental presence on the NICU. The WKZ NICU is a 24-bed level III NICU, divided into three units, with an annual intake of more than 600 admissions. Infants of 24 weeks of gestation and upwards are admitted and treated in this NICU, and it is one of the few NICUs which performs heart surgery in the Netherlands. Parental presence is a right for every infant. <sup>(20,21)</sup> Therefore, parental presence is allowed 24 hours a day on the WKZ NICU.

### Study size

It was expected to include 200 parents during the observation period of four months, since there are annually about 600 NICU admissions. This sample size seems adequate, since this is a reliable reflection of the WKZ NICU population.

### Variables

#### *Primary parameters*

The primary parameters were: parental presence frequency and duration (in minutes) per 24 hours; and parental activities. The parameters were collected from fathers and mothers separately.

#### *Secondary parameters*

To examine the influence of parental and infant characteristics, the clinical characteristics of both were collected. In addition, the following data was collected on the infants: socio-demographic

characteristics, indication for admission, level of illness, treatment, length of NICU stay, and complications such as sepsis. Parental characteristics that were collected were: socio-demographic characteristics, state of the mother's health and her obstetric history, and number of children. A complete description of the collected characteristics and operationalization of the variables, is presented in Table 1.

In the results section, the characteristics are divided into subgroups according to GA. This is in order to create homogenous groups, since survival rate, level of illness, and length of stay are dependent of the GA, and thus might influence parental presence.

*Insert table 1*

### Data sources

There was no observation form available in the literature to collect information about the primary variables. Therefore, to measure the primary parameters, an observation form was developed – see appendix 1. Two experts in the field evaluated the face validity of the observation form as positive. These forms, which were filled out during every shift by nursing staff, were added to the nursing file of every infant. Parental presence was also registered in the patient data management system (PDMS), and described by the nurses in their report. The observation forms, information from PDMS, and the nurses' reports were all used to register parental presence.

Secondary parameters were collected from the medical, nursing, and social workers' records. Driving distance and social economic status (SES) were calculated from the information provided.

### Statistical methods

Descriptive statistics were presented with means and standard deviations for continuous normally distributed variables; medians, and interquartile ranges for continuous non-normally distributed variables; and proportions and absolute numbers for categorical variables.

Differences in the duration of presence between types of delivery, additional diagnoses and treatments, type of feeding, first child, Ronald McDonald House, work state, social network, religion, and mortality were examined through the independent t-test or Mann Whitney test. For the following categorical variables: ward, indication for admission, ethnicity, mother's state of health, obstetric history, and admission week, the univariate analysis of variance (ANOVA) or the Kruskal Wallis was used. For differences between the presence of the father and mother, the

paired t-test or Wilcoxon signed rank test was used. Correlation was used to examine the coherence between duration of presence and birth weight, length of NICU stay, age, SES, driving distance, Perinatal Extension, Version II (SNAPPE-II), Apgar score, GA, duration of kangaroo care, visit frequency, and other children.

To examine the influence of the independent clinical characteristics on the dependent duration of presence, a stepwise backward multiple linear regression was performed. Since the dependent variable was continuous, and a linear relationship between the dependent and independent variables was assumed, a linear regression, with a backward model, was chosen in order to achieve the highest total explained variance.<sup>(22)</sup> All significant characteristics from the above-mentioned tests were applied to the linear regression. In order to avoid overloading of the model, only ten variables were put into the model at once, and ten events per predictor were deemed necessary.<sup>(23)</sup> Categorical independent variables were dummy-coded before analysis. All tests were performed for the father and mother separately. Data analysis was performed using IBM SPSS version 21. Statistical significance was in all tests assumed when  $p < 0.05$ .

### *Missing Data*

For descriptive statistics of the primary variables, the available case analysis was used, since it was expected that missing data was random. Because there were multiple observations per day for the primary variables, it was still possible to make reliable statements about the mean duration of the presence, even when there were days missing. Therefore, in all the analyses, all parents were included. Secondary parameters were excluded in cases where there were more than 10% missing values, since this may have biased the results.<sup>(24)</sup>

### Ethical considerations

Ethical approval was obtained by the local ethics committee of the UMCU. In order to observe the natural occurrence of parental presence and to avoid potential bias, no informed consent was obtained. The data was processed anonymously, and was not traceable to any person.

## Results

### Participants

During the study period, 174 infants met the inclusion criteria. For twelve infants, the observation form was not filled out and therefore they were excluded from the study. Of the 162 remaining infants, ten died. Clinical characteristics are presented in Tables 2 and 3.

*Insert Table 2 and 3*

### Missing data

The rate of missing values was for social network 80%, work status of father 71%, and religion 52%, and these were excluded from the analyses.

### Primary parameters

The duration of parental presence during the first month is described, since the mean time of NICU admission was  $\leq 31$  days in 88% of the infants.

#### *Duration*

The total time of presence of at least one of the parents varied during the first week, as shown in Table 4. After the first week, the median time of presence of at least one of the parents varied between three and four hours a day, as illustrated in Figure 1.

During the infant's first week of life, the duration of only mother's presence on the NICU increased every day, before it stabilized. After the first week, the range of motherly presence on one day varied between 0-570 minutes, IQR(90-210). Fathers' presence on the NICU stabilized after four days. Thereafter, the range of fathers presence varied between 0-240 minutes, IQR(0-55). The presence of both parents together at the same time on the NICU increased during the first four days, before it stabilized. From the fourth day, the range of parental presence was between 0-540 minutes, IQR(30-195).

#### *Frequency*

The frequency of presence of the mother on her own was stable from the first day, with a median of once a day, IQR(1-2). During the first four days, the presence of the father alone was also a median of once a day, IQR(1-1). Thereafter, the median frequency of the father decreased to 0 IQR(0-1). During the first four days of the infant's life, the frequency of both parents together had a median frequency of 2, IQR(1-2). Thereafter, the frequency decreased to a median of 1, IQR(1-2).

### *Activities*

Almost all parents had physical contact with their infant on the first day, and 7% of the infants received kangaroo care. An overview of the duration of kangaroo care during the first week is presented in Table 4. Before parents attempted to perform an activity by themselves, they first watched how the NICU nurse performed the activity, then carried out the activity together with the nurse. After four days, 50% of the parents were involved in activities besides physical contact, in the care of their infant. After a week, this involvement increased to 80% and the median time of kangaroo care stabilized to 60-120 minutes a day, IQR(0-285). Mothers carried out activities more often, compared to fathers. The activities performed by the parents were mostly: physical contact, holding during investigations, measuring the infants temperature, changing the diaper, and kangaroo care. Mothers were sometimes present to pump breast milk next to their infant. Furthermore, parents were regularly present on the NICU for meetings with the doctor. Other activities performed by the parents included (breast)feeding, skin and oral care, helping with tube-feeding, and the changing of linens.

*Insert Table 4 and figure 1.*

### Influencing characteristics:

The duration of presence for both parents was significantly higher from the second week of admission, compared to the first week ( $p=0.000$ , Table 5). Mothers were present significantly longer than fathers ( $p=0.000$ ). A vaginal delivery, higher visit frequency, the performing of kangaroo care, higher birth weight, and BPD, resulted in a significantly longer duration of presence for both the father and mother during the admission. The number of children ( $r= -0.31$ ) and driving distance ( $r= -0.28$ ) for both parents were significantly negatively correlated with the duration of presence. However, when dichotomized into one versus multiple children, this factor was only of significant influence on the mother's presence. Mothers were present for a mean time of 191 minutes a day when it was a first child; and 157 minutes if there were other children. In addition, mothers were present for longer if their infant had a neurological admission indication. GA was significantly correlated ( $p=0.05$ ) with the father's presence during the entire time of admission ( $r=0.16$ ); a higher GA resulted in more fatherly presence. Mothers were only longer present during the first two weeks with infants with a higher GA; thereafter, there was no further significant difference in her duration. Furthermore, lower Apgar scores in the case of the



mother, and a higher score on the SNAPPE-II, resulted in a negative influence for both parents only during the first two weeks.

In the multiple regression, the method of delivery, birth weight, duration of kangaroo care, and visiting frequency all were shown to be significant for the duration of presence of both parents. Finally, parental presence was significantly higher with infants who died, compared to infants who stayed alive ( $p=0.01$ ).

*Insert Table 5.*

## Discussion

The aim of this study was to identify parental presence in terms of frequency, duration, and activities on the NICU, in relation to characteristics of both the infants and parents. During the first week after birth, the duration of parental presence increased every day, before it stabilized at three to four hours a day. Mothers were present significantly longer, compared to fathers. Activities performed by the parents were mostly: physical contact, holding during investigations, measuring the infants temperature, changing the diaper, and kangaroo care. The study also revealed that a vaginal delivery, shorter driving distance, higher visit frequency, the performing of kangaroo care, a higher birth weight, the infant being a first child, and BPD, all resulted in a significantly longer duration of presence for both the father and mother during the admission period. Furthermore, a higher gestational age resulted in a significantly longer duration of fathers presence.

There were some similarities between the results of the current study, and the existing literature. In this study, the duration of kangaroo care was positively correlated with duration of parental presence, and even revealed a significant influence on presence. Heineman et al. showed that kangaroo care helps mothers to feel in control and needed, which increases their presence.<sup>(11)</sup> This could explain why parents are longer present with their infant when they are able to perform kangaroo care. Our study showed that this factor not only influences mothers' presence, but fathers' as well. Therefore, it seems highly important to start kangaroo care as soon as the infant's condition permits. Clear appointments about starting kangaroo care are highly recommended, so that this is not left up to the personal preferences of the nurse. In addition, Heineman et al. concluded that opportunities for parents to take over their infant's care increased their motivation to stay.<sup>(11)</sup> Our study showed that parents were present for a longer duration from the second week of admission, and that 80% of parents were involved in the care after one week. Probably one of the reasons for this increased duration was the increased participation in the care of their infant, which empowers parents in their role.<sup>(25)</sup> Another explanation could be the parents' fear of becoming attached to an infant that they might lose, as described by Bouwstra et al.<sup>(10)</sup> Parents might think that they will be less attached by being less present. Only qualitative research, however, will fully explain this result.

There were some differences between the current study and the literature. Our study showed that mothers were significantly more present, compared to fathers. This is because mothers have maternity leave during their infant's admission, while fathers often have to go back to work. Normally, when an infant is born healthy, parents are the primary caregivers for their infant. We

were able to show that parents were only present with their infant for three to four hours a day, after the first week. This is a low level of presence in comparison to other countries. On Swedish NICUs, the policy is that parents are the primary caregivers for their infant during their stay on the NICU. <sup>(26,27)</sup> Sweden has a completely different culture compared to the Netherlands; Swedish parents do not even contemplate not being present. <sup>(26,27)</sup> In addition, parental presence is facilitated by the Swedish social system – it is thereby possible for parents of sick infants to have leave of absence from work, with an adequate allowance. <sup>(26)</sup> In other countries, such as Canada, there are already advancements in examining programs to increase parental participation on the NICU. <sup>(25)</sup> In the Netherlands, not only do policies and attitudes on the NICU regarding parental participation need to change, but also the culture. Through the VOICE program, there will be an initiation of increased parental participation on the NICU. Finally, a Caesarean section was seen to influence parental presence negatively in this study. Although a Caesarean is physically debilitating only for the mother, it was seen to result in less time present for both parents. This is an important finding, and one that should be addressed in the future so that solutions can be sought to increase parental presence following Caesarean section. These mothers need added facilities to be able to stay longer. For each parent, individual needs should be examined at the point of admission, to enable greater presence.

In order to evaluate the findings of this study, its limitations need to be considered. Three parameters of interest were excluded because of >10% missing values. As a result, not all variables that might influence parental presence were examined fully, which might have implications for the generalizability of the results. Furthermore, the observation period was relatively short, and therefore the incidence of ROP, sepsis, IVH and NEC were low. It is likely that these parameters influence parental presence, but a larger sample is needed in order to reveal significant differences. Finally, all the information about the primary parameters were collected by the NICU nurse, and registered in a variety of sources. This could have introduced some observer bias.

A strength of this study was that almost a third of the annual NICU admissions were included in it. Of these, only 7% of parents who met the inclusion criteria were excluded from the study, on account of lack of data about the primary variables. This allows for strong conclusions to be made, and contributes to the generalizability of the results. Furthermore, multiple observations were made each day of the primary variables, and these were conducted for the duration of the infant's stay on the NICU. This contributed to the reliability of the data collection. Finally, data was collected from fathers and mothers separately, and there were as many fathers enrolled as

mothers. As shown, there were significant differences between the parents; by analyzing the parents separately, insight was provided into the differences between them.

For future research, it is recommended that there be examination of the influence of the missing values, and additional diagnoses. When all the characteristics of potential influence have been sufficiently examined, the next step will be to gain insight into the reasons why these characteristics influence parental presence, through qualitative research. Finally, effective interventions should be investigated to increase parental presence and participation.

### **Conclusion**

This study shows that parents are present for 13%-17% of the day on the NICU. It takes almost a week before the majority of the parents participate in the care of their infant. After the first week, parental presence, as well as participation, increases. Therefore, it is important to empower parents to participate in the care of their infant, in order to increase their presence. Kangaroo care, the frequency of visits, birth weight, and the nature of the delivery, all reveal a significant influence on the duration of parental presence. Therefore, it is important to provide adapted facilities for mothers after Caesarean section, to enable them to stay at the NICU for as long as they would like.

### **Recommendations**

In current practice the conditions and support necessary for parents to take up their parental role should be examined and facilitated. It is recommended that, for future study, qualitative research be conducted to gain insight into the reasons why the characteristics influence parental presence; this would allow for the developing of appropriate interventions to increase parental presence and participation. Finally, it is evident that attitudes on NICUs and in the Dutch culture need to change, to better allow parents the opportunity to be present with their admitted infant.

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**Tables**

Table 1 collected characteristics

| <b>Infant</b>  | <b>Outcome</b> | <b>Unit of measure/ range</b> |
|--|----------------|-------------------------------|
| Indication for admission                                   | Categorical    |                               |
| Gestational Age (GA)                                       | Continue       | Weeks                         |
| Birth weight   | Continue       | Grams                         |
| Sex  | Dichotomous    | Male/female                   |
| Apgar score at one and five minutes                        | Continue       | 0 – 10                        |
| Mechanical Ventilation (MV)                                | Dichotomous    | Yes/No                        |
| Infant Respiratory Distress Syndrome (IRDS)                | Dichotomous    | Yes/No                        |
| Surgery  | Dichotomous    | Yes/No                        |
| SNAPPE-II <sup>(28)</sup>                                  | Continue       | 0 – 143*                      |
| Type of feeding  | Dichotomous    | Mother milk/ formula          |
| Duration of kangaroo care <sup>(29)</sup>                  | Continue       | Minutes                       |
| Length of stay on the NICU, if applicable                  | Continue       | Days                          |
| Additional diagnoses:                                      |                |                               |
| Necrotizing enterocolitis (NEC)                            | Dichotomous    | Yes/No                        |
| Retinopathy of Prematurity (ROP)                           | Dichotomous    | Yes/No                        |
| Bronchopulmonary Dysplasia (BPD)                           | Dichotomous    | Yes/No                        |
| Patent Ductus Arteriosus (PDA)                             | Dichotomous    | Yes/No                        |
| Intraventricular hemorrhage (IVH) or cerebral haemorrhages | Dichotomous    | Yes/No                        |
| Sepsis   | Dichotomous    | Yes/No                        |
| Mortality  | Dichotomous    | Alive/dead                    |
| <b>Parents</b>   |                |                               |
| Driving distance   | Continue       | Kilometers                    |
| Ronald McDonald House                                      | Dichotomous    | Yes/No                        |
| Social economic status (SES) using the zip code            | Continue       | -6.75 - 3.06**                |
| Ethnicity  | Categorical    | Country of birth              |
| Religion   | Dichotomous    | Yes/No                        |
| Living together/ single                                    | Dichotomous    | Living together/ single       |
| Mothers age  | Continue       | Years                         |
| Social network   | Dichotomous    | Yes/No                        |
| Work status of father                                      | Dichotomous    | Working/ not working          |
| Number of children, including the admitted infant          | Continue       |                               |
| Health state mother, divided in:                           | Categorical    |                               |
| Normal   |                |                               |
| Hypertensive disorders related to pregnancy                |                |                               |
| Postpartum hemorrhage >1000ml                              |                |                               |
| Intensive Care (IC) admission                              |                |                               |
| Obstetric history, divided in:                             | Categorical    |                               |
| Normal   |                |                               |
| Miscarriage  |                |                               |
| Subfertility   |                |                               |
| IVF/ICSI   |                |                               |
| Deceased children  |                |                               |

*Snappe II Score for Neonatal Acute Physiology, Perinatal Extension, Version II*

\* Increase of SNAPPE-score is an increase of the severity of illness

\*\* Increase in SES is an increase in SES

Table 2 infant baseline characteristics divided in gestational age

|                                     | Premature<br>24-26 weeks:<br>n=20 | Premature<br>27-28 weeks:<br>n=26 | Premature<br>29-32 weeks:<br>n=49 | Premature<br>33-36 weeks:<br>n=17 | A term<br>37-42 weeks<br>n=50 |
|-------------------------------------|-----------------------------------|-----------------------------------|-----------------------------------|-----------------------------------|-------------------------------|
| Male/ female:                       | 8 / 12                            | 22 / 4                            | 25 / 24                           | 10 / 7                            | 29 / 21                       |
| GA, weeks (mean $\pm$ SD):          | 25 $\pm$ 0.9                      | 28 $\pm$ 0.5                      | 30 $\pm$ 1                        | 34 $\pm$ 1                        | 39 $\pm$ 1.5                  |
| Birth weight, g<br>(mean $\pm$ SD): | 783 $\pm$ 122                     | 1125 $\pm$ 282                    | 1388 $\pm$ 354                    | 2614 $\pm$ 880                    | 3334 $\pm$ 511                |
| Apgar 1 min<br>(median – range):    | 5 (1-8)                           | 5.5 (1-8)                         | 6 (1-9)                           | 7 (0-9)                           | 8 (0-9)                       |
| Apgar 5 min<br>(median – range):    | 7 (4-9)                           | 8 (2-9)                           | 8 (3-10)                          | 8 (4-10)                          | 9 (2-10)                      |
| Snappe score<br>(mean $\pm$ SD):    | 41 $\pm$ 17                       | 31 $\pm$ 19                       | 21 $\pm$ 17                       | 18 $\pm$ 15                       | 22 $\pm$ 14                   |
| NICU stay, d<br>(mean $\pm$ SD):    | 36 $\pm$ 21                       | 33 $\pm$ 17                       | 14 $\pm$ 9                        | 12 $\pm$ 14                       | 7 $\pm$ 5                     |
| Admission*, (n/%)                   |                                   |                                   |                                   |                                   |                               |
| Premature:                          | 20 (100%)                         | 26 (100%)                         | 44 (90%)                          | 0 (0%)                            | 0 (0%)                        |
| Asphyxia:                           | 0 (0%)                            | 0 (0%)                            | 0 (0%)                            | 1 (6%)                            | 12 (24%)                      |
| Respiratory Distress:               | 0 (0%)                            | 0 (0%)                            | 2 (4%)                            | 9 (53%)                           | 9 (18%)                       |
| Surgery:                            | 6 (30%)                           | 0 (0%)                            | 1 (2%)                            | 1 (6%)                            | 4 (8%)                        |
| Neurologic:                         | 0 (0%)                            | 0 (0%)                            | 0 (0%)                            | 0 (0%)                            | 9 (18%)                       |
| Congenital Malformations:           | 0 (0%)                            | 0 (0%)                            | 0 (0%)                            | 4 (24%)                           | 12 (24%)                      |
| Other**:                            | 0 (0%)                            | 0 (0%)                            | 2 (4%)                            | 2 (12%)                           | 4 (8%)                        |
| Formula/ mother milk:               | 3 / 17                            | 7 / 19                            | 11 / 38                           | 5 / 12                            | 22 / 28                       |
| Surgery, (n/%):                     | 7 (35%)                           | 3 (12%)                           | 1 (2%)                            | 3 (18%)                           | 7 (14%)                       |
| NEC, (n%):                          | 2 (10%)                           | 2 (8%)                            | 1 (2%)                            | 2 (12%)                           | 3 (6%)                        |
| IVH/ CH, (n/%):                     | 6 (30%)                           | 7 (27%)                           | 8 (16%)                           | 1 (6%)                            | 10 (20%)                      |
| Sepsis, (n/%):                      | 7 (35%)                           | 8 (31%)                           | 4 (8%)                            | 4 (24%)                           | 4 (8%)                        |
| BPD, (n/%):                         | 8 (40%)                           | 7 (27%)                           | 1 (2%)                            | 0 (0%)                            | 0 (0%)                        |
| PDA, (n/%):                         | 13 (65%)                          | 14 (54%)                          | 3 (6%)                            | 0 (0%)                            | 0 (0%)                        |
| ROP, (n,%):                         | 5 (25%)                           | 4 (15%)                           | 0 (0%)                            | 0 (0%)                            | 0 (0%)                        |
| Mortality, (n/%):                   | 4 (20%)                           | 1 (4%)                            | 0 (0%)                            | 0 (0%)                            | 5 (10%)                       |

GA, Gestational Age; NEC, Necrotizing Enterocolitis; IVH, Intraventricular hemorrhage; CH, cerebral hemorrhage; BPD, Bronchopulmonary Dysplasia; PDA, Patent Ductus Arteriosus; ROP, Retinopathy of Prematurity

\* The frequencies is above the sample size, since some premature infants had more than one indication for admission

\*\*Other indications for admission: infection, pre-dysmaturity, NEC, hypoglycemia, gastro-intestinal problems



Table 3 parental baseline characteristics

|  | Premature<br>24-26 weeks:<br>n=20 | Premature<br>27-28 weeks:<br>n=26 | Premature<br>29-32 weeks:<br>n=49 | Premature<br>33-36 weeks:<br>n=17 | A term<br>37-42 weeks<br>n=50 |
|--|-----------------------------------|-----------------------------------|-----------------------------------|-----------------------------------|-------------------------------|
| Ethnicity, (n/%)                           |                                   |                                   |                                   |                                   |                               |
| Dutch:                                     | 18 (90%)                          | 19 (73%)                          | 42 (86%)                          | 16 (94%)                          | 40 (80%)                      |
| Middle-East:                               | 1 (5%)                            | 3 (12%)                           | 3 (6%)                            | 1 (6%)                            | 3 (6%)                        |
| Other*:                                    | 1 (5%)                            | 4 (15%)                           | 4 (8%)                            | 0 (0%)                            | 7 (14%)                       |
| Obstetric history, (n/%)                   |                                   |                                   |                                   |                                   |                               |
| Normal:                                    | 9 (45%)                           | 17 (65%)                          | 32 (65%)                          | 12 (71%)                          | 38 (76%)                      |
| Miscarriage:                               | 4 (20%)                           | 5 (19%)                           | 11 (22%)                          | 4 (24%)                           | 9 (18%)                       |
| Subfertility:                              | 2 (10%)                           | 1 (4%)                            | 4 (8%)                            | 0 (0%)                            | 1 (2%)                        |
| IVF/ICSI:                                  | 4 (20%)                           | 2 (8%)                            | 0 (0%)                            | 1 (6%)                            | 0 (0%)                        |
| Deceased child:                            | 1 (5%)                            | 1 (4%)                            | 2 (4%)                            | 0 (0%)                            | 2 (4%)                        |
| Health state mother, (n/%)                 |                                   |                                   |                                   |                                   |                               |
| Normal:                                    | 19 (95%)                          | 22 (85%)                          | 35 (71%)                          | 11 (65%)                          | 45 (90%)                      |
| PIH:                                       | 1 (5%)                            | 2 (8%)                            | 10 (20%)                          | 2 (12%)                           | 3 (6%)                        |
| Other complications**:                     | 0 (0%)                            | 2 (8%)                            | 4 (8%)                            | 4 (24%)                           | 2 (4%)                        |
| Vaginal/ cesarean:                         | 15 / 5                            | 17 / 9                            | 18 / 31                           | 11 / 6                            | 33 / 17                       |
| Age mother, years<br>(mean $\pm$ SD):      | 29 $\pm$ 5                        | 31 $\pm$ 5                        | 31 $\pm$ 5                        | 31 $\pm$ 4                        | 30 $\pm$ 5                    |
| Number of children<br>(median - range):    | 1 (1-4)                           | 1 (1-4)                           | 2 (1-3)                           | 2 (1-5)                           | 2 (1-7)                       |
| Social Economic Status<br>(mean $\pm$ SD): | 0.19 $\pm$ 1.07                   | -0.17 $\pm$ 1.7                   | 0.63 $\pm$ 1.05                   | 0.40 $\pm$ 1.25                   | 0.51 $\pm$ 1.09               |
| Driving distance, km<br>(median - range):  | 10 (1-69)                         | 19 (1-68)                         | 17 (1-87)                         | 10 (1-81)                         | 15 (1-72)                     |

PIH, Pregnancy Induced Hypertension

\*Other ethnicity: East-European, South-European, South-American, African

\*\* Other complications: HELLP, bleeding, IC admission

Table 4: duration of parental presence and kangaroo care

|                               | Day 1         | Day 2          | Day 3          | Day 4           | Day 5          | Day 6           | Day 7          |
|-------------------------------|---------------|----------------|----------------|-----------------|----------------|-----------------|----------------|
| <b>Total presence in 24/h</b> |               |                |                |                 |                |                 |                |
| Median (IQR):                 | 75 (40 - 150) | 130 (90 - 180) | 150 (90 - 210) | 165 (120 - 225) | 150 (95 - 225) | 150 (120 - 240) | 180 (90 - 240) |
| Range:                        | 15 - 465      | 30 - 480       | 0 - 510        | 20 - 480        | 0 - 375        | 0 - 405         | 0 - 480        |
| <b>Mother</b>                 |               |                |                |                 |                |                 |                |
| Median (IQR):                 | 30 (24 - 60)  | 60 (30 - 83)   | 60 (45 - 120)  | 90 (60 - 135)   | 90 (30 - 120)  | 90 (15 - 150)   | 60 (4 - 116)   |
| Range:                        | 0 - 240       | 0 - 180        | 0 - 270        | 0 - 420         | 0 - 240        | 0 - 300         | 0 - 210        |
| <b>Father</b>                 |               |                |                |                 |                |                 |                |
| Median (IQR):                 | 30 (30 - 45)  | 30 (15 - 60)   | 30 (0 - 33)    | 20 (7 - 53)     | 0 (0 - 20)     | 0 (0 - 60)      | 0 (0 - 60)     |
| Range:                        | 0 - 150       | 0 - 480        | 0 - 180        | 0 - 120         | 0 - 120        | 0 - 120         | 0 - 120        |
| <b>Both parents</b>           |               |                |                |                 |                |                 |                |
| Median (IQR):                 | 60 (30 - 120) | 105 (60 - 150) | 120 (60 - 180) | 130 (90 - 210)  | 120 (60 - 210) | 120 (60 - 240)  | 120 (60 - 210) |
| Range:                        | 0 - 435       | 0 - 390        | 0 - 510        | 0 - 465         | 0 - 375        | 0 - 375         | 0 - 480        |
| <b>Duration Kangaroo care</b> |               |                |                |                 |                |                 |                |
| Median (IQR):                 | 0 (0 - 0)     | 0 (0 - 23)     | 0 (0 - 60)     | 0 (0 - 90)      | 60 (0 - 90)    | 60 (0 - 120)    | 60 (0 - 90)    |
| Range:                        | 0 - 240       | 0 - 150        | 0 - 180        | 0 - 150         | 0 - 270        | 0 - 240         | 0 - 300        |

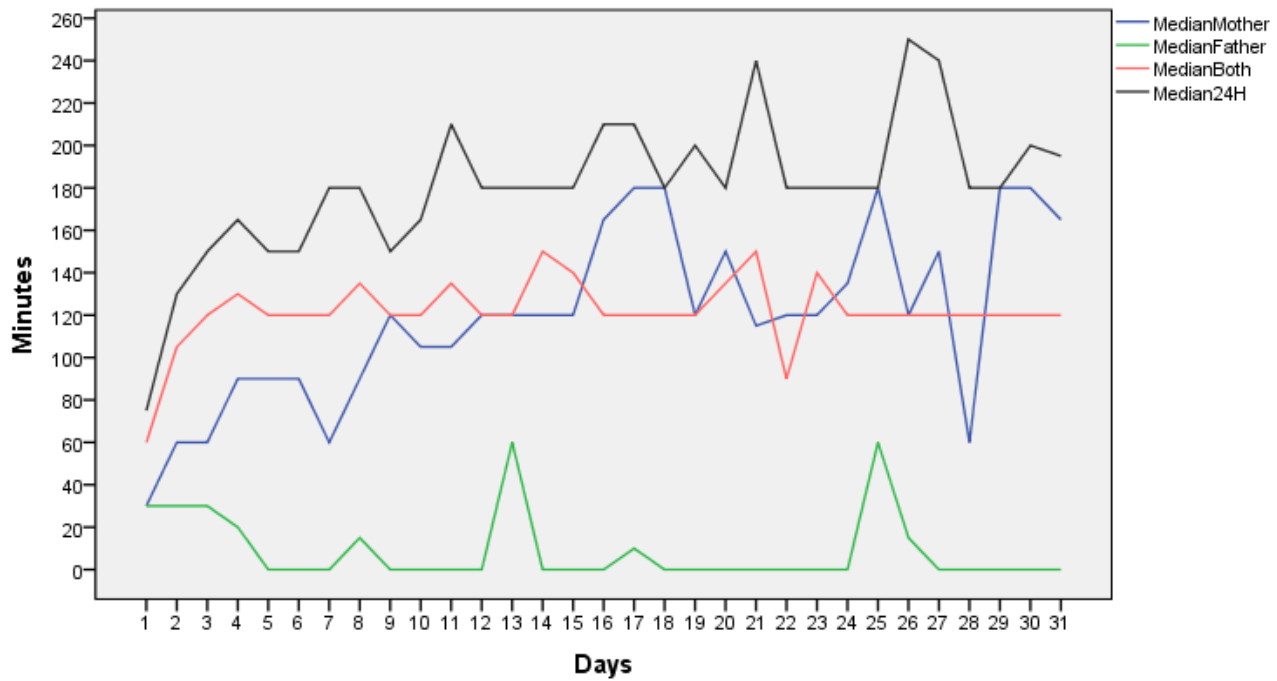


Figure 1: median time of presence mother, father, both parents together and total presence during 24 hours of at least one of the parents

Table 5: differences between groups for father and mother

|  | Mother      |             |        | Father        |            |        |
|--|-------------|-------------|--------|---------------|------------|--------|
|  | P value     | 95% CI      | R      | P value       | 95% CI     | R      |
| Vaginal compared to cesarean:                                  | <b>0.00</b> | 14 – 61     |        | <b>0.03</b>   | 4 – 52     |        |
| First compared to multiple children :                          | <b>0.01</b> | 10 – 58     |        | 0.15          | -6 – 42    |        |
| Ronald McDonald House:   | <b>0.00</b> | 17 – 66     |        | <b>0.00</b>   | 13 – 64    |        |
| Surgery:   | 0.15        | - 66 – 10   |        | 0.75          | - 43 – 31  |        |
| Type of feeding:   | 0.70        | - 32 – 22   |        | 0.29          | - 41 – 12  |        |
| Retinopathy of Prematurity (ROP):                              | 0.48        | - 72 – 35   |        | 0.94          | - 53 – 49  |        |
| Bronchopulmonary Dysplasia (BPD):                              | <b>0.05</b> | - 85 – -0.5 |        | <b>0.04</b>   | - 93 – -9  |        |
| Sepsis:  | 0.11        | - 58 – 7    |        | 0.86          | - 35 – 29  |        |
| Intraventricular hemorrhage (IVH):                             | 0.06        | - 6 – 1     |        | 0.15          | - 54 – 8   |        |
| IRDS:  | 0.13        | - 5 – 43    |        | 0.42          | - 14 – 35  |        |
| Mechanical Ventilation (MV):                                   | 0.63        | - 18 – 30   |        | 0.91          | - 23 – 26  |        |
| Patent Ductus Arteriosus (PDA):                                | 0.10        | - 58 – 5    |        | 0.12          | - 56 – 7   |        |
| Necrotizing enterocolitis (NEC):                               | 0.22        | - 92 – 22   |        | 0.93          | - 56 – 51  |        |
| Father compared to mother:                                     | <b>0.00</b> | - 43 – -24  |        | <b>0.00</b>   | - 43 – -24 |        |
| 1 <sup>st</sup> compared to 2 <sup>nd</sup> week of admission: | <b>0.00</b> | - 46 – -18  |        | <b>0.03</b>   | - 27 – -11 |        |
| Ward:  | 0.99        |             |        | 0.52          |            |        |
| Indication for admission:                                      | <b>0.05</b> |             |        | 0.24          |            |        |
| Neurologic compared to premature 29-32 weeks*:                 | <b>0.02</b> | 8 – 174     |        |               |            |        |
| Ethnicity:   | <b>0.03</b> |             |        | <b>0.03**</b> |            |        |
| East-European compared to middle east*:                        | 0.04        | 3 – 276     |        |               |            |        |
| Health state mother:   | 0.59        |             |        | 0.685         |            |        |
| Obstetric history:   | 0.22        |             |        | <b>0.04**</b> |            |        |
| Birth weight:  | <b>0.00</b> |             | 0.233  | <b>0.01</b>   |            | 0.220  |
| NICU stay:   | 0.28        |             | 0.095  | 0.54          |            | 0.053  |
| Age mother:  | 0.13        |             | -0.128 | 0.14          |            | -0.125 |
| Social Economic Status (SES):                                  | 0.30        |             | 0.086  | 0.80          |            | 0.021  |
| Driving distance:  | <b>0.00</b> |             | -0.309 | <b>0.00</b>   |            | -0.250 |
| SNAPPE overall:  | 0.61        |             | -0.049 | 0.33          |            | -0.092 |
| Snappe1 <sup>st</sup> week:                                    | <b>0.01</b> |             | -0.259 | <b>0.03</b>   |            | -0.218 |
| Apgar1 overall:  | 0.27        |             | 0.093  | 0.37          |            | 0.076  |
| Apgar1 1 <sup>st</sup> week:                                   | <b>0.02</b> |             | 0.212  | 0.08          |            | 0.162  |
| Apgar1 2 <sup>nd</sup> week:                                   | <b>0.02</b> |             | 0.259  |               |            |        |
| Apgar5 overall:  | 0.17        |             | 0.118  | 0.57          |            | 0.048  |
| Apgar5 1 <sup>st</sup> week:                                   | <b>0.00</b> |             | 0.265  | 0.06          |            | 0.172  |
| Apgar5 2 <sup>nd</sup> week:                                   | <b>0.04</b> |             | 0.240  |               |            |        |
| Gestational Age (GA) overall:                                  | 0.06        |             | 0.158  | <b>0.05</b>   |            | 0.160  |
| GA 1 <sup>st</sup> week:                                       | <b>0.00</b> |             | 0.299  |               |            |        |
| GA 2 <sup>nd</sup> week:                                       | <b>0.03</b> |             | 0.242  |               |            |        |
| Kangaroo Care:   | <b>0.00</b> |             | 0.375  | <b>0.00</b>   |            | 0.249  |
| Frequency of visit:  | <b>0.00</b> |             | 0.497  | <b>0.00</b>   |            | 0.645  |
| Number of children:  | <b>0.00</b> |             | -0.278 | <b>0.02</b>   |            | -0.191 |

IRDS, infant respiratory distress syndrome

\* Bonferroni post-hoc test; \*\* Bonferroni insignificant

**Dutch summary**

Titel: Ouderlijke aanwezigheid en activiteiten op een Nederlandse NICU; een observationele studie

Achtergrond: Gedurende een opname van een baby op een neonatale intensive care unit (NICU) is het belangrijk dat ouders aanwezig zijn, voor een gezonde en veilige ontwikkeling van de baby en om stress bij ouders te verminderen. Voordat er echter interventies geïmplementeerd kunnen worden om de aanwezigheid van ouders te verhogen, moet er een baseline meting worden uitgevoerd om de huidige aanwezigheid van ouders op de NICU te onderzoeken en mogelijk beïnvloedende karakteristieken.

Doel: Identificeren van de frequentie en duur van ouderlijke aanwezigheid en hun activiteiten op de NICU in relatie tot karakteristieken van ouders en de baby.

Methode: Een observationele studie is uitgevoerd doormiddel van observaties door NICU verpleegkundigen van januari tot mei 2016 op een Nederlandse NICU. Alle baby's die langer dan 24 uur werden opgenomen zijn geïnccludeerd.

Resultaten: 162 baby's zijn geïnccludeerd, waarvan 10 overleden. Ouders waren drie tot vier uur per dag aanwezig. Na een week participeerde 80% van de ouders in de zorg. Moeders waren significant langer aanwezig dan vaders. Een vaginale bevalling, hogere bezoek frequentie, langere duur van kangoeroen, hoger geboortegewicht, BPD, eerste kind, de tweede opnameweek en langer, en een kortere reisafstand resulteerde in significant langere aanwezigheid van zowel vader als moeder. Ouders waren significant langer aanwezig als een kind overleed.

Conclusie: Ouders waren 17% van de dag aanwezig op de NICU. Het duurde een week voordat het grootste deel van de ouders participeerde in de zorg voor hun kind. Kangoeroen, bezoek frequentie, geboortegewicht en de beval wijze bleken van significante invloed op de duur van ouderlijke aanwezigheid.

Aanbevelingen: In de praktijk moet worden onderzocht welke omstandigheden en ondersteuning nodig is voor ouders om hun ouderlijke rol op te pakken. De attitude op NICU's en de Nederlandse cultuur moeten veranderen, waardoor het voor ouders mogelijk is om aanwezig te zijn bij hun opgenomen kind.

**English abstract**

**Title:** Parental presence and activities on a Dutch NICU; an observational study

**Background:** The presence of an infant's parents during a Neonatal Intensive Care Unit (NICU) admission is important, for the healthy and safe development of the infant, and to reduce parental stress. Before implementation of interventions to increase parental presence, a baseline measurement was needed to assess the current parental presence on the NICU, and potential influencing characteristics.

**Aim:** Identify the frequency and duration of parental presence, and their activities on the NICU, in relation to the characteristics of the infant and parents.

**Method:** An observational study was performed, through observations by NICU nurses between January and April 2016, on a Dutch NICU. All infants admitted for over 24 hours were included.

**Results:** 162 infants were included, of which ten died. Parents were present for three to four hours per day. After a week, 80% of the parents participated in the care of their infant. A vaginal delivery, higher visit frequency, longer duration of kangaroo care, higher birth weight, BPD, being a first child, the second admission week and following, and a shorter driving distance, led to significantly increased presence for both parents. Mothers were present significantly longer than fathers. Finally, parental presence was significantly longer in infants who died.

**Conclusion:** Parents were present 17% of the day on the NICU. It took almost a week before the majority of the parents participated in the care of their infant. Kangaroo care, visit frequency, birth weight, and the method of delivery, found to exert a significant influence on the duration of parental presence.

**Recommendations:** In current practice, there is a need for the conditions and support for parents in taking up their parental role to be examined and facilitated. Attitudes on the NICU and within Dutch culture need to change, so parents have the opportunity of being present with their admitted infant.

**Key words max 5 words:** characteristics, infants, parental presence, participation, NICU

**Appendix 1**

Observatielijst ouderlijke aanwezigheid en activiteiten

Patiënt sticker

**Activiteit:**

- 1 = Aanwezigheid, zonder specifieke activiteit
- 2 = Aanraken van de baby
- 3 = Troosten bij onderzoek
- 4 = Luiers verschonen
- 5 = Temperaturen
- 6 = (Borst)voeding
- 7 = Huidverzorging
- 8 = Mondverzorging
- 9 = Kangoeroën
- 10 = Overige, nml:

| <b>Datum</b> | <b>Tijd in minuten<br/>OF<br/>Tijd van.. tot ...</b> | <b>Vader/Moeder/<br/>Beide ouders*<br/>omcirkelen</b> | <b>Activiteit</b> | <b>Dienst:<br/>Dag/Avond/Nacht*<br/>Omcirkelen</b> |
|--------------|--|---|-------------------|--|
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
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|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
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|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |
|              |  | V/M/B   |                   | D/A/N  |