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Family-Centered Care from the Perspective of Parents of Children Cared for in a Pediatric Intensive Care Unit: An Integrative Review

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Abstract

Problem—The Institute for Patient- and Family-Centered Care`s (IPFCC) definition of family-centered care (FCC) includes the following four core concepts: respect and dignity, information sharing, participation, and collaboration. To date, research has focused on the provider experience of FCC in the PICU; little is known about how parents of children hospitalized in the pediatric intensive care unit (PICU) experience FCC.

Eligibility Criteria—Articles were included if they were published between 2006 and 2016, included qualitative, quantitative, or mixed methods results, related to care received in a PICU, and included results that were from a parent perspective.

Sample—49 articles from 44 studies were included in this review; 32 used qualitative/mixed methods and 17 used quantitative designs.

Results—The concepts of respect and dignity, information sharing, and participation were well represented in the literature, as parents reported having both met and unmet needs in relation to FCC. While not explicitly defined in the IPFCC core concepts, parents frequently reported on the environment of care and its impact on their FCC experience.

Conclusions—As evidenced by this synthesis, parents of critically ill children report both positive and negative FCC experiences relating to the core concepts outlined by the IPFCC.

Implications—There is a need for better understanding of how parents perceive their involvement in the care of their critically ill child, additionally; the IPFCC core concepts should be refined to explicitly include the importance of the environment of care.

Keywords

Family-Centered Care; PICU; parent; Institute for Patient and Family Centered Care

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Introduction

The Institute for Patient- and Family-Centered Care (IPFCC) defines family-centered care (FCC) as encompassing four core concepts: respect and dignity, information sharing, participation in care and decision-making, and collaboration between patients, families, and the healthcare team (www.ipfcc.org). In pediatrics, respect and dignity encompass how the child and the child's family are treated; information sharing involves communicating with and making information available to patients and families in formats they understand. Participation entails including the family in decision making and the child's care at the level the family chooses, and collaboration comprises partnering with families to improve policy, programs, and infrastructure. As an approach to care, the goal of FCC is to improve patient and family satisfaction and care outcomes; FCC has the potential to influence health care delivery at levels ranging from social and institutional policies to daily interpersonal interactions with staff and family (www.ipfcc.org).

Partnerships between families and the health care team are essential in pediatrics where children are often unable to self-report symptoms or treatment preferences due to their developmental stage or health status. Thus, parents are charged with communicating on the child's behalf, necessitating that parents be included in their child's care. Additionally, parents are most often responsible for the child's care after discharge, making critical that they are involved in care and decisions during the child's hospitalization to aid in the transition to home. Multiple professional organizations have released statements stressing the importance of adopting FCC as a policy in the pediatric hospital environment (e.g., The Institute of Medicine, 2001; American Academy of Pediatrics, 2003, 2012; American Nurses Association, 2008, 2015); however, the extent to which FCC as defined by the IPFCC is enacted in pediatric critical care units (PICU) is largely unknown. To inform understanding of FCC in pediatric intensive care, an integrative literature review was performed; this paper reports on the findings.

Background

As a mode of care delivery, FCC is relatively new in the care of pediatric patients and families. As recent as the mid-20th century children were cared for in hospital wards with no or minimal visitation allowed from family members. Parents of children with chronic health conditions and key advocacy groups joined together to bring about change and prioritized FCC in the late-20th century (Johnson, 1990). Slowly the care of hospitalized children has shifted to a more family-centered model; however the PICU has been slow to adopt these standards (Butler, Copnell, & Willetts, 2013; Foglia & Milonovich, 2011).

The introduction of FCC in pediatric settings was intended to change how providers interact with families and care for hospitalized children. Based on FCC principles, the family is central to the child's health and pediatric care should focus on partnership with the family (Just, 2005). These ways of interacting can be challenging in PICUs which have traditionally limited family visitation, involvement in direct care, and decision-making (Kuo et al., 2012). Published first-hand accounts of parents who have had children treated in a PICU illustrate poor implementation of the core concepts of FCC as envisioned by the IPFCC (Merk & Merk, 2013; Wills & Wills, 2009).

While others have examined FCC implementation in pediatric environments including the PICU, these syntheses have focused on healthcare professionals' experiences and perspectives rather than those of parents. Given that parents are the voice, advocate, and caregiver for their child including during critical pediatric illness, their perspective is critical to understanding FCC implementation in the PICU. The overall purpose of this review was to examine parents' perspectives on and experiences with implementation of the FCC core concepts in the context of having a child in the PICU.

Aims

The primary aim of this integrative review (Whittemore & Knafl, 2005) was to examine the extent to which published research articles concerning parent perspectives on their involvement in their child's care in a PICU demonstrate implementation of the four core concepts of FCC. Secondary aims were to determine if the definitions of these four concepts require refinement or expansion to incorporate parental perspectives and experiences, and whether the evidence suggests additional core concepts reflecting parents' perspectives on FCC.

Methods

Search method

The searches were guided by the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA: Moher, 2009). Search strategies were developed by the first author (CH) in consultation with a research librarian. The databases searched between July and October 2016 included: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Excerpta Medica Database (Embase), PubMed, and PsycINFO. To be included in this review, reports had to be available in English, published between January 1, 2006 and October 31, 2016, include qualitative, quantitative, or mixed methods results, relate to the PICU, and include results of parental perspective via parent report regarding PICU care. To reflect the most recent research on FCC in the PICU and ensure timeliness and clinical relevance, the literature search was limited to reports published within the last 10 years. Articles that included other care environments or reports of healthcare professionals' experiences were included only if the parent report and PICU environment were distinguishable among the results. Excluded were firsthand accounts, editorials, and other works that were not primary research.

Search terms included PICU, pediatric intensive care unit, family-centered care, parent, collaboration, decision-making, participation, and information. Keywords and Medical Subject Heading (MeSH) terms were customized to the database searched. Additionally, truncation of words was used when appropriate to reflect syntax and search rules common to individual databases (Havill et al., 2014).

Search outcome

Refer to Figure 1 for search outcomes.

Quality appraisal

The first author critically appraised the retained articles using the Mixed Methods Appraisal Tool (MMAT) (Pluye et al., 2011), a tool designed to assess the methodological quality for systematic reviews that contain qualitative, quantitative, and mixed methods studies. An article could score 0, 25, 50, 75, or 100% based on how many assessment items the article addressed. No articles were excluded based on poor quality; for individual quality scores see Table 1.

Data Abstraction and Synthesis

Data were extracted from included reports using an extraction template structured to summarize results related to each FCC core concept as outlined by the IPFCC, as well as evidence for refining core concepts definitions and/or adding concepts not previously explicated as central to FCC. The first author (CH) extracted data from the remaining articles using the template, and then either the second (KK) or third author (SS) reviewed the abstractions for completeness and conceptual fit. The authors met to review and resolve data extraction discrepancies.

Results

Table 1 summarizes the articles included in this integrative review. The IPFCC core concepts respect and dignity, information sharing, and participation were evident in the reports of parent perspectives; collaboration was mentioned just once in the implications section of one article. An additional review finding was the impact of the physical and cultural environment of the PICU on the parents' perception of FCC implementation. In the following sections we discuss our findings based on each IPFCC core concept, the need for FCC model refinement, and parent report of whether implementation of the FCC core concepts was met in the PICU.

Respect and Dignity

The IPFCC defines respect and dignity as "health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care" (www.ipfcc.org). We operationalized this core concept as results addressing "how patients and their families are treated". Themes included perceptions of the PICU physical and cultural environment and expressions of compassion and support from providers.

Perceptions of the PICU Physical and Cultural Environment—A common theme throughout the research reports was the PICU environment and how it impacted parents' experiences. Although not explicitly mentioned in the definitions of any core concept, the PICU environment (e.g., patient room, overall unit, waiting room) was experienced by parents as conveying respect and dignity for the family and their situation and, attempts to preserve dignity through attention to the child and parents' privacy and emotional decompression, or lack thereof.

The structural layout of PICUs ranges from open units where patient spaces are separated only by curtains, semi-private room units that house 2-4 patients, and private room units. Parents identified aspects of each layout that contributed to their comfort or discomfort. Parents interpreted rooms that were clean and comfortable (Abuqamar, Arabiat, & Holmes, 2016), close by waiting rooms (Sturdivant & Warren, 2009), and availability of telephones and lockers (Meert, Briller, Schim, & Thurston, 2008a) as indicators of respect. For parents, lack of respect was communicated by unavailability of bathrooms for families on the unit (Carnevale et al., 2011), and the time-consuming process for accessing the PICU from the waiting room (Meert et al., 2008a). For parents, other indicators of lack of respect included the PICU noise level, which made relaxation or rest difficult (Abuqamar et al., 2016; Meert et al., 2008a), small room size, inadequate space for personal items or a comfortable chair near the bedside (Majdalani, Doumit, & Rahi, 2014; Meert et al., 2008a), no facilities for parents to address their personal needs such as hygiene, nutrition, or rest (Meert et al., 2008a; Vasli, Dehghan-Nayeri, Borim-Nezhad, & Vedadhir, 2015), and no distractions for parents such as television (Smith da Nobrega Morais & Geraldo da Costa, 2009). When a waiting area was associated with the PICU, parents also found negatives related to this. Parents remarked that the waiting area was generally an uncomfortable social space where stressed family members exhibited a wide range of emotional and sometimes distressing behaviors, with no one “in charge” (Meert et al., 2008a). One report described the waiting room furniture as not conducive to sitting or resting (Sturdivant & Warren, 2009).

Expressions of Compassion and Support from Providers—In the PICU, delivering care in ways that parents experience as dignified and respectful requires not only technical skill, but behaviors that convey the staff’s compassion, support, and understanding of families’ experiences. Parents discussed how being treated like a human being conveyed respect (Colville et al., 2009). Respect was conveyed through professional attitudes (Latour et al., 2011a) and by listening to parents without judgment (Meyer, Ritholz, Burns, & Truog, 2006). They commented that nurses were compassionate, kind, and caring (Cantwell-Bartl & Tibballs, 2013; Smith da Nobrega Morais & Geraldo da Costa, 2009; Sturdivant & Warren, 2009), treated their child with love and tenderness (Mattsson, Arman, Castren, & Forsner, 2014), and provided what parents perceived to be good care (Mortensen et al., 2015; Smith da Nobrega Morais & Geraldo da Costa, 2009). While not specifically referring to nurses, other articles reported that parents thought that the attention their child received was caring and compassionate, and staff relayed empathy and commitment to providing good care (Delemos et al., 2010; Latour et al., 2011a; Meyer et al., 2006; Sturdivant & Warren, 2009). Parents also discussed respect as it was shown to their child; providers conveyed a sense of love, comfort, and care for their child and treated the child as an individual (McGraw et al, 2012). Parents noticed when providers respected the personhood of their child by knowing their name and gender (Meert, Briller, Schim, Thurston, & Kabel, 2009). Physicians too were viewed as being kind and compassionate; parents appreciated when they delivered information in consoling and supportive tones (Meert et al., 2008b). Parents in one study stated, “She treated my daughter as a mother more than a physician” (Majdalani et al., 2014, p. 221). Parents who witnessed resuscitation attempts on other children were comforted by seeing the staff display emotions during these events (Tinsley et al., 2008).

Parents also experienced behaviors that did not convey respect and dignity. Parents commented on a perceived lack of compassion (Abib El Halal et al., 2013; Cantwell-Bartl & Tibballs, 2013; Meyer et al., 2006), cold and callous communication (Abib El Halal et al., 2013, Meert et al., 2007; Meert et al., 2008b), and inappropriate body language by providers (Colville et al., 2009). Parents in one report described feeling abandoned by their physician after their child’s death (Meert et al., 2007). In the study by Maxton (2008), mothers commented that they felt nurses would judge them if the mother cried; one parent noted having been chastised by a nurse for crying. Cantwell-Bartl & Tibballs (2013) found that parents reported hearing insensitive comments by nurses and that providers had poor interpersonal skills and a lack of empathy; lack of empathy by providers was also reported by Meyer et al. (2006).

Common courtesies such as providers introducing themselves, and being addressed directly by physicians were viewed as signs of respect (Levin, Fisher, Cato, Zurca, & October, 2015; Stickney et al., 2014b). Conversely, Aronson, Yau, Helfaer, and Morrison (2009) found that medical team members introduced themselves to parents just 11% of the time when observed on rounds. In a study by Colville et al. (2009), parents reported that providers did not introduce themselves. Furthermore, Delemos et al. (2010) found that only one third of enrolled parents could identify the physician in charge of their child’s care.

Parents also experienced absence of respect when they perceived physicians as “talking down” to them (Carnevale et al., 2007), and when staff caused them to “feel like a number” (Meert et al., 2008b). Delemos et al. (2010) found that parents perceived discrimination based on race, education, and income that strained relationships with providers; some parents felt that medical costs impacted their child’s care (Carnevale et al., 2011). Parents felt disrespected when providers did not honor their religious or faith traditions near the child’s end of life (Meert et al., 2009). Some parents of children with severe antecedent disabilities reported that providers lacked understanding or appreciation of their child as a person and their baseline level of function (Graham et al., 2009). Parents of children with severe anomalies perceived their child as being treated less than human because of their developmental differences (Meert et al., 2009).

Parents appreciated providers who gave compassionate, honest, and trustworthy support regardless of the child’s age or condition, as shown through body language, words, or actions (Meert et al., 2009). Parents reported high satisfaction scores when they felt supported by nurses (Mortensen et al., 2015). In a study by Roets, Rowe-Rowe, and Nel (2012), 71% of mothers felt emotionally supported when providers assured them about their child’s likely recovery and 61% when providers displayed emotional concern. This study also revealed that 44% of parents felt emotionally supported when providers were friendly and spoke in a friendly manner, overall, the articles included in this review suggest that implementation of respect and dignity continues to be unmet from the perspective of parents with children in the PICU.

Information Sharing

Information sharing is defined as “health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful.

Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making" (www.ipfcc.org). In coding the extracted data, the authors operationalized information sharing as "results addressing communication and availability of information to families". We identified four themes related to information sharing: using understandable language, medical rounds, amount/type of communication, and satisfaction with communication.

Using understandable language—Across reports, the evidence suggested that for parents the most important aspect of communication was that clinicians used language that the family could comprehend. Parents expressed needing information: in "normal people language" rather than medical jargon that parents didn't always understand (Abib El Halal et al., 2013; Carnevale et al., 2007; Majdalani et al., 2014), and in "layman's terms" (Stickney et al., 2014b) so it is understandable (Jee et al., 2012, Sturdivant & Warren, 2009). Parents in the study by Meert et al. (2008b) indicated that the pace at which information was given was important for how well they absorbed information, given the stress, fatigue, and emotions evoked by some conversations. Some parents indicated that terminology used by providers led them to misunderstand the severity of their child's illness (Maxton, 2008), or why certain procedures were not being performed (Abib El Halal et al., 2013). Additionally, parents in the study by Majdalani et al. (2014) indicated that they would be hesitant communicating with or asking questions in a language that was not their preferred language. Parents recommended that when communicating with families in regions where multiple languages are common, the staff should communicate in the parents' preferred language as both a sign of respect and to maximize comprehension.

Medical Rounds—Medical rounding in the PICU are opportunities for parents to participate in and to be an active part of the information exchange guiding their child's care. Medical rounding was a focus for nine articles included in this review. Parent experiences with medical rounding are pertinent to both information sharing and participation. Aronson et al. (2009) found that 98% of parents liked to be present for rounds and 97% thought it was helpful to hear the discussion of the child's case by the group. Ninety-one percent of parents said their presence during rounds gave them more confidence in the medical team caring for their child. Similarly, Cameron, Schleien, and Morris (2009) reported that 89% of parents believed that being present during rounds helped them to understand their child's condition and the treatment plan. Although some parents reported that hearing multiple treatment options discussed during rounds caused stress, 36% believed rounds promoted transparency between parents and providers. Parents also reported that participating in medical rounds about their child provided opportunities to receive and exchange information with the team (Graham et al., 2009; Ladak et al., 2013; Levin et al., 2015; McPherson, Jefferson, Kissoon, Kwong, & Rasmussen, 2011), ask questions (Graham et al., 2009; Phipps et al., 2007), and correct misinformation that the staff had about the child (McPherson et al., 2011). Stickney et al. (2014b) reported that parents found benefit from rounds in that they were able to hear the plan of care directly from the team and observe team interactions. Medical rounds also helped the parents to understand the role of each team member in their child's care. Yet some parents reported not being comfortable with participating in medical team rounding. Parents reported feeling anxious (Graham et al., 2009; Levin et al., 2015) about information they might hear and they preferred that someone update them individually after rounds (Graham et al., 2009; Stickney, Ziniel, Brett, & Truog, 2014a).

Amount/Type of Communication—Across studies, parents indicated preferences related to the amount and type of information as well as the delivery mode. Parents reported expecting and needing regular, frequent feedback on their child's progress and condition (Ames et al., 2011; Carnevale et al., 2011; Delemos et al., 2010; Majdalani et al., 2014, Mattsson et al., 2014; Meert et al., 2008b; Meyer et al., 2006; Stickney et al., 2014b; Sturdivant & Warren, 2009). Parents in the Ames et al. (2011) study indicated as those who know the child best, part of their parental role was to acquire information about their child's treatment and condition. Parents expressed preferences regarding certain aspects of communication including: coordination of communication between team members (Delemos et al., 2010), that information be delivered in person (Meert et al., 2008a), at the child's bedside (Meyer et al., 2006), that physicians sit while doing so (Meert et al., 2008b), and also be readily accessible for updates and to address parents' questions, which may not be formulated until after the information has been digested (Meert et al., 2008b; Oxley, 2015).

Satisfaction with Communication—Similar to the type and amount of information preferred, parents expressed satisfaction and dissatisfaction with communication in the PICU. Parents reported that doctors and nurses communicated well (Cantwell-Bartl & Tibballs, 2013; Carnevale et al., 2007, Meert et al., 2008b) and humanely (Cantwell-Bartl & Tibballs, 2013; Carnevale et al., 2011) with parents. They also preferred communication that was open, honest, patient, and clear (Colville et al., 2009; Delemos et al., 2010; Graham et al., 2009; Jee et al., 2012; Meert et al., 2008b).

Contrary to those who expressed satisfaction with communication, parents were dissatisfied when they felt "talked down to" by physicians, when physicians seemed cold, detached, or rushed (Carnevale et al., 2011), or when staff were perceived as insensitive when communicating (Cantwell-Bartl & Tibballs, 2013; Meert et al., 2007, Meert et al., 2008b). Parents reported being concerned when they thought that information was being withheld from them (Abib El Halal et al., 2013; Cantwell-Bartl & Tibballs, 2013; Carnevale et al., 2007; Latour et al., 2011a; Meert et al., 2007; Meert et al., 2008b) or that they were ignored by staff when expecting to receive updated information (Meert et al., 2008b). Parents reported getting inconsistent information from various providers, which resulted in confusion and frustration (Colville et al., 2009; Delemos et al., 2010; Meert et al., 2008b; Meert et al., 2009; Meyer et al., 2006). Parents reported receiving different or contradictory information and perceived "finger pointing" between providers; they thought there were too many providers involved in care to know what others were doing (Meert et al., 2009). Despite examples of perceived poor communication, implementation of information sharing was largely met from the perspective of parents of children in the PICU.

Participation

The IPFCC defines participation as "patients and families are encouraged and supported in participating in care and decision-making at the level they choose" (www.ipfcc.org). We operationalized this core concept as “taking part in the care of the ill child” and our analysis identified four major themes: parents as experts, how parents participated, impact of environment/providers on participation, and medical rounds as a forum for participation.

Parent as experts—Parents are the “experts” regarding their child, and important values or considerations of the family’s context should be considered in their child’s care. Across the included studies, parents reported how they were treated as experts and also how their expertise was ignored. Parents considered themselves the experts on their child and expected to contribute valuable information to staff (Graham et al., 2009; McPherson et al., 2011; Stickney et al., 2014b). Parents were pleased when the staff solicited their advice and when they witnessed staff implement their suggestions when communicating with or comforting the child (Ames et al., 2011); parents stated they valued being listened to (Meyer et al., 2006). Parents of children with severe antecedent conditions were most comfortable with their child’s care when parent input was considered with regard to the child’s functioning prior to hospitalization (Graham et al., 2009).

Delemos et al. (2010) found that parents had more confidence in physicians who asked for parents’ opinions and considered parent observations about the child. However, other studies reported that some parents did not feel as though they were listened to by staff (Abuqamar et al., 2016; Carnevale et al., 2007; Delemos et al., 2010) and believed that this resulted in poorer outcomes for their child (Delemos et al., 2010). Parents said they were hesitant to express dissenting thoughts or concerns about their child’s care because they didn’t want to be labeled as difficult (Delemos et al., 2010) or annoying (Smith da Nobrega Morais & Geraldo da Costa, 2009); one mother noted that she must be a “good girl” to ensure a good relationship with the staff and therefore good care for her child (Smith da Nobrega Morais & Geraldo da Costa, 2009). This highlights the power differential imbedded in the interactions between various providers and parents that inherently shape the PICU as a unique care environment.

How parents participated—Parents sought to be present and involved in the care of their critically ill child (Ames et al., 2011; Graham et al., 2009; Latour et al., 2011a; McGraw et al., 2012; Meert et al., 2007; Meert et al., 2009; Meyer et al., 2006; Rennick et al., 2011; Roets et al., 2012; Sturdivant & Warren, 2009). Some parents referred to the importance of being at the bedside to care for and comfort the child (Ames et al., 2011). Others participated by being vigilant to the child’s health status and care (Graham et al., 2009; McGraw et al., 2012; Sturdivant & Warren, 2009) and advocating for their child (McGraw et al., 2012; October et al., 2014). Nonetheless, some included reports provided evidence of parents being unable to participate in the physical care of their child at the level they desired because of the highly technical nature of the PICU environment and its cultural structures. Mothers in the Cantwell-Bartl and Tibballs (2013) study reported a loss of intimacy with their infants due to limits placed on their contact with the child because of their critical condition and the child’s equipment needs, which they linked to problems “bonding”; three mothers and five fathers said they had no bond with their infant, that the infant “belongs to the staff”. Parental roles in the child’s care were also altered in the context of the hospitalization of a chronically ill child who had been cared for at home; parents had difficulty reconciling what care they were allowed to provide in the PICU versus the care they were responsible for providing at home (Graham et al., 2009). Parents described feelings of fear, helplessness, and stress related to their inability to participate in care at the desired level (Colville et al., 2009; Jee et al., 2012; Smith da Nobrega Morais & Geraldo da Costa, 2009); one mother stated the PICU felt like a “prison” but that she had to stay and participate for the sake of her child (Smith da Nobrega Morais & Geraldo da Costa, 2009).

Decision making was an important theme in how parents participated in the care of their child in the PICU. A wide range of preferences for participation in treatment decisions was revealed, from parents who wanted physicians to make all decisions (Latour et al., 2011a), those who wanted shared decision making with physicians (Carnevale et al., 2011, Delemos et al., 2010; Madrigal et al., 2012, Majdalani et al., 2014; Meyer et al., 2006), and those who felt decision making was solely a parental responsibility (Carnevale et al., 2007; Madrigal et al., 2012). Some parents indicated that they were not allowed to participate in decision making to the extent they preferred (Abib El Halal et al., 2013; Carnevale et al., 2007; Carnevale et al., 2011; Ebrahim et al., 2013). These results highlighted how important information sharing might be in shaping parents’ ability to participate. If information is withheld, lacking, skewed, not given in a timely manner, or presented too quickly or in complex language, parents feel that they are unable to understand and equally participate in the decision making processes.

Impact of Environment/Providers on Parent Participation—In the PICU environment with its amount of equipment and sensory stimulations, parents may need guidance from providers to be active in care at the bedside. Parents acknowledged that nursing staff was helpful in showing them ways to be involved at the bedside and how to physically care for the ill child (Ames et al., 2011; Latour et al., 2011a; Mattsson et al., 2014). Parents in the Mattsson et al. (2014) study noted that nurses “built a bridge” to the children so the parents could reach them, meaning that nurses showed parents how and where to make physical contact with the child to participate in their care. As much as providers can facilitate parent participation, in the included studies parents predominantly reported environment- and provider-related barriers to participating in their child’s care at the level they preferred. Parents reported that PICU sights and sounds were anxiety provoking (Colville et al., 2009); frequent reminders not to touch equipment connected to their child likely made this worse (Macdonald et al., 2012). Parents reported needing but not receiving guidance from nurses about how or where they could touch their child (Ames et al., 2011). Carnevale et al. (2007) reported that some parents thought nurses imposed a physical barrier to the child. Authors of multiple studies reported that parents described the PICU environment as constraining parent’s participation because of lack of places for parents to sit at the bedside and having to leave the PICU when patient emergencies arose (Colville et al., 2009; Macdonald et al., 2012; Maxton, 2008; Meert et al., 2008a; Meert et al., 2009; Vasli et al., 2015). Baird et al. (2015) found that PICU rules impacted how family members participated in care and how much time they could be at the bedside. These findings were echoed by those of another study in which parents reported they were only allowed to visit their child in the PICU for 2 hours per day (Abuqamar et al., 2016).

Parents also identified ways the PICU environment facilitated their parenting by offering possibilities for parents to personalize the room to their child's tastes (Macdonald, Liben, Carnevale, & Cohen, 2012). Parents felt having a private room lent to having sufficient privacy and quiet for them and their child (Latour et al., 2011a). However, reports more often stated how the environment impeded parenting behaviors. When describing their child's PICU room, parents mentioned lack of privacy and ability to control who entered their room (Abib El Halal et al., 2013; McGraw et al., 2012). Parents from one study commented that the PICU environment was not designed with children in mind such as child-friendly décor or allowing items from home (Vasli et al., 2015). Parents in PICUs without private rooms were asked to leave during crises with other children on the unit (Gaudreault & Carnevale, 2012; Meert et al., 2008a) Parents unwillingly witnessed uncomfortable or graphic scenes due to a lack of privacy and wanting to stay with their own child during such an event (Gaudreault & Carnevale, 2012). Parents commented on social disturbances on the unit that led them to question their (and their child's) safety (Meert et al., 2008a).

Medical Rounds—As stated earlier, involvement in medical rounds could be an avenue for parents to both gain updated information about their child and participate in care decisions. Cameron et al. (2009) reported that 75% of parents who participated in rounds felt that this allowed them to be more involved in treatment decision making. Among parents participating in rounds, some reported reduced personal tension related to the child's condition (Ladak et al., 2013), equated participation with fulfilling their parental role to engage in their child's care (Levin et al., 2015), or felt welcomed and enjoyed attending rounds (Stickney et al., 2014b). As stated previously, some parents reported that rounds could be anxiety provoking and stressful (Cameron et al., 2009), while 10% of parents in the McPherson et al. (2011) study were unsure if they had participated in rounds. These findings illustrate the need to better educate PICU providers on ways that they can explain the rounding process to parents and teach them how to actively engage to the level they choose.

Collaboration

The IPFCC defines collaboration as "patients and families are also included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care" (www.ipfcc.org). While no included articles reported collaboration as defined by the IPFCC, they do provide evidence of changes implemented in some settings (Abid El Halal et al., 2013). Based on the limited findings of this integrative review, however, broader implementation of collaboration with parents is needed in designing policies and programs that inform the culture and education delivered in these settings, and designing the physical spaces of PICU environment.

Discussion

This integrative review provides a comprehensive description of published reports regarding parent appraisals of implementation of the four IPFCC acknowledged core concepts in the PICU. Of the four core concepts, evidence of implementation being met and unmet with regards to respect and dignity, information sharing, and participation was present in the parent report articles and provide direction for advancing the implementation of FCC in the PICU. Evidence of collaboration as defined by the IPFCC was not present in the parent report literature we included, but this might also be a limitation of a retrospective review of published research. Our review also revealed that the core concepts, while explicitly defined by the IPFCC, have overlapping qualities. For instance, the PICU environment had implications for respect and dignity, information sharing, and participation. Although evidence of collaboration was not observed, implementation of collaboration (as defined by the IPFCC) and its outcomes have the potential to impact the environment for the enhancement of FCC in the PICU. As such, based on the results of this integrative review, we propose that environment be conceptualized as both physical and cultural spaces that are experienced by parents as affecting respect and dignity, information sharing, and participation in FCC in the PICU (Figure 2). We recognize that collaboration exists in many hospitals but this might not have been an aim of the studies identified for this review.

Providing environments where parents can be present, have unrestricted visitation, perform basic activities of daily living and hygiene tasks for themselves, and feel comfortable, safe, and welcomed is a basic form of respect and dignity that each parent should be afforded while their child is in the PICU. In a study by Roscigno, Savage, Grant, and Philipsen (2013), parents of children with traumatic brain injury reported parental role limitations when their ability to visit their child in the PICU was regulated or when hospital personnel acted as gatekeepers preventing access to their child. In pursuing implementation of FCC in the pediatric environment, unrestricted parental visitation should be a basic right.

Parents appreciated having places to receive information from staff who sit down, indicating a need for an environment that allows for this type of information exchange. LeGrow, Hodnett, Stremler, and Cohen (2014) developed a parent briefing intervention in which pediatric physicians and nurses were asked to use a briefing template and physically sit with parents while updating them on their child’s condition. Parents responded positively to the intervention, they felt their presence was helpful and important and that they were able to have questions and concerns addressed and procedures explained. There was no indication of whether physically sitting with the parents changed the parent perception of the communication or whether it was the structured briefing with a physician and nurse that made the difference. Regardless, this study highlights that parents find on-going personalized information exchange with physicians and nurses to be necessary and important to help parents understand their child’s medical information. The environment of the child’s room was perceived by parents as impacting their ability to physically participate in their child’s care; for parents to be active in care at the level they choose staff should instruct parents as to how PICU equipment supports the child and how parents can safely touch, hold, and participate in care. Equipment configurations may need modifications so parents can physically reach the bedside to engage in the child’s care. Geoghegan et al. (2016) found that parents of children in the ICU believed that nurses facilitated parents’ involvement in the care of their child. The parents in this study looked to nurses to both physically and emotionally guide them in how to care for their child while hospitalized in the ICU.

Themes relating to information sharing addressed the type and amount of information, as parents' overall satisfaction with communication and medical rounding. Mentioned by many families as key to implementation of information sharing being met was use of understandable language, meaning both the family's preferred language and lay language to describe the child's condition, prognosis, and treatment. Additionally, recognizing that information exchange and uptake might be impacted by parent stress, fatigue, and anxiety is important for PICU staff.

When studying parents of infants hospitalized in the neonatal intensive care unit (NICU), Mackley, Winter, Guillen, Paul, and Locke (2016) found that during times of complex information exchange regarding the condition and care of their infants, one third of parents scored as having suspected limited health literacy. Furthermore, when assessing nurses' subjective interpretations of parent understanding of complex information in discharge teaching, they perceived adequate comprehension by parents 83.3% of the time while 32% of parents exhibited suspected limited health literacy. This result underscores the need for ongoing communication of understandable information to parents of children in the PICU, for validation that what the family "heard" is what the providers intended to convey, and for clarification of misunderstandings. Repeating information in multiple formats (spoken, written, or visual demonstration) might help frazzled parents to absorb the wealth of complex information they are given while stressed. The IPFCC definition for information sharing indicates that practitioners communicate in ways that are affirming and useful to families. In addition, we recommend modifying this definition to include using simple, minimally technical terms that families can understand in the family's preferred language, and then verifying that parents understood the information correctly.

Some parents viewed participation in medical rounds as means to exchange information with the healthcare team. However, staff should find alternative ways of sharing information with those parents who declined participation in medical rounds or who experience them as confusing or anxiety provoking. Parent participation in medical rounds should not be a substitute for frequent individualized information exchanges with families. Treating parents with respect includes respecting their decision whether to participate in medical rounds and determining what alternative opportunities are available for them to participate in care and exchange information with staff.

The analysis identified four participation themes including parents as experts, how parents participate, impact of environment and providers, and medical rounds. As defined by the IPFCC, parents should be encouraged and supported to participate in care at the level they choose. Key to this are shared understandings between parents and providers regarding how, when, and the amount of participation each parent desires. Developing plans for parent participation and frequently re-evaluating this plan for changes is important to support parents' participation and establish how they will do that. Because the evidence suggests that rounds are an important forum for information sharing and communication, providers should frequently discuss with parents whether their preference about participating in rounds has changed as their child's stay in the PICU progresses and as the environment becomes more familiar, the child's condition evolves, and parent anxiety fluctuates.

This review found no evidence that parents reported having been engaged in efforts with other members of the healthcare team or health care system on policy and program development, facility design, and education. We speculate that collaboration is happening in the FCC of pediatric patients but this work is not currently in the research literature. The IPFCC website lists hospitals with established patient and family advisory councils to improve FCC; the first author of this paper is a member of such an advisory board. Patient and family advisory boards/councils are becoming more prevalent at children’s hospitals across the United States in an effort to collaborate and improve the FCC experience (www.ipfcc.org); these boards/councils should be encouraged to publish the results of any programs of research or quality improvement programs they implement.

Implications for practice, research and education

This integrative review reveals that despite the push for FCC in the PICU environment, parent report indicates there is still much work to be done to ensure full implementation. Parents reported both positive and negative implementation of FCC as related to three of the IPFCC core concepts. This review adds a parent perspective to the body of FCC literature and highlights areas in which FCC implementation is both met and unmet. Additional research is needed to determine the knowledge base of clinicians in regard to FCC so that when parents report areas in which implementation of the FCC core concepts are unmet, we can understand whether these perceptions can be attributed to lack of understanding, lack of effort, or lack of institutional support. Understanding factors contributing to the disconnect between how FCC is defined and implemented is an important future step.

Strengths and limitations

This integrative review is the first to report solely on parent perspectives of the implementation of FCC core concepts as defined by the IPFCC. Limitations include the analysis of published literature that may not have reported all of its data; authors of the included studies may have only reported on data relevant to their research question and in turn parent report data specific to FCC concepts were not included in their results. This integrative review contained a large number of participants across studies and even though fathers were underrepresented compared to mothers, the number of studies including fathers in the sample is evidence of the strength of the PICU literature overall. This review used rigorous extraction methods including checks on each data extraction by a second reviewer and a mixed methods quality appraisal tool to assess quality of the included reports, which overall were above average.

Conclusion

Implementation of family-centered care is considered the benchmark in caring for pediatric patients and their families. Parents of children cared for in the PICU often struggle with the severity of their child’s illness and how to care for their child in this environment. The findings from this integrative review reveal per parent report that they encounter positive and negative implementation of core concepts of FCC while their child is in the PICU. Nurses and other health care providers must be cognizant of the core concepts of FCC and how their actions can impact parents both positively and negatively.

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Highlights

- A revised conceptualization of FCC in the PICU is proposed.
- Parents indicate that the environment of care greatly impacts the delivery of FCC.
- Parents report positive and negative encounters with FCC in the PICU.

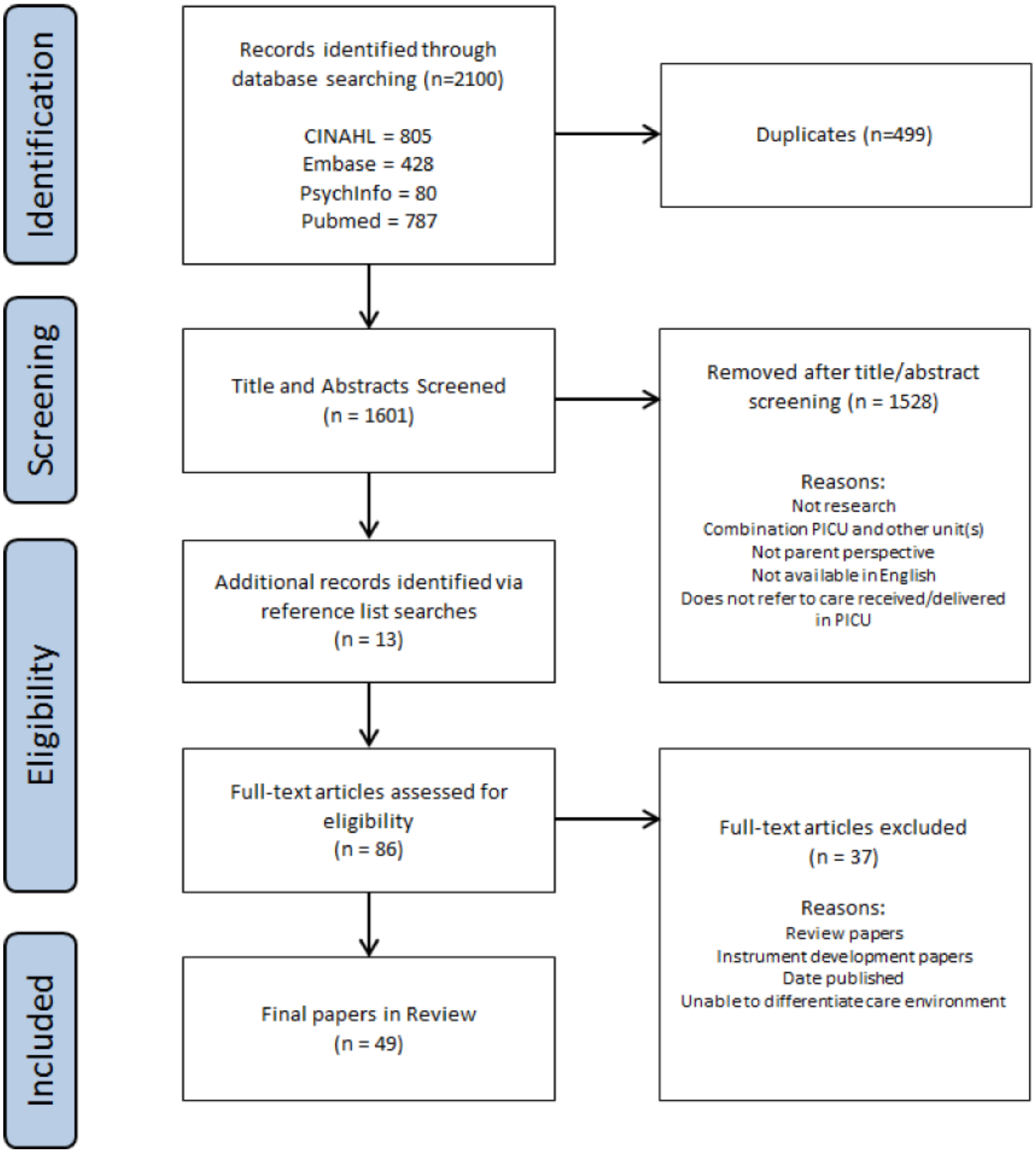

Figure 1.

PRISMA flow chart of search process

Figure 2.

Conceptualization of FCC in the PICU as a result of this integrative review. The evidence suggests that participation, respect and dignity, and information sharing are all impacted by environment. No evidence of collaboration was found in the included articles and as such this concept is not included in our post-review conceptualization.

Table 1

Author, year, country	Approach/Aim	Sample Characteristics	Quality Score	Results
Mixed Methods Designs				
Cameron et al. (2009), United States	Prospective, observational and survey-based design to evaluate the effect of parental presence on PICU rounds	Rounding was observed on 130 patients in a PICU. 52 parents participated in semi-structured interviews.	50%	Parents report increased satisfaction from participation and provide new information when on rounds. However, parental presence may limit discussion during rounds which may limit discussion during rounds which may adversely affect patient care.
Cantwell-Bartl & Tibballs (2013), Australia	Mixed methods design to evaluate the psychosocial status of mothers and fathers of infants with hypoplastic left heart syndrome (HLHS)	29 parents of alive children with HLHS. 16 mothers and 13 fathers.	75%	All parents of surviving children with HLHS exhibited clinical levels of traumatic stress, the PICU environment alienates parents from their infants and interferes with parent-infant bonding.
Levin et al. (2015), United States	Prospective, crosssectional approach to identify areas for improvement in family-centered rounds from both family and provider perspective	232 rounds observed. 61 mothers, 25 fathers, 6 others surveyed.	75%	Families and providers agreed that rounds keep the family informed. Families offered advice that providers could improve upon rounds by being more considerate and courteous.
McPherson et al. (2011), Canada	Mixed methods design to develop a detailed understanding of the physical, professional and interpersonal contexts of a PICU in order to develop a feasible, relevant and sustainable approach to parental inclusion on rounds	Survey: 32 parents of 32 children. Interview: 3 parents.	50%	Parents indicated a strong desire to participate in pediatric intensive care unit rounds.
October et al. (2014), United States	Mixed methods design to identify factors important to parents making decisions for their critically ill child. Good parent framework.	43 parents of 29 children for whom a family conference was being convened. 25 mothers	75%	Most common components of being a good parent described by parents included focusing on their child’s quality of life, advocating for their child with the medical team, and putting their child’s needs above their own.
Qualitative Designs				
Abib El Halal et al. (2013), Brazil	Descriptive design to explore parents’ perspectives of the quality of the care offered to them and their terminally ill child in the child’s last days of life	15 parents of 9 children who had died in 2 PICUs.	75%	Quality of communication was low. Parental participation in decision-making was low. Families reported uncompassionate attitudes from medical staff.
Ames et al. (2011), Canada	Descriptive interpretive design to explore parents’ perception of the parental role	7 parents of 7 children admitted to the PICU and being prepared for discharge. 2 fathers and 5 mothers.	75%	Three main themes emerged: (1) being present and participating in the child’s care; (2) forming a partnership of trust with the PICU health care team; and (3) being informed of the child’s progress and treatment plan as the person who “knows” the child best.
Baird et al. (2015), United States	Grounded theory approach to identify best practices in	7 parents of children admitted to a PICU with complex	100%	The existence of explicit and implicit rules in a PICU

Author, year, country	Approach/Aim	Sample Characteristics	Quality Score	Results
Mixed Methods Designs				
	parent/nurse interactions in the PICU for the parents of children with complex chronic conditions. Symbolic interactionism framework	chronic conditions. 5 mothers and 2 fathers.		were identified, all of which negatively affected the family's ability to receive care that was attentive to their needs.
Carnevale et al. (2007), France and Quebec, Canada	Grounded theory approach to examine whether physicians or parents assume responsibility for treatment decisions for critically ill children and how this relates to subsequent parental experience	19 mothers, 12 fathers of children in the PICU.	75%	In France, physicians were predominantly the decision makers, in Quebec, parents were the most common decision maker.
Carnevale et al. (2011), Italy	To report on how life-sustaining treatment decisions are made for critically ill children in Italy, and how these decisional processes are experienced by physicians, nurses, and parents. Cultural interpretive framework	9 parents of children who had a life-sustaining decision made in the PICU. 7 mothers, 2 fathers.	75%	Uncovered "private worlds" of parents in the PICU. Parents struggle with their dependence on physicians and nurses to provide care for their child and strive to understand what is happening to their child.
Colville et al. (2009), United Kingdom	Qualitative portion of a larger mixed methods study reporting on the psychological distress in parents 8 months after child's discharge from PICU	50 parents of 34 children. (17 mother father pairs, 15 mothers, 1 father)	75%	Parents report significant and persisting distress after having a child previously admitted to the PICU.
DeLemos et al. (2010), United States	Qualitative portion of a larger mixed methods study to explore the role of communication in building trust between intensivists and parents	122 parents of 96 children admitted for at least 48 hours in a PICU. 87 mothers and 34 fathers.	75%	Parents articulated that communication was integral to building trust. Parents wanted communication that was honest, inclusive, compassionate, clear and comprehensive, and coordinated.
De Weerd et al. (2015), Netherlands	Longitudinal approach to describe the perceptions of parents, doctors, and nurses of suffering of critically ill children	29 parents of 29 children admitted to a PICU	75%	Parents considered suffering caused by or associated with visible signs as discomfort. Various aspects of the child's suffering and admission to a PICU caused suffering in parents.
Author, year, country	**Approach/Aim**	**Sample Characteristics**	**Quality Score**	**Results**
Gaudreault & Carnevale (2012), Canada	Grounded theory approach to examine the experiences of parents encountering the critical deterioration and resuscitative care of another child in the PICU where their own child was admitted	10 parents of critically ill children who witnessed the resuscitation of another child. 4 fathers, 6 mothers.	75%	Despite using coping strategies, the experiences were distressing in the majority of cases, although sometimes comforting. Witnessing critical events had divergent effects on parental trust with healthcare professionals.
Graham et al. (2009), United States	Exploratory approach to describe the experience of PICU hospitalization from the perspective of parents of children with severe, antecedent disability	8 parents of 8 children admitted to a PICU with severe antecedent disabilities. 7 mothers, 1 father.	100%	Major themes emerged including: know my child's baseline, integrate and bridge multiple services, disconnect between role of parent at home vs. parent in the PICU, high-stakes learning environment, PICU admission does not equate

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Mixed Methods Designs				
				with respite, heterogeneity within group, and lack of fit within the acute care model.
Latour et al. (2011a), Nethlerlands	Retrospective approach to explore and to identify accounts of the parents' experiences of a PICU admission of their child	39 mothers, 25 fathers of 41 children discharged from PICUs.	75%	Six major themes emerged including: attitude of the professionals, coordination of care, emotional intensity, information management, environmental factors, and parent participation.
McGraw et al. (2012), United States	Retrospective approach to examine how parents of children dying in the pediatric intensive care unit understood their role and discuss implications for care and policy	Parents of 18 children who died in a PICU.	75%	Many of the factors deemed important by parents related to their capacity fo be a "good parent" to their child throughout their stay in the PICU.
Macdonald et al. (2012), Canada	Ethnographic approach to examine the experience of families whose children were hospitalized in a PICU	18 children. 17 mothers, 11 fathers of children hospitalized in a PICU	75%	Thre was a disconnect between the espoused model of FCC and quotidian professional practices.
Majdalani et al. (2014), Lebanon	Phenomenological approach to understand the lived experience of Lebanese parents of children admitted to the PICU in Beirut	10 parents of children admitted to a PICU for at least 48 hours, 5 mothers, 5 fathers.	100%	All parents described their experience in the PICU as strange, new and mysterious. They described their experience as a "journey into the unknown".
Mattsson et al. (2014), Sweden	Phenomenological approach to investigate the meaning of caring in the PICU from the perspective of parents. Guided by the caring theory	7 mothers, 4 fathers of 7 children admitted to PICUs.	100%	The phenomenon of caring is experienced exclusively when it is directed toward the child. The following aspects of caring were illustrated in the themes arising from the findings: being a bridge to the child on the edge, building a sheltered atmosphere, meeting the child's needs, and adapting the environment for family life.
Maxton (2008), Australia	Phenomenological approach to provide understanding of the meaning for parents who were present or absent during a resuscitation attempt on their child in the PICU	Parents of 8 children who experienced a resuscitation event in the PICU. Eight interviews, 2 with only one parent, 6 with both parents.	75%	There is an inherent need for parents to choose to be present during resuscitation to make sense of the situation. Those who did not witness their child's resuscitation were more distressed than those who did.
Meert et al. (2007), United States	Retrospective approach to investigate parents' perspectives on the desirability, content, and conditions of a physician-parent conference after their child's death in the PICU	56 parents of 48 children who had died in a PICU. 37 mothers, 17 fathers, 2 other.	75%	Many parents want to meet with the intensive care physician after their child's death. Parents seek to gain information and emotional support, and to give feedback about their PICU experience.
Meert et al. (2008), United States	To explore parents' environmental needs during their child's hospitalization and death in the PICU	33 parents of 26 children who died in a PICU. 20 mother, 12 father, 1 other.	75%	The PICU environment affects parents at the time of their child's death and produces memories that are vivid and long lasting.
Meert et al. (2008), United States	Secondary analysis approach to describe parents' perceptions of their conversations with	56 parents of 48 children who died in a PICU. 37 mothers, 17 fathers, 2 other.	75%	When discussing bad news, parents want physicians to be accessible and to provide honest and complete

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Mixed Methods Designs				
	physicians regarding their child's terminal illness and death in the PICU			information with a caring affect, using lay language, and at a pace in accordance with their ability to comprehend.
Meert et al. (2009), United States	To gain a deeper understanding of parents' needs around the time of their child's death in the PICU	Interview: 33 parents of 26 children who died in a PICU. 20 mother, 12 father, 1 other. Focus Group: 13 parents of 10 children who died in a PICU.	75%	Four overarching categories of parental need emerged: who I am, while my child was dying, my child's death context, and my bereavement journey.
Meyer et al. (2006), United States	Retrospective approach to identify and describe the priorities and recommendations for end-of-life care and communication from the parents' perspective	56 parents of children who died in a PICU after withdrawal of life support. 36 mothers, 20 fathers.	75%	Parents identified six priorities for end of life care including honest and complete information, ready access to staff, communication and care coordination, emotional expression and support by staff, preservation of the integrity of the parent-child relationship, and faith.
Michelson et al. (2011), United States	Retrospective approach to examine clinicians' and parents' reflections on pediatric intensive care unit family conferences in the context of discussion about end of life decisionmaking	18 parents of 13 children who died in a PICU. 11 mothers, 7 fathers.	75%	Limited data from parents limited the ability to comment on parent perceptions of family conferences.
Author, year, country	**Approach/Aim**	**Sample Characteristics**	**Quality Score**	**Results**
Oxley (2015), United Kingdom	Phenomenological approach to explore the lived experiences of parents whose children have been admitted to a PICU	5 mothers, one couple of children hospitalized in a PICU.	50%	The lived experience of a parent with a child in the PICU is fraught with varying emotions with the beginning of the journey and the ending of the PICU admission causing the most anxiety.
Rennick et al. (2011), Canada	To describe how mothers experienced involvement in their children's care through a Touch and Talk intervention	65 mothers of children undergoing an invasive procedure in the PICU.	75%	The overarching theme centred on the importance of comforting the critically ill child, this included being there for the child, making a difference in the child's pain experience, and feeling comfortable and confident
Smith da Nobrega Morais & Geraldo da Costa (2009), Brazil	To understand the existential experience of mothers of chidlren hospitalized in a PICU. Framed by the humanistic nursing theory	5 mothers of children admitted to a PICU.	75%	The relationship between mothers and the nursing professionals throughout the PICU stay was important. Mothers reported experiencing fear, despair, and loneliness in the face of the child's PICU stay.
Stickney et al. (2014a), United States	To compare perceptions, goals, and expectations of health care providers and parents regarding parental participation in morning rounds and target specific areas of opportunity for educational interventions	13 mothers, 6 fathers, 2 other of children admitted to a PICU.	75%	Parents believed goals for rounds included helping parents achieve an understanding of the child's current status and plan of care. Parents reported a strong desire to provide expert advice about their children and expected transparency from the care team.

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Mixed Methods Designs				
Vasli et al. (2015), Iran	Ethnographic approach to define culture of FCC in PICU of one of the Iranian hospitals and to detect its related cultural and baseline factors	4 parents of children admitted to a PICU.	100%	The prevailing atmosphere in care was paternalistic as there was a huge gap between conceptually or theoretically accepted application of FCC in PICU and what is practically administrated.
Quantitative Designs				
Abuqamar et al. (2016), Jordan	Cross-sectional descriptive design to identify parental perceptions on pediatric intensive care-related satisfaction within three domains: child's care, environment and parent-staff communication	123 parents of children admitted to a PICU with chronic underlying conditions. 45 fathers, 78 mothers.	100%	Availability of health care professionals, the support and the information they share with the child's parents are all significant to parent's satisfaction and hence to better quality of care.
Aronson et al. (2009), United States	Prospective observational design to determine the impact of family presence during PICU rounds on family satisfaction, resident teaching, and length of rounds	100 family members. 67 mothers, 26 fathers, 7 other.	75%	On the first day of admission, family members were less likely to understand the plan, to feel comfortable asking questions, or to want bad news during rounds. They were more likely to have privacy concerns and to want one individual to convey the plan after rounds. Family satisfaction with being present for rounds was high, family members liked being present (98%) and thought (97%) it was helpful to hear the entire presentation and discussion of their child's case.
Drago et al. (2013), United States	Observational approach to explore whether family characteristics or opinions affected their likelihood of being present on rounds or the family's perception of rounds	100 family members of children in a PICU, 67 mothers, 26 fathers, 7 other.	75%	Families felt that participating in family centered rounds improved the care of the child.
Ebrahim et al. (2013), Canada	Prospective longitudinal approach to describe parent satisfaction, involvement, and presence after admission to PICU	103 parents of 91 children previously admitted to a PICU.	100%	Parent satisfaction was high, however satisfaction was lower in parents of children receiving more ICU therapies.
Jee et al. (2012), United Kingdom	Prospective cohort approach to evaluate and compare the needs, stressors, and coping strategies of mothers and fathers in a PICU	91 sets of parents of children admitted to a PICU. 91 mothers and 91 fathers.	100%	Parents identified the need for honest, open, timely, and understandable information, with access to their child as paramount. Feelings of uncertainty and helplessness were particularly stressful.
Ladak et al. (2013), Pakistan	Non-randomized before-after design to assess whether family-centered rounds improve parents' and health care professionals' satisfaction, decrease patient length of stay, and improve time utilization when compared to traditional practice rounds in a population with a low literacy rate,	82 parents of children who were hospitalized for at least 48 hours in a PICU. 41 from traditional rounds (24 fathers, 17 mothers), 41 from FCC rounds (25 fathers, 16 mothers).	100%	Parents were satisfied with both forms of rounds, however, they appeared to have a greater preference for family-centered rounds. FCC rounds were a resource for parents.

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Mixed Methods Designs				
	socioeconomic status, and different cultural values and beliefs			
Latour et al. (2011b), Nethlerlands	To explore similarities and differences in perceptions on pediatric intensive care practices between parents and staff	559 parents of children admitted to a PICU	50%	Compared with parents' perceptions, nurses and physicians undervalued a substantial number of PICU items. Parents rated items related to information provision as important.
Author, year, country	**Approach/Aim**	**Sample Characteristics**	**Quality Score**	**Results**
Madrigal et al. (2016), United States	Prospective cohort approach to assess sources of support and guidance on which parents rely when making difficult decisions in the PICU	86 parents of 75 children hospitalized in a PICU for greater than 72 hours. 60 mothers, 26 fathers.	75%	Most parents chose physicians, nurses, friends, and extended family as their main sources of support and guidance when making a difficult decision.
Madrigal et al. (2012), United States	To assess parental decision-making preferences in the high-stress environment of the PICU	Parents of 75 children admitted to a PICU for more than 72 hours. 66 mother responses, 29 father responses.	75%	The majority of parents preferred shared decision making (40%) with their doctors or making the final decision/mostly making the final decisions on their own (41%).
Mortensen et al. (2015), Denmark	Cross-sectional approach to investigate the association between parents' experience of nursing care and levels of traumatisation, to identify potential gender differences within this group, and to examine the possible relationships among the severity of a child's illness, the parents' fear of losing their child, and the parents' experience of support and devlopment of acute stress disorder symptoms	Parents of 47 children admitted to a PICU. 47 mothers, 44 fathers.	75%	One third of parents had ASD or subclinical ASD. Mothers with very young children had higher levels of acute stress. Fathers exhibited higher stress when their children had higher illness severity scores.
Needle et al. (2009), United States	Exploratory approach to examine the impact of parental anxiety on comprehension of medical information within 24 hours of a child's admission to the PICU	Parents of 35 children admitted to a PICU with high Pediatric Risk of Mortality scores. 27 mothers, 8 fathers.	100%	62% had state anxiety that was significantly higher than a validated sample of patients with GAD. Mechanical ventilation was a significant predictor of high parental state anxiety.
Phipps et al. (2007), United States	Prospective, blinded, observational approach to evaluate parental presence during bedside medical rounds in a PICU	48 mothers, 29 fathers, 3 grandparent, 1 other of children hospitalized in a PICU.	100%	Parents reported satisfaction with participation in rounds, they do not perceive violations to privacy.
Roets et al. (2012), South Africa	To describe emotional support given to mothers of children in ICUs and make recommendations to nurse managers regarding family-centred nursing care in PICU's in South Africa	62 mothers of children admitted to a PICU.	100%	15 stressors were identified by mothers.
Smith et al. (2007), United States	To identify the impact of providing parent bed space in the PICU, allowing for continual parental presence, on stress of parents of critically ill children	138 mothers, 34 fathers, 5 other of children in PICUs that had undergone renovations.	100%	Stress scores were significantly lower for parents who utilized the parent bed spaces in the new PICUs.

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Mixed Methods Designs				
Stickney et al. (2014b), United States	Cross-sectional survey approach to compare the experiences and attitudes of healthcare providers and parents regarding parental participation on morning rounds	70 mother, 28 father, 2 other of children admitted to a PICU	75%	A majority of parents wished to participate in rounds, parents indicated they understood the format and content of rounds.
Sturdivant & Warren (2009), United States	Exploratory descriptive approach to identify and explore the perceived met or unmet needs of family members who had children hospitalized in the PICU. Framed by crisis and human needs theories.	13 mothers, 3 grandmothers, 2 aunts, 1 father, 1 other of childen with a chronic physical condition requiring frequent hospitalizations in a PICU	50%	The overall items under the subscale assurance ranked the highest as perceived needs always met/usually met. The overall items under the subscale support ranked the lowest as perceived needs never met/sometimes met.
Tinsley et al. (2008), United States	Retrospective approach to determine parents' perception of the effects of their presence during the resuscitation efforts of their child and whether they would recommend the experience to other families	30 mothers, 9 fathers, 2 grandmothers of children who underwent resuscitation and died in a PICU at least 6 months prior.	50%	The majority of parents recommend being present during CPR and believe all families should be given the option to be present.