

# Family-centered care in pediatric critical care units: A critical review

Patricia Rubio-Garrido<sup>1,2</sup>, Leticia Bazo-Hernández<sup>1</sup>, Anna Enrich-Font<sup>2</sup>, Ana María Montserrat-Gala<sup>3</sup>, Cristina Pavón-García<sup>4</sup>, María-Concepción Lasmarías-Ugarte<sup>1</sup>, María-Antonia Martorell-Poveda<sup>1</sup>, María Francisca Jiménez-Herrera<sup>1,5</sup>

<sup>1</sup>Department of Nursing, Rovira i Virgili University, Tarragona, <sup>2</sup>Department of Nursing, Vall d'Hebron University Hospital, <sup>3</sup>Department of Nursing, Gimbernat and Tomàs Cerdà University Schools, <sup>4</sup>Department of Nursing, Catalan Institute of Health, Barcelona, Spain, <sup>5</sup>Department of Nursing, Borås University, Borås, Sweden

## Abstract

Family-centered care (FCC) in pediatric intensive care units (PICUs) arises as a response to the need to humanize medical care, integrating families as active allies in the care of the hospitalized child. This approach seeks to improve the quality of care, the emotional well-being of caregivers, patient adaptation, and prioritizing principles such as respect, communication, participation, and mutual support. This review article highlights the positive impact of FCC on the reduction of stress, anxiety, and hospital stay, as well as on the satisfaction of family members. Strategies such as humanization of the environment through play activities, psychological support, and preparation for transition after PICUs are essential. However, their application is still uneven and faces institutional, organizational, and training barriers. Systematic implementation of the model requires the commitment of the healthcare team, continuous training, and tools to evaluate its real impact. The active involvement of families not only favors the recovery of the child but also improves the perception of the care received, becoming a key indicator of quality in pediatric intensive care.

**Keywords:** Family coping, family health, humanization, intensive care unit pediatric, professional family relationships

**Address for correspondence:** Dr. Patricia Rubio-Garrido, Ps. de la Vall d'Hebron, 119 08035. Barcelona, Spain.  
E-mail: pat.rubio.garrido@gmail.com

## INTRODUCTION

Family-centered care (FCC) emerged in the late 20<sup>th</sup> century when the psychosocial and developmental needs of children gained recognition, shifting from disease-focused to patient-centered care. Dorothea E. Orem's Self-Care Deficit Theory emphasized the needs

of individuals across their growth stages, health status, and characteristics.<sup>[1]</sup>

Humanizing care involves respecting the person's values and decisions, providing dignity, and anticipating needs. Initially, pediatric care focused solely on medical techniques and treatments in pediatric intensive care units (PICUs), neglecting other aspects.<sup>[2]</sup> Humanization requires the entire

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**Table 1: Summary of articles**

Reference	Study population	Type of study	Main results
Abela <i>et al.</i> (2020)	Literature review of 33 articles	Quantitative and qualitative studies	Main sources of stress, needs of reporting families, psychological, physical, and social impact
Baird <i>et al.</i> (2015)	19 participants between PICU team and families	Qualitative study	The complexity of the modern healthcare environment requires the creation of rules of coexistence
Broden <i>et al.</i> (2022)	8 families of deceased children in the PICU	Qualitative descriptive study	4 main categories: Being together, making sense of clinical developments, managing external factors, and navigating a range of emotions
Buckley <i>et al.</i> (2019)	134 PICU and cardiac critical care unit nurses	Quantitative cross-sectional study	Nurses have low/moderate levels of emotional exhaustion, depersonalisation, and high levels of emotional performance
Craske <i>et al.</i> (2019)	11 minors were interviewed	Qualitative study	Family collaboration in the assessment of abstinence may have reciprocal benefits in moderating parental stress
Dahav and Sjöström-Strand. (2018)	12 families of children admitted to PICU for 3 days or more	Qualitative study	Well-informed, participatory experiences reduce the stress and anxiety associated with PICU admission
De Andrade <i>et al.</i> (2017)	19 nurses working in a PICU and NICU	Descriptive and qualitative study	Importance of the family as a trigger, as well as the recognition of structural and organisational obstacles
Denis-Larocque <i>et al.</i> (2017)	10 nurses with PICU experience between 2.5 and 25 years	Descriptive interpretative study	Maintaining a trusting relationship is essential for the care of PICU families through caregiver role training
Fisk <i>et al.</i> (2022)	11 participants from PICU in patients	Qualitative descriptive study	Main categories: Advocacy and decision-making; emotional and physical support
Foster <i>et al.</i> (2016)	Articles between 1998–2014 in PICU	Bibliographic review of 59 articles	The items stress, communication, and needs were interconnected and influenced by individual or group variables
Hakio <i>et al.</i> (2015)	31 families with children in the PICU and mixed ICU	Qualitative, cross-sectional study	Family education was associated with good functioning, health, and social support
Hill <i>et al.</i> (2018)	Articles published between 2006 and 2016	Literature review 49 articles	Health professionals should be aware of the basic concepts of FCCs and how their actions can affect families
Hill <i>et al.</i> (2019)	3 families treated in a PICU	Qualitative descriptive study	The core concepts of the FCCs are information sharing, participation, respect, and dignity
Hwang <i>et al.</i> (2017)	PICU families	Descriptive	Implementation projects according to their units and resources to optimise results and promote the FCC field
Iwata <i>et al.</i> (2019)	323 family members of children admitted to mixed ICUs	Quantitative, clinical trial	Depression and anxiety were related to female gender and infant mortality, stress, social support, and hospitalization
Kostie (2019)	PICU families	Quantitative, descriptive of performance	Evaluations of the programme show numerous positive results of the family-based education initiative
Manente <i>et al.</i> (2017)	Families with children admitted to PICU, articles 2004–2016	Literature review of 12 studies	The transition from ICU to general hospitalisation can be stressful and anxiety provoking for patients and families
Manning <i>et al.</i> (2018)	26 persons: children, their siblings, parents, and carers	Descriptive	They expressed support after overcoming the critical illness, needing information, emotional, social, and general well-being
Mol <i>et al.</i> (2018)	100 PICU family members	Prospective quantitative study	Families were very satisfied with the quality of care, family involvement, and the provision of adequate information
Mortamet <i>et al.</i> (2017)	33 families present during the clown shows	Quantitative	The degree of family satisfaction was not significantly associated with the clinical stability of the child, although it was a positive effect
Mortensen <i>et al.</i> (2015)	90 PICU families	Quantitative cross-sectional study	17% of parents and 6.8% of nonpregnant parents met the diagnostic criteria for acute stress disorder
October <i>et al.</i> (2018)	39 interviews with PICU Families	Qualitative and quantitative study	In a family conference: limit the monologue, highlight the attendees, short turns, an open ending, and limit medical jargon
Oxley (2015)	6 PICU families	Qualitative study	The lived experience of parents of children admitted to the PICU is full of emotions
Pasek <i>et al.</i> (2019)	35 parents of children admitted to the cardiac PICU	Exploratory quantitative study	Most frequent and highlighted domains: Emotional health of the child, importance of emotional health, and psychological disturbances
Richards <i>et al.</i> (2017)	Families with children admitted to the PICU. Studies until 2015	Literature review	FCCs promote communication between families and doctors: “More effective, efficient and empathetic paediatric care”
Sansone <i>et al.</i> (2022)	13 per day between families and health workers	Qualitative study	3 main themes: Social and spiritual support, emotions, feelings, and distress of the caregiver and life in the PICU
Segantini <i>et al.</i> (2018)	19 PICU and NICU nurses	Qualitative Descriptive study	Humanisation in health, and FCCs are still done instinctively and not systematically by nurses

Contd...

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Reference	Study population	Type of study	Main results
Segers <i>et al.</i> (2019)	Families of patients admitted to a PICU/NICU	Literature review	There was strong evidence of a significant decrease in NICU length of stay with FCCs
Tripathi <i>et al.</i> (2015)	300 participants including health team and families	Qualitative study	Implementation of FCCs in the PICU using an evidence-based approach through multidisciplinary rounds

NICU: Neonatal ICU, PICU: Pediatric ICU, ICU: Intensive care units, FCCs: Family-centred care

team to view families as essential partners in care, adapting language, collaborating, and supervising practices. This approach helps families feel involved, and patients benefit from the comfort of having loved ones nearby.<sup>[3,4]</sup>

FCC principles – respect, information, education, coordination, involvement, and support – are well known but inconsistently applied.<sup>[5]</sup> Measuring family satisfaction requires active family participation. The goal of FCC is to improve care quality by empowering families and fostering collaboration between healthcare providers and family members.<sup>[6,7]</sup>

## KEY COMPONENTS OF FAMILY-CENTERED CARE

### Coping strategies

Communication and information are highlighted as an important need for coping with a stay in a critical care unit.<sup>[3,4,6,8-10]</sup> Another tool would be the humanization of care through play activities distracting the child and the family.<sup>[11]</sup>

### Perceptions and feelings

Admission to an intensive care unit generates negative feelings such as anxiety, depression, stress, and uncertainty in families.<sup>[10,12-14]</sup> Negative perceptions of both healthcare staff and families improve and increase satisfaction with family involvement in the FCC.<sup>[7,13,14]</sup>

In the article by Manning *et al.*, they refer to the need to improve the integration of families. It explains how children highlighted the need for family support to understand the situation and adapt to the new reality.<sup>[4]</sup>

Psychological support is an improvement in the social impact experienced during admission.<sup>[15-20]</sup>

### Information gathering techniques

It is important to provide correct information and training to FCC.<sup>[21-23]</sup> The study by Kostie explains how interviews with parents revealed how their intervention helped them to understand the situation, thus helping them to participate in the care of the child.<sup>[22]</sup>

Group and individual sessions on FCCs and preparation for transition after admission to the PICU allow families to be accompanied in their new roles and increase their satisfaction.<sup>[24,25]</sup>

The study by Manente *et al.*, highlights that the transition from the PICU to general hospitalization can be a stressful experience and may lead to anxiety for both patients and their families. To avoid this, information on family needs should be collected.<sup>[24]</sup>

### Implementation of the family-centered care model

For the humanization of care, it is essential to take into account the physical and cultural environment of the PICU.<sup>[21,24,26,27]</sup> Hill *et al.*'s study demonstrates how collaboration between families and caregivers contributes to increased quality and safety of care.<sup>[28]</sup>

In the study by Segantini *et al.*, it is shown how the humanized approach to health according to the FCCs is still done by nurses in an instinctive and unsystematic way due to organizational and training obstacles.<sup>[26]</sup>

The study by de Andrade *et al.* explored the perspective of nurses in the FCC setting, which revealed the existence of difficulties: low collaboration between professionals, lack of continuing education programs addressing this issue, and institutional barriers.<sup>[29]</sup>

Children admitted to critical care units need to incorporate the family into the care model. For this reason, the training and collaboration of health professionals must be encouraged.<sup>[5,30,31]</sup>

## IMPACT OF FAMILY-CENTERED CARE ON THE HUMANIZATION OF PEDIATRIC INTENSIVE CARE UNIT CARE

The integration of FCCs is increasingly evident in our hospitals, especially in intensive care units. However, its implementation not in all hospitals limits the possibility of performing an exhaustive statistical analysis to determine the effectiveness of the care provided. Likewise, it is necessary to deepen the tools for measuring the application of the FCC model, considering it as an indicator of the quality of clinical practice.

From the perspective of humanization of PICU care, several studies, such as that of Hakio *et al.*, support the importance of FCC to promote effective communication and better emotional support.<sup>[9]</sup> In addition, studies such

as Mortensen *et al.* and Manning *et al.* highlight how to address psychological and emotional needs during the PICU stay.<sup>[4,18]</sup>

In recent years, additional humanization strategies have gained attention, including the presence of clowns in the PICU. As reported in the study by Mortamet *et al.*, this intervention contributes to the humanization of the hospital environment and is perceived by parents as having a positive impact on both their children and themselves.<sup>[11,21]</sup>

It is essential to recognize family involvement as a key aspect in the development and adaptation of the health and illness process of the hospitalized child in the PICU [Table 1].

## CONCLUSIONS

Integration of FCC in PICUs has a positive impact on the reduction of stress, anxiety, and hospital stay of patients, as well as on the satisfaction of family members. While barriers such as hospital regulations and procedures can hinder this integration, training both healthcare professionals and families is essential for effective collaboration. Initiatives such as parent support groups and workshops help families navigate the challenges of PICU stays, making them more manageable. Further research into parental perspectives can improve healthcare services and overall satisfaction.

### Author's contribution statement

PR: Concepts, design, definition of intellectual content, literature search, data acquisition, data analysis, manuscript preparation, manuscript editing, and manuscript review. LB: Manuscript review and guarantor. AE: Design, definition of intellectual content, literature search, data acquisition, data analysis, manuscript preparation, manuscript editing, and manuscript review. AM: Design, definition of intellectual content, literature search, data acquisition, data analysis, manuscript preparation, manuscript editing, and manuscript review. CP: Design, definition of intellectual content, literature search, data acquisition, data analysis, manuscript preparation, manuscript editing, and manuscript review. ML: Manuscript preparation, manuscript editing, and manuscript review. MM: Manuscript review and guarantor. MJ: Manuscript review and guarantor.

### Data availability statement

The data that support the findings of this article are available from the corresponding author, [PR], upon reasonable request.

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## Conflicts of interest

There are no conflicts of interest.

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