

## Review Article

### The Role of Family in Caring for Critically Ill Children: A Narrative Review

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#### Article Information

Received: 21 April 2025

Revised: 20 June 2025

Accepted: 20 July 2025

Available online: 29 July 2025

#### Keywords

Caring, children, critically ill, intensive care unit, role of family

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<https://journal.umtas.ac.id/index.php/healthcare/index>

#### Doi

<https://doi.org/10.35568/healthcare.v7i2.6528>

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#### ABSTRACT

Critically ill children in intensive care units face complex physical and emotional challenges that also impact their families. Family-centered care (FCC) is widely recognized as a key model in pediatric critical care, promoting collaboration, respect, and shared decision-making between families and healthcare providers. However, the roles of families in such settings remain varied and underutilized across different healthcare systems and cultural contexts. This narrative review aims to explore the roles of families in caring for critically ill children in intensive care units. Articles were retrieved from PubMed, ScienceDirect, EBSCOhost, and Google Scholar using keywords such as “critically ill children,” “family involvement,” and “family-centered care,” with Boolean operators “OR” and “AND.” Inclusion criteria included free full-text access, publication years between 2020–2025, and English or Indonesian language. From 11,345 articles screened, 10 met the inclusion criteria and were analyzed. The review identified several key family roles, including providing emotional support and security, physical and emotional presence, advocacy and care partnership, participation in daily care, communication and shared decision-making, creating a sense of home and normalcy, coping and post-discharge involvement. Families contribute not only emotional and physical support but also advocacy, caregiving participation, and partnership in decision-making, all of which enhance patient outcomes and support holistic care delivery. Nurses are pivotal in operationalizing family-centred care principles and ensuring meaningful family involvement in caring for critically ill children in the intensive care unit.

## INTRODUCTION

Critically ill children admitted to Intensive Care Units often experience significant physiological instability alongside profound emotional and psychological stress. In such high-stakes environments, the role of the family, particularly parents, has gained increasing recognition as an essential component of comprehensive, holistic care (van Wyk et al., 2024; Veena, 2024). Beyond the technical and medical complexities of critical care, the Neonatal Intensive Care Unit (NICU) and Pediatric Intensive Care Unit (PICU) environment is inherently distressing for both children and their families, often leading to heightened levels of emotional distress, anxiety, and a sense of powerlessness, particularly for parents who may experience a loss of their usual identity and role (Aljawad et al., 2025; Davidson et al., 2017; Franco Fuenmayor et al., 2024; Shdaifat et al., 2022).

Family-centred care (FCC) has emerged as the gold standard in pediatric healthcare, advocating for collaboration, mutual respect, and shared decision-making between families and healthcare professionals (Abukari & Schmollgruber, 2023; Khalili et al., 2024). Within the PICU context, FCC transforms parents' role from passive onlookers to active participants in care. This paradigm encourages parents to provide emotional support, engage in daily routines, and advocate for their child's needs. Such involvement contributes to the child's well-being and promotes family resilience in adversity (Abukari & Schmollgruber, 2023; Poole et al., 2023). As frontline healthcare providers, nurses are pivotal in facilitating meaningful family engagement and ensuring that FCC principles are operationalized in the clinical setting.

Despite broad endorsement of family participation, challenges remain in how these roles are recognized, supported, and implemented across diverse healthcare

settings. Differences in healthcare systems, cultural expectations, and institutional policies can significantly influence the extent and nature of family involvement in pediatric critical care (O'Meara et al., 2022; Seaton et al., 2024). These variations highlight the need for further exploration of the diverse roles that families play in the care of critically ill children, especially as their participation often evolves throughout hospitalization. Additionally, post-discharge support remains an area requiring greater attention, as the transition home can be fraught with challenges that continue to affect both the child's and family's recovery process.

The urgency of this research becomes evident given the growing recognition of the importance of family involvement in the care of critically ill children. While the FCC has been widely acknowledged as an effective model in enhancing child and family well-being, its implementation across critically ill children in the intensive care unit remains inconsistent. Some healthcare facilities may have policies that support family involvement, while others face barriers related to resources and a hospital culture that may not fully endorse active family participation (Seaton et al., 2024). Moreover, there is a lack of in-depth research on the optimal ways to engage families, considering the differences in family dynamics, emotional experiences, and cultural and social contexts.

Furthermore, although several studies have focused on the role of families in caring for critically ill children in intensive care, most of the research tends to focus on specific aspects, such as the emotional support provided by families or their involvement in medical decision-making. There is a limited body of work that comprehensively explores how families interact with the healthcare team, their involvement in daily routines, as well as the challenges they face both during hospitalization in the PICU and

post-discharge (O'Meara et al., 2022; Poole et al., 2023). Therefore, this research aims to fill this gap by thoroughly examining the various roles families play in caring for critically ill children, including emotional support, advocacy, communication, and involvement in decision-making and daily care routines.

The novelty of this study lies in its multidimensional approach to understanding family roles within the context of FCC in children critically ill in the intensive care unit. This research not only investigates family involvement in providing emotional support or participating in medical processes but also explores broader aspects, such as the influence of culture on family engagement, the challenges faced during the transition home, and the importance of effective communication between families and healthcare providers. Additionally, the study considers external influences, such as hospital policies and available social support, that may impact family participation. Thus, the findings of this research are expected to contribute significantly to developing policies and best practices for implementing FCC in various children's intensive care unit settings, as well as offer a more comprehensive understanding of how to facilitate active family roles in the care of critically ill children.

This narrative review aims to synthesize and critically examine the existing literature on the roles of families in the care of critically ill children in the intensive care unit. It seeks to inform and enhance nursing practice. Furthermore, it aims to offer practical recommendations for integrating family-centred approaches into children's critical care, ultimately promoting better outcomes for both children and their families during and after their intensive care unit stay.

## METHOD

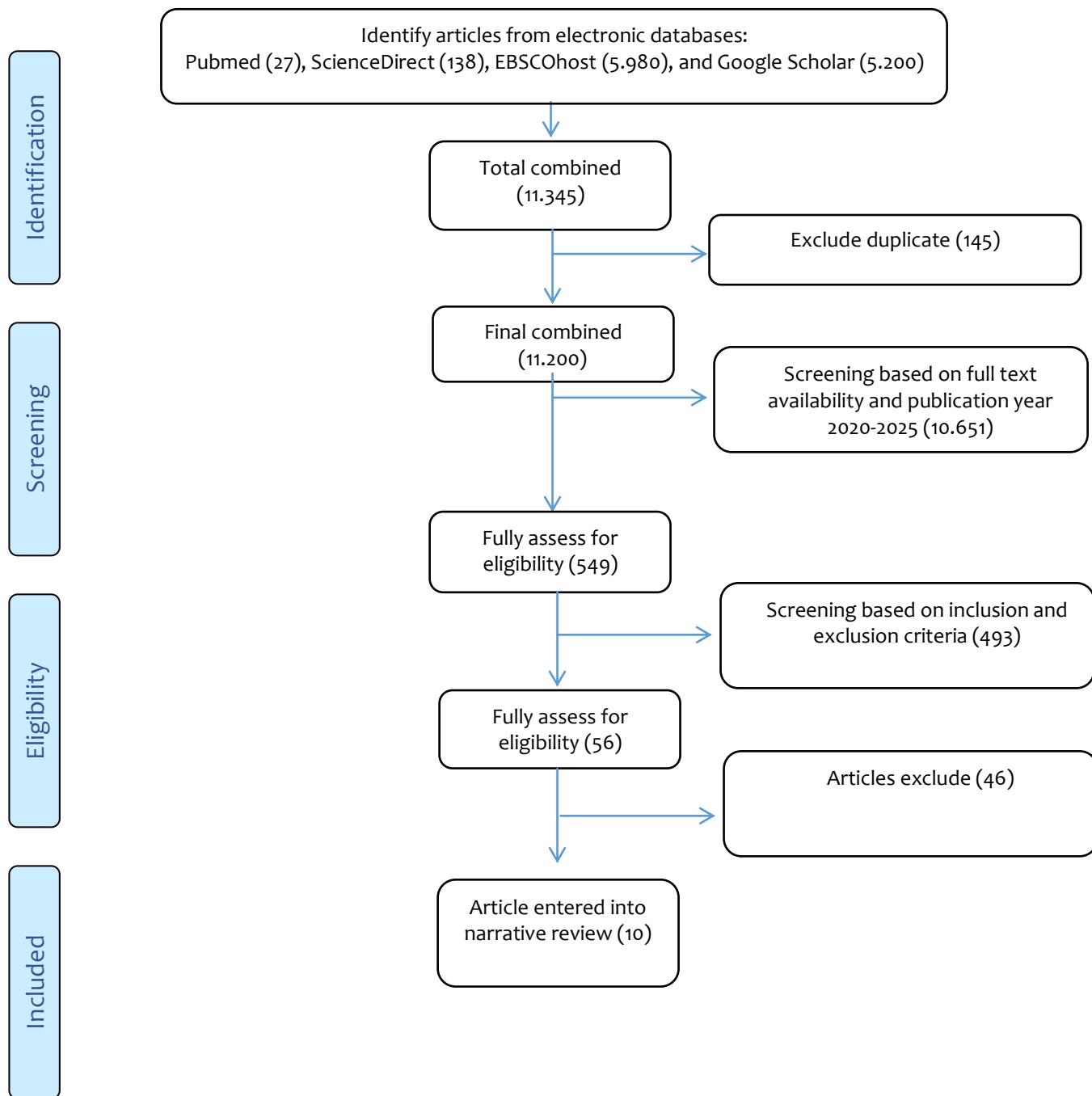
The appropriate research method used in this literature review is a narrative review. This literature review aims to identify the role of family in caring for critically ill children in the intensive care unit. The narrative review process framework used refers to Ferrari (2015) narrative review framework. The narrative review framework consists of five stages: identifying scientific literature in the database, identifying keywords, selecting articles based on inclusion and exclusion criteria, and writing results and discussions. The literature search in this study used articles that discussed the role of family in caring for critically ill children in the intensive care unit. The search in this literature study used several databases, namely PubMed, ScienceDirect, EBSCOhost, and Google Scholar. The search used the PEO technique to make it easier to get the appropriate literature. The P (population/problem/patient) in this study is critically ill children and families in intensive care rooms in both the Neonatal Intensive Care Unit (NICU) and the Pediatric Intensive Care Unit (PICU), E (Exposure) used in this study is the active role or involvement of families in child care, and O (Outcome) used is the impact on children, families, and clinical practice. To determine keywords, authors used the boolean AND and OR. The keywords used were critically ill children OR children in PICU OR children in NICU AND family involvement OR role of family OR family participation OR family-centred care OR FCC AND intensive care unit OR critical care.

The inclusion criteria were articles discussing the role of family in caring for critically ill children in the intensive care unit, free full-text, years of publication between 2020-2025, quantitative research design, qualitative, observational studies, mixed-methods, reviews, and articles in Indonesian or English. At the same time, the

exclusion criteria included articles that discussed the role of families in child care in pediatric care rooms other than intensive care units. After the author selected the studies based on the results of the article search from each database, the author outlined the results of the search and selection of studies and listed them in a chart, as in Figure 1. After obtaining relevant articles, the next step was to analyze their findings and integrate them into the writing.

In conducting this literature study, the author applied the principles of research ethics. According to Artal and Rubenfeld (2017), several ethical standards apply when conducting literature reviews, namely avoiding duplicate publications, avoiding plagiarism, being transparent, and ensuring that published data has been extracted accurately.

**Figure 1 Flow Diagram Selection Articles**



**Table 1 Results of the Article Analysis**

No.	Author and Title	Purpose	Research Method	Population and Sample	The Role of Family	Result
1.	Ryan et al. (2025) Parental and family presence are essential: A qualitative study of children's lived experiences with family presence in pediatric intensive care	To explore the lived experiences of critically ill children in relation to the presence of parents and family members during their stay in the Pediatric Intensive Care Unit (PICU)	Qualitative research using interpretive phenomenological analysis (IPA)	Children aged 6–17 years who had been admitted to a PICU in Canada within the last 6–12 months; total sample: 17 children	Families provided emotional security, reduced fear and loneliness, advocated for the child's needs, and acted as a consistent presence in an otherwise clinical and unfamiliar environment.	The presence of family was described by children as vital to their sense of comfort, safety, and emotional well-being. Their absence was associated with fear, confusion, and disconnection. Family members were perceived as essential allies.
2.	Seaton et al. (2024) Creating a home with a critically ill child: A qualitative study exploring the experiences of parents of children admitted to paediatric critical care following treatment in neonatal care	To explore the experiences of parents whose children were admitted to paediatric critical care units after receiving neonatal intensive care, focusing on their transition and adaptation process	Qualitative study using semi-structured interviews and thematic analysis	About 21 parents (from 17 families) of children with prolonged admissions to pediatric critical care units in the UK, following discharge from neonatal intensive care	Parents acted as constant caregivers, emotional supporters, and advocates. They aimed to "create a home" for their children within the clinical environment, maintaining a sense of normalcy and identity.	Families experienced emotional strain but showed resilience in adapting to the pediatric critical care context. They emphasized the need for continuity in care, partnership with staff, and creating a nurturing environment.
3.	Abukari and Schmollgruber (2023) Concepts of family-centered care at the neonatal and paediatric intensive care unit: A scoping review	To explore the conceptualization and application of FCC in NICU and PICU	Scoping Review	Various studies on NICU and PICU about FCC	Engagement in care, communication, and shared decision-making.	Respect and dignity, communication, participation, and collaboration were the fundamental concepts of FCC that emerged in the NICU and PICU.
4.	Anggraini et al. (2023)	To examine the effect	Quantitative –	Parents of	Direct care involvement,	Greater parental involvement

No.	Author and Title	Purpose	Research Method	Population and Sample	The Role of Family	Result
	Parental involvement in child care on parental stress and anxiety in the intensive care unit of parental involvement on stress and anxiety	Cross-sectional	children in ICU (n=60) in Indonesia	emotional presence.	correlated with lower stress and anxiety levels.	
5.	Poole et al. (2023) “I want to be there. I have to be there.”: Parents’ perceived barriers and facilitators to bedside presence in the pediatric intensive care unit	To explore parents' perceived barriers and facilitators to being present at the bedside of their critically ill child in the Pediatric Intensive Care Unit (PICU)	Qualitative descriptive study using semi-structured interviews and thematic analysis	About 31 parents (mothers and fathers) of children who had been admitted to PICUs across multiple hospitals in Canada	Family members, especially parents, acted as emotional supports, care partners, and advocates for their children. Their physical presence at the bedside was considered essential to both the child's well-being and their own.	Parents identified various barriers (e.g., institutional rules, financial constraints, emotional fatigue) and facilitators (e.g., supportive staff, flexible policies, accommodations) affecting their ability to stay bedside.
6.	Miller et al. (2022) Parental presence at the bedside of critically ill children in the pediatric intensive care unit: A scoping review	To review parental presence at bedside in PICU	Scoping Review	Studies on parental presence in PICU	Physical and emotional presence, decision-making.	Supported recovery; barriers include policy and staff attitudes of parental presence at the bedside of critically ill children. Parental presence at the bedside (PPB) of critically ill children in the pediatric intensive care unit (PICU) is necessary for operationalizing family-centred care.
7.	O’Meara et al. (2022) Family outcomes after the pediatric intensive care unit: A scoping review	To map and synthesize existing evidence on the physical, psychological, and social outcomes experienced by family members of children who have been	Scoping review following PRISMA-ScR guidelines; articles were selected from multiple databases and	Included 124 studies conducted between 2000–2020, focusing on family members (primarily	Families were central to the care process, not only as caregivers during hospitalization but also as individuals experiencing significant psychosocial outcomes post-discharge.	Common outcomes included parental stress, anxiety, post traumatic stress disorder (PTSD), and changes in family functioning. The review highlighted a lack of standardized follow-up care and called for family-centered interventions and support models.

No.	Author and Title	Purpose	Research Method	Population and Sample	The Role of Family	Result
		admitted to the Pediatric Intensive Care Unit (PICU)	analyzed for thematic content	parents) of PICU patients, with a mix of qualitative, quantitative, and mixed-method designs		
8.	Grandjean et al. (2021) Sources of stress, family functioning, and needs of families with a chronically ill child: A qualitative study	To explore stress sources and needs of families with critically ill children	Qualitative Interviews	– Parents of chronically ill children in PICU. Thirty-one families, including mothers only (n = 12), fathers only (n = 8), or mother and father (n = 11) in German	Emotional support, coping, care participation.	This study highlighted the importance of caring for families with critically ill children. Parents reported high negative emotional responses that affect their family functioning. Families's experience was highly dependent on how health care providers were able to meet the parental needs, provide emotional support, reinforce parental empowerment, and allow high quality of care coordination.
9.	Oude Maatman et al. (2020) Factors influencing implementation of family-centered care in a neonatal intensive care unit	To explore factors that influence the implementation of Family-Centered Care (FCC) in neonatal intensive care units (NICUs) from the perspective of healthcare professionals	Qualitative exploratory study using semi-structured interviews and thematic analysis	About 17 healthcare professionals (including nurses, neonatologists, and nurse managers) working in NICUs across three hospitals in Sweden and	Family is viewed as a partner in care, with FCC aiming to involve parents actively in daily care activities, decision-making processes, and communication with healthcare providers.	Several factors influenced FCC implementation, including unit culture, staff attitudes, communication skills, parental presence policies, and availability of physical space. Staff training and organizational support were crucial.

No.	Author and Title	Purpose	Research Method	Population and Sample	The Role of Family	Result
				the Netherlands		
10.	Hadi et al. (2020) The effectiveness of applying the family-centered care method to pediatric patients with stress hospitalization	To assess the effectiveness of FCC in reducing pediatric hospitalization stress	Quasi-experimental	Children and families in pediatric ward (n=30) in Indonesia	Active involvement in daily care.	FCC reduced stress among hospitalized children.

## RESULTS

The results of searching for articles according to keywords and based on the publication years 2020-2025 in four databases showed results in PubMed as many as 27 articles, ScienceDirect as many as 138 articles, EBSCOhost as many as 5,980 articles, and Google Scholar as many as 5,200 articles. After going through the screening stage based on the criteria, ten articles were obtained discussing the family's role in caring for critically ill children in the intensive care unit. The results of the article analysis can be seen in Table 1.

This narrative review synthesizes findings from ten studies published between 2020 and 2025, encompassing scoping reviews, qualitative studies, and quasi-experimental designs. The designs of the studies included five qualitative studies, three scoping reviews, one quasi-experimental study, and one mixed-method study.

The reviewed studies on family roles in pediatric critical care were conducted across various international healthcare settings, reflecting diverse cultural perspectives and healthcare systems. The countries where the research was carried out are Canada, the United States, the United Kingdom, Sweden, the Netherlands, Switzerland, Ghana, and Indonesia.

Across various studies, families, particularly parents, emerged as essential components in the care of critically ill children. Their roles extended beyond traditional caregiving and encompassed several interconnected emotional support and security, physical and emotional presence, advocacy and care partnership, participation in daily care, communication and shared decision-making, creating a sense of home and normalcy, coping and post-discharge involvement.

## DISCUSSION

This narrative review highlights the multifaceted roles of families, especially

parents, in caring for critically ill children admitted to intensive care units. Across diverse geographic and cultural contexts, family involvement emerged as an indispensable component of children's critical care, contributing to the child's well-being and shaping the clinical environment and outcomes.

Across various studies, families, particularly parents, emerged as essential components in the care of critically ill children. Their roles extended beyond traditional caregiving and encompassed several interconnected domains as follows:

### **1. Emotional Support and Security**

Families, particularly parents, served as a source of emotional stability for critically ill children. Their continuous presence at the bedside reduced fear, loneliness, and anxiety, creating a familiar and secure environment amid the highly clinical setting of the PICU (Ryan et al., 2025; Seaton et al., 2024; Shdaifat et al., 2022). Children and healthcare providers perceived this emotional support as essential and contributed to the child's psychological well-being and recovery (Miller et al., 2022).

### **2. Physical and Emotional Presence**

Several studies underlined the importance of physical presence, where parents offered comfort through physical proximity, touch, and soothing verbal interactions (Miller et al., 2022; Poole et al., 2023). For many families, being at the bedside was not only a supportive act but a non-negotiable aspect of their parenting role, enhancing emotional connections and easing children's distress (Ryan et al., 2025).

### **3. Advocacy and Care Partnership**

Parents frequently assumed the role of advocates for their children, ensuring that their preferences, comfort, and dignity were upheld during care planning and interventions (Grandjean et al., 2021; O'Meara et al., 2022). Through ongoing interactions with the healthcare team, they contributed to individualized care and

safeguarded their child's voice in clinical decisions.

#### **4. Participation in Daily Care**

Beyond emotional support, families actively participated in daily care routines, such as hygiene, feeding, or soothing their child, thus maintaining parental identity and reducing the sense of helplessness often experienced in critical care settings (Anggraini et al., 2023; Hadi et al., 2020; Oude Maatman et al., 2020; Shdaifat et al., 2022). This involvement supported normalization and preserved family dynamics within the institutional environment.

#### **5. Communication and Shared Decision-Making**

Effective communication and collaborative decision-making between healthcare providers and families created trust and mutual respect. Family-centered care (FCC) models emphasized two-way communication that empowered families and recognized their expertise in understanding their child's unique needs (Abukari & Schmollgruber, 2023, 2024; Latour et al., 2024; Poole et al., 2023; Shdaifat et al., 2022). Shared decision-making made families feel valued as integral team members in the care process.

#### **6. Creating a Sense of Home and Normalcy**

Parents often transform the sterile hospital environment by introducing familiar items or routines to help their children maintain a sense of normalcy. This effort to 'create a home' within the hospital helped preserve family bonds and the child's sense of self, particularly in long-term stays (Grandjean et al., 2021; Seaton et al., 2024).

#### **7. Coping and Post-Discharge Involvement**

The family's role did not end upon discharge. Several studies noted the prolonged psychosocial impacts of PICU experiences on families, including stress, anxiety, and the burden of ongoing care

responsibilities (Anggraini et al., 2023; O'Meara et al., 2022; Stalder et al., 2024). These findings underscore the need for continued support for families during post-discharge transitions.

In conclusion, this review emphasizes families' holistic and dynamic role in caring for critically ill children in the PICU. Their contributions span emotional, physical, and decision-making domains, significantly influencing the child's outcomes and the family's long-term well-being. Healthcare providers must acknowledge, support, and partner with families to deliver practical, compassionate, and family-centred pediatric critical care.

#### **Implications for Nursing Practice**

The findings of this review have significant implications for neonatal and pediatric critical care nursing. Nurses are pivotal in operationalizing family-centred care principles and ensuring meaningful family involvement in the PICU (Butler et al., n.d.; Meert et al., 2013; Paulsamy et al., 2024; Richards et al., 2017; Shdaifat et al., 2022). First, nurses must actively facilitate and encourage parental presence at the bedside, recognizing it as a therapeutic intervention that promotes emotional stability and comfort for the child. Providing flexible visiting policies and supportive environments can enhance this presence. Second, nurses should empower families through effective communication, involving them in care planning and shared decision-making processes. This includes using clear, compassionate language, providing regular updates, and respecting family insights about their child's condition and needs. Building trust and mutual respect enhances collaborative care and improves health outcomes.

Third, integrating families into daily care routines, such as assisting with hygiene or soothing the child, can preserve parental roles and reduce feelings of helplessness.

Nurses should assess and accommodate each family's readiness and preferences for participation while offering education and emotional support as needed.

Fourth, nurses must acknowledge and address the psychosocial needs of families during hospitalization. The transition to home care may involve providing counselling resources, connecting families to peer support networks, and coordinating post-discharge follow-up to ensure continuity of care.

Ultimately, nurses must act as caregivers for the critically ill child and as advocates and partners for the entire family unit. Incorporating these practices can foster a compassionate, holistic care environment that supports optimal healing and long-term family resilience.

## CONCLUSIONS AND RECOMMENDATION

This narrative review underscores families' integral role in caring for critically ill children in the intensive care unit. Families contribute not only emotional and physical support but also advocacy, caregiving participation, and partnership in decision-making, all of which enhance patient outcomes and support holistic care delivery. Their continued involvement during hospitalization and post-discharge reflects the necessity of family-centered approaches in pediatric critical care.

Based on these findings, we recommend that healthcare institutions:

1. Implement and support flexible policies that prioritize family presence and participation in care.
2. Provide ongoing training for healthcare professionals, particularly nurses, on family-centred communication and engagement strategies.
3. Develop structured programs to involve families in daily care activities and shared decision-making.

4. Establish support systems for families addressing emotional, informational, and post-discharge needs.

5. Encourage interdisciplinary collaboration that includes families as essential partners in care planning.

Adopting these recommendations may enhance the quality of care, promote emotional resilience for families, and ultimately improve outcomes for critically ill children in intensive care settings.

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