Stress and discomfort in the care of preterm infants: A study of the Comfort Scale and the Newborn Individualized Developmental Care and Assessment Program (NIDCAP®) in a Dutch level III NICU
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Chapter

How satisfied are parents supported by nurses with the NIDCAP® model of care for their preterm infant?

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How satisfied are parents supported by nurses with the NIDCAP®

ABSTRACT

Main purpose of implementing the Newborn Individualized Developmental Care and Assessment Program (NIDCAP®) in our Neonatal Intensive Care Unit from perspective of quality of care was to bring about an improvement in the satisfaction of parents. This was measured by means of the NICU Parent Satisfaction Form and the Nurse Parent Support Tool. Parents were significantly more satisfied with caregiving according to NIDCAP® principles than they were with the traditional care for their premature infants.
INTRODUCTION

The scope of customers’ participation in the evaluation of healthcare service has broadened during the last decade. In particular, customers' satisfaction has become a widely accepted measure of quality of care. Satisfaction, defined as a personal evaluation of care services and care providers, is viewed as vital in the assessment of quality of care.1

A common problem with satisfaction rating instruments is that ratings are universally high. Many factors have been identified as contributing to the overall positive responses, including social desirability, implicit threat, hesitate to express negative opinions, and item wording.2-7 Conceptual issues regarding patients’ (parents’) satisfaction were subject of research mainly in the 1980s – 1990s. Yet, the theoretical basis of patients’ satisfaction with their hospital experience as well as patients’ satisfaction with nursing care remained unclear. More recently research on patients’ perceptions of nursing care showed four conceptual categories - seeing the individual patient, responding, explaining, and watching over - as major contributors to the level of satisfaction.8

Hall and Dorman’s systematic review of 221 satisfaction studies reported on the mediating role that satisfaction may play between care provider behavior and changes in health status of patients.9 They identified external factors that contribute significantly to patients’ satisfaction, such as the experience of the caregiver and the type of care provided. Additional factors were the number of items and the specificity of the questionnaire, and whether or not the questionnaire was internally constructed.

In child health care the parents are asked, as legal guardians, to rate the quality of care.10,11 Mitchell-DiCenso et al pointed out that parental satisfaction is highly dependent on the amount and quality of communication between care providers and parents.12 Parents convey a strong message to care providers about the importance of being kept informed about the care their infant is receiving and the infant’s progress. Satisfaction identifies the match between the unit culture and the parents’ expectations.13

Previous research has indicated that parents of infants hospitalized in a neonatal intensive care unit (NICU) are particularly stressed by the appearance and behavior of their sick infant and by the alterations in their parental role.14-16

Encouraging parents to spend more time with their infants and to actively participate in their care is believed to facilitate parental role development.17 Knowledge of nurses’ attitudes regarding parents and other family members’ participation in care is limited, though the literature indicates that the nature and extent of parental participation is presently under nurses’ control.17

Parental feedback, similar to parental satisfaction, provides data to compare changes in nursing care and allows monitoring of trends for improvement. However, only one study was found on the support of nurses to parents, while no studies were found
relating the increase of the parental involvement to a decrease of stress and/or parental satisfaction.14

Knowing how stressful the period in a NICU is and knowing parents are distressed by the loss of their expected parental caregiving role with their newborns, we hypothesized that implementing family-centered developmental care could make a difference. The Neonatal Individualized Developmental Care and Assessment Program (NIDCAP®) changing practice from profession-centered approach to an approach involving shared decision making and responsibility in caregiving, would contribute to improvement in parents’ perceived support and satisfaction.

METHODS

The study was carried out in the level III NICU of the Emma Children’s Hospital / Academic Medical Center in Amsterdam, The Netherlands. Parents of 50 infants born before 30 weeks of gestational age and living in the region of Amsterdam were included in the study. Excluded were parents of infants with chromosomal, syndromal or congenital abnormalities, as well as infants with congenital infections. Parents speaking insufficient Dutch or English were excluded as well. The Medical Ethics Committee approved the study.

The control group (25 infants) received traditional neonatal care practiced at that time. After collecting data of this group, the NIDCAP was introduced.18 The intervention group received care according to general NIDCAP principles (Figure I). After written informed consent was obtained, formal observations of the infants’ behavior were started within

Figure 1 Newborn Individualized Developmental Care and Assessment Program

NIDCAP® is an integrated developmental care intervention. The major instrument used in the NIDCAP is repeated, formalized observations of the infant by a specially trained and certified person. These observations focus on efforts at self-regulation, as revealed by approach or avoidance behavior. When the sensory input is appropriate, the infant will move toward the stimuli and demonstrate self-regulatory behavior. When the input is overwhelming or inappropriate in timing, the infant shows avoidance or stress behavior. Caregiving plans, including recommendations concerning individualized care, and environmental changes are designed on the basis of the current developmental stage and medical condition of the infant, as well as on the needs of the family. As the infant matures, these recommendations are modified in an appropriate manner. Caregivers learn to watch sensitively and note the reactions of the infant to different types of handling and care, and thus make continuously appropriate adjustments. NIDCAP is family centered; the goal is to empower the family as part of the healthcare team.
three days after birth. These observations where repeated every seven to ten days for as long as the infant remained in the unit. Recommendations resulting from the observations were discussed in detail with the professional in charge and the parents.

Data collection of the control group took place between August 2001 and April 2002, followed by data collection of the intervention group between October 2002 and July 2003.

Between these periods professionals were trained in the theoretical principles and practical skills of NIDCAP. The data concerning parents’ satisfaction and perceived support from nurses were collected by means of the NICU- Parent Satisfaction Form (NICU-PSF) and the Nurse Parent Support Tool (NPST). We also collected parental demographics about age, ethnic background, education level and socioeconomic status, and data about gestational age, birth weight, gender, and multiple births. Data concerning the severity of illness of the infant were collected by means of the Neonatal Therapeutic Intervention Score (NTISS) and the infants’ length of stay in the NICU.

Both questionnaires (NICU-PSF and NPST) were translated from English to Dutch by one of the nurses in collaboration with the nurse researcher (JW). Thereafter, a bilingual (English/Dutch) neonatal nurse teacher translated the questionnaires back into English. The latter was sent to the authors of both scales and approval was received.

The scale was tested with three parents on comprehensiveness and clarity of the items before the study.

Both questionnaires were given to parents on the day their infant was transferred to another hospital or was discharged home, together with a written request to send back the questionnaire as soon as possible in the envelope provided. The parents were asked for permission to contact them if the questionnaires were not received within the following three weeks.

Assessment tools
The NICU-PSF is a self-reporting questionnaire developed to measure parents’ perceptions of care. It targets areas for improvement and evaluates the quality of care delivered, in meeting and exceeding the needs and expectations of parents and their families who receive neonatal care services. The NICU-PSF is a 62-item questionnaire with closed and open-ended questions. The concepts include general satisfaction, continuity of care, communication and information, preparedness, involvement in care, being a parent, being near the baby, support, and follow up. The final questions are about pleasures and disappointments and suggestions for improvement. Different rating scales were used, such as a 5-point rating scale ranging from “extremely satisfied” to “not at all satisfied” or “excellent” to “poor”. Questions reporting frequencies ranged from “all the time” to “none of the time” and “prepared” to “not nearly prepared”. There were also some questions with dichotomous and categorical responses. The number of (sub)questions per concept differed from 3 to 12.
Scores differed per concept due to the number of questions per concept from 3 to 57 points, because of the number of questions per concept. The scale has been tested for reliability and validity. Internal consistency ($r_{ic}$) is reasonably good for four categories (0.52-0.67) and good for five categories (>$0.70$).\textsuperscript{15} Content validity was established through literature review, parent open/ended interviews, parent panel, neonatal staff review, and pilot pretesting. Discriminant validity was tested by determining the correlations of the items and by comparing the correlations to other constructs; internally consistency was reached. Criterion validity was not achieved because of the lack of a gold standard instrument for comparison.\textsuperscript{20}

The NPST is a self-reporting instrument\textsuperscript{21} item. Parents are asked to rate the amount of nursing support they received from the nursing staff on a Likert-type scale as follows: 1 = almost never, 2 = not very often, 3 = some of the time, 4 = most of the time, and 5 = almost always. The scoring is done by summing the items that are rated, divided by the number of items completed. The range of scores is from 1 to 5 with higher scores reflecting greater amounts of perceived support from the nursing staff. The scale makes use of four dimensions - information, appraisal, emotional support, and nursing care - to measure the amount of support. (1) The information dimension includes informational support, supportive communication, and ongoing information related to the child’s illness, treatments, care and related issues. (2) The appraisal dimension involves nurses’ esteem support on respecting, enhancing, and supporting the parent role. (3) The emotional support dimension involves helping parents to cope with their responses and needs related to the child’s illness. (4) The nursing care dimension incorporates the quality of care provided to the child. The psychometric properties have been tested. The internal consistency of the NPST is high, Cronbach’s $\alpha$ being 0.95 (mothers: 0.94 and fathers: 0.96). Validity was supported by correlating the total scale score with the Stress Support Scale ($r = 0.76$).\textsuperscript{19}

**RESULTS**

General

Characteristics of parents as well as their infant are summarized in Table I. In the control group, 2 infants died and their parents did not receive the questionnaires. The last infant to be included was one of a twin; therefore both were included, leading to 24 infant-parent dyads for analysis. In the intervention group, 25 dyads were analyzed. Some differences were seen between the groups. The infants of the intervention group had a significantly lower birth weight (Mann Whitney U-test = 193.00, $p = 0.032$). Significantly more twins were included in the control group (Fisher exact test value = 5.975, $p = 0.015$). No differences were seen between the mothers groups. Fathers in both groups differed in age and educational level, but the differences were not statistically significant.
No between-group differences were seen for the NTISS. Mean score on day 1 was 25.25 (SD = 4.47) for the control group and 24.60 (SD = 5.14) for the intervention group (ns). The length of stay was 35.71 days (SD = 22.62) for the control group and 47.44 days (SD = 28.00) for the intervention group, not a statistically significant difference.

### Table I Characteristics of (surviving) study infants and their parents

<table>
<thead>
<tr>
<th></th>
<th>Control group N = 24</th>
<th>Intervention group N = 25</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gestational age, wk</td>
<td>28.5 (26.0-29.9)</td>
<td>28.3 (25.6-29.9)</td>
</tr>
<tr>
<td>Mean birth weight, g</td>
<td>1162 (760-1465)*</td>
<td>1043 (615-1325)*</td>
</tr>
<tr>
<td>Male/ female</td>
<td>14 / 10</td>
<td>9 / 16</td>
</tr>
<tr>
<td>Singleton / multiples</td>
<td>10 / 10†</td>
<td>19 / 6†</td>
</tr>
<tr>
<td>Parents married or attached</td>
<td>24</td>
<td>22</td>
</tr>
<tr>
<td>Mean maternal age at delivery, y</td>
<td>30 (21-39)</td>
<td>32 (16-40)</td>
</tr>
<tr>
<td>Maternal ethnic origin</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Western / non Western</td>
<td>14 / 3</td>
<td>15 / 7</td>
</tr>
<tr>
<td>Maternal education level‡</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Middle</td>
<td>11</td>
<td>12</td>
</tr>
<tr>
<td>High</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Mother working</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes/no</td>
<td>12 / 5</td>
<td>13 / 9</td>
</tr>
<tr>
<td>Mean father’s age, y</td>
<td>33 (20-41)</td>
<td>38 (31-61)</td>
</tr>
<tr>
<td>Father’s ethnic origin</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Western / non Western</td>
<td>13 / 4</td>
<td>17 / 2</td>
</tr>
<tr>
<td>Father’s education level‡</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Middle</td>
<td>10</td>
<td>6</td>
</tr>
<tr>
<td>High</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>Father working</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes/no</td>
<td>17 / 0</td>
<td>16 / 3</td>
</tr>
</tbody>
</table>

* Mann Whitney U-test = 193, p = 0.032
† Fisher’s exact test value = 5.975, p = 0.015
‡ Low = < high school
Middle = high school
High = > high school
Response
Response rate for both questionnaires was high. In the control group, 23 of 24 (96%) questionnaires were returned, 19 filled in by mothers (83%) and 4 by fathers (17%). In the intervention group 23 of 25 (92%) questionnaires distributed were returned, 16 completed by mothers (70%) and 7 by fathers (30%). The parents of three infants did not return the questionnaires, for various reasons, after being approached twice. One mother was very ill and moved to another city at that time, one mother could not find the time because of illness of her baby, and one mother refused to complete the questionnaire.

NICU-PSF Results
In this study, NICU-PSF questions concerning follow up were not included in the analysis as these questions were not yet relevant, because most children were still hospitalized when the parents completed the questionnaires. Open-ended questions were analyzed separately; 50 close-ended (sub)questions were also taken into analysis. The minimum possible score was 50 points and the maximum possible score was 243 points. The control group scored a mean of 174.04 (range: 136-217, SD = 20.98) and the intervention group 185.67 (range: 149-219, SD = 17.74), a statistically significant difference (Mann Whitney U-test = 154.5, p = 0.041). Almost all separate concepts also showed an increase in their mean scores; see Table II. Only the concept of preparedness showed a statistically significantly difference, with the mean control versus intervention group being 13.83 versus 16.38 (Mann Whitney U-test = 162.0, p = 0.038). The concept of being a parent had a slightly lower mean score (9.39, SD = 1.73) in the intervention group compared to the control group (9.78, SD = 2.09) (ns).

<table>
<thead>
<tr>
<th>Concept</th>
<th>Mean (SD) Control group</th>
<th>Intervention group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall rating</td>
<td>26.17 (3.59)</td>
<td>27.50 (2.99)</td>
</tr>
<tr>
<td>Care of the baby</td>
<td>17.96 (3.42)</td>
<td>19.09 (4.02)</td>
</tr>
<tr>
<td>Communication with staff</td>
<td>46.22 (7.76)</td>
<td>49.59 (5.83)</td>
</tr>
<tr>
<td>Involvement in care</td>
<td>17.17 (5.20)</td>
<td>18.64 (5.13)</td>
</tr>
<tr>
<td>Being prepared</td>
<td>13.83* (3.81)</td>
<td>16.59* (4.52)</td>
</tr>
<tr>
<td>Support</td>
<td>20.78 (4.00)</td>
<td>21.52 (5.84)</td>
</tr>
<tr>
<td>Being a parent</td>
<td>9.78 (2.09)</td>
<td>9.39 (1.73)</td>
</tr>
<tr>
<td>Being near your baby</td>
<td>22.13 (2.77)</td>
<td>22.04 (3.35)</td>
</tr>
<tr>
<td>Total score</td>
<td>174.04† (20.98)</td>
<td>185.62† (17.74)</td>
</tr>
</tbody>
</table>

* Mann Whitney U-test = 162, p = 0.038, † Mann Whitney U-test = 154.5, p = 0.041
NPST Results

On the NPST, the control group had a mean total score of 4.10 (range: 3.00-5.00, SD = 0.59); the intervention group had a slightly but not statistically significant higher mean value of 4.26 (range: 3.71-5.00, SD = 0.37). The correlation between support (NPST) and satisfaction (NICU-PSF) scores was outstanding (r = 0.893).

Additional Analyses

We examined the correlations among scores on the NICU-PSF, NPST and NTISS score, the length of stay; and socioeconomic status. We found no significant correlations. As part of the intervention, behavioural observations were performed. The number of observations varied from 2 to 9 with a median of 4 observations per infant per admittance. There was no correlation between the number of behavioural observations performed and the scores on the NICU-PSF or NPST in the intervention group.

We also looked at possible differences in scores of fathers and mothers on the NPST and NICU-PSF. The total scores on both scales as well as the scores for the separate concepts of the NICU-PSF were comparable.

The open-ended questions of the NICU-PSF on positive experiences during the stay in the NICU were categorized. Parents of the control group most frequently mentioned the (unexpected) progress made by the infant, the gifts they received because of national holidays and pictures made by the nurses, and the stories nurses wrote in the infants’ diaries. Parents also made some remarks on the kindness of nurses and their way of communicating with parents. The parents of the intervention group, however, remarked mostly on the support, involvement, interest, and honesty of the nurses and the explanation of behavioural observations. Some parents made a remark on the national holiday gifts and on the progress of their infant.

Parents of the control as well as the intervention group mentioned the setbacks and medical complications of their infants as the major negative events experienced. Control group parents also mentioned negative experiences concerning transfer policies and communication around transfer and feelings of powerlessness. The intervention group mentioned several times the discrepancy between nurses in the way they handle the recommendations from the behavioural observations.

DISCUSSION AND CONCLUSION

Differences in characteristics (birth weight, and number of twins) between control and intervention group is a factor one needs to bear in mind when interpreting the results. Additionally, in the intervention group were three single mothers while all control group parents were either married or were living with partners. All factors mentioned could be of influence on satisfaction and perceived support. Another limitation is the translation
of the instrument. We did the commendable back translation, but we tested the Dutch version in a small (N = 3) sample only.

The response rates in our study are high (96% and 92%) and should be regarded as sufficient enough to give a valid impression of the opinion regarding satisfaction among parents in our NICU. A response rate of 60% for questionnaires is mentioned in literature as probably sufficient.22

In the literature, no cut off point is given for the NICU-PSF. We hypothesized that parents who experienced NIDCAP care would be more satisfied than parents who experienced traditional care. The high mean score of the control group made it difficult to improve. Considering that we have only just started with NIDCAP, we are content with the extent of improvement so far. We anticipate ongoing improvement of satisfaction rates will be seen within the next year after which a third satisfaction measurement will be scheduled.

Evaluating the separate concepts of the NICU-PSF, we expected changes in concepts like involvement in care and being a parent. These concepts can be seen as the measurement of the core concepts of NIDCAP. Only small changes in these concepts, however, were seen, probably because of the fact that parents adapted to the NIDCAP much faster than professional caretakers. Professionals had to go through a process of changing their attitudes. Nurses in particular needed some time to change, feel comfortable and become satisfied with the NIDCAP23 (also J. M. Wielenga et al, unpublished data, 2004). Nurses reported feelings of intimidation because of parents telling them what to do, loss of control, and parents trying to take over.

The scores on the NPST reflected the small changes in satisfaction. The score was high in the control group as well as in the intervention group (4.10 vs 4.26). Miles et al found comparable mean scores in their study comparing Caucasian and Negroid women (4.19, SD = 0.56 vs 4.14, SD = 0.79).14 According to them, the perceived support from the nurses suggests that parents are highly satisfied with their encounters with the nurses. It also indicates that the nurses are frequently perceived as providing emotional, informational, and esteem support and are perceived as giving a high level of care to their sick infant. The higher the parents rate the amount of support, the higher the satisfaction rates. With traditional care scoring as high as it did, it seemed almost impossible to expect a significant increase after implementing NIDCAP. This is complicated by the fact that satisfaction is measured among parents of infants receiving traditional care not knowing about other care possibilities.

Implications
As a result of this study, we became aware of areas needing improvement in nursing care. On the basis of the answers to the open-ended questions, we started quality improvement projects on better-preparedness to the transfer back to a regional hospital. We now evaluate each referral back. Furthermore, in weekly reflection sessions, the way nurses
handle and make choices in care are discussed to decrease the discrepancy between nurses and to teach them to see the infant as part of a family. Premji and Chapman studied the experiences of nurses with developmental care. They identified “putting the baby first” as the basic social process used by nurses implementing developmental care. Considering that the developmental care model is clearly family focused, it remained unclear why these nurses still focused their attention almost entirely on the baby.

The value of measuring parents’ satisfaction in regard to NIDCAP introduction is increasingly important and necessary to document quality improvement. The transition to developmental care requires moving from a profession-centered approach to an approach involving shared decision making and responsibility in caregiving. Three major themes are involved with this shift: acknowledging the central role of the parent in the care of the infant, fostering the parent as a competent caregiver, and integrating the roles of coach, teacher and facilitator into the existing technically expert nurse role. Professionals in neonatal care need to be educated to perform these new roles.

The lesson learned is: With the introduction and consequently implementation of developmental care and subsequent improvement of parental satisfaction levels, the first activity to accomplish is giving a piece of the professional autonomy of nurses back to where it belongs, namely, to the parents, as concluded from the remarks made by nurses and parents in this study.

Changing the culture of care to family-centered individualized developmental care in the NICU is slow process; it is more of a journey than a destination. Measuring the progress of this quality improvement should be a continuous process. The results of this study, shortly after introduction of NIDCAP, are positive and encourage us to continue working according to NIDCAP.

ACKNOWLEDGEMENTS
We would like to thank all the parents who so generously gave of their time to complete the questionnaires. We would like to thank Ingrid Hankes Drielsma and Ellen te Pas for translation of the NPST and NICU-PSF and for commenting on the manuscript. We would also like to thank Gavin ten Tusscher for commenting on the manuscript. The study was supported by a grant 1015.0004 from ZorgOnderzoek Nederland (ZON) 1015.0004 and the Emma Children’s Hospital / Academic Medical Center.
REFERENCES