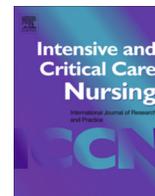




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Research article

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



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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 organisation 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.

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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 provided 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 hospitalisation 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 optimise 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; Montiroso 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, 2001a,b). 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 (Institute for Patient-and Family-Centered 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 four 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 (Institute for Patient-and Family-Centered 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](#).

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) for Change/	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 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

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

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

* $p < .05$.

** $p < .01$.

by the Institute for Patient and Family-centred Care (Institute for Patient-and Family-Centered 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 (Institute for Patient-and Family-Centered 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., 2019).

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 Yildız, 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 organisational 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 organisations based on their experiences.

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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.

Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <https://doi.org/10.1016/j.iccn.2018.07.005>.

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