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The current practice of family-centred care in Italian neonatal intensive care units: A multi-centre descriptive study

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Conflict of interest

The authors declare no conflict of interest.

Contributions

All authors have agreed on the final version and meet at least one of the following criteria: - substantial contributions to conception and design, acquisition of data or analysis and interpretation of data; - drafting the article or revising it critically for important intellectual content.

Ethical statement

The medical ethical review board of the Bambino Gesù Children's Hospital IRCCS approved the study (protocol n. 828 OPBG 2014).

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The list of the members of The Italian NICUs FCC Study Group is included in Supplementary file - List of study group members.

ABSTRACT

Objectives: To explore family-centred care practices in Italian neonatal intensive care units and describe areas for improvement.

Methods: A cross-sectional, multicentre, survey was conducted using the Italian language version of “Advancing family-centred new-born intensive care: a self-assessment inventory”. The instrument is divided into 10 sections rating the status of family-centred care (1=not at all, 5=very well) and ranking the perceived priority for change/improvement (1=low, 3=high). A representative group of staff and parent for each unit were invited to complete the survey. Data was collected between January and June 2015. Correlations among unit characteristics and sections within the survey were explored.

Settings: All Italian neonatal intensive care units (n=105) were invited.

Results: Forty-six (43.8%) units returned the survey. The “Leadership” section scored highest in status of family-centred care (mean=3.45; SD 0.78) and scored highest in priority for change (mean=2.44; SD 0.49). Section “Families as Advisors and Leaders” scored lowest both in status (mean=1.66; SD 0.67) and in priority for change (mean=2.09; SD 0.59). The number of discharged infants was positively correlated with many sections in priority for change (r 0.402-0.421 $p<.01$).

Conclusion: This study showed a variability in the organization of family-centred care practices in Italian neonatal intensive care units and the need to involve parents as partners in the care team. Although family-centred care is considered important by Italian neonatology healthcare professionals, much remains to be done to improve family-centred care practices in neonatal intensive care units in Italy.

IMPLICATIONS FOR CLINICAL PRACTICE

- Neonatal intensive care units need to assess their family-centred care practices to identify the needs for change and improve clinical practice
- More efforts should be made to raise awareness among neonatal intensive care staff about the importance of partnering with families as an interdisciplinary team
- Innovative leadership at hospital and unit level are key elements to develop and support institutional policies consistent with international family-centred care standards
- Continuing education and training programmes for neonatal intensive care staff must be provide to implement and support high quality family-centred care practices.

INTRODUCTION

Family-Centred Care (FCC) is an approach to the planning, delivery and evaluation of health care grounded in a mutually beneficial partnership among patients, families, and health care practitioners (Institute for Patient-and Family-Centred Care, 2018). In the Neonatal Intensive Care Unit (NICU), the hospitalization of an infant can be a stressful event for infants and families and may interrupt the parent-infant attachment process (Lee et al., 2014). The aim of FCC is to support families and their infants to optimize their relationship and health outcomes. Studies have demonstrated that FCC in NICUs facilitates parent–infant interaction (Feeley et al., 2011; Lee et al., 2014; Melnyk et al., 2008; Milgrom et al., 2013; O’Brien et al., 2013), prepares parents to take an active role in infant pain management, and have more positive views about their role in the post-discharge period (Franck et al., 2012). Furthermore, FCC can benefit parent and infant health outcomes (Bastani et al., 2015; Melnyk et al., 2006; Montirosso et al., 2012; Ortenstrand et al., 2010).

Patient-Centred Care is one of the six quality goals for health systems and should support patient and family involvement in daily care delivery (Committee and Institute for Patient-and Family-Centered Care, 2012; Institute of Medicine (USA) Committee on Quality of Health Care in America, 2001). Thus, FCC must be integrated in the culture and organisation of NICUs (Coombs et al., 2017; Davidson et al., 2017; Saunders et al., 2003). However, despite the evidence, FCC practices continue to be inconsistent or not standardised in many countries (Latour, 2005). In several NICUs, parents’ presence during medical rounds and procedures is still restrained, as well as the visiting of grandparents and siblings (De Bernardo et al., 2017; Dunn et al., 2006; Greisen et al., 2009; Harrison, 2010; Pallás-Alonso et al., 2012).

Italy has 105 NICUs and FCC has never been explored or assessed nationally. An instrument is available to assess FCC practices in clinical settings and enables to assess

the priorities for changing FCC practices (Advancing Family-Centered Newborn Intensive Care, 2004). To our knowledge, no national survey has been published on FCC practices in NICUs using this recognised instrument developed by the Institute of Patient and Family Centred Care. Therefore, the aim of our study was to explore the current state of FCC practices in Italian NICUs from the views of the multi-disciplinary team and to identify priorities for change.

METHODS

Study design

The study used a multi-centre, cross-sectional survey design and data were collected between January and June 2015.

Participants

All level III Italian NICUs (n=105) were invited to participate. The nurse managers or medical director of each NICU were contacted by e-mail or telephone. They were informed about the aim of the study and participation was voluntary. The survey was mailed to the NICUs that accepted the invitation and consented to take part in the study.

The participants were invited to return the completed survey within 30 days. A reminder e-mail or a phone call were made to non-responding units after 4 weeks. Data collection lasted five months because the survey was not sent at the same time to all participating NICUs.

The instrument

The ‘Advancing family-centred new-born intensive care: a self-assessment inventory’ was used to collect the data. The instrument was developed by the Institute for Patient Family-Centred Care (Advancing Family-Centered Newborn Intensive Care, 2004). The instrument consists of 98 items and 82 sub-items, divided into 10 sections, assessing FCC practice (Supplementary file - Table 1). The guidelines recommend that the self-

assessment instrument should be completed by the multi-disciplinary team. The team was asked to rate every item on the current status of FCC using a 5-point Likert-type scale (1= not at all, 5= very well) and rank the perceived priority for change or improvement on a 3-point Likert-type scale (1= low, 3= high). The survey also included five open-ended questions inviting participants to report about their experiences in implementing FCC, the benefits and outcomes of these changes, and the challenges encountered.

The instrument was translated into Italian with the permission of the Institute for Patient Family-Centred Care following a two-phase process: translation of the instrument and cultural adaptation. The translation and cultural adaptation process was conducted using a 10-step method (Wild et al., 2005). This included forward (English-Italian) and back (Italian-English) translation by two independent native English translators. Then, the instrument was tested for cognitive equivalence with a multidisciplinary group of 10 experts (NICU nurse managers, research nurses, physicians). They provided feedback on the content and readability of the items. Ten items did not achieve an 80% positive response rate and were reformulated. Most of the changes were related to language and grammar to improve clarity. For instance, item number 4.18: "...disclosure of errors to families" was changed into "...communication of errors to families". The layout of the instrument was maintained with the only difference of adding numeration to the items to avoid mistakes in data imputation.

Data collection

The participating NICUs were asked to complete the survey jointly with the nurse manager, the medical director, a representative group of NICU staff and ideally including a number of parents. Every NICU was asked to respond together as a team to a single survey. The NICU team should discuss each item in the survey and jointly

agree on which answer to give. The time needed to complete the survey was around one hour.

A sheet was attached to the survey to describe the characteristics of the participating NICU such as number of beds, nurse/patient ratio, number of infants discharged in 2013, number of very low birth weight (VLBW), infants discharged in 2013, and the role of the professionals.

Data analysis

Data were collected and analysed by the coordinating centre. Each NICU was given a study number to ensure confidentiality.

Cronbach's α was calculated for each of the 10 sections in the instrument to test the reliability of the Italian version. Mean and standard deviations were calculated to determine the outcomes of the items. Pearson's correlation was used to assess the correlation between the domains of the instrument and the NICU characteristics.

One-way analysis of variance was used to compare continuous variables by geographical areas, followed by Tukey's post hoc test. A $P < 0.05$ was considered statistically significant. All statistical analyses were performed using SPSS Version 22 (Armonk, NY: IBM Corp).

Ethical considerations

The study protocol was approved by the Ethics Committee of the Bambino Gesù Children's Hospital (protocol n. 828 OPBG 2014). Personal data regarding human subjects were not collected. Completing and returning the instrument was considered to provide consent to use the data provided by the participating NICUs.

RESULTS

Characteristics of the study population

Forty-six (43.8%) of the 105 Italian NICUs accepted to participate and returned the self-assessed instrument. The NICUs represented all regions of Italy: North 31 (67.4%); Central 9 (19.5%); and South and major islands 6 (13%). The characteristics of the NICUs are shown in Table 1. The VLBW infants represented 20% of all infants discharged from the NICUs. The instruments were completed mainly by a multidisciplinary team (n=37, 80.4%). The instruments of the remaining units (n=9) were completed by single informants (nurse managers and/or medical director). A total of 237 healthcare providers and eight parents completed the instrument (Table 2).

Reliability of the survey

The internal consistency of all sections was adequate with Cronbach's α ranging from 0.75 to 0.96 for Status and from 0.84 to 0.97 for Priority for Change (Table 3).

FCC Status and Perceived Priority for Change or Improvement

The results of the FCC Status and Priority for Change are presented in Table 3.

The "Leadership" section scored highest in Status (mean=3.45; SD=0.78) and received one of the highest scores (mean=2.44; SD=0.49) in Priority for Change.

The section "Families as Advisors and Leaders" scored lowest both in Status (mean=1.66; SD=0.67) and in Priority for Change (mean=2.09; SD=0.59).

The correlation among the factors of each section (Status and Priority for Change) showed that most of the variables were positively correlated with one other (Table 4).

The mean and scores of each item are presented in Supplementary file Table 2.

Correlations among variables

The correlation analysis, among the results of the sections regarding FCC Status or the perceived Priority for Change showed strong and positive correlation. The strongest correlations were related to the Status of "Information and Education for Families"

section with a “Personnel Practices” section for perceived Priority for Change. The section of “Families as Advisors and Leaders” for FCC Status, had a similar positive correlation.

Moreover, the section “Information and Education for Families” for FCC Status, was significantly positively correlated with almost all sections regarding the Priority for Change (Table 5). The “Leader” section for FCC Status was positively correlated with the sections “Definition of Quality/ Philosophy of Care” and “Pattern of care” for perceived Priority for Change.

Non-significant differences were observed among the NICUs where the survey was completed by a multidisciplinary group and those where a single professional was responsible for completing the survey.

Pearson’s correlation between the NICU descriptive variables and sections of the instrument showed that the number of discharged or transferred infants presented a positive correlation with many sections regarding “Priority for Change”. These were: “Definition of Quality/ Philosophy of Care” ($r=0.407$; $p<.01$), “Families as Advisors and Leaders” ($r=0.421$; $p<.01$), “Patterns of Care” ($r=0.404$; $p<.01$), “Family and Infant Support” ($r=0.402$; $p<.01$) and “Personnel Practices” ($r=0.326$; $p<.05$) (Supplementary file Table 3).

Content of open-ended questions

Almost all NICUs completed at least one open-ended question ($n=44$; 95.6%).

The main themes involved: the importance of the relationship between health providers and parents; the benefits of FCC for parents, infants and staff; economic and staffing difficulties to implement FCC; and staff education and leadership oriented to FCC as future challenges (Supplementary file - Table 4). Finally, the respondents reported that completing the instrument provided an opportunity for discussing various intervention strategies to improve FCC practices in their unit.

DISCUSSION

This is the first study representing a large sample of Italian NICUs assessing the current status of FCC and identifying areas of change or improvement using the ‘Advancing Family-Centred Newborn Intensive Care: a self-assessment inventory’ developed by the Institute for Patient and Family-centred Care (Advancing Family-Centred Newborn Intensive Care, 2004). The findings of the study are representative due to a large sample of participating NICUs covering different geographical areas in Italy. The process of completing the instrument according to the guidelines of the instrument had an educational value because it informed participants about the core concepts and strategies of FCC. We believe that self-evaluation can trigger NICU professionals to identify the needs for change and improve FCC in NICUs. Periodic self-evaluation conducted by multi-disciplinary teams with this instrument or similar instruments, such as the Baby Friendly Hospital Initiative, can serve as a guide to support NICU teams to reform or improve FCC practices (Advancing Family-Centered Newborn Intensive Care, 2004; World Health Organization, 2009; Nyqvist et al., 2013; Smith et al., 2011).

The characteristics of the participating NICUs showed some variability in the organisation of the units and in the volume of activity. This is mostly visible in the number of beds and in the number of discharged infants. Also the nurse-to-patient ratios varied across the participating NICUs which is similar in other studies involving large number of Italian NICUs (Corchia and Orlando, 2012; Gagliardi et al., 2016).

Our study showed that the “Status of FCC” sections that obtained the highest scores were “Leadership” and “Definition of Quality/ Philosophy of Care”. Also for “Priority for Change”, one of the most highly scored sections was “Leadership”. Thus, health professionals highly considered all the leadership aspects but at the same time they believed the leaders of the units needed to improve their role and functions related to

quality of care and the models for collaboration with families in clinical care. The role of the nurse manager was highly considered to ensure and improve the quality of care through planning, organizing, coordinating, directing and controlling (Huber, 2010). Nevertheless, as reported by Butler et al. (2014), studies related to FCC practices in paediatric intensive care settings do not measure or discuss the organisation of nursing care. Instead, several institutional factors have been reported to cause limitations in applying family-centred care in clinical practice (Butler et al., 2014). Roets et al., (2012) suggest that nurse managers should guide the implementation process of a program to empower nurses to emotionally support families and children in pediatric intensive care units. A study conducted in a NICU setting reported that staff value the support of both formal and informal leaders in FCC (Benzies et al., 2018).

The importance of the leadership role in enhancing FCC has been reported in previous studies as organisational support (Trajkovski et al., 2016) or as a facilitator in new practice especially considering medical leadership (Thébaud et al., 2017). Robison reported that without consistent leadership and clear accountabilities, care in the NICU could depend on individual philosophy or on the mood of the healthcare providers (Robison, 2003). The consequence of the lack of organisational processes and leadership vision is that infants and families experience inconsistent quality of care (Robison, 2003). Therefore, we positively consider the fact that nurse managers and medical directors, participating in the multidisciplinary teams, were aware of their role and of the need for more efforts to improve their position. Moreover, this issue is crucial due to the important role that authentic leaders could play in creating professional practice environments that foster high-quality care (Spence Laschinger and Fida, 2015). As suggested by Coombs et al. (2017), leaders at unit or hospital levels play a key role in advocating for resources and interdisciplinary collaboration to ensure that all families of critically ill patients receive the recommended support (Coombs et al., 2017).

The section “Families as Advisors and Leaders” resulted in a low mean value both for Status and Priority for Change. On the contrary, the “Pattern of Care” section obtained a high mean value. These results show the great sensibility of Italian NICU staff regarding the involvement of families in the care of their infants but also the lack of consciousness of considering families (single family, family associations and volunteering) as a real resource for the NICU organisational not exclusively for their own baby. Several studies have demonstrated the benefits of partnership and the active role family members in championing the organisation in various healthcare settings (Bookout et al., 2016; Cunningham and Walton, 2016; Halm et al., 2006; Landis, 2007; Levick et al., 2014; Wadsworth and Harmer, 2016; Zarubi et al., 2008). Therefore, we believe that more efforts should be made to raise awareness among NICU staff about the importance of partnering with families but also to develop policies and procedures supporting the participation of parents as part of an interdisciplinary team (Craig et al., 2015; Marini et al., 2017).

Families can help health professionals to gain a balanced view of the NICU impact on families and help to choose the most appropriate staff for this critical care setting (Janvier et al., 2016). For instance, Keisling et al. (2017) showed how the engagement of a full-time family faculty member and parent led curricula including didactic and experiential components are associated with greater identification and adoption by trainees of family-centred attitudes, skills, and practices. Other authors have also described the experiences of parent-to-parent support in NICU to enhance this potential resource in clinical practice (Levick et al., 2014; Voos et al., 2015).

The positive correlation among some sections of Status and the “Personnel Practice” section for Priority for Change, probably demonstrates the difficulty to translate FCC principles into daily practices. Innovative policies at hospital level and organisational strategies could address and align daily FCC practices (Abraham and Moretz, 2012;

Boztepe and Kerimoğlu Yıldız, 2017; Coombs et al., 2017; Dunn et al., 2006; Skene et al., 2016). Furthermore this approach is necessary especially in larger units with higher numbers of infants discharged as emerged by the findings of our survey.

The “Information and Education for Families” section for Status proved to be positively correlated with almost all the sections concerning Priority for Change. This confirms the centrality of the family education process, including communication and care relationship models and its repercussions at different levels to facilitate family presence and engagement (Davidson et al., 2017; Davidson and Zisook, 2017; Umberger et al., 2018).

Finally, staff education was reported as a major issue in the open ended questions. A well-designed programme that involves all staff members could enhance FCC attitudes and practices (Axelin et al., 2014) and is suggested by international recommendations (Davidson et al., 2017; National Guideline Clearinghouse, 2013). Therefore, we suggest every NICU to reassess their training and education programmes for staff to improve FCC practices. Moreover, the organisation of NICUs needs to be revised according to international FCC guidelines to deliver more efficient and homogeneous care (Davidson et al., 2017).

LIMITATIONS

Some study limitations need to be addressed. A limitation is the possible response bias due to the low participation from the Southern Italian region. Possibly the own perception of delivering a poor level of FCC could be explained why some nurse managers refused to participate in the study. In the invitation we specified that “there is no right or wrong answer to the survey, but each unit should give its own answer”.

Although we encouraged the NICUs to include parents in the team, participation of parents in the NICU teams to complete the survey was low. We mainly collected the

health providers' views, which was consistent with the findings of the survey regarding the family's role.

CONCLUSION

Our study provides a contribution to the highlighted areas for the improvement of the organisation and quality of FCC practices in NICUs. We suggest that NICUs complete the instrument a second time, for instance after one year, to assess whether different dimensions of FCC have improved the efficacy of the ongoing improvements, the quality of FCC provided from the initial survey, and which strategies are still needed. Furthermore, we found that priority for changes primarily considered the enhancement of an innovative leadership oriented to FCC and ongoing education of NICU staff. Adherence to international FCC standards and relevant organizational strategies are fundamental in implementing FCC in clinical practice. Further research is needed to investigate the views of NICU families and identify strategies to improve NICU organizations based on their experiences.

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Table 1. Characteristics of the NICUs

	NICUs <i>n</i>	Mean	SD	Min	Max
Total number of beds	46	20.04	7.58	7	37
Intensive care beds	46	7.60	3.45	2	20
Post- intensive care beds	45	10.85	4.86	0	21
Neonatal pathology beds	8	8.88	4.61	4	17
Patient/Nurse ratio NICU	46	2.94	0.89	2	5
Patient/Nurse ratio Post NICU	45	5.26	1.84	3	13
Number of patients' rooms	46	3.70	3.28	1	21
Number of NICU patients' rooms	46	1.43	0.99	1	6
Number of Post-NICU patients' rooms	45	2.05	2.68	0	15
Number of NICU infants discharged/transferred*	45	333	163.75	45	812
Number of VLBW infants discharged/transferred*	43	67	48.20	11	238

*data representing the year 2013; NICU= Neonatal Intensive Care Unit; SD=Standard Deviation;

VLBW=Very Low Birth Weight

Table 2. Composition of the multidisciplinary teams

	Nurses	Physicians	Rehabilitation therapists	Psychologists	Parents	Others	Total
N.	137	57	13	14	8	16	245
%	55.9	23.3	5.3	5.7	3.3	6.5	100.0

Table 3 Mean, Standard Deviations and Cronbach's α values of the FCC sections (Status and Priority for Change)

Status (rank 1-5)		Mean	SD	Cronbach's α
1.	Leadership	3.45	0.78	0.86
2.	Definition of Quality/Philosophy of Care	3.38	0.71	0.88
3.	Families as Advisors and Leaders	1.66	0.67	0.83
4.	Patterns of Care	3.04	0.69	0.93
5.	Information and Education for Families	2.32	0.62	0.83
6.	Charting and Documentation	2.29	0.71	0.75
7.	Family and Infant Support	3.10	0.80	0.93
8.	Quality Improvement	2.15	1.03	0.94
9.	Personnel Practices	2.53	0.79	0.94
10.	Environment and Design	2.46	0.82	0.96
Perceived Priority for Change/ Improvement (rank 1-3)		Mean	SD	Cronbach's α
1.	Leadership	2.44	0.49	0.84
2.	Definition of Quality/ Philosophy of Care	2.41	0.47	0.88
3.	Families as Advisors and Leaders	2.09	0.59	0.97
4.	Patterns of Care	2.26	0.42	0.92
5.	Information and Education for Families	2.30	0.55	0.92
6.	Charting and Documentation	2.18	0.52	0.85
7.	Family and Infant Support	2.27	0.54	0.96
8.	Quality Improvement	2.46	0.64	0.89
9.	Personnel Practices	2.20	0.51	0.94
10.	Environment and Design	2.34	0.55	0.97

Table 4 Correlation among factors of questionnaire's sections scores (Status and Priority for Change)

	Status									
	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
1. Leadership	1									
2. Definition of Quality/ Philosophy of Care	0.608**	1								
3. Families as Advisors and Leaders	0.350*	0.308*	1							
4. Patterns of Care	0.500**	0.587**	0.326*	1						
5. Information and Education for Families	0.440**	0.571**	0.438**	0.622**	1					
6. Charting and Documentation	0.514**	0.676**	0.328*	0.730**	0.578**	1				
7. Family and Infant Support	0.512**	0.495**	0.338*	0.722**	0.482**	0.684**	1			
8. Quality Improvement	0.365*	0.583**	0.582**	0.508**	0.559**	0.513**	0.399**	1		
9. Personnel Practices	0.622**	0.599**	0.325*	0.659**	0.571**	0.690**	0.700**	0.466**	1	
10. Environment and Design	0.450**	0.426**	0.424**	0.407**	0.240	0.276	0.530**	0.538**	0.424**	1

	Perceived Priority for Change/ Improvement									
	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
1. Leadership	1									
2. Definition of Quality/ Philosophy of Care	0.556**	1								
3. Families as Advisors and Leaders	0.441**	0.482**	1							
4. Patterns of Care	0.360*	0.688**	0.625**	1						
5. Information and Education for Families	0.347*	0.322*	0.638**	0.627**	1					
6. Charting and Documentation	0.431**	0.454**	0.710**	0.631**	0.817**	1				
7. Family and Infant Support	0.307*	0.491**	0.553**	0.745**	0.746**	0.696**	1			
8. Quality Improvement	0.326*	0.223	0.536**	0.486**	0.737**	0.629**	0.548**	1		
9. Personnel Practices	0.365*	0.458**	0.623**	0.574**	0.552**	0.727**	0.701**	0.596**	1	
10. Environment and Design	0.227	0.166	0.272	0.485**	0.609**	0.546**	0.620**	0.674**	0.521**	1

* $p < .05$, ** $p < .01$

Table 5 Correlation among variables: Status sections and the Priority for Change sections

Status	Perceived Priority for Change/Improvement									
	1. Leadership	2. Definition of Quality/Philosophy of Care	3. Families as Advisors and Leaders	4. Patterns of Care	5. Information and Education for Families	6. Charting and Documentation	7. Family and Infant Support	8. Quality Improvement	9. Personnel Practices	10. Environment and Design
1. Leadership	0.084	0.335*	-0.050	0.295*	-0.039	0.023	0.137	-0.004	0.161	0.000
2. Definition of Quality/Philosophy of Care	0.213	0.189	0.128	0.272	0.164	0.140	0.236	0.231	0.311*	0.238
3. Families as Advisors and Leaders	-0.028	-0.005	0.246	0.172	0.131	0.209	0.236	0.323*	0.373*	0.175
4. Patterns of Care	0.242	0.226	0.255	0.343*	0.147	0.235	0.198	0.257	0.282	0.321*
5. Information and Education for Families	0.292*	0.323*	0.304*	0.294*	0.203	0.320*	0.364*	0.170	0.440**	0.250
6. Charting and Documentation	0.161	0.129	0.046	0.234	0.148	0.212	0.169	0.169	0.213	0.228
7. Family and Infant Support	0.063	0.137	-0.030	0.073	-0.241	0.061	-0.099	0.012	0.184	-0.007
8. Quality Improvement	0.041	0.064	0.126	0.131	0.147	0.086	0.224	0.272	0.232	0.194
9. Personnel Practices	0.152	0.192	0.052	0.231	0.017	0.138	0.092	-0.047	0.158	0.066
10. Environment and Design	0.297*	0.179	0.134	0.088	-0.030	0.047	-0.032	0.187	0.227	-0.133

* $p < .05$, ** $p < .01$

Supplementary file - Table 1. FCC self-assessment inventory Sections and items

Sections	N. of items	N. of sub-items
1. Leadership	6	2
2. Definition of Quality/ Philosophy of Care	6	6
3. Families as Advisors and Leaders	9	12
4. Patterns of Care	24	3
5. Information and Education for Families	9	6
6. Charting and Documentation	9	0
7. Family and Infant Support	14	13
8. Quality Improvement	2	2
9. Personnel Practices	7	11
10. Environment and Design	12	27
Total	98	82

Supplementary file - Table 2. FCC self-assessment inventory, mean values for each item: Status and Priority for Change

N. items per section		Description of the items			Status			Perceived Priority for Change/Improvement			
		N	Mean	SD		N	Mean	SD			
1. Leadership											
1.1	Leaders of the unit understand and actively promote family- centered care.				46	3.72	0.86	43	2.51	0.63	
1.2	Leaders of the unit, through their words and actions, consistently incorporate the infant’s and family’s experience of care in the definitions of quality and safety outcomes.				46	3.54	0.86	44	2.59**	0.54	
1.3	Leaders of the unit, through their words and actions, encourage and support staff and physicians for practicing family-centered care.				46	3.65	0.99	44	2.43	0.63	
1.4.a	Leaders of the unit are role models for collaboration with families: – In the clinical care of the infant.				46	3.78	0.94	44	2.59**	0.54	
1.4.b	-in facility design planning.				45	3.07	1.14	43	2.40	0.70	
1.4.c	-In planning, implementing, and evaluating the unit’s policies and programs.				45	3.13	1.14	43	2.37	0.72	
1.5	Leaders of the unit promote collaborative relationships with other departments in the hospital where infants and families are served (e.g. maternity, radiology, surgery).				45	3.80**	1.01	46	2.30*	0.70	
1.6	Hospital leaders are committed to and actively promote family- centered newborn intensive care.				46	2.89*	1.25	43	2.51	0.67	
					Status			Perceived Priority for Change/Improvement			
2. Definition of Quality/ Philosophy of Care					N	Mean	N		N	Mean	SD
2.1	The unit has defined quality health care and this definition includes how infants and families will experience care.				46	2.87	1.07	43	2.26*	0.73	
2.2	The unit has clearly stated principles or values guiding how care will be provided and what is expected relative to the experience of care (e.g. philosophy of care, vision, mission, or values statements).				46	2.98	1.27	44	2.30	0.82	
2.3.a	The definition for how care will be delivered reflects the principles of family-centered care and articulates: – The importance of conveying respect and preserving the dignity of each infant and his/her family.				46	4.15**	0.92	44	2.34	0.78	

2.3.b	– Acknowledgement of the individuality, culture, capacity, and abilities of each family.	46	4.00	0.97	43	2.40	0.70
2.3.c	– A broad definition of family that includes the right for families to define their family.	44	3.50	1.07	44	2.39	0.66
2.3.d	– The importance of families to the care and comfort of their infants.	46	4.00	0.90	45	2.42	0.58
2.3.e	– The importance of collaborating with families at all levels of care.	46	3.59	0.91	44	2.50**	0.63
2.4	The concepts of the philosophy of care are shared with families in a variety of ways (e.g., family handbook, admission materials, hospital/unit web page).	46	3.57	1.03	44	2.48	0.63
2.5.a	The philosophy of care is taught as part of: – Orientation for new unit employees.	46	3.35	1.22	43	2.47	0.63
2.5.b	– Orientation for students and trainees in the unit.	45	3.33	1.13	44	2.50**	0.59
2.5.c	– Continuing education for employees and physicians.	46	3.50	1.12	45	2.16	0.80
2.6	- Families of infants who experienced care in the unit were involved in the development of mission/philosophy of care statements for the unit.	46	1.70*	0.90	45	2.42	0.66

		Status			Perceived Priority for Change/ Improvement		
3. Families as Advisors and Leaders		N	Mean	SD	N	Mean	SD
3.1	There is a functioning family advisory council (e.g., meets regularly, at least quarterly) that reports to unit or hospital leadership.	44	1.57	1.09	41	2.02	0.82
3.2	Goals, projects, and accomplishments of the family advisory council are documented and evaluated.	42	1.55	1.06	39	1.92	0.81
3.3.a	Parents of infants who have experienced care in the unit are involved in advisory/leadership roles through committees and task forces such as:	44	1.82	1.17	40	2.08	0.69
3.3.b	– Family education.	45	1.69	1.13	41	1.90	0.77
3.3.b	– Facility design planning.	45	1.69	1.13	41	1.90	0.77
3.3.c	– Quality improvement.	45	1.91	1.18	41	2.07	0.79
3.3.d	– Patient safety.	45	1.82	1.19	40	2.18	0.81
3.3.e	– Developmental care.	45	1.93	1.25	41	2.15	0.76
3.3.f	– Pain management.	45	1.76	1.17	41	2.22	0.79
3.3.g	– Discharge/transition planning.	45	1.91	1.20	41	2.17	0.70
3.3.h	– Hospice/palliative care.	45	1.42	0.89	40	2.13	0.79

3.3.i	– Bereavement support.	44	1.66	1.10	39	2.28	0.72
3.3.j	– Ethics/infant care review.	44	1.55	0.95	40	2.10	0.78
3.3.m	– Diversity/cultural competency.	45	1.49	0.92	39	2.23	0.74
3.3.n	– Service excellence.	45	1.49	0.82	39	2.13	0.80
3.3.o	– Research and evaluation.	45	1.36	0.77	39	2.10	0.79
3.4	Families of infants who experienced care in the unit are trained and supported to provide peer-to-peer support.	45	2.24**	1.21	44	2.34**	0.75
3.5	Families are involved in evaluating family-centered programs and resources.	45	1.69	1.02	44	2.16	0.81
3.6	Families are involved in staff orientation and continuing education for the unit.	45	1.24	0.71	42	1.93	0.78
3.7	In academic medical centers, family members are involved in teaching students and professionals-in-training.	34	1.24	0.74	33	1.88	0.82
3.8	There is a paid position(s) for a family leader to facilitate the development of family-centered initiatives within the unit.	44	1.16*	0.68	43	1.60*	0.76
3.9	There is a staff member assigned to serve as a liaison for collaborative endeavors with families and between family advisors/leaders and staff, physicians, and administrators.	45	1.87	1.29	45	2.09	0.79

		Status			Perceived Priority for Change/ Improvement		
4. Patterns of Care		N	Mean	SD	N	Mean	SD
4.1	Family members are not viewed as visitors; they are always welcome to be with their infant and fully participate in care.	46	3.70	1.07	45	2.44	0.66
4.2	Families are integral members of the health care team.	46	3.22	1.15	46	2.41	0.62
4.3	Unit practice consistently affirms to families the primacy of their relationship with their infants.	46	3.93	0.93	45	2.42	0.66
4.4	Clinical pathways reflect that parents are caregivers, nurturers, and decision makers for their infants.	46	2.78	1.21	45	2.51	0.59
4.5	Mothers and their partners are actively supported to provide breastmilk for their infant.	46	4.74**	0.54	44	2.30	0.85

4.6	Staffing patterns promote continuity of care for infants and families.	45	3.64	1.19	44	2.34	0.71
4.7	Families can remain with their infant during nurses' shift change.	46	2.41	1.63	44	1.93	0.82
4.8.a	During rounds, families may choose to: – Remain with their infant.	46	2.70	1.76	43	1.93	0.80
4.8.b	– Participate in rounds.	44	2.05	1.61	41	1.71*	0.81
4.9.a	Families' choices, about whether or not to remain with their infant are respected and supported by staff during situations such as: – Transition from delivery room to the newborn intensive care unit.	45	2.84	1.49	42	1.98	0.72
4.9.b	– Painful/invasive procedures.	45	2.33	1.26	43	2.09	0.68
4.9.c	– Resuscitation.	45	1.73	1.18	43	1.79	0.71
4.10	Care practices support the neurobehavioral development of the infant.	46	3.87	1.02	45	2.56**	0.59
4.11	Staff support parents in their appreciation and pride in their infant's individuality and development.	46	4.33	0.87	44	2.27	0.82
4.12	Staff ask families about their observations, goals, and priorities for their infant.	46	3.11	1.06	46	2.41	0.62
4.13	Staff identify strengths in all infants and their families and incorporate these in the care plan.	46	2.83	1.32	46	2.39	0.68
4.14	Staff collaborate with the family in assessment and management of their infant's pain.	46	2.96	1.21	45	2.51	0.72
4.15	Staff prepare families to support their infant during painful procedures.	46	3.00	1.21	45	2.38	0.72
4.16	Families have the opportunity to learn and practice caregiving throughout their infant's hospitalization.	45	4.40	0.94	43	2.40	0.82
4.17	Communication among families, staff, and physicians is ongoing and offered in a variety of formats (e.g. chart, email, bulletin boards at infant's bedside, pagers, telephone contact).	45	3.11	1.30	44	2.41	0.69
4.18	There is written policy and actual practice by staff of disclosure of errors to families.	45	1.67*	1.21	45	2.02	0.83
4.19	Care is coordinated with families and across disciplines and departments.	44	1.86	1.11	45	1.96	0.80
4.20	Families participate in inter- disciplinary meetings to plan their infant's care if they wish.	46	1.93	1.37	46	2.04	0.89
4.21	Families have help with transitions in their infant's care (i.e. unit to unit, hospital to other facility, hospital to home, and hospital to community services).	46	3.61	0.93	45	2.47	0.66

4.22	Families are encouraged to participate in planning for discharge as early as is appropriate based on their infant's status.	46	3.91	0.96	44	2.34	0.75
4.23	Families identify their learning needs and priorities regarding care after discharge and these are used in planning for discharge	46	3.43	1.31	45	2.40	0.75
4.24	The family's primary physician/ pediatrician participates in discussions and planning regarding transition of the infant to home.	46	1.96	1.37	46	2.39	0.80

		Status			Perceived Priority for Change/ Improvement		
5. Information and Education for Families		N	Mean	SD	N	Mean	SD
5.1	There is continual, open, and honest communication among families and staff.	46	3.78**	0.99	46	2.59**	0.62
5.2	Antepartum patients and their families have opportunities to discuss issues with newborn intensive care staff and physicians and prepare for care in this setting prior to admission to the unit.	46	2.98	1.29	41	2.39	0.74
5.3	A range of informational and educational programs and materials, in a variety of formats, are available to families.	45	2.71	1.18	44	2.48	0.63
5.4	The unit's information and educational materials reinforce the belief that families are essential members of the health care team.	45	2.78	1.36	44	2.39	0.69
5.5	Written information is provided in primary languages and appropriate educational levels of families served by the unit.	45	2.36	1.19	44	2.41	0.76
5.6	Trained interpreters are available.	46	3.65	1.43	43	2.42	0.79
5.7.a	There is a patient and family resource center accessible to families and staff with: – Paid staff or trained volunteer to assist families and staff.	46	1.63	1.08	43	2.02	0.83
5.7.b	– Information on infant development, prematurity and other conditions.	46	1.61	1.09	43	2.26	0.85
5.7.c	– Useful programs and materials.	46	1.52	0.94	44	2.18	0.84
5.7.d	– Useful written and audio- visual materials.	46	1.46	0.96	44	2.16	0.83
5.7.e	– Internet access.	46	1.57	1.11	43	2.12	0.85
5.7.f	– Useful bookmarked Web sites.	46	1.54	1.13	43	2.07*	0.86
5.7.g	– Skills training lab.	46	1.43*	1.00	43	2.14	0.86

5.8	Individualized and understandable discharge instructions are provided to families	46	4.20	0.89	45	2.40	0.75
5.9	Families of infants who experienced care in the unit are involved in developing and evaluating informational/ educational materials and programs for families.	46	1.57	1.07	46	2.28	0.81

		Status			Perceived Priority for Change/ Improvement		
6. Charting and Documentation		N	Mean	SD	N	Mean	SD
6.1	Families' goals are identified and documented.	45	1.62	0.91	45	2.22	0.82
6.2	Families have easy access to the medical record/chart.	46	2.46	1.46	44	1.98	0.82
6.3	Families have the opportunity to record observations and concerns in the medical record/chart.	46	1.11*	0.48	46	1.83*	0.83
6.4	Documentation about the developmental strengths and needs of each infant is included in the chart.	46	2.00	1.19	45	2.29	0.73
6.5	There is an up-to-date developmental care plan included in each infant's chart.	46	2.48	1.44	46	2.46**	0.66
6.6	Language used in documentation promotes recognition of family strengths and competence.	46	2.37	1.31	45	2.24	0.71
6.7	Families are offered a means to collect and organize important information regarding their infant that they can share with other providers.	46	1.87	1.19	45	2.07	0.78
6.8	Transition goals and/or plans developed in collaboration with community providers and families are included in the medical record/chart for infants who will be receiving care from community services after discharge.	45	2.51	1.56	43	2.35	0.78
6.9	Documentation procedures protect the infant's right to privacy and confidentiality in a manner consistent with the intent of the Health Insurance Portability and Accountability Act (HIPAA).	46	4.20**	1.11	44	2.16	0.89

		Status			Perceived Priority for Change/ Improvement		
7. Family and Infant Support		N	Mean	SD	N	Mean	SD
7.1	Staff and physicians ask parents to identify family members and close friends who will support them and their infant.	46	2.57	1.22	44	2.18	0.66
7.2	Mothers who are hospitalized on another unit or in another hospital are kept fully informed about their infant.	46	3.63	1.12	44	2.48**	0.66

7.3	Fathers, or others in parenting roles, are supported and encouraged as partners in care.	46	4.24**	0.77	43	2.33	0.78
7.4	A designated staff member or trained volunteer is available to support families and provide updates on their infant's status during transports, surgery, or procedures.	46	2.93	1.44	43	2.19	0.82
7.5	Staff or trained volunteer support is available to ensure that visits by siblings, and extended family members are positive experiences.	45	2.36	1.57	43	2.05	0.82
7.6	There is a range of emotional, spiritual, and practical supports available to families.	46	3.46	1.19	45	2.36	0.74
7.7	Peer and family-to-family support is available and accessible to families.	46	2.63	1.34	45	2.36	0.80
7.8	There is affordable, temporary housing for families available near the unit	46	3.37	1.51	43	2.35	0.81
7.9	Financial support (e.g., for parking, transportation, lodging, meals etc.) is available to help families with special financial needs served by the unit.	46	2.70	1.46	43	2.28	0.73
7.10.a	Before discharge from the unit, families are linked with appropriate medical, developmental, and support services such as the following: – Home health care.	43	3.91	1.34	39	2.26	0.79
7.10.b	– Equipment and pharmaceutical supplies.	45	4.13	1.08	41	2.15	0.79
7.10.c	– Respite care providers.	43	1.93*	1.37	39	2.03*	0.87
7.10.d	– Specialized child care.	45	3.91	1.28	40	2.20	0.79
7.10.e	– Early childhood intervention services.	45	3.84	1.21	39	2.41	0.75
7.10.f	– Social services.	44	3.84	1.14	40	2.33	0.80
7.10.g	– Community-based emergency services.	45	3.18	1.48	40	2.18	0.81
7.10.h	– Primary care.	45	3.33	1.57	39	2.31	0.77
7.10.i	– Family support programs.	45	2.51	1.47	40	2.35	0.77
7.10.j	– Parenting education.	44	2.25	1.28	39	2.23	0.81
7.10.m	– Mental health services.	45	2.89	1.39	41	2.12	0.87
7.10.n	– Substance abuse treatment.	45	3.22	1.52	42	2.19	0.80
7.10.o	– Child abuse prevention and treatment programs.	45	2.44	1.41	44	2.16	0.83
7.10.p	– Other services identified by families.	44	2.20	1.30	44	2.16	0.86

7.11	Grief counseling and other bereavement support is available to families.	46	2.85	1.51	44	2.36	0.75
7.12	Families are supported and assisted in making arrangements when their infant dies.	46	3.67	1.19	43	2.35	0.72
7.13	Families of infants who experienced care in the unit are trained and supported to provide bereavement support.	46	2.59	1.41	44	2.41	0.69
7.14	There is an ethics committee available to families, staff, and physicians.	46	2.91	1.58	45	2.36	0.86

		Status			Perceived Priority for Change/ Improvement		
8. Quality Improvement		N	Mean	SD	N	Mean	SD
8.1	Family-centered care is acknowledged as an attribute of high quality care and outcome measures include indicators for family-centered practice.	46	2.80**	1.42	45	2.56**	0.69
8.2.a	Families of infants who experienced care in the unit are involved in: – Quality improvement initiatives.	46	2.04	1.19	44	2.36*	0.75
8.2.b	– Developing the questions and format for tools that measure family perceptions of the experience of care.	46	1.87*	1.20	45	2.47	0.73
8.2.c	– Responding and finding solutions to information gathered through mechanisms that measure family perceptions of the experience of care.	46	1.89	1.20	45	2.42	0.75

		Status			Perceived Priority for Change/ Improvement		
9. Personnel Practices		N	Mean	SD	N	Mean	SD
9.1.a	Families of infants who experienced care in the unit are involved in: – The hiring process for staff and physician leaders.	46	1.17	0.61	45	1.51	0.82
9.1.b	– Orientation of new employees, physicians, students and trainees.	46	1.09*	0.35	45	1.47*	0.79
9.1.c	– Staff development.	46	1.26	0.68	45	1.58	0.81
9.1.d	– Continuing medical education programs.	46	1.50	1.09	44	1.68	0.86
9.2	Staff reflect the diversity of the communities served by the unit.	45	2.36	1.32	43	1.88	0.85

9.3	Position descriptions and performance appraisals define expectations for behaviors consistent with family-centered concepts.	45	2.87	1.41	44	2.18	0.72
9.4.a	Each position description and performance appraisal clearly articulates the necessity of collaborating with: – Families at all levels of care.	46	3.28	1.26	45	2.22	0.77
9.4.b	– Staff across disciplines and departments.	46	3.26	1.29	45	2.20	0.82
9.4.c	– Providers in the hospital and community.	46	3.17	1.30	45	2.20	0.76
9.5.a	Orientation and in-service programs support staff and physicians in acquiring family- centered knowledge, skills, and attitudes, and specifically there is educational programming for: – Conveying respect to infants, families, and other staff and physicians.	46	2.87	1.33	45	2.42	0.69
9.5.b.1	– Communicating effectively with families: – Gathering information from families.	46	3.20	1.17	45	2.51	0.63
9.5.b.2	– Providing medical and other information in ways that are understandable for families.	46	3.28	1.17	45	2.49	0.63
9.5.b.3	– Conveying “bad news” in a supportive manner.	46	3.24	1.21	45	2.51	0.66
9.5.b.4	– Sharing information with families about errors.	46	2.28	1.40	45	2.07	0.92
9.5.c	Fostering the confidence and competence of families.	46	3.13	1.34	45	2.42	0.69
9.5.d	– Respecting families’ choices regarding the care of their infant.	46	2.91	1.30	45	2.31	0.73
9.5.e	– Supporting families’ coping strategies.	45	2.82	1.32	44	2.41	0.76
9.5.f	– Supporting families with end- of-life decision-making.	45	3.11	1.47	44	2.57**	0.70
9.5.g	– Overcoming linguistic, cultural, and other barriers to effective collaboration.	46	3.30**	1.38	45	2.51	0.70
9.5.h	– Communicating effectively with staff and physicians within the unit and across disciplines.	46	3.15	1.26	45	2.49	0.66
9.5.i	– Collaborating with family advisors and leaders in policy and program planning, implementation, and evaluation.	46	1.89	1.25	45	2.16	0.85
9.6	There are a variety of support opportunities for staff and physicians (e.g., reflective practice, bereavement support, mentoring programs, and counseling).	46	1.93	1.08	45	2.51	0.73

9.7	There are rewards and recognition for family-centered practice.	46	1.17	0.61	45	2.22	0.90
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		Status			Perceived Priority for Change/ Improvement		
10. Environment and Design		N	Mean	SD	N	Mean	SD
10.1.a	The overall design of the unit creates a healing environment through the use of: – Color and texture.	45	2.60	1.47	45	2.27	0.78
10.1.b	– Art that reflects the community and cultures served.	46	1.80	1.17	45	2.18	0.78
10.1.c	– “Warm” and appropriate lighting.	46	2.78	1.35	44	2.36	0.72
10.1.d	– Pleasing sounds and aromas	46	1.98	1.24	45	2.40	0.72
10.1.e	– Control and reduction of noise.	46	2.85	1.21	45	2.64	0.70
10.1.f	– Carefully planned traffic patterns.	45	2.42	1.25	44	2.39	0.72
10.1.g	– Proportion and scale.	44	2.34	1.29	44	2.52	0.66
10.1.h	– Ease of navigation.	45	2.51	1.27	44	2.52	0.66
10.1.i	– Protection of privacy for patients and families.	46	2.39	1.15	44	2.68**	0.52
10.1.l	– Respite areas for families and staff.	45	2.62	1.44	45	2.44	0.76
10.1.m	– Views of nature and access to outdoor areas.	46	2.54	1.39	44	2.25	0.81
10.2.a	The following create positive, welcoming first impressions for families arriving at the hospital/ unit: – Parking areas.	46	2.54	1.47	45	2.42	0.78
10.2.a	– Hospital main entrance and lobby.	45	3.04	1.38	43	2.23	0.81
10.2.a	– Unit reception area and information desk.	45	2.84	1.38	44	2.30	0.80
10.3	- Signage is welcoming and helpful to families served by the unit.	45	2.67	1.19	44	2.48	0.70
10.4	- Signage is in the language of those communities served by the unit.	45	2.16	1.38	44	2.45	0.76
10.5	- There is an option of a private room for each infant and his/ her family.	45	1.47	1.08	44	2.36	0.81

10.6.a	The design of the infant's room or bedspace includes: – Privacy for the infant and family.	45	1.71	1.14	43	2.42	0.79
10.6.b	– Individually controlled lighting.	45	2.73	1.59	43	2.26	0.85
10.6.c	– Adequate design and individual accommodations to protect infants from harmful stimuli including lighting, noise, smells, and movement.	45	2.53	1.52	42	2.45	0.77
10.6.d	– Comfortable chairs.	46	2.78	1.30	45	2.47	0.69
10.6.e	– Sleeping area for family members	46	2.02	1.45	45	2.24	0.86
10.6.f	– Secure storage for personal belongings.	45	3.13	1.52	44	2.32	0.86
10.6.g	– A home-like environment with the opportunity to personalize space.	45	2.00	1.21	45	2.40	0.81
10.6.h	– Designated staff work area.	46	2.59	1.51	44	2.36	0.81
10.7	- Treatment rooms allow for privacy and family presence and participation.	46	2.35	1.35	44	2.25	0.81
10.8.a	There are supportive spaces such as: – A private consultation room.	46	3.22**	1.59	44	2.39	0.81
10.8.b	– A family lounge.	46	2.57	1.71	43	2.21	0.86
10.8.c	– Shower facilities.	45	2.31	1.73	45	2.13	0.92
10.8.d	– Kitchen facilities/access to nutritious snacks	45	2.62	1.76	45	2.04	0.95
10.8.e	– Laundry facilities.	45	1.69	1.20	44	1.91*	0.88
10.8.f	– Access to business facilities (e.g., fax machine, Internet access, telephone).	46	1.50*	1.01	44	1.95	0.91
10.8.g	– A place for prayer or quiet reflection.	45	2.84	1.58	43	2.14	0.92
10.9.a	Privacy is maintained for families for: – Breastfeeding/pumping.	45	2.76	1.33	45	2.44	0.76
10.9.b	– Cuddling and enjoying their infant.	45	2.73	1.36	45	2.42	0.78
10.9.c	– Providing skin-to-skin care	45	2.82	1.42	45	2.42	0.81
10.10	- Facilities assure privacy for families whose infant has died.	46	3.02	1.50	45	2.56	0.70
10.11	- There is space away from the bedside for families to learn and practice new caregiving skills.	46	1.85	1.26	44	2.25	0.84

10.12	- The security system provides appropriate protection without being inhibitive to family members and visitors.	45	2.69	1.40	45	2.29	0.84
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*lower mean value per section ** higher mean value per section

Supplementary file- Table 3. Correlation among all the descriptive variables of the NICUs and the results of the sections of the survey referred to Priority for Change

** $p < 0.05$, ** $p < 0.01$*

	Total N. beds	N. intensive care beds	N. post- intensive care beds	Nurse patient ratio NICU	Nurse patient ratio POST NICU	Total N. hospitali- zation areas	N. NICU hospitali- zation areas	N. Post- NICU hospitali- zation areas	Total N. infants discharged/ transferred	N. VLBW infants discharged/transf- erred
1. Leadership	0.107	0.053	0.063	-0.089	-0.175	0.158	0.154	0.114	0.238	0.230
2. Definition of Quality/ Philosophy of Care	0.233	-0.040	0.230	0.025	-0.094	0.173	0.063	0.100	0.407**	0.018
3. Families as Advisors and Leaders	0.086	-0.039	0.186	-0.034	-0.099	0.071	0.070	0.026	0.421**	0.143
4. Patterns of Care	0.180	-0.047	0.185	-0.107	-0.090	-0.005	-0.111	-0.029	0.404**	-0.110
5. Information and Education for Families	-0.100	-0.149	-0.092	-0.031	-0.096	-0.045	-0.039	-0.079	0.181	-0.069
6. Charting and Documentation	-0.012	-0.136	0.105	-0.176	-0.198	0.157	0.243	0.083	0.262	0.107
7. Family and Infant Support	0.096	-0.068	0.116	0.037	-0.099	-0.055	-0.021	-0.094	0.402**	0.095
8. Quality Improvement	0.184	0.149	0.114	-0.011	0.013	0.052	-0.003	0.051	0.257	0.127
9. Personnel Practices	0.111	0.084	0.097	-0.107	-0.136	0.098	0.207	0.054	0.326*	0.108
10. Environment and Design	0.039	0.109	-0.094	0.018	-0.054	-0.088	-0.069	-0.067	0.269	0.085

Supplementary file- table 4 Themes of the open-ended questions

Open-ended questions	NICUs <i>n</i>	Principal themes	e.g. Verbatim
Are there other ways that the unit demonstrates a commitment to family-centred care?	36	<ul style="list-style-type: none"> - nurses- parents relationship - parents involvement - meeting with health providers and parents - unit open 24/7 h. - parents' association support 	"Constant engagement of the staff in family's involvement, in parents meeting and in senior parents meeting (that are in experimental phase)." (Unit 7)
What are the benefits/outcomes evolving from implementing family-centred care?	25	<ul style="list-style-type: none"> - newborns-parents-nurses interaction - anxiety and stress decrease - parents autonomy - parents-newborns attachment - reduction in length of hospital stay 	"We realized that working with families is an important resource even for avoiding errors." (Unit 20)
What are the biggest challenges the unit faces in implementing family-centred care (e.g., identifying families to serve on committees, attitudes of staff, cut-backs in personnel)?	27	<ul style="list-style-type: none"> - lack of staff - economic limits - work with parents 24/7 h. 	"The historical period that our country is experiencing and the paucity of staffing have not facilitated the implementation of FCC, but it didn't discourage any of us." (Unit 3)
What are the opportunities for family-centred change for the unit at this time (e.g., a desired cultural change, a planned renovation, a new quality improvement team, a contract negotiation, a community-based outreach program, managed care)?	33	<ul style="list-style-type: none"> - staff training on the concepts and practice of the FCC - leadership of the unit addressed to FCC 	"Top Management Policy that promotes FCC" (Unit 11)
Reflect on the findings of this assessment and their relevance and importance to the strategic priorities and quality and safety agendas for the hospital and newborn intensive care.	21	<ul style="list-style-type: none"> - overview of FCC implementation - aspects to improve FCC 	<p>"The need to punctually assess the state of FCC in our Unit enables us to provide:</p> <ul style="list-style-type: none"> - constructive dialogue between the different professions - more objective judgment on the FCC aspects to be improved - awareness of the relevance of unresolved issues" <p>(Unit 13)</p>

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