

## What do professionals need for an Open-Paediatric Intensive Care Unit (PICU)? A focus group study on PICU professionals

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### Key points

Literature concerning Quality Improvement Projects suggests that it is essential to study the context to investigate and to better understand what are the main conditions influencing quality improvement and how to maximise its effectiveness (if and how to implement intervention). Also important is how the context influences implementation and outcomes.

### Abstract

#### Background

PICU is a complex stressful, high- tech environment for professionals, parents and critically ill children. Literature suggests that knowing the context is crucial in determine the suitable interventions to act. Professionals' needs in the Italian context need to be investigated. The aim of the study was to highlight the healthcare professionals' perceptions of their needs regarding the concept of Open PICUs and the presence of parents during their child's stay in the PICU, without highly restricted visiting policies.

#### Methods

Qualitative approach ( multi-professional focus group) was used. The transcription and categorization followed the principles of "content analysis". Criteria concerning validity, reliability, confirmability and replicability have been satisfied.

#### Results

Results identified the following 4 main categories of needs, which were considered important by the participants: communication skills, education on the centrality of parents; the organization of the presence of parents, and suitable spaces.

The majority of the participants viewed Open PICUs positively but need an improvement of: communication skills, education regarding "centredness of the parent", a better organization of the presence of the parent and suitable spaces for the parent in the Unit .

#### Conclusions

Our study shows that focus group approach is useful to gain qualitative data in a PICU.

Strategic health care plans ought to focus, much more than in the past, on models that allow families to stay close to their children during the most severe stages of their illness. The Family Centred Care model is not easy to implement in settings with an intensive use of technological equipment. Open PICUs are not just

places where parents have more time to see their children, but require a profound transformation into a place where health professionals and technical competences, join with relational competences to achieve family empowerment. Open PICUs would be pointless, or even counterproductive, if they were not supported by improvement and major awareness of the scope of ethical practice, with a view to provide a full and competent coverage of the clinical, ethical and relational issues relating to children and their parents, even in end-of-life situations.

**Keywords:** Intensive care units; nurses; parents; parent-child relations; child; nursing; family-centered.

### **Background**

Literature concerning Quality Improvement Projects (QI) (1, 2) suggests that it is essential to study the context to investigate and to better understand 1) What are the main conditions influencing QI (1,2); 2) How to maximise the effectiveness of QI (if and how to implement intervention), and how the context influences implementation and outcomes.

Understanding the specific context can help researchers to adapt the QI to the local situation, instead of simply reproducing interventions by copying experiences from other colleagues or countries, and create “their own framework”.

Literature describes the context of Paediatric Intensive Care Units (PICUs) as complex, changing, high-tech, stressful environment both for the professionals who work there and the children and their parents (3).

One of the first barriers met by parents during their child’s admission to the PICUs were the highly restrictive visiting policies, limiting the presence and access of parents, as well as the communicative relationship between parents and professionals (4).

Family-Centred-Care guidelines suggest that parents should be able to enter PICUs at any time and be provided with facilities on a 24/7 basis (4). To improve quality of care, parents should be considered as important partners that collaborate with professionals. In

addition, it is widely recognized that children’s memories of their stay in the PICU would not be positive (3, 5).

In the discussion of this paper we focused on another two important points: 1) there is no evidence that the presence of parents increases the risk of infection in Open PICUs; and 2) when children and parents stay together, even during high-stress situations (resuscitation, invasive procedures) they are less stressed and anxious (6). Before designing interventions aimed at encouraging the presence of parents in PICUs we should consider that it is not just a question of allowing parents to stay longer with their children during visiting hours (7), but there are some variables which can interact with and influence outcomes. For this reason, it is important to have a clear overview of the specific local context (1,2).

Comparing Italian PICUs with PICUs in other countries, it is recommended to align Italian visiting policies with those of an ‘Open PICU’, open for parents on a 24/7 basis. An innovative ‘Italian Framework for Parents in PICUs’ should be designed taking into account health professionals’ attitudes towards a Family-Centred-Care approach. Parents should not be considered just as visitors but partners in care also in the Italian context (8). There is a lack of evidence related to the Italian context and the ‘complex interventions’ or QI necessary to implement this change in the organization of Italian PICUs.

Since the hospital management was already planning to renew the ward involved, developing more knowledge about the specific needs of the health professionals working in our PICU seemed the best way to drive forward the change in the direction of ‘Open PICU’.

The aim of this study was to highlight the healthcare professionals’ perceptions of their needs regarding the concept of Open PICUs and the presence of parents during their child’s stay in the PICU, without highly restricted visiting policies. The research question was: What do physicians and nurses find important (and

require) when caring for critically-ill children and their parents in the PICU?

## **Methods**

### *Design*

A descriptive study using a qualitative approach with focus groups (9). Since the aim of the study was to investigate the healthcare professionals' perceptions of their needs regarding the concept of Open PICUs, the qualitative approach was the most appropriate, so that participants could describe their personal experiences, feelings and thoughts. With this approach (10,11) it is possible to include more participants and they can freely interact in the group discussion.

### *Setting*

The present study was conducted in a PICU in the North-West of Italy, in compliance with the national and international innovative trends to open up PICUs to parents allowing them to stay with their sick children. The PICU where this study was conducted, is one of the most important and multi-disciplinary paediatric intensive care units in Italy. It is ideally subdivided in PICU, NICU, post-surgery intensive care. In addition, the hospital is a leader in advanced paediatric care and it is Joint Commission International Accredited.

We obtained the approval of the hospital's Ethical Committee before starting this study. The study was conducted in Autumn 2010.

### *Participants*

The focus group participants were: 6 paediatric nurses and 1 anaesthetist working in the PICU; 1 moderator, and 1 person taking notes. In the hospital, all nurses are either paediatric nurses or have specific training in the paediatric care. Participants were all paediatric nurses and the anaesthetist had specific training in paediatric intensive care. The participants' age ranged between 25-37 years and their experience in the PICU between 2-15 years. Regarding the gender, all the nurses were females and the anaesthetist was a male. Participants were enrolled on a voluntary basis and were informed that a new PICU would have been designed in the following

months, and that their opinion could have facilitated changes in structural features, services and visiting policies.

### *Data collection*

An audiotape and some slides illustrating the topic were used and participants signed a consent form. Some demographic data were included in the form (age, gender, job). The moderator guided the discussion with some open-questions, planned after an accurate literature review. The first open question explored their personal experience with Open PICUs and parental presence. The other open questions explored their perception of needs and possible interventions. Before starting the focus group discussion, participants were asked to choose a nickname and to repeat it before each answer in the discussion to facilitate verbatim transcriptions and correlations between answers. Participants were informed that all the data would have been kept anonymous and the nickname used only for verbatim transcription.

### *Data analysis*

After verbatim transcriptions, two researchers carefully read, analysed, coded (separately and independently) the transcriptions 'line by line' through the content analysis" (12).

Then, they met to discuss their analysis to reach an agreement on the categories. During the data analysis the topic "perception of needs regarding Open PICUs" drove the entire categorization process.

Saturation of the qualitative data was pointed out during the in-depth discussion of the Focus Group. The researchers decided that, as suggested by literature (13,14), there was no need to organise further focus groups.

### *Validity and reliability*

To achieve reliable qualitative data relating to the conclusions, we decided to adopt the Lincoln and Guba's 'Four criteria' (15): credibility, confirmability, transferability and dependability.

Credibility was demonstrated by data saturation and independent analysis. After data analysis, the researchers gave nurses the possibility to review the themes that had emerged.

Variability in the sample regarding age, gender, profession confirmed the confirmability of the conclusions.

Reliability was confirmed by agreement on the coding performed by the two researchers.

Finally, the results were discussed with other colleagues who at the time of the study were on annual leave: transferability of the results was confirmed.

In addition, the moderator and the person taking notes were familiar with how to conduct focus groups

## Results

Results identified the following 4 main categories of needs, which were considered important by the participants: communication skills, education on the centrality of parents; the organization of the presence of parents, and suitable spaces.

### *The need for Communication Skills*

It was emphasized that *'physical contact'* was an element of strength for both the parent and the child, and that *'parents have the right to stay with their children'* and this right could not be denied. In addition, *'parents are anxious and worried for their children'*, with the result that *'children get excited when they see their parents'*. Participants pointed out that they would like to improve their skills to communicate with parents, especially in critical situations. In fact, the parents' presence during critical situations and the sight of their sedated child, as *'if he/she was dead'*, were considered negative elements.

However, the presence of a parent at his/her child's bedside was perceived as a positive factor for the child by most of the participants. Two nurses reported that parents were a *'reference point for their children'*. They stated that it is important not only to inform the parents but also to know when to *'give the right answers at the right time'*. Participants were aware they could improve

their effective communication skills. A young nurse confessed that sometimes it is easy to give information about *'hygiene, visiting hours, procedures (with brochures) instead of trying to engage in a direct conversation with the mother'*. On the contrary, a senior nurse declared: *"I remember that in the past, my teachers used to tell me that it was better to be 'professional' and not to enter into confidence with the parents: it would be too stressful for me if the child then dies"*.

Participants agreed that sometimes it is so stressful that they *"do not have any words to say, or suggestions to give"*. One nurse with 5 years of experience said *"only because you say that you are not able to enter in touch, in an empathic touch, with the mother. It is stressful because she is alone, with her/his critically ill child ....praying"*.

### *The need for education on the centrality of parents*

Participants frequently mentioned that parents sometimes were anxious and this did not help to keep their children calm. *'Tranquillity'* is cited both in terms of *'presence of the parents'* that calms children down and as *'the mother's ability to maintain her child's feeling'* of reassurance.

Giving parents the possibility to stay beside their children in the PICU was seen by the participants as a positive factor for the parents. In addition, participants declared that when parents are well-informed about the procedures, they are less anxious. The physician stated that it is important to understand when parents wish to be informed or educated regarding a specific topic or regarding the clinical conditions of the child, which should be at *'the right time, neither too late nor too early'*.

On the contrary, parents become scared and stressed in critical situations, when they are left alone without receiving any information. Participants agreed that it is sometimes difficult to understand what is *'the right amount of information parents want'*, when their child is seriously ill. It seemed crucial to improve their

knowledge of how to put parents ‘*at the centre of care*’ while they are at the beside of their child in the PICU.

#### *The need to better organize the presence of parents*

With regard to workload, the presence of a parent in the PICU was described as a strength, since ‘*it benefits to nursing*’ and parents can collaborate with child management. On the other hand, participants pointed out that during the management of critical situations, parents’ emotions can have a negative impact on nursing activities and obstacle procedures. Two nurses declared that parents sometimes ‘*interfered with the daily activities*’. The PICU is a complex environment where children are in critical conditions. Maybe during an emergency the healthcare team prefer not to have parents near their children. Participants suggested that sometimes the nurses working in the PICU are so busy that they do not have the time to give parents all the information they need ‘*they ask everything to everybody*’. It would be better to design an intervention to improve the provision of information. In addition, there is evidence in literature that when parents are well informed and educated they collaborate much better with the healthcare team.

#### *The need to have suitable space*

In relation to the premises and services available, it was emphasized that there should be ‘*suitable space at each bedside to accommodate parents, and promote and maintain a peaceful atmosphere*’ and a room for the family members adequately equipped and comfortable so that families can stay as long as they wish and also have the chance to wind down away from the child’s bedside.

There was some concern about ensuring privacy, especially when ‘*in the same room there is another child facing a critical situation*’.

Finally, some issues were raised relating to the onset and management of infections in hospitalized children caused by the presence of other family members.

#### **Conclusions**

In our study, the majority of the participants viewed Open PICUs positively. There is extensive evidence concerning the positive impact of allowing parents to stay with their children admitted to the PICU. Our findings confirmed that professionals agreed about the fact that Open PICUs reduced the level of anxiety and stress in children and their parents (3). Participants viewed positively Open PICUs, except for the parents’ interferences in the delivery of care and parental anxiety that does not help the child keep calm. The PICU environment is stressful, changing, and complex for children, parents and professionals (3), who focus their interventions on the medical prescriptions in relation to the changing critical conditions to avoid errors. Improved structured programmes for healthcare professionals and parents are suggested to facilitate Family-Centred-Care interventions.

We found that parents were seen by professionals as a ‘*point of reference*’ for the child even in critical conditions, so it is crucial to inform and educate parents to stay calm, in this way they help the child and have an active role in their partnership with the professional. Participants reported that they wanted to improve their communication skills and learn more about how to deal with issues related to the centrality of the parent during his/her stay in the PICU.

Participants seemed to be proud to have parents stay with their children 24 hours a day, but at the same time they wanted to provide the best possible care to the child. They would like to be sure that they have a ‘*safe relational approach*’, improved by active learning and not only acquired through personal experience.

In literature (16,17) six domains have been identified and which can be related to the applicability of Family Centred Care to Open PICUs: Respect, Information and Education, Coordination of care, Physical Support, Emotional Support, Involvement of parents. These domains are referred to both parents and professionals.

Evidence suggests (4, 18, 19 ) that professionals have difficulties in translating these domains into their daily practice, although the related concepts are well known.

This could be a possible explanation to the difficulty that they could have in building an effective relationship with the parents. Our study is in line with these data: participants felt they needed to improve their knowledge and ability to get parents involved in the care process, considering and providing their physical and emotional support.

In our study, Information and Education between professional and parents, through effective and 'understandable information' given at the 'right time', appeared to be a major challenge. In literature (21,22) it is shown that this type of intervention can decrease parents' anxiety and stress, and increase trust in and collaboration with health professionals.

Our study also confirmed the domain of Coordination of Care. Professionals need suitable spaces and a plan to organise the presence of parents in PICUs to avoid any 'interference with the daily activities'.

Strategic health-care plans ought to focus, much more than in the past, on models that allow families to stay close to their children during the most severe stages of their illness, considering the needs of the staff. The Family-Centred-Care Model is not easy to implement in settings with an intensive use of technological equipment (4). A three-phase project like "Creating Opportunities for Parental Empowerment" (COPE) is an example of facilitation for parents focused on their understanding of their child's psychosocial and physical care, during and after hospital admission (22). In fact, it is widely recognised that involving parents in caring for their sick children improves their ability to cope with the management of the disease. In addition, there is evidence that the parents can be involved in the rounds: there is no interference with the communication and education process (22) and the level of their satisfaction is high. Programmes like COPE include training

sessions for healthcare professionals as well (23), as participants suggested.

Parents would like to be present even in case of resuscitation or invasive procedures. Literatures recommends (24) this approach, but in our study it is considered important to give firstly, the best care to the child, sometimes without any kind of information to the parent if they have no time (25). Participants are conscious that this is an organizational problem to take into account.

In the future, the new PICU should include beds, spaces, services for parents and for the health care team. Improving spaces could resolve privacy issues and gather information.

Furthermore, Open PICUs require a profound transformation into a place where professionals and technical competences, jointly with relational competences, can achieve family empowerment.

Open PICUs would be pointless, or even counterproductive, if they were not supported by the improvement and major awareness of the scope of ethical practice, with a view to provide a full and competent coverage of the clinical, ethical and relational issues relating to children and their parents, even in end-of-life situations.

To be effective, an Open PICU project must involve specific training sessions for the whole health care team to achieve a shared level of awareness.

In our study we found that parents can benefit to their work. In agreement with the literature, partnership between parents and professionals should be promoted together with the concepts of involvement, parental presence, shared responsibility and negotiation (25). Measuring parent satisfaction might help to define their specific needs also in the Italian context. Comparing parents' and professionals' perspectives using validated instruments (25,26), such as EMPHATIC-N, could improve partnership and improve a way of working collaboratively on quality of care improvement in Italian PICUs too. In addition, it should be crucial to know



when, how, and why parents interfere in the daily activities to encourage this behaviour and stimulate collaboration.

#### *Limits*

The major limit of this study is that it was conducted only in one site. Given the limited research on this topic in the Italian context to date, the findings from this qualitative study is however an important step. Further studies are needed to develop an “Italian or Local Framework”. Our findings encourage the need to gain a better understanding about parents’ and professionals’ involvement experiences and perceptions, to design future interventions. The ethical aspects of privacy, as well as infection control issues, are considered essential for Open PICUs and must be ensured by appropriate structural and organizational procedures.

In the future, more research is recommended to explore the Italian context from the perspective of professionals, parents and children.

#### *Implication for practice*

We found that professionals had specific needs that have an impact on the organisation and on nursing management. Furthermore, the qualitative approach proved to be useful to outline the professionals’ perception of regarding their needs. Nursing managers can be consider the validity of this approach to conduct further exploratory surveys with the staff.

In our study professionals agree that while visiting is beneficial to patients, open visiting hours are an impediment to practice. Education for professionals can contribute to built a set of recommendations for best practice where open or flexible visiting hours should be used as guidelines, and not only as rules (27).

As reported in literature, we found that nurse managers needed improve the way the patients should request information: data clearly showed that this need has to be addressed. Education, organisation of “face to face meetings” with parents, and suitable spaces require a global vision which should be consistent with “One’s own framework” created by describing the context. At

least in the Italian context, this study leads to a new research question: Is Nursing leadership ready to support Open PICUs? What is the perception of Italian Nursing Leadership regarding Open PICUs and parental presence?

This study does not answer this question, but adds a specific point of view: the needs of the Italian Professionals (28) .

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#### **Conflict of interest**

The authors decalre no conflict of interest

#### **References**

1. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ*. 2008; 337: 1655
2. Øvretveit J. Understanding the conditions for improvement: research to discover which context influences affect improvement success. *BMJ Qual. Saf.* 2011; 20(Suppl. 1): 18-23
3. Smith AB. Parent bed spaces in the PICU: effect on parental stress in the PICU. *Ped Nurs.* 2007; 33(3): 215-21
4. Latour JM. et al. Parent satisfaction in pediatric intensive care. A critical appraisal of the literature. *Ped Criti Care Med.* 2005; 6: 578-584
5. Taylor RL et al. (2010) Children’s conceptualization of the term ‘satisfaction’: Relevance for measuring health outcomes. *Child Care Hlth Dev.* 2010; 36: 663-669

6. Mangurten J et al. Effects of family presence during resuscitation and invasive procedures in pediatric emergency department. *J Emerg Nurs.* 2006; 32(3): 225-233.
7. Griffin T. Family-centered care in the NICU. *J of Perinat Neonat Nurs* 2006; 20(1): 98.
8. Giannini A. Open intensive care units the case in favour. *Minerva Anestesiologica* 2008; 73(5): 299-305
9. Pope C et al. Qualitative research in health care. Analyzing qualitative data. *BMJ.* 2000 ; 320: 114-116
10. Sim J, Snell J. Focus group in physiotherapy. Evaluation and research. *Physiotherapy.* 1996; 82: 189-198
11. Sim J Collecting and analysing qualitative data: issues raised by the focus group. *J Adv Nurs.* 1998; 28 : 345-352
12. Neundorf Kimberly A. *The Content Analysis Guidebook* Thousand Oaks, CA: Sage Publications. 2002
13. Stewart D, Shamdasani P. *Focus group theory and practice.* Sage Publications, Beverly Hills, CA. 1990
14. McLafferty I. Focus groups interviews as a data collecting strategy. *J Adv Nurs.* 2004; 48(2); 187-194
15. Lincoln YS & Guba EG *Naturalistic Inquiry.* Newbury Park, CA: Sage Publications , 1985
16. Committee on Hospital Care, American Academy of Pediatrics. Family Centred care and the paediatrician's role. 2003; 112: 691-697
17. Hutchfield K. Family Centred Care: a concept analysis *J Adv Nurs.*1999; 29: 1178-1187
18. Latour JM ,Haines C. Families in the ICU : do we truly consider their needs, experiences and satisfaction ? *Nurs Crit Care* 2007; 12: 173-174
19. Latour JM et al. Parent Satisfaction in the pediatric ICU: *Pediatric Clinics of North America.* 2008; 55: 779-790
20. Co JP, Ferris TG, Marino BL, Homer CJ, Perrin JM. Are the Hospital characteristics associated with the parental views of pediatric in patient care quality? *Pediatrics.* 2003; 111: 308-314
21. Studdert DM, Burns JP, Mello MM, Puopolo AL, Truog RD, Brennan TA .Nature of conflict in the care of pediatric intensive care patients with prolonged stay . 2003; 112: 553-558.
22. Melnyk BM et al Creating Opportunities for parents empowerment: Programme effects on the mental health/ coping outcomes of critically ill young children and their mothers *Pediatrics.* 2004; 113: 597-607
23. Phipps LM, Bartke CN, Spear DA, Jones LF, Foerster CP, Killian ME, Hughes JR, Hess JC, Johnson DR, Thomas NJ.Assessment of parental presence during bedside pediatric intensive care unit rounds: effect on duration, teaching, and privacy *Ped Crit Care Med.* 2007 8(3):220-224
24. Basal Afaf A, Om Ebrahim A. Al Sai, Hend M. Elazazy Perception of Health Care Providers, Patient's Families and Patients Towards Family Presence During Invasive Procedures in Emergency Care Units. *J Am Sci.* 2012; 8 (11):152-161
25. Lewandosky LA, & Tesler MD Family-centered care: Putting it into action the SPN/ANA guide to family-centered care. Washington, DC: American Nurses Association, 2003
26. Latour JM Construction and psychometric testing of the EMPHATIC questionnaire measuring parent satisfaction in the pediatric intensive care unit. *Intens Care Med.* 2011; 37(2): 310.
27. Ciufu D, Hader R, Holly C Comprehensive systematic review of visitation models in adult critical care units within the context of patient- and family-centred care. *Int J Evid Based Healthc.* 2011; 9(4):362-87.
28. Botma Y, Botha H , Nel M. Transformation: are nurse leaders in critical care ready? *J Nurs Manag.* 2012; 20: 7 921–925.