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Elements of Family-Centered Care in the Pediatric Intensive Care Unit: An Integrative Review

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Abstract

This paper reports result from a systematic search and thematic analysis of qualitative literature to identify key issues related to family-centered care, behaviors, and communication skills that support the parental role and improve patient and family outcomes in the PICU. Five themes were identified: 1) sharing information; 2) hearing parental voices; 3) making decisions for or with parents; 4) negotiating roles; and 5) individualizing communication. These themes highlight several gaps between how parents want to be involved and perceive clinicians engage them in the care of their child. Parental preferences for involvement differ in the domains of information sharing, decision making, and power-sharing across a spectrum of parental roles from parents as care provider to care recipient. The PICU setting may place clinicians in a double bind trying to both engage families and protect them from distress. Asking families of critically ill children about their preferences for participation across these domains may improve clinician-family relationships.

Keywords

Health Communication; Family Nursing; Intensive Care Units, Pediatric; Terminal Care; Professional-Family Relations; Patient-Centered Care

Background

A child's admission to a pediatric intensive care unit (PICU) is an overwhelming time for the patient and family because of the emotional intensity they experience and the medical complexity of the care being given.¹ Most deaths of pediatric patients in the hospital occur in the PICU² and, regardless of the outcome, families may experience feelings of uncertainty and fear of a poor outcome or the death of the child.³ Additional causes of psychological

distress in parents include parental role disturbance and poor communication experiences with health care teams.^{4–6} Psychological effects can be long-lasting,⁷ and there is an association between the distress parents experience and the long-term psychological well-being of the child.⁸ Family-centered care (FCC) is a partnership approach to care that supports the parental role and involvement of parents in the care of their child.^{9–12} FCC promotes dialogic communication between families and clinicians that aims to support “more effective, efficient, and empathic pediatric health care”¹³ and is proposed as an important contributor to addressing family distress and improving long-term outcomes of children and their families.

While the idea of FCC is considered the gold standard of care in pediatrics,¹⁴ there are several challenges to its implementation, especially in the PICU setting. First, there is a lack of agreement on the definition of FCC^{12,15} and definitions often consist of a broad list of principles,¹⁶ making it difficult to evaluate its effectiveness. Second, patients in the PICU often have unstable and/or unpredictable medical conditions, making it difficult to forecast definitive outcomes, which can lead to greater anxiety for parents^{1,4,17} and more communication challenges.¹³ In addition, average lengths of stay in the PICU are relatively short (with a median of 2 days¹⁸) which means that clinicians must try to develop trusting relationships with families in a short time frame. Third, clinicians have reported difficulty in implementing the elements of FCC in the care of hospitalized children and key principles have been found lacking in the literature.^{6,15,19,20} This suggests that these elements are more reflective of idealistic principles meant to change practice and empower families but are not based on evidence of clinical practice as it currently exists. Further, some elements of FCC involving relationships, negotiation, shared care, and partnership may be implemented incorrectly or be viewed negatively by clinicians and family members.²⁰ The purpose of this paper is to review qualitative research that describes elements of FCC in the PICU with the purpose of identifying FCC behaviors and communication skills that support the parental role and improve patient and family outcomes.

Methods

We conducted a comprehensive review of qualitative and mixed methods empirical research on nurse and physician communication with parents of critically ill children in the PICU, using a systematic approach. We limited the search to studies that reported using qualitative and mixed methods research to examine how FCC was being framed and to further refine the concepts and definitions of FCC as it applies in pediatrics. Searches were performed using PubMed and CINAHL databases and included publications for all articles up to April 2015. We used a broad range of search terms relevant to FCC (see Table 1) because previous research only using the search term “family-centered care” missed articles that report on elements of FCC due to the limited search strategy.¹⁵ In preparation for this systematic literature review, a concept analysis was first performed to define FCC in the PICU and inform the search strategy. For this review, FCC is defined as including some or all of the following elements:

1. the mutual exchange or sharing of information and goals between clinicians and parents, including advocacy by parents for their child^{21–26}

2. decision-making about day-to-day caregiving, medical care, or withdrawal or limiting of life-sustaining treatment^{24,27–30} and
3. negotiation of roles in providing care to the child or the negotiation of presence during interventions and medical communication events^{22,26,30–35}

This search strategy identified an initial set of 780 articles, including 231 duplicates which were removed. The titles and abstracts of the 549 articles were then evaluated for the inclusion and exclusion criteria (see Table 1 for criteria). After this review, another 481 articles were omitted; the remaining 68 full-text articles were read and an additional 35 articles were excluded because they did not meet the inclusion criteria, leaving a final set of 33 articles published between 1990–2015 (see Figure 1. PRISMA diagram).

The full texts of the 33 articles meeting inclusion criteria were then further evaluated to determine if there was any discussion about including the voice of parents as described in Table 1. For example, the unidirectional sharing of information from clinician to family alone did not meet the inclusion criteria; we also required there be some description of the family sharing information with clinicians, participating in decisions, negotiating their role or presence at the bedside, or advocating for the child. Once selected for inclusion, each article was read at least once to get a sense of the whole and then reviewed again to abstract the following structured data elements: the country of origin; research question and design; theoretical or conceptual frameworks used to guide the project; methodological orientation; methods of sampling, data collection and analysis; and key findings related to family-centered care including information-sharing, parental advocacy or expertise, negotiation, how mutual goals or needs/expectations were defined, and support of family participation. The findings were then read across studies to identify and group similar themes.³⁶

Results

Overview of the articles

Of the 33 articles included in this synthesis, 29 used only qualitative methods and four used mixed methods (see supplementary materials). The majority of studies were performed either in the United States or in Europe. The majority of data (81% of the studies) were collected through focus groups and interviews, or open-ended survey questions; 19% of the studies involved direct or indirect observation (e.g., either as ethnographic studies or audio-recording of actual communication events). Study designs were mostly cross-sectional; 19% used longitudinal designs, of which 6% collected longitudinal data but did not analyze those data over time. Parental views were included in 30 of the 33 studies.

Diversity

All of the studies reported demographic information about study participants' gender. Of the 30 articles that included parents as participants, only 12 articles (36%) included information about race, ethnicity, or nationality, all of which were performed in the United States except one from the Netherlands³⁷ and one from Italy.³⁸ Five of the 10 articles in the United States that include demographic information describe samples with 75% or more White participants. There were 17 articles that include clinicians as participants, of which only 4

articles (24%) describe the ethnicity, race or nationality of the clinicians.^{37,39–41} Only four articles (12%), all from the United States, discuss any influence of cultural or language differences or socioeconomic status indicators (such as race and class) in relation to biases and their effects on communication.^{40–43}

Synthesis of Findings

From this literature review, we identified 5 main themes related to FCC: 1) sharing information with parents; 2) hearing parental voices; 3) making decisions for or with parents; 4) individualizing communication; and 5) negotiating roles. From this analysis, we highlight several gaps between how parents of critically ill children in the PICU describe how they want to be involved and how they perceive clinicians actually engage families in the care of their child.

Sharing information with parents

Parents seek honest, clear, and complete information^{42,44–50} to be able to actively participate in decision- making^{47,51} and in the physical care and comfort to their child,^{43,44,47} as well as to cope with uncertainty and fear of a poor outcome..^{42,49,52} Access to information can make parents feel more prepared, less helpless, and give them a sense of control.^{42,44,49,52} Parents reported that they wanted to receive information even when it was potentially distressing^{42,43,53} and wanted to be informed about decisions even when clinicians are the primary decision-makers.^{43,51,52,54} Two articles by Carnevale et al (2006; 2007) suggest that improved coping may help parents feel less fear and regret, and facilitate closure and grieving if the child dies.

Despite parental desires for clear, complete and honest information, several studies found that clinician communication often entailed use of medical terminology, euphemisms and complex speech that was difficult for parents to understand.^{40,43,54–56} Other studies reported that some clinicians withhold information,⁵² avoid being transparent with the intention of protecting families from distressing information,⁵⁶ and manage the timing and kind of information that parents receive. For example, clinicians are reportedly more reserved about what they say during rounds when parents are present, such as information about poor care at other facilities or medical errors.⁵⁷ However, withholding information can lead to parental distress⁵⁸ and contribute to a sense of powerlessness and fear,⁵² insecurity and anxiety,⁵⁸ a stressful search for information,⁴⁹ and an erosion of trust in clinicians.⁵⁶

Clinicians report that they attempt to balance hope with realism in the information they give families.^{46,59} Gordon et al.⁶⁰ describes a balance of hope and realism as an outcome of parental understanding of both prognostic uncertainty and the reasons and implications of tests and procedures. However, uncertain information may conflict with families' preferences for clear information and may make parents wonder if they can trust the clinician's competence, commitment, or transparency⁴⁵ and put clinicians in a difficult situation.

Hearing parental voices

Parents report wanting clinicians to listen to them, answer questions, address their concerns and incorporate their knowledge into the treatment plan. They want to be involved to improve the child's quality of care by sharing important information, correcting misinformation, helping to avoid medical errors, and preventing infections^{42–45,48,53,61}. Similarly, parents want to share their specialist knowledge of the child,^{45,53} including cues and indicators of pain,^{44,52} and physical, emotional and spiritual needs.⁴⁷ Yet some parents report that their medical knowledge is often either not solicited or disregarded,^{38,62} and their questions and concerns are left unaddressed.^{39,52,55} A study by de Vos et al.³⁷ found that only a third of clinicians invited families to share their observations about the child's ability to interact or their perceptions of the child's level of comfort. Both Van Cleave et al.⁴⁰ and de Vos et al.³⁷ found that in family conferences clinicians spoke a disproportionate amount of time.

The unequal power and authority to direct care between parents and clinicians makes it difficult for parents to speak up about concerns they have, ask questions, or challenge a clinician's decision because of concerns that this behavior would jeopardize their relationship with providers upon whom they depend for their child's care.^{63–65} Clinicians have also described power differentials that reduced parental involvement, citing parental concerns about “rock[ing] the boat” by asking questions.⁵⁷ One observational study found that nurses labeled parents who advocated and asked questions as “difficult” with negative impacts on subsequent interactions.³⁹

Listening to parents is essential in order for parents to be in partnership with clinicians⁶² and to establish a trusting relationship.⁴⁴ However, clinician biases may prohibit the development of a partnership with parents of minority ethnic and racial backgrounds. One study in the United States found that parents were less likely to communicate concerns if they felt they were viewed negatively.⁴² Furthermore, racial and ethnic minority parents were more likely to report, unsolicited, that clinicians did not listen to them. Racial and ethnic minority parents gave accounts of events in which they perceived that clinicians were discriminating against them and making assumptions based upon race, language, and insurance status, which made communication difficult. In combination, this information suggests that racial and ethnic minority families may feel less comfortable communicating concerns and being in partnership with clinicians than non-Hispanic White families. It is unclear to what extent clinicians were aware of the influence of biases on communication. In another study in the United States, Bartel et al.⁴¹ describe how physicians did not discuss how differences in race or socioeconomic status may have influenced communication with families and may not have wanted to admit to failures in communication. Open dialogue about the role of biases in communication may facilitate greater self-awareness and improved patient and family experiences.

Making decisions for or with parents

Studies based in France, Italy, Turkey, and the Netherlands described an ethical and legal norm called “beneficent paternalism” in which the role of the physician is to make treatment decisions for critically ill children,^{37,48,50,54} and then parents are given the option to assent

or dissent to the decision. In contrast, in the United States and Canada, the ethical and legal norm is for parents to make decisions for critically ill pediatric patients based on a best interest standard in which an attempt to balance benefit and harm is made.^{13,48} Across countries, however, studies report beliefs that physicians make decisions for parents because they believe that parents do not have the necessary knowledge to participate in such complex decision-making and that parents would otherwise be burdened with feeling culpable and responsible if the child were to die.^{37,46,48} While Bartel et al.⁴¹ and Michelson et al.⁴⁶ in the United States describe parents as being ultimately legally responsible for end-of-life decisions, Michelson, Patel, Haber-Barker, Emanuel, Frader⁴⁶ also describe a process of secondary decision-making in which clinicians influence the decisions parents make by limiting the choices available or how information is delivered, with the goal to reduce the burden of decision-making for parents. In a longitudinal observational study in the Netherlands, de Vos et al.³⁷ describe a decision-making process in which parents were more involved earlier in the hospital stay with sharing information and preferences. However, decisions to withdraw LST were ultimately made by clinicians who would allow time for parents to adapt to this decision if they disagreed. These authors also report that clinicians wanted to protect parents from decisional regret by taking responsibility for the decisions and not including parents, yet parents were found to be capable of participating in difficult decisions despite feeling intense emotions. Furthermore, in a comparison of practices in France and Quebec, there was no pattern between parental involvement in life-support or surgical treatment decision-making and subsequent feelings of regret or guilt.⁴⁸

Individualizing communication

The literature reports a range of parental preferences for communication, such as level of participation in decision-making or type and degree of information that is shared. Some parents want to defer decisions to physicians and other parents want to be more involved and have physicians support their decisions.^{38,48,50,51,54,58,66} Some parents have reported that they wanted only basic information about the care being provided to their child⁴⁴ and that they did not want to be informed until care plans were certain⁴² because hearing varying perspectives on potential diagnoses and their child's medical history increased their anxiety and confusion.^{62,67} However, other parents reported that they wanted to be informed about the different aspects of the care plan that clinicians were considering⁴² and to know as much as possible to better understand their child's condition.^{44,62} For example, Meyer, Ritholz, Burns, Truog⁴⁹ found that parents had different levels of tolerance for uncertainty and complexity and that some parents preferred to know all the viewpoints when there were conflicting perspectives among the health care team, while others preferred talking with just one spokesperson. Greater comfort levels with differing perspectives may have been because they experienced greater cohesion overall in the information from their clinical team⁴⁹ and not because of fundamental differences in communication styles.

Negotiating roles

Role negotiation is defined as collaborating with parents in deciding the level of involvement on the part of parents in providing care to the child, including presence at the bedside and participation in decisions. Overall, there was little discussion about negotiation of roles in this literature. In one study, clinicians indicated that they should have the authority to

determine if parents can be present during resuscitation events.⁶³ The common practice was for clinicians to ask parents to leave during resuscitation events without inquiring about parental preferences or consulting with other clinicians. In regards to negotiating the level of parental involvement in decisions, Carnevale et al.⁴⁵ report that clinicians were unclear as to how to determine decisional-authority in different circumstances, and de Vos et al.³⁷ found that none of the physicians in their study assessed parental preferences for level of decision-making involvement.

There was some indication that barriers to role negotiation include power differentials and differing priorities. de Vos et al.³⁷ found that some parents expressed strong objections to decisions made by clinicians while others complied, resulting in differences in parental influence on the ultimate decision. Because clinicians did not actively solicit parental preferences for participation in decision-making, it is unclear if different behavior is a result of preferences for participation or different comfort levels or cultural norms about challenging power differentials between clinicians and families. Baird et al.³⁹ found that parental behaviors to seek individualized care were perceived by nurses as problematic and challenging. DeLemos found that some parents were less likely to communicate concerns if they felt they were viewed negatively.⁴² Additionally, racial and ethnic minority parents were more likely to report, unsolicited, that clinicians did not listen to them. This suggests that power differentials present in relationships between clinicians and parents may impede negotiation and are of particular concern for parents racial and ethnic minority parents.

A few studies report that clinicians prioritize efficiency, rules, and norms over family needs and participation. Jefferson and Paterson⁶³ reported that clinicians' made decisions regarding parental presence during resuscitation events based on their personal goals for either an efficient procedure or to maintain the child-parent relationship.. Baird reported that clinicians are challenged to respond to competing priorities to both deliver safe and efficient care while also giving patient and families a satisfying experience. These goals are often in tension with each other because clinicians have come to prioritize rules and norms that do not necessarily meet the needs of individual patients and families. Macdonald et al.⁶⁸ also found that there was a conflict between the interests of families and clinicians, and rules regarding behavior and noise levels were applied to parents and not to PICU staff. These different standards for behavior are attributed to whether parents are viewed as (and made to feel like) guests or visitors^{38,68} or members of the health care team.³⁹

Discussion

FCC has been described as existing along a continuum of clinician-family partnership.¹² This continuum ranges on one end from emphasizing the role of parents as care providers, actively contributing their knowledge, observations, and expertise about their child to the plan of care along *with* clinicians, to the other end in which parents are viewed as care recipients, who are being cared *for* by clinicians who take responsibility for distressing decisions and procedures.¹⁵ The literature highlights three domains of the clinician-family partnership in the PICU with varying levels of family involvement: information sharing, power sharing, and goal sharing (see Figure 2). The continuum includes variation across these three domains such that families may be at one end or the other, or some combination

of both providing and receiving care. These are three domains in which parental roles may be negotiated. FCC in pediatric critical care is a dynamic construct that is unique to different families and that may vary over time.

Our review suggests that in general, clinicians in the PICU are still the ones who determine the level of parental access to information, participation in decisions, and presence during procedures.^{37,46,48,52,56,57,63} Exercising this authority may be done to achieve the well-intentioned goal of alleviating family distress, but it also serves the medical-centered goals of efficiency and the enforcement of rules and norms.^{39,63,68} In contrast, parents reported a wish to have a more active role in their child's care, in which they had greater access to information,^{42,43,46–50,53} more participation in the development of treatment plans,^{42–44,53,61} and more recognition and inclusion of their knowledge and concerns about the child.^{44,51,62} This involvement may reduce parental emotional distress by allowing them to fulfill a parental role to protect their child's life and ensure higher quality of care.

Family preferences and needs for their roles as care recipient and care provider may vary depending on the clinical situation and personal characteristics of families, such as the nature of the patient's diagnosis or a family's ability to manage uncertain and complex information. Thus, it is not possible to deliver FCC in a one-size-fits-all approach. It is necessary to negotiate with parents the level of involvement they have by inquiring into their preferences and tailoring communication to their needs. While it has been recommended that communication and decision-making involvement be individualized for the preferences and needs of families,^{38,42,49} parental roles are not often negotiated and there is a lack of specific guidance for how clinicians can do so.

There are specific challenges to clinician-family partnership in the PICU setting, such as the high level of technology, complexity of care, and uncertainty of prognosis, that may place clinicians in a double bind in multiple ways. Clinicians feel responsible for protecting parents from experiencing emotional distress related to participating in treatment decisions that parents may later regret,^{46,48} receiving uncertain or distressing information,^{52,56,57} or being witness to stressful events.⁶³ Clinicians may view the selection, modification, or obfuscation of information that parents receive and the limitation of the degree of parental involvement in decisions as therapeutic communication strategies to protect parents from experiencing psychological distress. However, some parents report distress when they do not have access to complete information or when they feel unable to advocate for their child's best interest.^{42,49,52,56,58} Clinicians may inadvertently increase parental distress by not giving complete information or not involving parents in care to the degree that they prefer. Furthermore, clinicians may have difficulty balancing the goals for physiological endpoints and patient and family satisfaction with communication and involvement, and view these in tension with each other. This results in a reliance on rules and norms that become prioritized at the expense of family participation in care and perpetuate power differentials that impede partnership.

With few exceptions, this body of research does not include a critical lens to power dynamics and status, which may influence the communication between clinicians and families. There is a lack of demographic information given in articles, with mostly

homogenous samples of non-Hispanic White participants (see supplementary materials), and little discussion of the influence of socioeconomic status or differences between clinicians and families in regards to ethnicity, race, or nationality on communication. Results from the study by DeLemos⁴² suggests that racial and ethnic minority families may feel less comfortable communicating concerns and being in partnership with clinicians than non-Hispanic White families. This is important because racial or ethnic minority families and those with lower literacy and education levels and/or who do not speak English, may not be able to participate in the child's care to the same extent as other families with different societal privileges. Parental participation gives parents a sense of control that may allow them to cope and could potentially alleviate the long-term impact of critical illness on the parents, family, and child. A decrease in parental involvement for subgroups of parents could contribute to health disparities. More research is needed in regards to the influence of biases on communication and the parental role in the PICU as well how communication may be modified to better accommodate families from different cultural backgrounds.

Conclusions

This review synthesized 33 qualitative and mixed methods studies with the purpose of identifying FCC behaviors and communication skills that support the parental role and improve patient and family outcomes. This review adds to the literature in three ways: 1) it provides details about the varying needs and preferences for parental roles across the continuum of family-centered care; 2) it provides evidence of the gap between how parents generally wish to be involved and how clinicians involve them and highlights that parents are rarely asked about their preferences for participation; and 3) it describes some of the specific challenges to implementing family-centered care in the PICU setting. Asking parents about their preferences for communication and participation may improve clinician-family relationships, improve the care of children, reduce conflict, and alleviate the emotional distress often experienced by parents due to parental role disturbance and poor communication. Further study is needed to understand how clinicians modify their communication with families, as well as the role of biases, cultural differences, and power differentials in communication, in order to develop effective interventions.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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References

1. Colville G, Darkins J, Hesketh J, Bennett V, Alcock J, Noyes J. The impact on parents of a child's admission to intensive care: integration of qualitative findings from a cross-sectional study. *Intensive Crit Care Nurs.* 2009; 25(2):72–79. [PubMed: 19019677]
2. Michelson KN, Steinhorn DM. Pediatric End-of-Life Issues and Palliative Care. *Clin Pediatr Emerg Med.* 2007; 8(3):212–219. [PubMed: 18438449]
3. Hickman RL Jr, Douglas SL. Impact of chronic critical illness on the psychological outcomes of family members. *AACN Adv Crit Care.* 2010; 21(1):80–91. [PubMed: 20118707]
4. Meert KL, Clark J, Eggly S. Family-centered care in the pediatric intensive care unit. *Pediatr Clin North Am.* 2013; 60(3):761–772. [PubMed: 23639667]
5. Aamir M, Mittal K, Kaushik JS, Kashyap H, Kaur G. Predictors of stress among parents in pediatric intensive care unit: a prospective observational study. *Indian J Pediatr.* 2014; 81(11):1167–1170. [PubMed: 24728700]
6. Foster M, Whitehead L, Maybee P. The Parents', Hospitalized Child's, and Health Care Providers' Perceptions and Experiences of Family-Centered Care Within a Pediatric Critical Care Setting: A Synthesis of Quantitative Research. *J Fam Nurs.* 2016; 22(1):6–73.
7. Balluffi A, Kassam-Adams N, Kazak A, Tucker M, Dominguez T, Helfaer M. Traumatic stress in parents of children admitted to the pediatric intensive care unit. *Pediatr Crit Care Med.* 2004; 5(6): 547–553. [PubMed: 15530191]
8. Colville G. The psychologic impact on children of admission to intensive care. *Pediatr Clin North Am.* 2008; 55(3):605–616. x. [PubMed: 18501757]
9. Hutchfield K. Family-centred care: a concept analysis. *J Adv Nurs.* 1999; 29(5):1178–1187. [PubMed: 10320502]
10. Malusky SK. A concept analysis of family-centered care in the NICU. *Neonatal Netw.* 2005; 24(6): 25–32.
11. Smith VC, Steelfisher GL, Salhi C, Shen LY. Coping with the neonatal intensive care unit experience: parents' strategies and views of staff support. *J Perinat Neonatal Nurs.* 2012; 26(4): 343–352. [PubMed: 23111723]
12. Kuo DZ, Houtrow AJ, Arango P, Kuhlthau KA, Simmons JM, Neff JM. Family-centered care: current applications and future directions in pediatric health care. *Matern Child Health J.* 2012; 16(2):297–305. [PubMed: 21318293]
13. Levetown M. Communicating with children and families: from everyday interactions to skill in conveying distressing information. *Pediatrics.* 2008; 121(5):e1441–e1460. [PubMed: 18450887]
14. Ramezani T, Hadian Shirazi Z, Sabet Sarvestani R, Moattari M. Family-centered care in neonatal intensive care unit: a concept analysis. *Int J Community Based Nurs Midwifery.* 2014; 2(4):268–278. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4201206/pdf/ijcbnm-2-268.pdf>. [PubMed: 25349870]
15. Mikkelsen G, Frederiksen K. Family-centred care of children in hospital - a concept analysis. *J Adv Nurs.* 2011; 67(5):1152–1162. [PubMed: 21272055]
16. Trivette CM, Dunst CJ, Allen S, Wall L. Family-centeredness of the Children's Health Care journal. *Child Health Care.* 1993; 22(4):241–256. [PubMed: 10130537]
17. Johnson BH. Family-centered care: facing the new millennium. Interview by Elizabeth Ahmann. *Pediatr Nurs.* 2000; 26(1):87–90. <http://www.ncbi.nlm.nih.gov/pubmed/12026323>. [PubMed: 12026323]
18. Marcin JP, Slonim AD, Pollack MM, Ruttimann UE. Long-stay patients in the pediatric intensive care unit. *Crit Care Med.* 2001; 29(3):652–657. <http://www.ncbi.nlm.nih.gov/pubmed/11373438>. [PubMed: 11373438]
19. Smith J, Swallow V, Coyne I. Involving parents in managing their child's long-term condition-a concept synthesis of family-centered care and partnership-in-care. *J Pediatr Nurs.* 2015; 30(1): 143–159. [PubMed: 25458112]
20. Foster M, Whitehead L, Maybee P. Parents' and health professionals' perceptions of family centred care for children in hospital, in developed and developing countries: a review of the literature. *Int J Nurs Stud.* 2010; 47(9):1184–1193. [PubMed: 20646708]

21. Coleman NE, Pon S. Quality: performance improvement, teamwork, information technology and protocols. *Crit Care Clin.* 2013; 29(2):129–151. [PubMed: 23537668]
22. Eggly S, Meert KL. Parental inclusion in pediatric intensive care rounds: How does it fit with patient- and family-centered care? *Pediatr Crit Care Med.* 2011; 12(6):684–685. [PubMed: 22067820]
23. Ladak LA, Premji SS, Amanullah MM, Haque A, Ajani K, Siddiqui FJ. Family-centered rounds in Pakistani pediatric intensive care settings: Non-randomized pre- and post-study design. *Int J Nurs Stud.* 2013; 50(6):717–726. [PubMed: 22704527]
24. Ingram TC, Kamat P, Coopersmith CM, Vats A. Intensivist perceptions of family-centered rounds and its impact on physician comfort, staff involvement, teaching, and efficiency. *J Crit Care.* 2014; 29(6):915–918. [PubMed: 25123794]
25. Mullen JE, Asher LM. Implementation of a nursing professional practice model of care in a pediatric hospital. *Pediatr Nurs.* 2007; 33(6):499–504. [PubMed: 18196713]
26. McAlvin SS, Carew-Lyons A. Family presence during resuscitation and invasive procedures in pediatric critical care: a systematic review. *Am J Crit Care.* 2014; 23(6):477–484. quiz 485. [PubMed: 25362671]
27. Bindner A, Hardin AO, Berkenbosch JW. Pediatric intensive care unit management and discharge of a severely autistic patient. *Internet Journal of Emergency and Intensive Care Medicine.* 2008; 11(2):7p. <http://ispub.com/IJEICM/11/2/6578>.
28. Walker-Vischer L, Hill C, Mendez SS. The experience of Latino parents of hospitalized children during family-centered rounds. *J Nurs Adm.* 2015; 45(3):152–157. [PubMed: 25689501]
29. Frazier A, Frazier H, Warren NA. A discussion of family-centered care within the pediatric intensive care unit. *Crit Care Nurs Q.* 2010; 33(1):82–86. [PubMed: 20019514]
30. Lewis-Newby M, Curtis JR. Family centered care at the end of a child's life: we must get this right. *Minerva Anesthesiol.* 2013; 79(12):1321–1323. <http://www.ncbi.nlm.nih.gov/pubmed/24296730>. [PubMed: 24296730]
31. Merk L, Merk R. A Parents' Perspective on the Pediatric Intensive Care Unit: Our Family's Journey. *Pediatr Clin North Am.* 2013; 60(3):773–780. [PubMed: 23639668]
32. Just AC. Parent participation in care: bridging the gap in the pediatric ICU. *Newborn Infant Nurs Rev.* 2005; 5(4):179–187. <http://offcampus.lib.washington.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=2009096072&site=ehost-live>.
33. Roets L, Rowe-Rowe N, Nel R. Family-centred care in the paediatric intensive care unit. *J Nurs Manag.* 2012; 20(5):624–630. [PubMed: 22823218]
34. Foster C, Monterosso L. The ventilator-dependent infant requiring palliative care in the neonatal intensive care unit: a literature review. *Neonatal, Paediatric & Child Health Nursing.* 2012; 15(1): 8–19.
35. Berube KM, Fothergill-Bourbonnais F, Thomas M, Moreau D. Parents' Experience of the Transition with their Child from a Pediatric Intensive Care Unit (PICU) to the Hospital Ward: Searching for Comfort Across Transitions. *J Pediatr Nurs.* 2014; 29(6):586–595. [PubMed: 25023951]
36. Whittemore R, Knafl K. The integrative review: updated methodology. *J Adv Nurs.* 2005; 52(5): 546–553. [PubMed: 16268861]
37. de Vos MA, Bos AP, Plotz FB, et al. Talking with parents about end-of-life decisions for their children. *Pediatrics.* 2015; 135(2):e465–e476. [PubMed: 25560442]
38. Lamiani G, Giannini A, Fossati I, Prandi E, Vegni E. Parental experience of end-of life care in the pediatric intensive care unit. *Minerva Anesthesiol.* 2013; 79(12):1334–1343. [PubMed: 24107829]
39. Baird J, Davies B, Hinds PS, Baggott C, Rehm RS. What impact do hospital and unit-based rules have upon patient and family-centered care in the pediatric intensive care unit? *J Pediatr Nurs.* 2015; 30(1):133–142. [PubMed: 25450441]
40. Van Cleave AC, Roosen-Runge MU, Miller AB, Milner LC, Karkazis KA, Magnus DC. Quality of communication in interpreted versus noninterpreted PICU family meetings. *Crit Care Med.* 2014; 42(6):1507–1517. [PubMed: 24394631]
41. Bartel DA, Engler AJ, Natale JE, Misra V, Lewin AB, Joseph JG. Working with families of suddenly and critically ill children: physician experiences. *Arch Pediatr Adolesc Med.* 2000;

154(11):1127–1133. <http://archpedi.jamanetwork.com/data/Journals/PEDS/8597/poa00112.pdf>. [PubMed: 11074855]

42. DeLemos D, Chen M, Romer A, et al. Building trust through communication in the intensive care unit: HICCC. *Pediatr Crit Care Med*. 2010; 11(3):378–384. [PubMed: 19770787]
43. Tomlinson PS, Swiggum P, Harbaugh BL. Identification of nurse-family intervention sites to decrease health-related family boundary ambiguity in PICU. *Issues Compr Pediatr Nurs*. 1999; 22(1):27–47. [PubMed: 10640064]
44. Ames KE, Rennick JE, Baillargeon S. A qualitative interpretive study exploring parents' perception of the parental role in the paediatric intensive care unit. *Intensive Crit Care Nurs*. 2011; 27(3):143–150. [PubMed: 21511474]
45. Carnevale FA, Farrell C, Cremer R, et al. Communication in pediatric critical care: A proposal for an evidence-informed framework. *J Child Health Care*. 2014
46. Michelson KN, Patel R, Haber-Barker N, Emanuel L, Frader J. End-of-life care decisions in the PICU: roles professionals play. *Pediatr Crit Care Med*. 2013; 14(1):e34–e44. [PubMed: 23249788]
47. October TW, Fisher KR, Feudtner C, Hinds PS. The parent perspective: "being a good parent" when making critical decisions in the PICU. *Pediatr Crit Care Med*. 2014; 15(4):291–298. [PubMed: 24583502]
48. Carnevale FA, Canoui P, Cremer R, et al. Parental involvement in treatment decisions regarding their critically ill child: a comparative study of France and Quebec. *Pediatr Crit Care Med*. 2007; 8(4):337–342. [PubMed: 17545930]
49. Meyer EC, Ritholz MD, Burns JP, Truog RD. Improving the quality of end-of-life care in the pediatric intensive care unit: parents' priorities and recommendations. *Pediatrics*. 2006; 117(3):649–657. [PubMed: 16510643]
50. Carnevale FA, Benedetti M, Bonaldi A, Bravi E, Trabucco G, Biban P. Understanding the private worlds of physicians, nurses, and parents: a study of life-sustaining treatment decisions in Italian paediatric critical care. *J Child Health Care*. 2011; 15(4):334–349. [PubMed: 22199173]
51. McGraw SA, Truog RD, Solomon MZ, Cohen-Bearak A, Sellers DE, Meyer EC. "I was able to still be her mom"--parenting at end of life in the pediatric intensive care unit. *Pediatr Crit Care Med*. 2012; 13(6):e350–e356. [PubMed: 22791096]
52. Carnevale FA, Canoui P, Hubert P, et al. The moral experience of parents regarding life-support decisions for their critically-ill children: a preliminary study in France. *J Child Health Care*. 2006; 10(1):69–82. [PubMed: 16464934]
53. Stickney CA, Ziniel SI, Brett MS, Truog RD. Family participation during intensive care unit rounds: goals and expectations of parents and health care providers in a tertiary pediatric intensive care unit. *J Pediatr*. 2014; 165(6):1245.e1241–1251.e1241. [PubMed: 25241179]
54. Kahveci R, Ayhan D, Doner P, Cihan FG, Koc EM. Shared decision-making in pediatric intensive care units: a qualitative study with physicians, nurses and parents. *Indian J Pediatr*. 2014; 81(12):1287–1292. [PubMed: 24752630]
55. Abib El Halal GM, Piva JP, Lago PM, et al. Parents' perspectives on the deaths of their children in two Brazilian paediatric intensive care units. *Int J Palliat Nurs*. 2013; 19(10):495–502. [PubMed: 24162280]
56. Maxton FJ. Parental presence during resuscitation in the PICU: the parents' experience. Sharing and surviving the resuscitation: a phenomenological study. *J Clin Nurs*. 2008; 17(23):3168–3176. [PubMed: 19012784]
57. McPherson G, Jefferson R, Kissoon N, Kwong L, Rasmussen K. Toward the inclusion of parents on pediatric critical care unit rounds. *Pediatr Crit Care Med*. 2011; 12(6):e255–e261. [PubMed: 21057363]
58. Latour JM, van Goudoever JB, Schuurman BE, et al. A qualitative study exploring the experiences of parents of children admitted to seven Dutch pediatric intensive care units. *Intensive Care Med*. 2011; 37(2):319–325. [PubMed: 21063674]
59. Michelson KN, Emanuel L, Carter A, Brinkman P, Clayman ML, Frader J. Pediatric intensive care unit family conferences: one mode of communication for discussing end-of-life care decisions. *Pediatr Crit Care Med*. 2011; 12(6):e336–e343. [PubMed: 21478794]

60. Gordon C, Barton E, Meert KL, et al. Accounting for medical communication: parents' perceptions of communicative roles and responsibilities in the pediatric intensive care unit. *Commun Med*. 2009; 6(2):177–188. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3277327/pdf/nihms-354601.pdf>. [PubMed: 20635554]
61. Orioles A, Miller VA, Kersun LS, Ingram M, Morrison WE. "To be a phenomenal doctor you have to be the whole package": physicians' interpersonal behaviors during difficult conversations in pediatrics. *J Palliat Med*. 2013; 16(8):929–933. [PubMed: 23808643]
62. Graham RJ, Pemstein DM, Curley MA. Experiencing the pediatric intensive care unit: perspective from parents of children with severe antecedent disabilities. *Crit Care Med*. 2009; 37(6):2064–2070. [PubMed: 19384200]
63. Jefferson R, Paterson B. Efficient or family-centred? Practitioners' goals in decisions regarding parental presence during invasive procedures. *Dynamics*. 2001; 12(3):14–20. [PubMed: 11982203]
64. Tomlinson PS, Harbaugh BL. Assessing ambiguity at the family-nurse boundary interface in pediatric health crisis. *J Pediatr Nurs*. 2004; 19(6):399–410. [PubMed: 15637581]
65. Carnevale FA. A description of stressors and coping strategies among parents of critically ill children--a preliminary study. *Intensive Care Nurs*. 1990; 6(1):4–11. <https://www.ncbi.nlm.nih.gov/pubmed/2329271>. [PubMed: 2329271]
66. Gilmer MJ, Foster TL, Bell CJ, Mulder J, Carter BS. Parental perceptions of care of children at end of life. *Am J Hosp Palliat Care*. 2013; 30(1):53–58. [PubMed: 22495794]
67. Cameron MA, Schleien CL, Morris MC. Parental presence on pediatric intensive care unit rounds. *J Pediatr*. 2009; 155(4):522–528. [PubMed: 19555968]
68. Macdonald ME, Liben S, Carnevale FA, Cohen SR. An office or a bedroom? Challenges for family-centered care in the pediatric intensive care unit. *J Child Health Care*. 2012; 16(3):237–249. [PubMed: 22308544]
69. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med*. 2009; 6(7):e1000097. [PubMed: 19621072]

Figure 1.
Prisma Flow Diagram⁶⁹

Table 1

Search Strategy

Keywords: family, families, family health, family/psychology, parent^{*}, mother, or father, end of life communication, decision making, communication^{*}, physician-patient relations, patient-centered care, family-centered care, patient participation, communication barriers, intensive care, pediatric intensive care, hospice and palliative care nursing, palliative medicine, terminal care, illness, interviews as topic, qualitative research, grounded theory, discourse analysis, phenomenology, and interview^{*}.

Inclusion Criteria	Exclusion Criteria
1. Empirical articles, in English, and in peer-reviewed journals	1. Literature reviews, opinion articles, non-empirical, and non-peer reviewed research.
2. Full text available	2. Focus on life after PICU
3. Pediatric ICU setting	3. NICU, outpatient, or home settings because parental roles and concerns are distinct.
4. Qualitative or mixed methods study design and methods	4. Content emphasized only giving information to parents as this describes only a minimum level of parental involvement (Hutchfield, 1999a)
5. Study participants included biological parents or legal guardians of PICU patients and/or physicians or nurses working in the PICU	5. Focused primarily on bereavement, organ donation, care delivered after the death of the child, death with dignity, or factors influencing decisions taken to withdraw care and not about the decision-making process itself.
6. Described the mutual exchange (or sharing) of information and goals between clinicians and parents, including advocacy by parents for their child, decision-making about day-to-day caregiving, medical care, or withdrawal or limiting of life-sustaining treatment, OR negotiation of roles in providing care to the child or the negotiation of presence during interventions and medical communication events.	

^{*} indicates “wild card” to include all possible endings