Perceptions of parents, nurses, and physicians on neonatal intensive care practices

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Abbreviations:

NICU: Neonatal Intensive Care Unit
NICU-PSF: Neonatal Intensive Care Unit - Parental Satisfaction Form
ICU: Intensive Care Unit
CCNFI: Critical Care Family Needs Inventory
SD: Standard Deviation

ABSTRACT

Objective: To identify satisfaction with neonatal intensive care issues as viewed by parents and healthcare professionals and to explore similarities and differences between parents and healthcare professionals.

Study design: A 3-round Delphi method to identify neonatal care issues (round 1) and to determine the importance of these issues (rounds 2 and 3) was conducted among nurses (n = 84) and physicians (n = 14), followed by an exploratory survey among parents (n = 259). Main outcome measures were 92 neonatal care-related items.

Results: Sixty-eight nurses and 13 physicians completed all 3 rounds. The first round yielded 419 neonatal care related statements, which were clustered into 92 items. The survey was completed by 148 (57%) parents. Parents rated 25 of 92 care items significantly higher than did the professionals (effect size of Cohen's d 0.31 to 1.14, $P \leq 0.02$). Two items related to medication administration had the largest effect size. Professionals rated 7 items significantly higher than did parents (Cohen's d –0.31 to –0.58, $P \leq 0.04$). One of these was assigning a physician and a nurse to the parents. Three were related to multicultural care.

Conclusions: This study revealed disparities between parents and neonatal intensive care unit staff on a number of care issues reflecting incongruity in recognizing parents' desires.

INTRODUCTION

Today's healthcare systems are influenced by politicians, health insurance companies, and patient organizations. These actors exert pressure towards efficiency and effectiveness of customer-driven care with a focus on patient-centered services and outcome measurements. Perceptions of patients have therefore become important outcome variables.[1,2] The complexity of a neonatal intensive care unit (NICU) requires a tailor-made instrument to measure parents' experiences. It should focus on the infant's comfort and on information-related issues, as these have been identified as most important for parents.[3] Another consideration is the family-centered care principle of neonatology.[4-6] Partnerships between parents and healthcare professionals and parental involvement in care processes are 2 examples that have been described as beneficial for parents.[7,8] There are reasons to believe, however, that family-centered care principles are not consistently applied in daily practice.[9,10] Notably, there is evidence that NICU nurses do not consistently work according to these practices.[11] It would be advisable, therefore, to incorporate concepts of family-centered care in satisfaction surveys.

The literature contains only a few satisfaction surveys in neonatology.[12-14] All originate from Northern America and date back to the 1990s. A literature review, parental interviews, and neonatal staff reports lie at the basis of the NICU-Parental Satisfaction Form (NICU-PSF), which, with 62 items, is the most comprehensive tool.[13] There are several arguments against the use of NICU-PSF in today's context. Since the validation of the NICU-PSF, neonatology has seen significant changes. These include, for example, communication strategies oriented toward the empowerment of parents, as promoted by the family-centered care movement. There also is the trend toward multiculturalism. Parents from different cultural backgrounds might require specific attention for different needs. These changes justify new initiatives to develop a parent satisfaction instrument suited to today's needs.[15] It is against this background that we performed 2 related studies.

The objectives of the studies were (1) to identify NICU nurses and physicians' perceptions of parental satisfaction with care issues and to reach a consensus on the identified issues, (2) to explore the parent's perceptions on satisfaction with care issues, and (3) to identify differences and similarities in opinions on care issues between parents and NICU healthcare professionals, including ethnic differences.

METHODS

The exploratory and descriptive studies were designed as a 3-round Delphi method for nurses and physicians and an exploratory survey method for parents. The Delphi study was conducted first. The results of this study were then used for the survey study among parents. Both studies were completed between May 2007 and May 2008. The medical ethical review board of the Erasmus University Medical Center gave approval for the study.

The setting was a 30-bed level III NICU in the Netherlands. The yearly admission rate is around 700 patients, from low-birth-weight preterm infants (≥24 weeks gestational age) to 4-week-old term neonates. Approximately 250 very-low-birth-weight infants are admitted annually. Participants were nurses and physicians as well as parents of infants. Eighty-four nurses and 14 physicians consented to participate in the Delphi study. In total, 259 parents were invited to complete the questionnaire (Figure 1). Excluded from the study were parents of infants admitted for less than 48 hours and those whose child died during NICU admission.

The Delphi method allows for a systematic consultation of a large number of experts and the collection, evaluation, and tabulation of these experts' opinions.[16] Its strength lies in 4 specific characteristics: anonymity, iteration, controlled feedback, and statistical group response. Anonymity is guaranteed by the use of questionnaires. Iteration is achieved by presenting a topic over a certain number of rounds. Controlled feedback and statistical group response take place in between rounds, when individual experts are informed about the opinions of the total group. The Delphi method used in this study is outlined in Figure 2. The first step (Delphi round 1) was a questionnaire round to identify neonatal care issues among nurses and physicians. The questionnaire contained demographic characteristics and a single question: What do you think parents find important in the care for their child? Participants were asked to provide a maximum of 5 issues. The qualitative data of this first Delphi round were matched with a framework developed from a literature review of validated satisfaction-with-care instruments related to neonatal, pediatric and adult intensive care.[15] The framework contained 78 care issues. The written responses of the first Delphi round were independently reviewed and coded into the framework by 2 researchers (J.M.L. and K.v.N). If responses did not fit within the framework, they were incorporated into new statements. After completion of coding, outcomes for both researchers were compared until consensus was reached. A third researcher (J.A.H) functioned as an auditor to review the process. The result was a questionnaire with 92 neonatal care items. The second step (Delphi round 2) elicited opinions of the participants in a quantitative questionnaire in which the items were clustered in 5 domains: information (20 items), care and treatment (23 items), organization NICU (20 items), parental participation (14 items), and professional attitude (15 items). The participants were asked to rate each item on a 6 point scale ranging from "completely unimportant" to "extremely important". In the third step (Delphi round 3) the same questionnaire was used. This time, the results of round 2, in terms of the group mean rating of every item, were included in the questionnaire to attain consensus among participants. The participants were asked to review the annotated items again on importance.

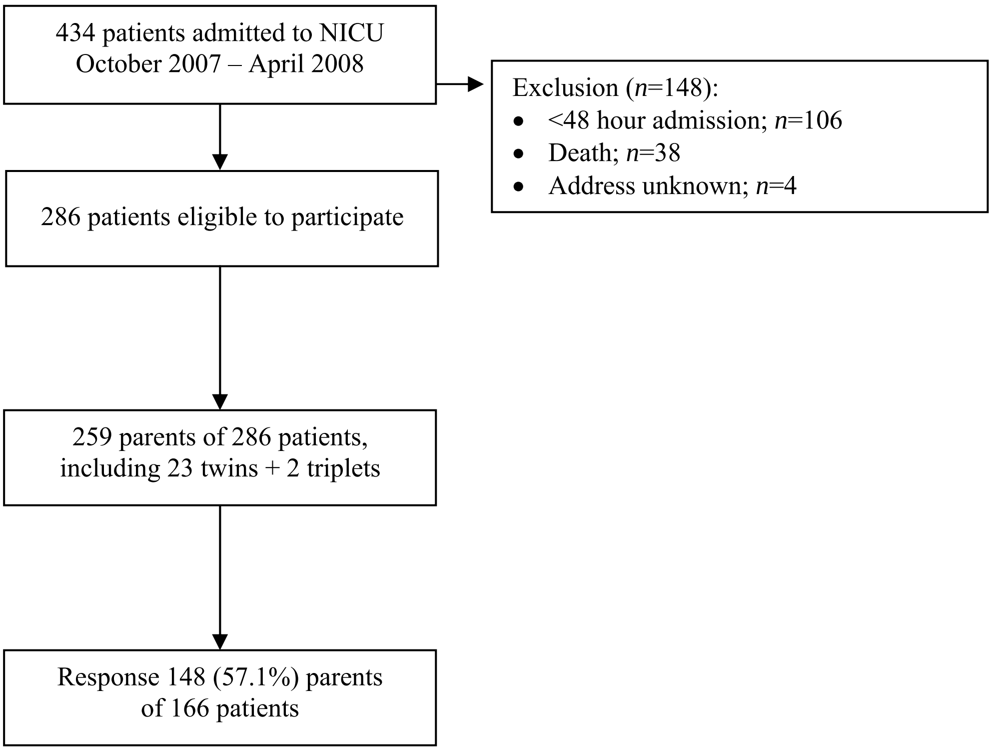

Figure 1 Flowchart inclusion of parents

In the exploratory study among parents a self-administered questionnaire, including the 92 items regarding neonatal care issues, was used. Parents were sent a letter explaining the aim of the study 2 to 3 weeks after discharge of their child from the NICU. They were invited to rate each item's importance on a 6 point scale ranging from "completely unimportant" to "extremely important". Parents were also invited to suggest additional items they considered valuable.

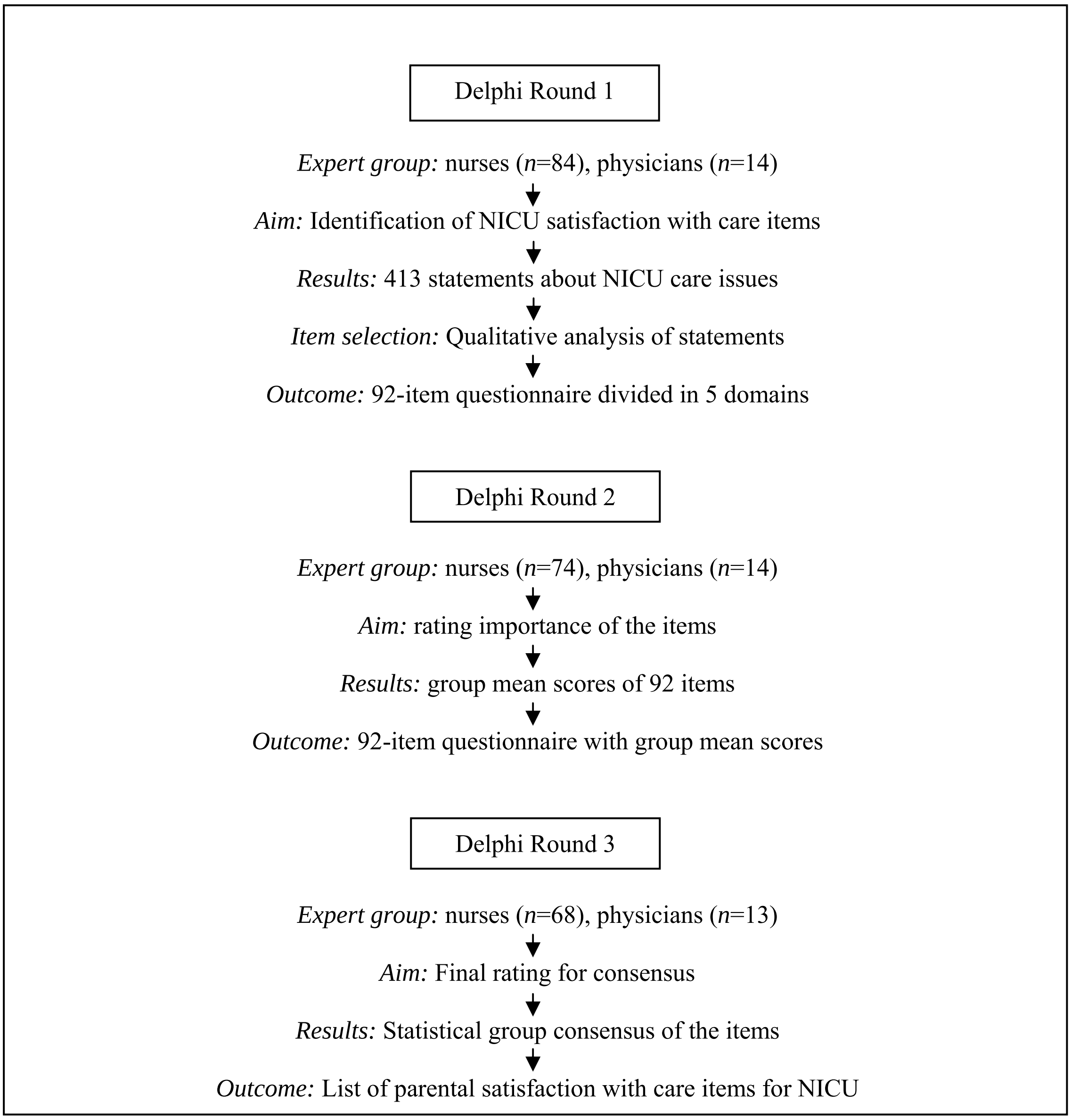

Figure 2 Delphi study design

The quantitative data were analyzed using SPSS (version 15, Chicago, Illinois). The demographic variables were analyzed by descriptive statistics. Significances between sex and type of profession of respondents and nonrespondents in the Delphi study were calculated with Fisher exact test. The *t* test for independent observations was used for the other demographic variables. Means and standard deviations were used for ranking the importance of the care items in both studies. The Cohen's *d*, standardized mean difference, was used to calculate the effect-size using the means and standard deviations of both the parents and the NICU professionals. The interpretation of the effect-size is small with a value of 0.2, medium with 0.5, and large >0.8.[17] Guided by the interpretation of the Cohen's *d*, we used an effect-size of ≥0.30 or ≤-0.30 as the cut off point for statistically meaningful differences which correspond to $P < 0.05$ (*t* test, 2-tailed). Related to the study aims, the *t* test for independent observations was used to calculate statistical differences of the importance of the items between the healthcare professionals and parents. All statistical testing took place at a 0.05 level of significance (2-tailed).

RESULTS

Of the 98 healthcare professionals who consented to participate in the Delphi study, 81 (83%) completed all three questionnaires (68 nurses and 13 physicians). Table 1 presents characteristics of the participants in each Delphi round. NICU experience ranged from 0.50 to 27 years and professional experience ranged from 1 to 35 years. The demographic variables for nonrespondents and respondents in round 3 did not differ significantly.

Table 1 Characteristics of NICU professionals

	R1 n = 98	R2 n = 89*	nonresponse R2 n = 9	R3 n = 81	nonresponse R3 n = 8	*P*
Sex (F/M)	88/10	80/8	9/0	73/8	8/0	1.00 ^{1}
Age, years: mean (SD)	37.5 (8.78)	37.5 (8.92)	36.8 (7.69)	37.6 (9.07)	36.0 (7.58)	0.59 ^{2}
Profession (nurse/physician)	84/14	74/14	9/0	68/13	7/1	1.00 ^{1}
Experience NICU in years: mean (SD)	7.2 (6.39)	7.2 (6.55)	6.11 (4.68)	7.2 (6.57)	7.9 (6.70)	0.79 ^{2}
Experience overall profession in years: mean (SD	12.3 (8.91)	12.4 (9.11)	11.3 (7.70)	12.6 (9.38)	10.3 (5.78)	0.31 ^{2}
Working Hours per week: mean (SD)	32.3 (8.87)	32.7 (8.94)	28.1 (7.49)	33.1 (8.53)	28.1 (11.98)	0.29 ^{2}

R indicates round; * one case missing; ^{1}Fisher exact test; ^{2}*t* test for independent observation.

The first round yielded 419 short statements on neonatal care issues, an average of 4.3 statements per participant. The statements were clustered into 5 domains: (1) information (n = 104); (2) care and treatment (n = 64); (3) organization (n = 30); (4) parental participation (n = 98); and (5) professional attitude (n = 123). The following step was to match these statements into the framework derived from the literature. Most of the statements (n = 266) matched with 1 of the 78 items of the framework. The remaining 153 statements were condensed into 14 new issues, each supported by 1 to 42 statements. Thus, the first Delphi round resulted a list of 92 care related items distributed over 5 domains.

In the 7-month data collection period 434 children were discharged. Parents (n = 259) of 286 children were eligible to participate. A total of 148 parents (57.1%) completed the questionnaire (Figure 1). Most families were Dutch (n = 102, 68.9%). The other 46 (31.1%) families were mainly from a Moroccan (n = 10), Turkish (n = 6), or Surinamese (n = 5) cultural background. The characteristics are presented in Table 2.

Table 2 Characteristics of infants and parents

	Infants (n = 166)		Parents (n = 148)	
Male	98	(59%)		
Gestational age in weeks: median (min-max)	32	(24-42)		
Birth weight in grams: median (min-max)	1900	(630-4620)		
Length of stay NICU in days: median (min-max)	8.5	(2-109)		
Ventilation days: median (min-max)	1	(0-31)		
Questionnaire completed by*				
Mother			80	(54.4%)
Father			13	(8.8%)
Both			52	(35.4%)
Legal guardian			2	(1.4%)
Ethnicity				
Dutch			102	(68.9%)
Non-Dutch			46	(31.1%)

*one case missing.

Generally, mean item scores were fairly high. Nevertheless, ranking of the 92 items on importance was possible based on the definition: highest mean albeit the lowest standard deviation (Table 3). Finally, 78 (52.7%) parents wrote comments in the last section of the questionnaire. However, the narratives did not add additional items but rather described personal situations complementing the 92 items.

Table 3 Similarities and differences of opinions of parents and healthcare professionals on neonatal care items

	Parents (n = 148)		Professionals (n = 81)			
	mean	SD	mean	SD	Cohen's *d*	*P*
Domain Information						
Parents are informed about the child's illness	5.81	0.47	5.60	0.59	0.40	0.008
Parents are informed about changes in the child's condition as soon as possible	5.79	0.42	5.57	0.57	0.44	0.002
Caregivers inform parents daily about the child's care and treatment	5.78	0.65	5.42	0.67	0.55	0.001
Caregivers provide honest information to parents	5.76	0.56	5.70	0.49	0.12	0.44
Parents are informed about tests and procedures	5.75	0.52	5.49	0.64	0.45	0.003
Caregivers answer parents' questions adequately	5.74	0.61	5.68	0.52	0.11	0.43
Caregivers inform the parents about the treatment consequences	5.68	0.71	5.44	0.65	0.35	0.02
Parents are informed about the child's future perspectives	5.57	0.73	5.36	0.70	0.29	0.04
Caregivers give no conflicting information to the parents	5.57	0.86	5.60	0.67	-0.04	0.75
Parents are informed about the (adverse) effects of the medication	5.52	0.79	4.74	0.85	0.95	0.001
Parents have easy access to information	5.44	0.74	5.21	0.67	0.33	0.02
Caregivers inform the parents in a way it is understandable for them	5.37	0.93	5.60	0.56	-0.31	0.04
Parents are informed about NICU rules	4.95	0.92	4.94	0.70	0.01	0.95
Caregivers inform the parents about breastfeeding	4.78	1.12	4.55	0.76	0.24	0.05
Caregivers provide not only oral but also written information	4.64	1.08	3.86	0.98	0.76	0.001
Caregivers inform the parents on the best moment for the parents	4.64	1.10	4.35	0.80	0.31	0.02
Caregivers' communication with non Dutch speaking parents is through an interpreter or the interpreter-telephone	4.64	1.56	5.31	0.75	-0.58	0.001
The way to the NICU is clearly signposted	4.60	1.10	4.86	0.82	-0.27	0.05
Parents are informed of visiting hours for other family members	4.34	1.26	4.25	1.00	0.08	0.55
Parents are informed about sanitary units	3.93	1.26	4.11	0.81	-0.17	0.19
Domain Care and Treatment						
The correct medication is given at the right time	5.84	0.39	5.27	0.61	1.14	0.001
Caregivers know their profession	5.83	0.45	5.77	0.46	0.13	0.31
Pain is prevented and/or treated	5.81	0.43	5.75	0.46	0.13	0.38

Caregivers react promptly to changes in the child's condition	5.76	0.46	5.68	0.50	0.17	0.23
Caregivers jointly pursue one goal: adequate care and treatment of child and parents	5.70	0.61	5.56	0.57	0.24	0.08
Caregivers are aware of the child's medical history	5.63	0.75	5.26	0.63	0.54	0.001
A caregiver always advises parents during acute admission or an acute situation	5.53	0.65	5.04	0.77	0.69	0.001
Parents know which physician and nurse are responsible for the care of their child	5.51	0.72	5.12	0.64	0.57	0.001
At discharge, caregivers provide clear information to colleagues	5.50	0.76	5.32	0.63	0.26	0.06
Caregivers are alert to the child's developmental growth	5.49	0.70	4.94	0.71	0.78	0.001
Caregivers are alert to the child's comfort	5.49	0.73	5.56	0.52	-0.11	0.41
Caregivers display a caring attitude towards infant and parents	5.45	0.68	5.33	0.57	0.19	0.16
Caregivers are considerate to the infant's needs	5.45	0.74	5.00	0.76	0.60	0.001
Caregivers prepare the parents for a (planned) NICU admission	5.43	0.80	4.83	0.87	0.72	0.001
Caregivers take care of the infant to lay neatly and well-cared for in the incubator/bed	5.42	0.73	5.25	0.62	0.25	0.06
Parents are adequately prepared for the child's discharge	5.28	0.85	5.12	0.68	0.21	0.12
Caregivers provide emotional support	5.23	0.73	5.17	0.69	0.08	0.59
An assigned physician and nurse serve as contacts for parents during prolonged ICU-stay	5.21	1.02	5.49	0.53	-0.36	0.008
Caregivers work with a team spirit	5.18	0.78	5.01	0.73	0.22	0.10
Caregivers adequately meet the needs of the parents	5.10	0.78	4.89	0.73	0.28	0.04
Parents realize they cannot always have a caregiver's immediate attention	4.85	0.96	4.69	0.80	0.18	0.19
Nurses inform the parents of the availability of the NICU social worker for a meeting	4.73	1.09	4.90	0.64	-0.20	0.17
The lactation nurse is available to provide specific support to parents about breastfeeding	4.55	1.18	4.51	0.94	0.04	0.66
Domain Organization						
Aggression by caregivers and parents is not tolerated in the NICU	5.62	0.75	5.64	0.56	-0.03	0.80
The infant's incubator/bed is clean	5.59	0.60	5.31	0.61	0.47	0.001
The NICU is clean	5.57	0.66	5.37	0.60	0.32	0.02
The NICU is well accessible by phone	5.51	0.78	5.53	0.53	-0.03	0.82
Moment of discharge is not influenced by bed capacity	5.38	0.90	4.67	0.89	0.79	0.001
The caregivers are efficiently organized	5.28	0.71	5.10	0.56	0.28	0.04
Visiting hours are flexible	5.28	0.86	5.12	0.68	0.21	0.14
Rooming-in near the NICU is possible	5.23	1.03	4.79	0.79	0.48	0.001
The NICU environment feels safe	5.20	0.88	5.10	0.63	0.13	0.30
Noise in the NICU is muffled as much as possible	5.11	0.89	5.05	0.71	0.08	0.56
Written information on unit rules, diseases and procedures are available in the NICU	5.03	0.94	5.09	0.62	-0.08	0.58
The infant's bed space is amply sufficient	5.01	1.01	5.15	0.73	-0.16	0.23
The NICU has comfortable furniture	4.76	1.04	4.75	0.75	0.01	0.94
The NICU has a special room for mothers to express milk	4.73	1.18	4.93	0.61	-0.22	0.16
The NICUs design is family-friendly	4.72	1.10	4.57	0.74	0.16	0.22
Every incubator has a camera to provide online contact between parents and infant	4.30	1.39	4.09	0.91	0.18	0.12

The waiting room is fitted comfortably	4.20	1.26	4.61	0.68	-0.42	0.002
Catering for parents is well taken care of	4.06	1.31	4.32	0.79	-0.25	0.08
A locker on the NICU is available for all parents	3.63	1.45	4.22	0.96	-0.49	0.001
The NICU have internet access for parents	3.22	1.55	3.18	1.20	0.03	0.64
Domain Parental Participation						
Parents trust the caregivers	5.72	0.48	5.58	0.55	0.27	0.07
Caregivers support the bonding between infant and parents	5.64	0.62	5.59	0.54	0.09	0.53
Caregivers and parents show respect to each other	5.61	0.63	5.15	0.57	0.77	0.001
Caregivers give instructions to the parents about care issues of the infant	5.56	0.72	5.58	0.50	-0.03	0.83
Caregivers stimulate parents to help in the care of the infant	5.52	0.74	5.48	0.53	0.06	0.65
Caregivers stimulate and support parents in kangaroo care	5.52	0.85	5.59	0.49	-0.10	0.52
Caregivers stimulate parents to stay close to their child during procedures and tests	5.38	0.84	4.91	0.73	0.60	0.001
Caring aspects for home are discussed before discharged	5.36	0.84	5.04	0.58	0.45	0.001
Caregivers stimulate the parents to be close to their infant	5.32	0.85	5.36	0.58	-0.06	0.74
Parents share in the decision-making on the care and treatment of their child	5.03	1.04	4.95	0.71	0.09	0.44
Caregivers facilitate parents in expressing their feelings	4.85	0.90	4.83	0.65	0.03	0.85
Caregivers regularly inform after parental experiences during the course of admission	4.83	0.93	4.99	0.56	-0.22	0.11
Parents receive and are suggested to keep a diary	4.71	1.19	4.69	0.74	0.02	0.73
At admission, caregivers ask parents their expectations	4.63	1.05	4.39	0.77	0.26	0.05
Domain Professional Attitude						
Caregivers give the highest priority to the child’s health	5.90	0.31	5.69	0.47	0.54	0.001
Caregivers adopt principles of hygiene	5.85	0.38	5.81	0.42	0.10	0.57
Caregivers provide equal care; irrespective of race, religion, sex, and education	5.75	0.51	5.64	0.53	0.21	0.14
Regardless the work pressure, the caregiver’s attention towards infant and parents is not allowed to slacken	5.58	0.73	5.09	0.66	0.71	0.001
Parents feel welcome at admission	5.57	0.59	5.47	0.59	0.17	0.20
Caregivers respect the child and parents	5.56	0.58	5.54	0.53	0.04	0.79
Caregivers refrain from unnecessary discussions at the child’s bedside	5.42	0.91	5.43	0.55	-0.01	0.87
Caregivers always work agreeably together	5.34	0.72	5.37	0.51	-0.05	0.72
Caregivers take time to listen to parents	5.30	0.74	5.23	0.55	0.11	0.46
Caregivers safeguard privacy of child and parents	5.28	0.78	5.37	0.58	-0.13	0.32
Caregivers show empathy to child and parents	5.11	0.89	4.98	0.55	0.18	0.16
Caregivers introduce themselves with name and position	5.03	0.96	4.89	0.67	0.17	0.18
Caregivers pay attention to siblings	4.57	1.18	4.64	0.70	-0.07	0.73
Caregivers are alert to the cultural background of the infant and parents	4.45	1.27	4.83	0.69	-0.39	0.008
Parents are offered religious / spiritual support	4.23	1.38	4.77	0.69	-0.52	0.001

Scores were rated on a 1 to 6-point scale from “completely unimportant” to “extremely important.”

Parents rated 25 of the 92 items as significantly more important than did the NICU professionals (Cohen's d, 0.31 to 1.14 , $P \leq 0.02$). Most of these items were in 2 domains: "Information" and "Care and Treatment" (Table 4). The largest effect size rated as very important by parents was related to medication: "parents are informed about the (adverse) effects of the medication" (Cohen's $d = 0.95$, $P < 0.01$) and "the correct medication is given at the right time" (Cohen's $d = 1.14$, $P < 0.01$). The professionals rated 7 items more important than the parents (Cohen's d between -0.31 and -0.58, $P \leq 0.04$) as listed in Table 5.

Table 4 Care items (n = 25) parents find more important than NICU professionals

	Parents (n = 148)		Professionals (n = 81)			
	mean	SD	mean	SD	Cohen's d	P
Domain Information						
Parents are informed about the child's illness	5.81	0.47	5.60	0.59	0.40	0.008
Parents are informed about changes in the child's condition as	5.79	0.42	5.57	0.57	0.44	0.002
Caregivers daily inform parents about the child's care and	5.78	0.65	5.42	0.67	0.55	0.001
Parents are informed about tests and procedures	5.75	0.52	5.49	0.64	0.45	0.003
Caregivers inform the parents about the treatment consequences	5.68	0.71	5.44	0.65	0.35	0.02
Parents are informed about the (adverse) effects of the medication	5.52	0.79	4.74	0.85	0.95	0.001
Parents have easy access to information	5.44	0.74	5.21	0.67	0.33	0.02
Caregivers provide not only oral but also written information	4.64	1.08	3.86	0.98	0.76	0.001
Caregivers inform the parents on the best moment for the parents	4.64	1.10	4.35	0.80	0.31	0.02
Domain Care and Treatment						
The correct medication is given at the right time	5.84	0.39	5.27	0.61	1.14	0.001
Caregivers are aware of the child's medical history	5.63	0.75	5.26	0.63	0.54	0.001
A caregiver always advices parents during acute admission or an	5.53	0.65	5.04	0.77	0.69	0.001
Parents know which physician and nurse are responsible for the	5.51	0.72	5.12	0.64	0.57	0.001
Caregivers are alert to the child's developmental growth	5.49	0.70	4.94	0.71	0.78	0.001
Caregivers are considerate to the infant's needs	5.45	0.74	5.00	0.76	0.60	0.001
Caregivers prepare the parents to a (planned) NICU admission	5.43	0.80	4.83	0.87	0.72	0.001
Domain Organization						
The infant's incubator/bed is clean	5.59	0.60	5.31	0.61	0.47	0.001
The NICU is clean	5.57	0.66	5.37	0.60	0.32	0.02
Moment of discharge is not influenced by bed capacity	5.38	0.90	4.67	0.89	0.79	0.001
Rooming-in near the NICU is possible	5.23	1.03	4.79	0.79	0.48	0.001
Domain Parental Participation						
Caregivers and parents show respect to each other	5.61	0.63	5.15	0.57	0.77	0.001
Caregivers stimulate parents to stay close to their child during	5.38	0.84	4.91	0.73	0.60	0.001
Caring aspects for home are discussed before discharged	5.36	0.84	5.04	0.58	0.45	0.001
Domain Professional Attitude						
Caregivers give the highest priority to the child's health	5.90	0.31	5.69	0.47	0.54	0.001
Regardless the work pressure, the caregiver's attention towards	5.58	0.73	5.09	0.66	0.71	0.001

Scores were rated on a 1 to 6-point scale from "completely unimportant" to "extremely important."

Table 5 Care items (n = 7) NICU professionals find more important than parents

	Parents (*n* = 148)		Professionals (*n* = 81)			
	mean	SD	mean	SD	Cohen's *d*	*P*
Domain Information						
Caregivers inform the parents in a way it is understandable for	5.37	0.93	5.60	0.56	-0.31	0.04
Caregivers' communication with non Dutch speaking parents is	4.64	1.56	5.31	0.75	-0.58	0.001
Domain Care and Treatment						
An assigned physician and nurse serve as contacts for parents	5.21	1.02	5.49	0.53	-0.36	0.008
Domain Organization						
The waiting room is fitted out comfortably	4.20	1.26	4.61	0.68	-0.42	0.002
A locker on the NICU is available for all parents	3.63	1.45	4.22	0.96	-0.49	0.001
Domain Professional Attitude						
Caregivers are alert to the cultural background of the infant and	4.45	1.27	4.83	0.69	-0.39	0.008
Parents are offered religious / spiritual support	4.23	1.38	4.77	0.69	-0.52	0.001

Scores were rated on a 1 to 6-point scale from "completely unimportant" to "extremely important."

Three statements in the questionnaire might be considered of importance for multi-cultural care: alertness to family's cultural background, the use of interpreters in communication, and religious or spiritual support. Parents of Dutch origin rated these 3 statements as significantly less important than did the professionals. In contrast, differences between the non-Dutch parents and the professionals were less evident and not significant (Table 6).

Table 6 Differences between professionals compared to Dutch parents and non-Dutch parents.

	Professionals (n = 81)	Dutch parents (n = 102)		Non-Dutch parents (n = 46)	
	Mean (SD)	Mean (SD)	Cohen's *d*	Mean (SD)	Cohen's *d*
Caregivers' communication with non Dutch speaking parents is through an interpreter or the interpreter-telephone	5.31 (0.75)	4.52 (1.56)	-0.68*	4.95 (1.53)	-0.32 (NS)
Caregivers are alert to the cultural background of the infant and parents	4.83 (0.69)	4.35 (1.27)	-0.49*	4.80 (1.31)	0.03(NS)
Parents are offered religious / spiritual support	4.77 (0.69)	4.18 (1.36)	-0.57*	4.44 (1.47)	-0.30(NS)

Scores were rated on a 1- to 6-point scale from "completely unimportant" to "extremely important."
* *P* (2-tailed) is <0.005; NS, not significant

DISCUSSION

Being more aware of family-centered care, healthcare professionals today strive to empower parents in the care of their child in the NICU. Insight into parental perceptions is available[3,18,19], but there appears to be a gap between knowledge and practice.[20,21] This is remarkable because the impact of family-centered care initiatives has positive effects on parental stress, comfort and confidence.[4] Thus, assessments of parental experiences and needs are warranted to improve our services towards better outcomes for infants and the well-being of parents.

Good examples of the gap between knowledge and practice are the seven statements that professionals rated as more important than did parents. For one, providing lockers for the parents was more important for the professionals and rated among the least important issues by parents despite the fact that lockers are not available in our NICU. Another important issue is the assignment of a physician and a nurse to the parents. In some countries this is a governmental requirement for all hospitals. The Dutch healthcare system has no statutory regulations. However, having a first responsible nurse and physician for every child and parents has been promoted for the past decade. The importance attached to it by the professionals might indicate that this issue has not been fully integrated in daily practice and requires attention.

Perceptions of family needs were documented by 2 studies in adult Intensive Care Units (ICU).[22,23] Both studies used the Critical Care Family Needs Inventory (CCNFI) scale.[24] In a third study, the CCNFI was adapted to the NICU population.[21] Family members generally rated the items higher than did the professionals. In all 3 studies, family members and parents rated items such as “knowing the prognosis,” “knowing the best possible care is given,” and “have questions answered honestly” as most important. This was also observed among the parents in the present study. They rated the statement about highest priority given to their child’s health as very important. The comparison is limited, however, by the fact that the instrument used in the present study differs from the CCNFI in number and concepts of the items and also measures another phenomenon.

Change in attitude of healthcare professionals toward provision of patient-driven care might be feasible when scientific evidence becomes available. A study among 292 parents and 197 neonatologists and nurses revealed that many parents (64%) would intervene to save infants regardless the condition or weight at birth, versus no more than 6% of the professionals.[25] In this respect, it appears that clinicians and parents do not always share the same values or beliefs in the care of their child.

Partnership between professionals and parents is being promoted, characterized by parental presence, involvement, open communication, and shared decision-making. These principles require a change in roles and attitudes of the NICU staff.[7,26] The results of the present study provide a scientific basis to share the expertise and needs of the parents with professionals. As an illustration, parents rated the items related to medication administration and information about the effect of medication significantly higher than did the professionals. This might demonstrate a changing attitude of parents to be more deeply involved in the care of their child. In this respect, the implication for the healthcare professionals is directed towards a reconsideration of the current parental wishes.

The political arena and communities in many countries are focusing on multicultural issues, integration of minority groups, and discrimination. Issues such as respect, violence, and equity have received increased attention in healthcare. For instance, the Netherlands is known for its multicultural society where pediatric departments in hospitals admit high proportions of infants and children from ethnic minority groups.[27] The assumption that parents of ethnic minorities have different preferences has been confirmed by studies from the United States.[28,29] In a large sample of parents of 36,238 children with special healthcare needs, satisfaction and the ease of using healthcare services was studied related to ethnic disparities.[29] Race and ethnicity were defined as white, black, and Hispanic. Parents with black and Hispanic race were significantly less satisfied with care than white parents. The authors noted that after multivariate adjustment for the interview language with parents, the difference disappeared. A more clinical question was addressed in a study examining ethnic differences between white, black, and Hispanic parents and their preferences to stay during their child’s painful interventions.[28] Among the 300 parents, 2 ethnic differences were found: The English-speaking Hispanic parents were less likely inclined to attend resuscitation, and they also preferred to let the physician decide on attending or not. Differences between parents of diverse cultural backgrounds became clear from the results of the present study. The non-Dutch group rated the 3 care items related to cultural issues as more important than did the Dutch group. Therefore, future research could focus on satisfaction instruments that allow comparative analysis of various groups of parents.

Some discrepancies between perceptions of parents and professionals can easily be explained. The nurses and physicians have generally extensive experience with neonatal care, for parents this is often a once in a lifetime experience. Factors such as information provision by the media are bound to change parents' perceptions. Therefore, the recent media attention to aspects of patient safety, such as medication errors, might have caused parents to rate the issue on timely and correct medication administration as one of the highest priorities.

The results of the study are limited by the opinions of parents and NICU professionals on NICU care issues of 1 neonatology center. Outcomes might be different when studying this phenomenon on an (inter)national level. Nevertheless, the current results may stimulate a review among physicians and nurses of their professional practices in the light of the opinions of parents. Listening or reading parental narratives might provide a deeper understanding of the complexity of parental needs and desires.[30]

As a clinical implication of this study, physicians and nurses would do well to review the neonatal care issues identified and relate these to their own clinical practices. Furthermore, the results might also be important for future training of neonatal healthcare professionals. Translating the parental experiences into education programs might enhance the professionals' communication skills because communication competencies are often underrepresented in training programs.[31] Additionally, insight into parental experiences of a NICU admission could also help in counseling women with high risk pregnancy.[32]

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