

HOW FAMILY-CENTERED CARE AND BEING A GOOD PARENT IMPACTS PARENT
EXPERIENCES IN THE PEDIATRIC INTENSIVE CARE UNIT

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ABSTRACT

Carrie A. Hill: How Family-Centered Care and Being a Good Parent Impacts Parent Experiences in the Pediatric Intensive Care Unit
(Under the direction of Sheila J. Santacroce)

Being a parent to a critically ill child requiring care in the pediatric intensive care unit (PICU) can be a stressful experience for parents. Family-centered care (FCC) has been shown to improve outcomes for pediatric patients and families, however there has been little research examining FCC in the PICU from the parent perspective. This dissertation consists of three distinct studies that examined the delivery of family-centered care and the parenting of a critically ill child in the PICU.

The first study synthesized the research literature regarding FCC in the PICU from the parent perspective based on the Institute for Patient and Family Centered Care (IPFCC) identified core concepts (e.g., respect and dignity, information sharing, participation, and collaboration). This literature synthesis revealed that parents described both met and unmet needs regarding the implementation of FCC and led to development of a conceptual model of FCC in the PICU that included respect and dignity, information sharing, and participation as interacting with one another within the physical and cultural environment of the PICU.

Based on the findings of the first study, the second study aimed to further develop the PICU FCC conceptual model and examined parental perspectives of the impact of the physical and cultural environment of the PICU in the delivery of FCC. The physical and cultural environment was found to exert both positive and negative contextual influence in the delivery of FCC per parent report.

The third study examined and expanded on parental perception of the good parent construct as applied to parenting a child in the PICU over the first year of life. Previously identified good parent themes including being an advocate, focusing on my child's quality of life, and being there for my child were present in parent interviews. Newly identified themes included knowing my child, developing

relationships with other PICU infants and families, and developing a trusting relationship with members of the health care team.

The findings of this dissertation add information to the PICU FCC body of literature by examining the delivery of FCC in the PICU from the parental perspective, acknowledging how the physical and cultural environments of the PICU impact parents of critically ill children, and informing how the good parent construct in the PICU evolves over time. Future studies are needed to explore facilitators and barriers to implementation of FCC in the PICU as conceptualized by the IPFCC and other professional organizations

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LIST OF ABBREVIATIONS

ACCH	Association for the Care of Children's Health
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CPR	Cardiopulmonary Resuscitation
DNR	Do Not Resuscitate
DOL	Day of Life
EMBASE	Excerpta Medica Database
GI	Gastrointestinal
GT	Gastrostomy Tube
FCC	Family-Centered Care
IPFCC	Institute for Patient- and Family-Centered Care
IRB	Institutional Review Board
MESH	Medical Subject Heading
MMAT	Mixed Methods Appraisal Tool
NGT	Nasogastric Tube
NICU	Neonatal Intensive Care Unit
PICU	Pediatric Intensive Care Unit

CHAPTER 1. FAMILY-CENTERED CARE

Background

Family-centered care (FCC) is an approach to planning, delivering, and evaluating health care through mutually beneficial partnerships among patients, families, and health care professionals. This approach to care encompasses the core values of respect and dignity, information sharing, participation in care and decision-making, and collaboration (Institute for Patient and Family-Centered Care, 2015).

Because infants and young children are unable to self-report their symptoms and care preferences due to their developmental stage or illness state, parents play critical roles in not only understanding the child's needs and goals for care, but also communicating these needs to nurses and other health care professionals. Thus, understanding how parents experience FCC while their child is hospitalized is fundamental to ensuring that its core values are achieved in practice.

With respect to the nursing care of infants and children, FCC is a relatively new approach. As recently as the mid-20th century, nurses tended to children in sterile open wards with no or minimal visitation allowed from family (Johnson, 1990; Jolley, 2007; Jolley & Shields, 2009). Children with chronic health conditions such as polio and tuberculosis were almost always institutionalized, leaving parents with little say or participation in their child's care or opportunity for visitation (Johnson, 1990; Jolley & Shields, 2009). In the 1980's, organizations like the Association for the Care of Children's Health (ACCH) developed programs and information materials in an effort to raise awareness of the value of FCC for the care of children with special health care needs. What many consider to be the first formal definition of family-centered care appeared in "Family-Centered Care for Children with Special Health Care Needs" (Shelton, Jeppson, & Johnson, 1987). In this publication, the authors defined eight dimensions of FCC and how each could be implemented in the health care setting. They described the FCC movement as being in its "infancy" (p. 54), and provided research that supported the need for FCC

for children with special health care needs. Additionally, they provided checklists for providers, parents, researchers, and hospitals, each aimed to promote and advance the delivery of FCC (Shelton et al., 1987).

In recent years, several major professional associations have released statements stressing the importance of adopting FCC as an approach to pediatric care (e.g., Institute of Medicine, 2001; American Academy of Pediatrics, 2003, 2012; American Nurses Association, 2003). As a result, pediatric care has shifted toward a more family-centered approach, with notably increased family presence at the bedside of the hospitalized child patient. The introduction of FCC in pediatric settings, particularly those settings providing intensive care to infants and children, has changed the way nurses interact with families and care for hospitalized children. The very nature of intensive care: fast paced, technology driven, and laden with uncertainty brings unique challenges and opportunities to the nurses providing care around the clock at the bedside (Foglia & Milonovich, 2011). A discussion of the intensive care environments that care for infants and children is presented next.

Evolution of the Intensive Care of Infants and Children

Caring for critically ill infants and children can be considered a specialty within a specialty (Foglia & Milonovich, 2011). Not only do these nurses need the education and training to perform in a critical care environment, they must also give consideration to the unique care that is required of infants and children. Hospital care of critically ill infants and children is generally provided in either the neonatal intensive care unit or the pediatric intensive care unit.

Neonatal intensive care unit (NICU). The neonatal intensive care unit cares for ill and/or premature newborn infants. In the United States, the first NICU's were established in the 1960's, however precursors to the modern NICU can be seen as early as 1903 when premature infants in glass incubators were placed on exhibit on the Coney Island boardwalk (PBS News Hour, 2018). Infants cared for in a NICU range from those who are born so prematurely that they need continuous invasive life support for survival, to those who are born full-term and are recovering from some type of birth trauma or subsequent secondary event. Modern NICU's have transitioned from an environment focused solely on the medical management of premature and critically ill infants to a place that should also recognize the

particular needs of the infant patient and their family (White, 2011). With both physical and psychological outcomes of the infant and family being linked to their treatment in the NICU, there is now an expected focus on providing a developmentally appropriate, nurturing environment for the infant and family (White, 2011).

Parents of infants admitted to a NICU may face uncertainty and unfamiliar surroundings. They often see their newborn for the first time behind the barrier of an incubator and must navigate the challenges of their parenting role in the foreign environment of the NICU. Research has shown that parents report feelings of stress, strain, separation, depression, despair and a lack of control (Obeidat, Bond, & Callister, 2009) after their infant is admitted to the NICU. These parents transition to feeling safer, more confident and connected to their infant, and being more active in care when nursing practices involved the parents in the care of their infant through decision making, daily care, and allowing them to touch, hold, or speak to their child routinely (Obeidat et al., 2009). Nurses in the NICU have a distinct responsibility and opportunity to guide parents as they assume this alternative form of the parenting role, that of a parent to a critically ill infant. NICU nurses must balance care for the medically-fragile newborn as well as the new parent; an understanding of the needs of new parents navigating the NICU care is important (Cleveland, 2008). In a review of NICU parent involvement, Cleveland (2008) identified practices such as parent empowerment and guided participation of care skills as being supportive behaviors that NICU nurses performed to assist in meeting needs of new parents. As an indication of the importance of FCC in the NICU, Van Riper (2001) found that the perceived delivery of FCC positively impacted mothers' satisfaction and psychological well-being in the NICU. In another study, NICU nurses were able to identify important aspects of FCC and indicated that parents should be actively involved in all aspects of their newborn's care (Higman & Shaw, 2008).

Pediatric intensive care unit (PICU). In the United States, the first PICU's were opened in Washington DC and Philadelphia, also in the mid 1960's (Epstein & Brill, 2005; Foglia & Milonovich, 2011). A typical PICU today will care for children with a range of life-threatening conditions including sepsis, respiratory distress, physical and/or emotional trauma, and congenital anomalies. Similar to the

NICU, the PICU environment requires that nurses possess expertise to manage the advanced technology required to sustain life in a critically ill child. While managing high patient acuity, the PICU nurse must also provide care and guidance for the parents and/or family members at the bedside. Distinctly different from the NICU, children in the PICU can range in age from neonate to young adult; nurses in the PICU do not routinely care for infant patients immediately after birth- these patients are most often treated in the NICU if they have yet to be discharged home. Because of this, PICU nurses infrequently encounter new parents who are in the midst of assuming their parenting role. Commonly parents of a child in the PICU have assumed their parenting role and have previously cared for/parented their child in a home environment, but there are some situations wherein a neonate may be discharged to home and then soon after develop symptoms that require surgery; these neonates would be cared for in the PICU.

Nurse and Parent Perspectives: Factors that Influence Family-Centered Care

Factors critical to the appropriate implementation of FCC include awareness of nurse and parent perspectives regarding FCC and its implementation. Referring to the adoption of FCC in the pediatric setting, Shelton, Jeppson, and Johnson stated “as with other ‘revolutions’, this one demands a great deal of the participants. Neither parents nor professionals are fully prepared for the new roles they must play in developing programs that are truly family-centered” (1987, p. 7). A discussion of both the nurse and parent perspectives on FCC, specifically in the PICU, is presented next.

Nurse perspectives. Incorporating the core values of FCC in the PICU can be particularly challenging given their historically strict and inflexible attitude toward family visitation, family participation in decision-making and family involvement in direct care. Nurses who work in the PICU have been notably slow to adopt FCC (Baird, Davies, Hinds, Baggott, & Rehm, 2015; Frazier, Frazier, & Warren, 2010; Kuo et al., 2012). The literature investigating FCC in the PICU from the perspectives of nurses, while scant, indicates that some nurses are resistant to practices consistent with FCC (Baird et al., 2015; Frazier et al., 2010; Maxton, 1997). Expressed nurse perspectives include negative feelings, beliefs and behaviors such as: parents getting in the way, nurses preferring to practice without interruption by parents, nurses avoiding contact with the family, and nurse perceptions of judgment by watchful parents

(Baird, et al., 2015; Maxton, 1997; Soderstrom, Benzein, & Saveman, 2003). Maxton (1997) reported nurses not wanting parents to be present at bedside at all times, perceiving parents as interfering with patient care, and not wanting parents to actively participate in care. Nurses also reported that they avoided contact with families that were deemed difficult or demanding by themselves or other staff members (Baird, et al., 2015; Soderstrom, et al., 2003). The lack of knowledge and unfavorable attitudes displayed by nurses is counter to the core values of FCC and helps explain the slow implementation of FCC by nurses in some PICU environments. Since nurses are the ones who interact with the family the most, if they do not embody those values in their practices, the environment may be seen as contrary to FCC by the family.

Parent perspectives. Of the studies that have addressed parental perspectives on involvement in care while in the PICU, the most often reported concern expressed by parents relates to parental role strain (Board & Ryan-Wenger, 2002; Frazier et al., 2010; Hall, 2005; Kirschbaum, 1990; Macdonald et al., 2012; Smith, Hefley, & Anand, 2007). Parental role strain can include the stress or strain experienced by parents when they are unable to perform normative behaviors or actions associated with the parenting role in western culture (Miles & Carter, 1982). During a child's hospitalization, these normative behaviors can include comforting, feeding, bathing, and protecting the child. Parents of hospitalized children have reported not feeling like a parent to their child, but merely a visitor (Aldridge, 2005; Ames, Rennick, & Baillargeon, 2011; Board & Ryan-Wenger, 2002; Frazier et al., 2010; Hall, 2005; Kirschbaum, 1990; Macdonald et al., 2012; Miles & Carter, 1982; Noyes, 1999; Smith, Hefley, & Anand, 2007; Tomlinson & Harbaugh, 2004; Uhl, Fisher, Docherty, & Brandon, 2013). Parents have reported perceiving the nurse as treating their child as the nurse's property and discouraging the parents from participating in the child's care (Macdonald et al., 2012; Maxton, 1997). Parents also reported perceiving that nurses treated the child's PICU room as their office and consistently asked the parents to leave the child's room when procedures were being performed (Macdonald et al., 2012). Furthermore, parents reported that they were hesitant to speak up and possibly upset nursing staff or become labeled as difficult or troublesome for fear this would result in poor nursing care for their child (Hall, 2005; McAllister &

Dionne, 2006; Moore & Beckwitt, 2003; Studdert et al., 2003). This idea of “retribution” for being a “difficult” parent is a recurring theme in the literature reporting parent perspectives, supported by the previously mentioned literature reporting nurse perspectives (Soderstrom et al., 2003). In a study by Hurst (2001), mothers said they were hesitant to push for partnership with nurses because their actions could be misconstrued by stressed nurses as interfering in care and thus adversely affect their child’s nursing care. Parents of children hospitalized with cancer also reported a hesitancy to upset nurses, indicating they believed their child will receive better care if the nurses liked the parents and the child (Moore & Beckwitt, 2003).

Despite these findings that suggest poor implementation of FCC practices as perceived by parents in the PICU, there is evidence of parents who reported satisfaction with and benefit from FCC implementation. Parents reported being thankful for participation in care of their critically ill child, one mother stated, “the nursing staff has been very good about letting me do the things that I am skilled to do” (Ames et al., 2011, p. 147). Additionally, parents felt empowered when staff looked to them to share their unique parental expertise on their child, thus informing the plan of care for the child (Ames et al., 2011).

Parent report of both positive and negative experiences with FCC implementation in the PICU provides evidence of the importance of developing a cultural environment that emphasizes understanding and sensitivity to the parents’ situation and need to be in their role while their child is hospitalized in the PICU. Often parents behave in a manner that is consistent with how they feel they can best love, or provide care for their child, which is the manifestation of what they believe a good parent would do.

Being a Good Parent to a Seriously Ill Child

Researchers have begun to explicate the construct of being a good parent to seriously ill children (Feudtner et al, 2015; Hinds et al, 2009; 2012; October, Fisher, Feudtner & Hinds, 2014). Based upon a content analysis of parent response to an interview question in her study about end-of-life care preferences of pediatric patients with cancer, Hinds et al (2009; 2012) found that parents of children with cancer at end of life indicated that when they parent their hospitalized child in a way that is congruent

with their personal views on being a good parent, they felt more able to make decisions on their child's behalf, and as a result, cope with and endure their child's dying and death. While these studies have explored parent perspectives on being a good parent of a child with cancer and in the PICU, more research is needed to advance our understanding of being a good parent in the PICU context, and in turn, the implications for delivery of FCC and how nurses might enhance FCC to better support parents. Specifically, no research has examined how parents' conceptions of being a good parent to a critically ill child evolve over time as they are faced with prolonged or repeated stays in the PICU. Additionally, we lack understanding of what being a good parent means to individuals in the midst of transitioning to the parental role when their infant must be hospitalized in a PICU immediately or soon after birth. When an infant requires intensive care soon after birth, a parent's ability to assume the parental role may be even more impaired because it was not allowed to develop fully prior to the hospitalization. Moreover, admission to the PICU interferes with normative parenting behaviors in the immediate postpartum period, which might affect the typical course of parental role attainment (Bialoskurski, Cox, & Hayes, 1999; Dodwell, 2010; Miles, Carter, Spicher, & Hassanein, 1984; Miles & Frauman, 1993; Odom & Chandler, 1990). Such is the case for parents of infants born with a complex congenital heart defect, the most common congenital defect in the United States today. Over 40,000 infants are born with a congenital heart defect each year, of which 4800 have defects so severe that the infant requires surgical intervention and prolonged intensive care shortly after birth to survive (March of Dimes, 2016).

As previously stated, infants requiring intensive care soon or immediately after birth are traditionally cared for in a NICU environment where nurses are familiar with the unique needs of new parents transitioning to their role of parenting a critically ill child. However, infants born with complex congenital heart defects needing surgical intervention are not routinely cared for in the NICU, but instead in a pediatric intensive care environment where nurses may not be as familiar in caring for new parents and especially those who are transitioning to the parental role. This situation creates a contextual misfit where the nurses caring for the newborn may not be entirely equipped to support the parents during this delicate transition to becoming a good parent. In providing FCC that encompasses respect and dignity,

sharing of information, and that fosters and encourages participation by parents to the level parents choose, nurses have the opportunity to support new parents in their efforts to be a good parent to their critically ill newborn while hospitalized in the PICU.

The FCC literature presented regarding nurse and parent perspectives on care practices illustrates a disconnect between the core values of FCC as envisioned by The Institute for Patient- and Family-Centered Care (IFPCC) and the enactment of those core values in the PICU environment. The disparity between nurse and parent expectations (Avis & Reardon, 2008; Coyne, 1995; Uhl et al., 2013) can create tension at the bedside, decrease satisfaction, and strain interactions of both parents and nurses (Hall, 2005; McAllister & Dionne, 2006; McGraw et al., 2012, Merk & Merk, 2013; Wills & Wills, 2009). Long after discharge, psychological distress has been shown to be elevated in parents whose children have been cared for in a PICU (Board & Ryan-Wenger, 2002; Colville et al., 2009; Ehrlich, Von Rosenstiel, Grootenhuis, Gerrits, & Bos, 2005). Knowledge of parent and nurse views on FCC in the PICU, specifically parent involvement in the care of their critically ill child will contribute to the development of interventions that will promote a shared understanding of FCC, a more productive working relationship between nurses and parents, and better parent and family outcomes. Unlike parents of a healthy newborn, parents of children requiring intensive care are challenged to understand and function in the foreign environment of the intensive care unit while negotiating involvement in their child's care with PICU clinicians, meaning they need to be given encouragement to parent their child, but also guidance on how to do that in this complex and foreign environment. Knowledge of parents' experiences with FCC and parenting in the context of the PICU is foundational to the development of interventions to facilitate FCC and maximize quality of life outcomes for the child and family by supporting parents in their pursuit to be a good parent to a child in the PICU.

Purpose Statement

The purpose of this dissertation is to describe parent views on FCC and their involvement in care for a critically ill child hospitalized in a pediatric intensive care unit. First, an assessment of the written research from the parent perspective was performed to systematically explore the evidence base for each

IPFCC acknowledged FCC core concept in the context of caring for children in the PICU (**Study 1**). A conceptual model of FCC in the PICU was proposed in this study. **Study 2** investigated the impact of the physical and cultural environment of the PICU and how it influenced parental perception of the delivery of FCC. Further development of the conceptual model produced in study 1 was also performed in study 2. Finally, building on the good parent construct, **Study 3** utilized a secondary analysis of an extant data set to further explore parent involvement in care from the perspective of parents of an infant with a complex congenital heart anomaly hospitalized in a PICU. Additionally, **Study 3** explored how parent perspectives on involvement in care and being a good parent changed over time. The long term goal of this program of research is the development and implementation of multi-level interventions to aid parents in communicating their values and beliefs to their child's health care team as a means to advance the child's care in ways consistent with FCC and the parent's views on being a good parent. The results of this program of research will inform clinician sensitivity to the importance of incorporating parents' perspectives into FCC, potentially bridging the gap between policies and reality, and in turn improving outcomes for parents of infants who are critically ill.

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CHAPTER 2. FAMILY-CENTERED CARE FROM THE PERSPECTIVE OF PARENTS OF CHILDREN CARED FOR IN A PEDIATRIC INTENSIVE CARE UNIT: AN INTEGRATIVE REVIEW

Overview

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.

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 (Institute for Patient and Family-Centered Care, 2017). 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 (Institute for Patient and Family-Centered Care, 2017).

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 & Knaf, 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

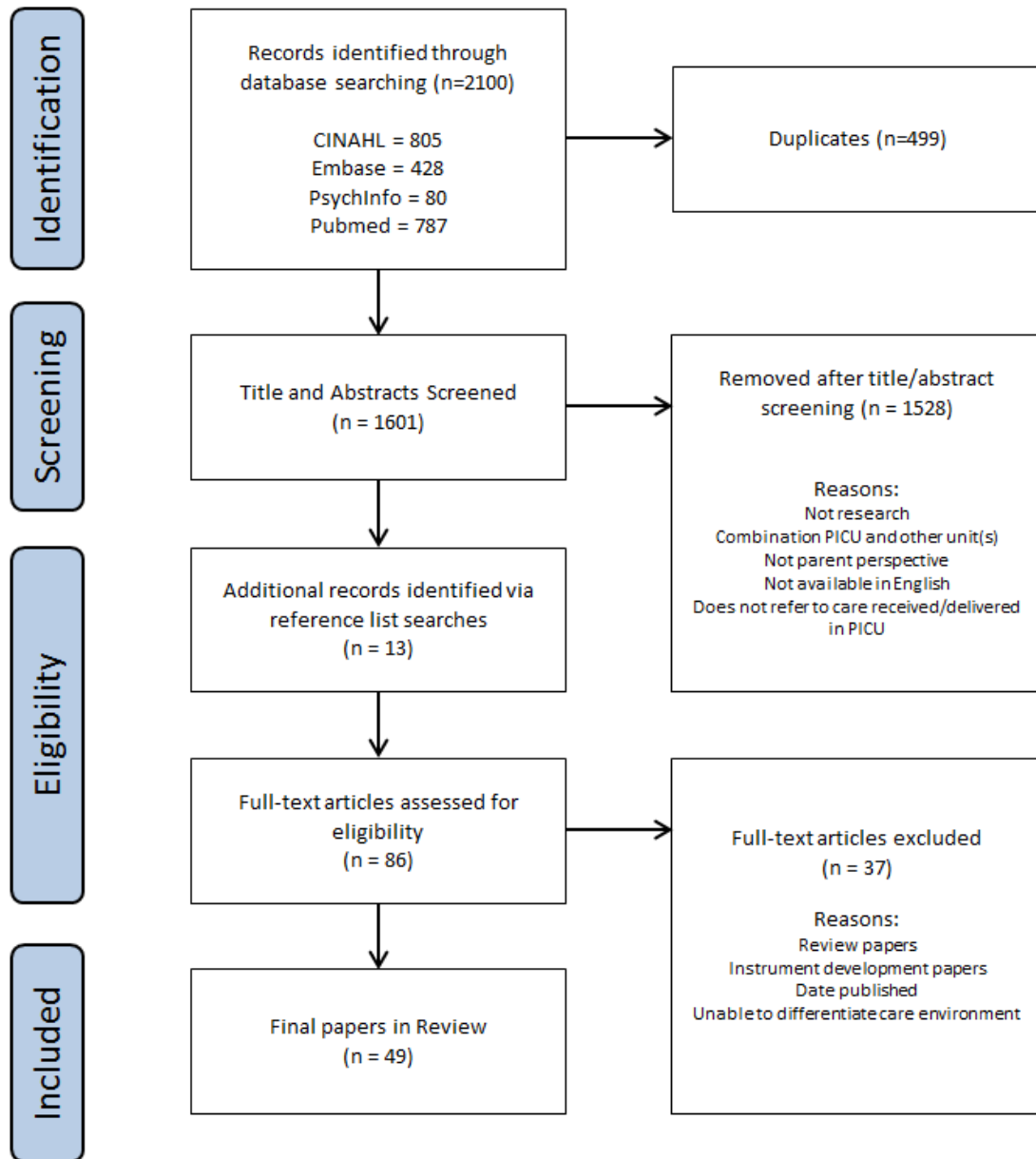
The searches were guided by the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA: Moher, 2009). Search strategies were developed by the first author (CH) in consultation with a research librarian. The databases searched between July and October 2016 included: Cumulative Index 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 first-hand 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.

Figure 2.1: PRISMA flow chart of search process



Quality Appraisal

The first author critically appraised the retained articles using the Mixed Methods Appraisal Tool (MMAT) (Pluye, Gagnon, Griffiths, & Johnson-Lafleur, 2009), 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 2.1.

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.

Table 2.1: Summary of articles included in the review

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, cross-sectional 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.

Author, year, country	Approach/Aim	Sample Characteristics	Quality Score	Results
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 parent/nurse interactions in the PICU for the parents of children with complex chronic conditions. Symbolic interactionism framework	7 parents of children admitted to a PICU with complex chronic conditions. 5 mothers and 2 fathers.	100%	The existence of explicit and implicit rules in a PICU were identified, all of which negatively affected the family's ability to receive care that was attentive to their needs.

Author, year, country	Approach/Aim	Sample Characteristics	Quality Score	Results
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.
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.

Author, year, country	Approach/Aim	Sample Characteristics	Quality Score	Results
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 roles of parent at home vs. parent in the PICU, high-stakes learning environment, PICU admission does not equate with respite, heterogeneity within group, and lack of fit within the acute care model.
Latour et al. (2011a), Netherlands	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 to 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%	There 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.

Author, year, country	Approach/Aim	Sample Characteristics	Quality Score	Results
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 physicians regarding their child's terminal illness and death in the PICU	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 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.

Author, year, country	Approach/Aim	Sample Characteristics	Quality Score	Results
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 decision making	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.
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 centered 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 about participating in care.
Smith da Nobrega Morais & Geraldo da Costa (2009), Brazil	To understand the existential experience of mothers of children 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.
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.

Author, year, country	Approach/Aim	Sample Characteristics	Quality Score	Results
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.

Author, year, country	Approach/Aim	Sample Characteristics	Quality Score	Results
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, socioeconomic status, and different cultural values and beliefs	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.
Latour et al. (2011b), Netherlands	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.
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%).

Author, year, country	Approach/Aim	Sample Characteristics	Quality Score	Results
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 development 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.

Author, year, country	Approach/Aim	Sample Characteristics	Quality Score	Results
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 children 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.

Results

Table 2.1 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” (Institute for Patient and Family-Centered Care, 2017). 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" (Institute for Patient and Family-Centered Care, 2017). 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, Kisson, 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” (Institute for Patient and Family-Centered Care, 2017). 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” (Institute for Patient and Family-Centered Care, 2017).

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.



Figure 2.2: Conceptualization of FCC in the PICU.

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.

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 (Institute for Patient and Family-Centered Care, 2017); 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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CHAPTER 3. PARENT PERCEPTIONS OF THE IMPACT OF THE PICU ENVIRONMENT ON DELIVERY OF FAMILY-CENTERED CARE

Overview

Objectives: To examine parent perception of how the physical and cultural environment of the pediatric intensive care unit impacted the implementation of family-centered care as outlined by the Institute for Patient and Family Centered Care and to further develop a previously described model of family-centered care in this environment.

Research Design: A qualitative descriptive design utilizing secondary analysis. Interview data from parents of infants hospitalized in the pediatric intensive care unit over the first year of life was analyzed via content analysis.

Findings: As previously reported in the literature, the family-centered care core concepts of information sharing, participation, respect and dignity and their respective subthemes were present in parent interviews. Parents indicated that the physical and cultural environment of the pediatric intensive care unit impacted how each of the core concepts was implemented by clinicians. The unit environment both positively and negatively impacted how parents experienced their child's hospitalization.

Conclusion: In the pediatric intensive care unit, family-centered care as operationalized as policy differed from actual parent experiences. The impact of the physical and cultural environment should be considered in the delivery of critical care, as the environment has been shown to impact implementation of each of the core concepts.

Introduction

Parents have described the pediatric intensive care unit (PICU) environment as a “wilderness of another world without any landmarks” (Hall, 2005, p.181). Contributing to this perception is that the work of sustaining lives of critically ill children requires the use of technology. Thus PICUs are often filled with constant noise from the multitude of alarms, monitors, and machinery. The PICU physical environment can be congested with life-saving equipment often minimizing the child patient in his or her hospital bed and leaving precious little free space at the bedside for parents or family members to participate. The PICU culture has traditionally been known to limit visitation by parents which further limits parental participation in their child’s care (Kuo et al., 2012). However, over the past few decades there has been a renewed effort to engage in family-centered care across pediatric units in the United States. With the push for pediatric care to be family-centered, the PICU culture is slowly shifting to include parents in every aspect of their child’s care and to encourage partnerships between parents and members of the health care team. Understanding the experience of parents of children in the PICU and their perception of family-centered care (FCC) will inform this ongoing work and potentially lead to more effective implementation strategies. The purpose of this study is to describe parent perceptions of FCC in the PICU, specifically how the PICU as a physical and cultural environment impacted parents of critically ill children.

Background

The Institute for Patient and Family-Centered Care (IPFCC) defines FCC as a partnership between families and health care professionals that contributes to better outcomes for patients and their family members, increased quality and safety, superior health care experiences, and enhanced satisfaction with care (Institute for Patient and Family-Centered Care, 2017). According to the IPFCC, FCC includes four concepts: respect and dignity, information sharing, participation in care and decision making, and collaboration between patients, families, and the healthcare team (Institute for Patient and Family-Centered Care, 2017). Multiple professional organizations have advocated for the delivery of pediatric

health care in a manner that is patient and family-centered (The Institute of Medicine, 2001; American Academy of Pediatrics, 2003, 2012; American Nurses Association, 2008, 2015).

In an integrative review focusing on parent perspectives on FCC, Hill, Knafl, & Santacroce (in press) examined the published research literature for evidence of the four core concepts as defined by the IPFCC. The literature provided evidence of both positive and negative parental perceptions on their experiences with care that included three of the core concepts of FCC (e.g., respect and dignity, information sharing, participation). However, the papers included in the review provided no evidence of collaboration, which was operationalized as collaboration between patients, families and the healthcare team at a programmatic and policy level. Another major finding of this integrative review was the extent to which the physical and cultural environment of the PICU impacted parents' perceptions of FCC. This important finding necessitated development of a conceptual model of FCC in the context of the PICU (Figure 3.1) that included the physical and cultural environments as influencing each of the three remaining core concepts observed in the parental report literature.



Figure 3.1: Conceptualization of FCC in the PICU.

The PICU is a physical and cultural environment in which the concepts of participation, respect and dignity, and information sharing overlap and interact in the delivery of FCC (taken from Hill, Knafl, & Santacroce, in press).

The importance of the physical environment (i.e., the makeup of the unit, patient room, and waiting room) in the enactment of respect and dignity, information sharing, and participation while in the

PICU is understandable. However, to understand the impact of the cultural environment, or the shared attitudes, values, goals, and behavioral practices of the PICU, one must understand how care has been delivered historically. In the past, hospitalized children were cared for exclusively by staff with little involvement in care or decision making by parents; parental visitation was also severely restricted (Johnson, 1990; Jolley, 2007; Jolley & Shields, 2009). As care of the hospitalized child changed in the late 20th and early 21st centuries, parents became more directly involved in care and decision making for hospitalized children. This necessitated family-centered partnerships with hospital staff, specifically nurses and physicians. While the care of children hospitalized in acute settings has made strides in the transition to a more family-centered model, PICUs have been slower to adopt this method of care delivery (Butler et al., 2013; Foglia & Milonovich, 2011). Generally speaking, the PICU cultural environment can be characterized as having limited family visitation and/or involvement in direct care and decision making (Baird et al., 2015; Frazier et al., 2010; Kuo et al., 2012). As a result of these constraints on the family, the PICU nurses were the child's primary and often only direct caregiver. Parents have reported feeling that their infant "belonged to the staff" (Cantwell-Bartl & Tibballs, 2013) and have perceived nurses as both facilitators (Ames et al., 2011; Latour et al., 2011a; Mattsson et al., 2014) and barriers (Ames et al., 2011; Carnevale et al., 2007; Macdonald et al., 2012) to parent participation in the child's care.

Parents are integral members of the partnership that is needed to ensure the successful delivery of FCC in pediatric critical care settings. As such, their perspective on how well FCC is being implemented is critical. The evidence has shown that parents have both positive and negative perceptions of the implementation of FCC in the PICU. While previous literature reviews have examined FCC in the pediatric acute and critical care environments (Foster et al., 2016; Foster et al., 2013; Kuhlthau et al., 2011), the review by Hill et al. (in press) was the first to focus solely on the parent perspective and resulted in a conceptual model of FCC in the PICU (Figure 1) that highlighted the fundamental role of the physical and cultural environment on the implementation of FCC. We conducted a secondary analysis of data from a longitudinal study of parent involvement in decision-making in an intensive care environment

to continue the development of the PICU FCC conceptual model by further elaborating the role of the physical and cultural environment.

Methods

This secondary analysis is based on interview data from a subsample of parents enrolled in a primary study that examined the trajectory of decision making for infants with complex life-threatening conditions (R01NR010548, P.I. Docherty). Institutional review board (IRB) approval was obtained from the first author's academic institution as well as from the IRB responsible for oversight of the primary study. An overview of the primary study is presented below.

Primary Study

The primary study (R01NR010548, P.I. Docherty) from which the data for this secondary analysis was obtained took place in a major academic children's hospital in the Southeastern United States. A longitudinal mixed-methods case-study design was used to examine the trajectory of parental decision making for infants with complex life-threatening conditions. Parent enrollment in the primary study was initiated at the birth of their infant (for infants whose condition was diagnosed prenatally) or within days of the diagnosis (for infants whose condition was diagnosed in the post-natal period). Subsequently, interview data, parent reported outcome data and infant clinical data were then collected at least monthly for one year for those infants who lived, and at least monthly until death and at 6 and 12 months following death for those infants who did not survive. In addition to monthly data collection, the investigators collected data when a major treatment event or decision occurred; there were multiple instances for which the monthly and event/decision data collections coincided and were combined to minimize parent burden.

Secondary Analysis

Design. In this secondary analysis, a qualitative descriptive design was used to continue development of the conceptual model of FCC in the PICU (Hill et al., in press) by examining parents' experience with the core concepts of FCC and how the physical and cultural environment of the PICU influenced those experiences.

Sample selection. The primary study sample consisted of infants diagnosed with three categories of conditions: complex congenital heart anomalies; extreme prematurity; metabolic conditions requiring stem cell transplantation. For the purposes of this study we used data from parents of infants with complex congenital heart anomalies cared for in a PICU environment (n=10 cases). The cases (defined as an index infant, the infant's mother and the infant's father) selected for this analysis were purposively sampled, with assistance from the primary study investigators, based upon the following criteria: (a) quantity and information richness contained in parent interview data; (b) informational variability based upon time of diagnosis (i.e., pre/post natal diagnosis); and (c) length of PICU stay. Our sampling goal was to achieve what Hennink et al. (2017) have called "meaning saturation", or the point at which themes or issues have been fully elaborated and "no further dimensions, nuances, or insights of issues can be found" (p. 594). The authors determined that saturation was achieved after completing the analysis of data from three cases (61 interviews, approximately 1500 pages of data). Each case contained an infant with a complex congenital heart anomaly and a married mother and father in their 30's. The first case infant was a female of minority race/ethnicity with a prenatal diagnosis who spent 151 days in the PICU. The second infant was a non-minority female with a post-natal diagnosis who spent 308 days in the PICU, while the third infant was a non-minority male with a pre-natal diagnosis who was hospitalized in the PICU for 25 days.

Data analysis. Data analysis entailed careful reading of the interview transcripts for each case and development of coding categories that were applied to the entire data set. A data management program was used to support data coding and analysis (Atlas. Ti, Scientific Software Development, Berlin, Germany). Using directed content analysis (Hsieh & Shannon, 2005) the first author coded the data using the FCC core concepts as defined by the IPFCC as the initial start list of codes. Following this initial round of coding, data related to each of the core concepts were reviewed to identify the nature of parents' experiences related to each of the core concepts. In this second cycle of coding, themes identified in the authors' integrative review (Hill et al., in press) were applied to the data related to each of the core concepts (Table 3.1). During this second round of coding, segments of data coded

participation in the first cycle coding were then further coded to reflect the nature or focus of parental participation using codes derived from the FCC themes identified in our prior review of the literature (Hill et al., in press). For example, a segment of data that was initially coded as *participation* was further sub coded to be *participation: parents as experts*, or *participation: impact of environment/staff*. A working codebook was developed that included definitions and text examples of all provisional and deductive FCC codes (Miles et al., 2014).

Trustworthiness. Given the first authors’ clinical experience in a PICU and impressions regarding the implementation of FCC in that setting, analytic memos were routinely composed throughout data analysis to track her assumptions and biases, and as a means to preserve analytic insights (Saldana, 2013). The working codebook was reviewed and refined during data analysis with input from the second author, an expert in qualitative research. In the interest of supporting trustworthiness and to evaluate the reliability of the coding, the second author (KK) performed code checks on 20% of the interview transcripts. The first and second authors met frequently to discuss the application of codes and to resolve discrepancies in coding, if any.

Table 3.1: Coding scheme

IPFCC Concept (First Cycle Codes)	FCC Conceptualization (from Hill et al., in press) (Second Cycle Codes)	Example
Respect and Dignity		
	Perceptions of the PICU Physical and Cultural Environment	“I was tired of the smell of the hospital”
	Expressions of Compassion and Informational, Physical, Cultural, and Emotional Support from Staff	“at that point the nurses and doctors really encouraged me to go home and take a break”
Information Sharing		
	Using Understandable Language	“He explained everything, he brought it down to a level that we understand that wasn’t over our head”
	Medical Rounds	“being on rounds and being able to articulate what you want to happen”
	Amount/Type of Communication	“you know by the third day I was like [sigh] “I cannot take

IPFCC Concept (First Cycle Codes)	FCC Conceptualization (from Hill et al., in press) (Second Cycle Codes)	Example
		another doctor” because it adds on to another layer of, right when you think you’ve heard everything... you get another layer dumped on you”
	Satisfaction with Communication	“Every nurse that we have had they have taken the time that when we first step into the room for them to completely explain where she <i>is</i> how she was like maybe the night <i>before</i> if they had to add any <i>medications</i> , and yeah they were all extremely informative”
Participation		
	Parents as Experts	“at that moment I realized that I always have to be on top of knowing this child really, really well, because at that moment I realized that I am the go-to person, I’m who they’re going to get information from”
	How Parents Participated	“I’ve had the opportunity to say ‘well this is my feeling about that’, and they do it”
	Impact of Environment/Staff on Participation	“I remember the third day when I came in and the nurses let me give her a bath”
	Medical Rounds	“being on rounds and being able to articulate what you want to happen”
Collaboration		No data present of collaboration on a programmatic and policy level as operationalized in Hill et al., in press.

Results

Our analysis revealed the previously discussed FCC core concepts of information sharing, participation, respect and dignity and their identified subthemes (Hill et al., in press) in the data from three cases. Based on parents’ report, we describe how each core concept and subtheme was manifested

in the PICU. We also examine how the parents perceived the physical and cultural environment of the PICU as influencing implementation of FCC, and parenting in the PICU.

Information Sharing

Parents of infants in the PICU valued regular, in-depth information exchanges with members of the health care team that explained options for treatment, provided details regarding their child's condition and care plan, and was conveyed using language that parents understood. The parents in each case indicated that after admission to the PICU and prior to any surgical procedures, the child's clinicians communicated information using images of the child's anatomy to thoroughly explain diagnoses and recommended procedures. Parents indicated that "he brought it down to a level that we understood and wasn't over our head" and that this type of information exchange "made it so black and white for me" and helped to allay parents' initial experience of being overwhelmed by the amount and complex nature of information received. Additionally, when preparing parents for procedures such as placement of tracheostomy and/or nasogastric feeding tubes, parents described how nurses used dolls and booklets to show how each tube would look and how to care for it. Parents described the dolls as a non-threatening approach that helped them become comfortable with the appearance and care of these medical devices. Parents discussed how they felt comfortable asking questions about their child's care and gained valuable information from the nurses who were a constant presence at the child's bedside. One mother stated, "The nurses... will give me information and they kind of explain things and I'm sitting there and they're doing things and we talk all day long".

Parent satisfaction with information sharing was diminished when they perceived clinicians as purposefully vague about their child's prognosis or treatment. In two of the three cases, the child's medical condition was complicated by multiple setbacks and did not follow the course initially anticipated by the clinicians. Both sets of parents indicated that when they asked physicians for more information, they were given "non-committal" answers to questions and vague date ranges for recovery or subsequent surgeries. Parents indicated decreased satisfaction with communication when this occurred and

subsequently pushed physicians for more concrete information about their child's condition and treatment plan.

Impact of the physical and cultural environment on information sharing. Each infant in this study had a complex congenital heart anomaly requiring life-saving intervention from multiple providers soon after birth. As the infants' conditions and treatment courses evolved, the number and type of clinicians involved increased. Although parents were satisfied with how individual clinicians communicated with them, each parent reported that miscommunication between clinicians created conflict and parental mistrust. One mother commented that she felt clinicians were "passing the buck" by suggesting that another clinician was responsible for critical decisions; she reported that no one was willing to take the lead and oversee her daughter's care. Further, one parent dyad likened information exchange among clinicians to a game of "telephone" where information transformed as it was reported across shifts and between clinicians.

As PICU stays lengthened and their child's condition evolved, parents experienced the team as no longer giving specific timelines for recovery and also as modifying and broadening treatment goals. Two parent dyads seemed frustrated by this; one of these fathers indicated that this vagueness was so the PICU team could "cover their asses" in case of a negative outcome. One mother described resigning herself to this approach to communication saying, "That's just how it works here" indicating her perception of the culture in the PICU. One father stated that vague goals and timelines benefitted his child by allowing her to progress at her own pace without pressure. All parents expressed that the frequent changes in the plan of care were both overwhelming and difficult to understand.

Participation

Parents wanted to actively participate in their child's care, and were initially involved in performing basic parenting tasks such as holding the infant, changing diapers and bathing. Over time, participation progressed to include more complex aspects of parenting such as participation in treatment decision making and care planning. Parents experienced this as being included as part of the team and their input was valued by clinicians; one mother stated, "My vote really counts". Parents of each of the

three infants reported they were comfortable participating in bedside medical rounds, which provided an opportunity to exchange information with the care team.

Over time, parents came to view themselves as experts on their child's behavior and care needs. Parents perceived that they were better able to identify their child's needs and wants than others. They also indicated that as the only constant presence in their child's care, they could readily distinguish subtle changes in the child's condition that might be overlooked by clinicians. One mother stated,

I know that a lot of times she'll follow a pattern and I can see it coming... I know her so well... I can watch the numbers fall on her, you know... I'll tell them like if they're not necessarily looking, I'll be like 'her blood pressure just dropped or heart rate, she's bradying, her heart rate is going to drop', I can see it coming and then they start doing stuff.

One of the mothers in the study who cared for her child at home in-between PICU admissions indicated that it was difficult to be back in the PICU and dependent on others to perform the tasks she had been performing at home. She initiated a conversation with the nurses to clarify expectations for her participation in her child's care and share her knowledge of what worked best while at home; she reported that the nurses incorporated her advice.

Impact of the physical and cultural environment on participation. The impact of the physical and cultural environment on parent participation was also evident in the data. All parents perceived the nurses as gatekeepers to participation in the basic aspects of their child's care. One mother stated, "It depends on the nurse working as to how involved I can be with daily cares", and another stated,

It would be really nice if the nurse decides you can play a part in your baby's care, 'cause if I would've known that day one I think it would've been a tremendous relief and I don't think I would've been as sad.

Two of the mothers expressed feelings of not being a mother to their children because of the abnormal circumstances in the immediate post-natal period and perceived barriers to participating in their child's care posed by the PICU staff and environment. In the first weeks of life, each infant was attached to multiple machines with varying numbers of tubes and lines snaking around the bedside; parents reported having to be taught how to safely perform basic parenting tasks made more difficult because of the equipment and tubes connected to their child. Parents commented that their participation was also

impacted by the nurse and respiratory therapist assigned to their child on a given shift. Parents had definite preferences regarding staff but little control over staff assignments. One mother indicated her stress level varied based on how “on top of things” she needed to be, based on which nurse and respiratory therapist were on duty.

Parents in this study reported participation in medical rounds, yet the specific nature of their participation was based on unit policy. Parents indicated that they were not “allowed” on morning rounds in which the entire interdisciplinary team was present, but could participate in afternoon rounds which involved only the medical team; they had not been given an explicit explanation for this distinction. Although parents reported modifying their visitation schedule to participate in afternoon rounds they nonetheless would have appreciated the option of participating in the rounds that best suited their schedules.

Parent participation was also impacted by unit policies when there were emergencies or cardiac arrests (codes) affecting children in the PICU. Parents indicated that they were “kicked out” of the unit during codes and often not permitted to return for many hours. One mother reported that she unintentionally witnessed emergencies and code events for other children. According to unit policy, she should have left during this time but was holding her child who was attached to an array of equipment and would have required the assistance of multiple nurses to return the child to bed. This mother reported that witnessing the code was “scary” because although the curtains were pulled during the emergency, “you could still hear everything”. Parents reported barriers to spending the night with their child, indicating there were no actual bed spaces for overnight visitation and limited room at the bedside for the reclining chairs that were provided.

Respect and Dignity

Parents noted how support from the health care team conveyed respect and dignity. Parents were positively affected by what they viewed as clinicians’ investment in their child’s care and survival; they identified instances when nurses showed genuine excitement or disappointment related to changes of their child’s illness trajectory; a mother commented that the nurses were her child’s “cheerleaders”. One

mother was moved when she was told that nurses had called or visited on their days off to check on her child after a surgery, and another mother was deeply moved when nurses came in from home to support her when her daughter died in the PICU. Parents frequently talked of the rapport with their nurses; the parents whose children experienced prolonged PICU stays developed relationships with staff that they described as feeling more like “friends than nurse and parent”. Likewise, a mother whose child spent minimal time in the PICU commented on her experience,

I will say everybody in the unit was almost um... so respectful to the primary parents, I mean just really... I mean they make you feel special as the parents and make you feel, I mean I really feel like they go out of their way to sort of bring you into the fold.

Parents also indicated that staff displayed respect for their spiritual needs by praying with them while their child was in the PICU.

On the other hand, parents also reported behavior that they experienced as not conveying respect and dignity. Parents of one child perceived that members of the health care team had “given up” on their child when the physicians mentioned withdrawal of intensive care as opposed to more treatment options; they indicated this was a source of distress and contributed to a sense of distrust and conflict with this physician.

Impact of the physical and cultural environment on respect and dignity. Parents had individual impressions of the physical and cultural environment of the PICU and how this impacted the way they were treated. Parents frequently referred to the “way things work” in the PICU. For example, parents discussed the hierarchy of power in the PICU (as they perceived it to be) and how this influenced who they believed could implement their requests. One mother stated, “The nurse practitioners I try and get to change things ‘cause they seem to kind of have more power”. Another mother believed that her understanding of what goes on in the PICU stemmed from being there when doctors “drop by” and listening to the nurses “talk to each other”.

Another environmental factor that parents perceived as impacting dignified and respectful care in the PICU was the lack of consistency in those providing care to their child. Parents commented on the frequency with which the nurses responsible for their child’s care had little, if any, experience caring for a

child in the PICU. This lack of consistent providers with PICU experience was especially disturbing to parents in one prolonged-stay family. For example, this mother stated,

Maybe people should just be able to stay in little homes where they know their people and stuff and place and...I know why floats have to happen, and stuff like that but just seems like...you're taking people out of their comfort zone putting them in a place where they're not quite sure and in those situations...it seems like it's a little more critical to have those people in place.

This parent dyad eventually requested that their child not be cared for by nurses who did not work in the PICU on a regular basis and that a consistent core group of nurses be assigned to their daughter.

As previously mentioned, one of the parent dyads in this study experienced trust issues with an attending physician that would develop into more diverse conflict with other health care team members. They perceived this physician as not respecting their care preferences and questioned whether the physician might engage in care that would harm their daughter. Given their understanding of the power hierarchy in the PICU and the institution overall, parents expressed concerns that there weren't "checks and balances" in place for disagreements between parents and attending physicians. This particular mother stated:

There needs to be more accountability at that level...If I have a problem with the nurse I go to the charge nurse. If I have a problem with the charge nurse I'll go to the NP, fellow, whoever like if I have a problem with them I go to the attending. Well what if I have a problem with the attending?

Since these parents perceived that no one was responsible for oversight of attending physicians, they were concerned for their child's safety when this particular physician was on duty.

Discussion

A research study investigating FCC practices once asked the question "an office or a bedroom?" when referring to the PICU environment (Macdonald et al., 2012). These authors found that FCC as theorized and operationalized as policy differed from actual parent experiences in the PICU. Building upon this observation, we aimed to further develop the conceptual model of FCC in the PICU as outlined by Hill et al. (in press). The parents in our study described multiple environmental factors that played a role in their perception of FCC in the PICU, indicating that the physical and cultural environment of the PICU exerts contextual influence in the delivery of care that encompasses the concepts of information

sharing, participation, and respect and dignity. We found no evidence of collaboration that reflected our operationalization of the IPFCC definition as involvement in programmatic and policy level collaboration. We did find evidence of collaboration between parents and clinicians related to care coordination, treatment plans, and delivery of care. Given the primary study’s aims, participants were not asked about their involvement in programmatic and policy level collaboration and collaboration as defined for this study was unlikely to be in our data. Accordingly, we cannot definitively refute the inclusion of collaboration in the PICU FCC conceptual model (Figure 3.2).

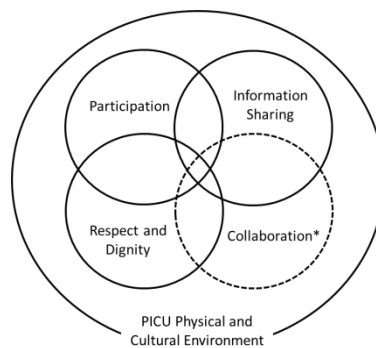


Figure 3.2: Further conceptualization of FCC in the PICU.

*Collaboration is tentatively present pending further investigation and development.

Information Sharing

Children cared for in the PICU often have conditions that are tenuous in nature and as such their plan of care can change quickly and without notice; this unpredictability was a source of uncertainty and thus stress for parents in this study. In her work with parents of hospitalized children, Mishel (1988) discussed uncertainty as a major variable in how parents perceived their child’s illness and thus their ability to incorporate information was largely impacted by their uncertainty. The situation this creates for parents and clinicians alike is both difficult and unavoidable given the critical, complex and sometimes rare nature of the illnesses faced by infants and children hospitalized in the PICU, compounded by the unfamiliar environment. Parents expressed that their satisfaction with information sharing and communication was decreased when they perceived clinicians as giving vague or broad answers to

parental questions, however because of the tenuous and unpredictable nature of pediatric critical care, clinicians might be unable to give information that will be perceived as anything but vague.

The possibility exists that more frequent exchange of information in the form of participation in family meetings or conferences and daily bedside medical rounds could help to lessen or at least normalize and convey sensitivity to parent uncertainty and in turn, distress related to changes in their child's plan of care. Research on family conferences in the PICU indicates that parent satisfaction with communication increased when providers considered competing demands on parent schedules (Levin et al., 2015), and discussed medical and treatment information in understandable language (Michelson et al., 2017), and in a patient and family-centered, empathetic manner (October et al., 2016). In our study, two parent dyads indicated that family meetings were commonplace to discuss their child's condition and treatment plan; these families had infants with prolonged stays where the plan of care changed frequently. Additionally, if PICU clinicians are hesitant to set specific treatment goals and timelines for a child because of their ever-changing condition, sensitive communication with parents that acknowledges the resultant uncertainty and impacts on parental stress could improve parent perception of information sharing. As a result, clinician sensitivity to and acknowledgement of parental uncertainty may have implications for the development of interventions that support information exchange with parents in the PICU who are dealing with uncertainty related to their child's illness and treatment plan. Additionally, development of strategies for information exchange that ensures parents both understand and are satisfied with the nature and specificity of information provided by clinicians could aid in reducing the information uncertainty experienced by parents in the PICU. Parents of children in the PICU have indicated that "keeping them informed" and "being honest" were important clinician strategies to support parent's while in the PICU (October et al., 2014). DeLemos et al. (2010) found that parents in the PICU were better able to build trusting relationships with their child's providers when the parents perceived communication to be honest, inclusive, compassionate, clear, comprehensive, and coordinated. In Mishel's uncertainty in illness theory, the ability to establish trusting relationships with clinicians caring for a loved one led to a lower level of overall uncertainty (Mishel, 1988).

The American Academy of Pediatrics recommends bedside medical rounds that are inclusive of family members as a pediatric inpatient practice standard (American Academy of Pediatrics, 2012). All parents in this study indicated that while they were not allowed to participate in morning interdisciplinary bedside rounds, they did attend afternoon bedside rounds as a means to exchange information and participate in their child's care. While no parent spoke of policies that prohibited their participation in morning rounds, two parent dyads frequently said they "weren't allowed on morning rounds" without further elaboration if this was an explicit unit policy stated to parents upon admission or one that was implicit in the PICU culture. Baird et al. (2015) found that both explicit and implicit unit-based rules impacted parents of children in the PICU. Additionally, the intersection of nurse and parent perceptions of unit-based rules impacted the delivery of family-centered care.

Participation

Early in our study, we found that all parents commented that nurses were both facilitators and barriers to parental physical involvement in their child's care; this belief is echoed in the literature regarding parent participation in the PICU (Ames et al., 2011; Cantwell-Bartl & Tibballs, 2013; Geoghegan et al, 2016). As their participation increased, parents began to view themselves as experts in the care of their child. Studies of prolonged stay parents reported that parents begin their child's stay in the PICU naïve, but over time come to better understand the unit and its culture. For example, Geoghegan et al. (2016) found that parents either developed strong relationships with the staff and came to know the culture of the unit, or they became increasingly stressed over time and their "needs and concerns escalated". This finding was true for our prolonged-stay parents as well in that one of the two parent dyads formed a highly functional working relationship with the health care team while the other dyad developed an active distrust of the clinicians and experienced multiple conflicts related to their child's care. Nurses in the Geoghegan et al. (2016) study also believed that long-stay parents became "institutionalized" to the PICU, meaning they develop an understanding of the environment and inner workings (or culture) of the PICU. This too was observed in our study in part when parents routinely

used previously unknown medical terminology when discussing their child's condition and their observations of the PICU environment.

Respect and Dignity

The parents in our study expressed that having consistent nurses for their child was important to them. Parents indicated that they preferred nurses who had previously cared for their child; one parent dyad specifically requested that a core group of such nurses be assigned. As a sign of respect for parent wishes, every attempt should be made to establish a core group of consistent nurses for each child in the PICU. Parents with prolonged stays were especially impacted by the continuity of care given the complicated nature of their child's condition and treatment course. Parents evaluated care quality based on how well nurses knew their child and the child's unique characteristics. As reported in Baird et al. (2016), parents preferred having consistent nurses and expressed relief when this occurred; parents experienced frustration when faced with frequent new caregivers and felt it necessary to remain vigilant at the bedside. Parents in the Geoghegan et al. (2016) study also expressed that finding out which nurse would be caring for their child would either produce the sentiment "Oh thank goodness" or "Oh, my God, this is going to be a hell of..." (p. e499). Perhaps one barrier to the implementation of consistent caregivers in the PICU is the nurses themselves. Nurses have indicated that they would prefer not to work with the same patients for multiple shifts because it could create boredom or possible attachment to a patient/family (Butler et al., 2015); many PICU nurses indicated that caring for the same patient repeatedly would not allow them to advance their knowledge or skills (Baird et al., 2016). In addition to respecting parent preferences for care of their infant and increasing satisfaction, neonatal intensive care unit outcomes research has shown that length of stay and duration of mechanical ventilation may be positively impacted by consistent nurse assignments (Mefford & Alligood, 2011).

Limitations

As mentioned previously, because of the secondary nature of this data, we were unable to control the course of each interview and probe further on some of the data related to our study aims (e.g., institution-wide programmatic and policy collaboration). Additionally, the study participants were all

cared for in the same institution and same PICU where the culture, management, and inherent policies may not reflect those at other institutions and PICUs. However, this data set was well suited to our study aims and the amount and longitudinal nature of our data allowed for analysis over time that revealed how parents with prolonged PICU stays perceptions of the environment changed over time. The rigorous data analysis and coding checks also aided trustworthiness.

Recommendations for Future Research

Continued research is necessary to ensure that the care delivered to patients and families in the PICU is family-centered and encompasses all core concepts. Parents of children in the PICU have indicated their dissatisfaction with communication and information sharing, focusing mainly on the uncertainty of their child's prognosis and the resultant vague and changing treatment plan.

Acknowledgement by clinicians of the unpredictability of a child's PICU trajectory as a source of stress for parents is needed. Further, interventions to support consistent, regular communication and improve parent satisfaction with information sharing are needed. Additionally, parents of children with a prolonged PICU stay have indicated their preference of having a consistent set of nurse caregivers for their children. Research should be performed to explicate the barriers, both environmental and cultural, that have prevented the assignment of consistent nurse caregivers from becoming a reality in the PICU. Moreover, while this study focused specifically on FCC in the PICU, the results found herein are not necessarily unique to the PICU and could be generalizable to other areas of pediatric care.

Conclusion

Parents of children hospitalized in the PICU endure considerable stress as a result of their child's critical illness; the environment of the PICU has been shown to both contribute to and alleviate parental distress. Parents expect that they will be able to participate in the care of their child, have open, honest and compassionate information exchange on a regular basis via family meetings and rounds, and that their wishes for consistent nurses will be respected. The physical and cultural environment of the PICU should be considered when attempting to deliver quality intensive care that is both patient- and family-centered as outlined by the IPFCC.

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CHAPTER 4. BEING A GOOD PARENT WHEN YOUR CHILD IS HOSPITALIZED IN THE PEDIATRIC INTENSIVE CARE UNIT; PARENT PERSPECTIVES

Overview

Purpose: To examine the parent perception of being a good parent to an infant in the PICU and how this parent perception changed over the first year of life.

Methods: Secondary analysis utilizing a longitudinal descriptive design and case-oriented approach guided by the good parent construct. Cases included qualitative data from mothers and fathers of three infants with complex congenital cardiac anomalies hospitalized in a PICU over the first year of life. Cases were examined within and across case to identify both previously identified and emergent good parent themes present in interview data.

Results: Previously identified good parent themes were widely present throughout the three sampled cases, including: being an advocate, focusing on my child's quality of life, being there for my child, and doing right by my child. Three newly identified good parent themes were present in each case, including: knowing your child, developing relationships with other PICU infants and families, and developing a trusting relationship with the members of my child's team.

Conclusions: Parents of infants hospitalized in the PICU believe being a good parent includes being a strong advocate as well as doing right by their child by focusing on the child's quality of life. Over the first year of life, parents come to know their child as an expert and place importance on the relationships they develop with other families and the PICU health care team. Parents of infants cared for in the PICU face unique challenges as they transition into their parental role; health care team members can assist parents during this time by recognizing that parent behavior is often a manifestation of their perception of "what a good parent would do".

Introduction

While any hospitalization of a child is difficult for parents, a critical illness and the subsequent hospitalization in an intensive care environment is an especially stressful time for parents with alteration of parental role as an often cited stressor (Turner, Tomlinson, & Harbaugh, 1990; Board & Ryan-Wenger, 2000). Traditional parental roles include responsibility for the care, comfort, and safety of one's children; a hospitalization in which parents must rely on nurses and physicians to provide care for a child may cause a parent to question how best to fulfill their parental roles. A systematic review of the research literature regarding parental participation in the care of hospitalized children found that parents wanted and expected to be involved in their child's care, as they would be at home (Power & Franck, 2008). To do so, parents need to be with the child, have information regarding their child's care, and receive practical and emotional support from health care staff (Power & Franck, 2008). Navigating the transition to the parental role with a newborn infant that requires care in a pediatric intensive care unit (PICU) can be particularly stressful; this is often the case for parents of infants diagnosed with a complex congenital heart defect- the most common congenital defect among those born in the United States (March of Dimes, 2015). While we know that parents want to be good parents to their critically ill children (October, Fisher, Feudtner, & Hinds, 2014), we understand little about how parents define "being a good parent" to infants with complex cardiac defects requiring care in a PICU. Using a case study approach, the aim of this analysis was to examine the construct of being a good parent to an infant requiring hospitalization in a PICU and how parents' definitions of this construct varied within- and across-cases over time.

Background

This study was guided by the construct "being a good parent" to my child as previously described in the literature, allowing for expansion of the previously identified themes and discovery of additional themes unique to parents with an infant in the PICU for management of a complex congenital heart defect. In 2009, Hinds and colleagues published research describing the construct "being a good parent" in the context of parental decision making for children with cancer, specifically decisions related to phase I trials, terminal care, and/or resuscitation for their child with cancer. Content analysis of parent

interview data produced themes related to parental definitions of “being a good parent to my dying child”, including: doing right by my child, being there for my child, conveying love to my child, being a good life example, being an advocate, letting the lord lead, not allowing suffering, and making my child healthy. Parents indicated that when they achieved care congruent with their internal definition of being a good parent, they were better able to make decisions on their child’s behalf as well as cope with and endure the dying and death of their child.

Building on the work by Hinds et al. (2009), October, Fisher, Feudtner, and Hinds (2014) applied the good parent construct to decision making for parents of critically ill children in the PICU. Similar to Hinds et al. (2009), October and colleagues identified themes in parent interview data that included focusing on my child’s quality of life, advocating for my child, putting my child’s needs above my own, making informed medical care decisions, staying at my child’s side, focusing on my child’s health and longevity, making sure my child feels loved, maintaining faith, and having a legacy. As shown in Table 4.1, many of the themes generated by Hinds et al. (2009) and October et al. (2014) are the same or similar across the acute care and intensive care contexts. However, the Hinds et al. (2009) data generated the unique theme “being a good life example”, while the PICU data generated the unique theme “having a legacy” in relation to being a good parent. Additionally, when asked how clinician actions could help parents be a good parent to their child, parents in the PICU identified the theme “let me be a parent to my child” (October et al., 2014).

A common issue cited in the PICU family-centered care literature is one of role alteration, where parents in the PICU felt their role had been changed from one of parent to visitor (Ames Rennick, & Baillargeon, 2011; Kirschbaum, 1990; Miles & Carter, 1982; Noyes, 1999; Tomlinson & Harbaugh, 2004). When an infant requires intensive care soon after birth, a parent’s ability to develop an attachment to their child and assume their parental role may be out of their control and altered because they do not always have continuous access to the child due to visitation policies and restrictions; they may also be unsure how to interact with the child given the child’s health condition and the technology present (Klaus & Kennell, 1983). Moreover, the child’s admission to the PICU interferes with normative

parenting behaviors in the immediate postpartum period, which in turn might affect the typical course of parental role attainment (Bialoskurski, Cox, & Hayes, 1999; Dodwell, 2010; Miles et al., 1984; Miles & Frauman, 1993; Odom & Chandler, 1990). Such is the case for many parents of infants with a complex congenital heart defect. Over 40,000 infants are born with a congenital heart defect each year, of which 4,800 have defects so severe that the infant requires surgical intervention and prolonged intensive care shortly after birth to survive (March of Dimes, 2015). While newborns requiring intensive care due to prematurity are cared for in a neonatal intensive care unit (NICU) where nurses are familiar with the unique needs of new parents, infants with complex congenital heart defects are most often cared for in the PICU where nurses may not be well equipped to support parents during this delicate role transition. Also poorly understood are parenting goals and perceptions about being a good parent in the context of a PICU hospitalization immediately or soon after birth, yet this knowledge is essential for the development of interventions to support parents of critically ill infants with complex congenital heart defects. Understanding how parents define being a good parent will provide PICU nurses and other clinicians with a foundational evidence base for supporting parents' ability to participate in their infant's PICU care in a way that is congruent with the parent's personal definition of being a good parent- ultimately improving outcomes for the parent, the infant, and the family. This study examined parental perceptions of what it means to be a good parent to a critically ill infant hospitalized in a PICU during the first year of life.

Table 4.1: Equivalent themes across good parent literature

Hinds et al. (2009)	Definition	October et al. (2014)	Definition
Doing right by my child	Making prudent decisions in best interest of child after weighing all options; meeting basic needs in unselfish way that require sacrifices	Putting my child's needs above my own Making informed medical care decisions	Parent strives to make quality, unselfish decisions in the best interest of the ill child even if there's conflict with the parent's wishes Parent must have the data to actively participate in making choices that benefit the ill child, are safe, and will be supported by the rest of the family
Being there for my child	Always at child's side and supportive regardless of challenges	Staying at my child's side	Parent prefers being at the bedside in case the child awakens, even if the ill child does not seem to know the parent is present
Conveying love to my child	Demonstrating to child by actions and words how cherished child is, even under difficult circumstances; focusing on child's quality of life and happiness	Making sure my child feels loved	Parent needs the ill child to know he is cherished to the last possible moment in life
Being a good life example	Trying to live life that teaches child to behave in positive ways, know right and wrong, make good choices, be respectful of others, and show sympathy to others	No equivalent theme	
Being an advocate for my child	Knowing what child wants and alerting staff to those wants; involving staff in care that parent is unable to perform; trying to stay focused on meeting child's needs at all times	Advocating for my child	Parent nurtures the child through the illness and alerts the clinical team to the child's physical, emotional, and spiritual needs
Letting the lord lead	Bringing child up to know God and find comfort in his constant presence; letting child know that parent prays for child every day	Maintaining faith	Parent believes in a higher power and trusts that the child will be healed
Not allowing suffering	Trying to prevent care that causes child to suffer but may no benefit child; wanting child to be able to die with dignity	Focusing on my child's quality of life	Parent desires the ill child to be comfortable with minimal pain or suffering
Making my child healthy	Helping child to be as healthy as long as possible and to function as normally as possible for as long as possible	Focusing on my child's health and longevity	Parent seeks to initiate every possible action to save the ill child with hopes that the child will get healthy
No equivalent theme		Having a legacy	Parent wants to honor the ill child's memory by allowing the child to live on in someone else

Methods

The data used in this secondary analysis were provided by a subsample of parents enrolled in a primary study that examined the trajectory of decision making for infants with complex life-threatening conditions (R01NR010548, P.I. Docherty). An overview of the primary study is presented below.

Primary Study

The primary study was completed in a major academic medical institution in the Southeastern United States. The primary study employed a longitudinal case-study design to examine the trajectory of decision making for infants with complex life-threatening conditions including extreme prematurity (<26 weeks gestation), complex congenital cardiac anomalies, or genetic diagnoses requiring a stem cell transplant; parents of infants with complex congenital cardiac anomalies cared for in a PICU environment were the data source for this secondary analysis. Parent enrollment in the primary study and data collection were initiated either following the infant's birth (when the infant's condition was detected during pregnancy) or diagnosis (when the infant's condition was detected after birth). Interview data, parent reported outcome data and infant clinical data were then collected at least monthly and after until either the infant's death or one year post-study enrollment. In addition to monthly data collection, the investigators collected data when a major treatment event or decision occurred; there were multiple instances for which the monthly and event/decision data collections coincided and were combined to minimize parent burden.

Secondary Analysis

Feasibility assessment. A preliminary study was performed to determine the feasibility of using the primary study interview data to examine and understand parent perspectives of being a good parent in a PICU setting. A case was purposively selected with the assistance of the primary study investigators on the basis of the amount and richness of data therein that, in their judgment related specifically to being a parent to an infant in the PICU; this case consisted of 10 interviews with the infant's mother and 9 interviews with the infant's father spanning 14 months. To determine whether these data contained themes previously identified in the good parent research (Hinds et al., 2009; October et al., 2014) the first

author performed directed content analysis (Hsieh & Shannon, 2005) of interview transcripts. Parents talked generally about parenting in the PICU, and addressed many of the themes present in the good parent construct including advocating for the child, being there for my child, maintaining faith, and making informed medical care decisions. Based on the results of the preliminary study, the authors concluded that previously described good parent themes were present in the interview data from the primary study and that a larger, more in-depth secondary analysis was feasible. The preliminary case was included in the final sample for the secondary analysis.

Design. This secondary analysis used a longitudinal descriptive design and case-oriented approach to analyze qualitative data; the analysis was informed by the good parent construct (Hinds et al. 2009). A longitudinal descriptive design allowed for extensive analysis of parent perspectives and how their perspectives changed over their child's first year of life. A case-oriented approach allowed for the examination and better understanding of this highly context dependent social role group (e.g., parents) by focusing on individuals in that group (Gerring, 2007). Utilizing a case-oriented approach to the interview data also enabled us to identify both previously identified and emergent good parent themes present in each individual case and how those identified themes were manifested to make each case "a case of" (Sandelowski, 1996). We aimed first to understand the manifestation of themes within each case as well as variation in the manifestation of themes across cases during the first year of the infant's life (Ayres, Kavanaugh, & Knafl, 2003). Since the individual parent was our unit of analysis, we were also interested in examining the extent to which parents evidenced shared or discrepant manifestation of themes.

Sample selection. This secondary analysis examined interview data from three cases (mother and father of an infant with complex cardiac anomaly) purposely selected from the primary study. As indicated above, the first case was selected with the assistance of the primary study investigators on the basis of the amount and richness of data contained within. The second and third cases were also purposely sampled based on the amount and richness of data, and to vary from the first case. The second case varied from the first in that the infant was diagnosed with a complex congenital heart anomaly in the postnatal period (as compared to prenatally), and the infant in the third case had a far less

complicated PICU course than the other two cases. Purposive sampling of cases continued until saturation was reached, that is, the same information was present from case to case and no new data related to further developing the original or newly developed good parent themes was identified (Corbin & Strauss, 1990); this occurred with secondary analysis of three cases (61 interviews, approximately 1500 pages of data). We were also mindful of code saturation; we found that no new inductive codes were identified when analyzing the third case that had not been identified in the first or second cases (Hennink, Kaiser, & Marconi, 2016).

Data analysis. Parent interviews and process notes were read in their entirety, and uploaded to a data management program (Atlas.ti, Scientific Software Development, Berlin, Germany) to support data coding and analysis.

Code development/coding. Directed content analysis (Hsieh & Shannon, 2005) of the interview transcripts was performed by the first author utilizing previously published themes relating to being a good parent as the framework for the analysis (Hinds et al., 2009; October et al., 2014). The first case was read in its entirety and provisional coding was implemented first using the previously published good parent themes as deductive codes; inductive coding was performed to identify themes not previously reported in the good parent literature. Equivalent good parent themes across studies by Hinds et al. (2009) and October et al. (2014) were combined for ease of coding and data analysis (see Table 4.1 for equivalent themes); equivalent themes were coded using the Hinds et al. (2009) nomenclature except for the theme *focusing on my child's quality of life*, in which the October et al. (2014) theme was used. Each deductive and inductive code was defined and a working codebook was created, including examples from the interview data (Miles, Huberman, & Saldana, 2014). The next case was then coded with the same steps as the first using the working codebook. When a new inductive code was identified, it was defined and added to the codebook.

Trustworthiness. Throughout the content analysis, the first author composed memos to track assumptions and beliefs that might have been shaped by her clinical experiences. Memos were also written frequently to document analytic insights and methodological decisions. The second author (KK),

an expert in qualitative research, reviewed the original codebook and performed code checks on 20% of the total interview transcripts (approximately 300 pages) to evaluate the reliability of the coding and to support trustworthiness. Interviews for code checks were chosen purposively, in that mother interviews from one case at study entry, mid-study, and study conclusion were selected for review to give the second author a sense of the entirety of that case. Next, a father and a mother interview from the second case at mid-study was chosen for review; these two interviews were chosen based on the amount of data coded therein, and to give the second author an opportunity to examine data from a contrasting case. The first and second authors met frequently to discuss the application of codes and resolve discrepancies. The research team continued to meet once coding checks were complete to discuss the ongoing analysis of the data.

Within-case and across-cases analysis. Each parent was first analyzed within-case and then across-cases to describe, both individual themes and the pattern of themes for each parent (Ayres et al., 2003), the experience of being a good parent to an infant in the PICU. A case summary template (see results) was developed for each case allowing for the comparison of data coded for each theme at a given study time point as well as examination of if and how the manifestation of themes changed over time. For example, when analyzing the data coded *being an advocate for my child* for each case, the first author viewed each interview passage labeled with this code and all associated memos to develop a description of how *being an advocate for my child* manifested itself in the interview data and how this manifestation evolved over the study. Each theme was then described and exemplar quotes were included where appropriate. Throughout progression of the within-case analysis, the first author noted variations in the manifestations of each theme from case to case. A matrix was constructed (Table 4.6) as a means to compare each theme across-case and to identify the uniqueness within cases (Ayres et al., 2003) of parenting a critically ill infant in the PICU. For example, when analyzing the theme *being an advocate for my child*, we first noted how the data coded for this theme was similar across each case. Next, if applicable, we determined how this theme was manifested in ways that were unique to each particular case but still relevant to the overall theme of *being an advocate to my child*.

Results

The analysis of the three cases sampled revealed themes about parent perceptions of ‘being a good parent’ to an infant diagnosed with a complex congenital cardiac anomaly cared for in the PICU. First, each case is presented as an individual “case of” to gain an in-depth understanding of that parent dyad’s experiences. A brief summary of each infant’s medical history, overall case events, and social history is given followed by presentation of previously described good parent themes and new themes identified in the analysis. Previously identified themes are presented below starting with the most prevalent of each theme based on the number of segments coded in the data. Summaries of previously identified themes and newly discovered themes found in each case over time are presented in individual tables following the narrative summary of the results of each case. Next, the commonalities and differences across-cases are presented, and the contextual factors regarding what it means to be a good parent to an infant hospitalized in the PICU are examined. For parent demographics and infant clinical data for each of the cases, see Table 4.2. In presenting the results, we use pseudonyms for the family members and describe the infants’ medical problems only in general terms in an effort to protect participants’ identities. Institutional review board (IRB) approval was obtained from the first author’s academic institution as well as from the IRB responsible for oversight of the primary study.

Table 4.2: Key demographics and clinical data by case

Case	Infant Gender	Parent Age and Marital Status	Race/Ethnicity	Approximate # of Days Spent in PICU	Co-morbid Condition	Prenatal Diagnosis
1	Female	Mother & Father in 30’s. Married	Minority	151	Yes	Yes
2	Female	Mother & Father in 30’s. Married	Not minority	308	No	No
3	Male	Mother & Father in 30’s. Married	Not minority	25	Yes	Yes

Case 1

The results for this case are derived from 10 interviews with the mother and nine interviews with the father spanning almost monthly from day of life (DOL) 1 to 13 months later.

Medical history/case events. Sasha was born at 39 weeks gestation via cesarean section to parents Sally and Roland. Sasha was diagnosed prenatally via routine ultrasound with a complex cardiac anomaly and upon further prenatal follow up was diagnosed with a genetic condition that impacts multiple organ systems. After birth, an additional cardiac structural anomaly was identified. Sasha was admitted to the PICU immediately after delivery, underwent her first open heart surgery at DOL 8 and was discharged home at DOL 21 with a nasogastric tube (NGT) in place to support feeding and medication administration. She had a re-admission soon after her initial discharge because of feeding difficulties and a second because of a surgical wound infection. Sasha then was at home for 4 months prior to being admitted to the PICU for a planned second open heart surgery at DOL 185. She experienced multiple complications from this surgery and was unable to be weaned from mechanical ventilation. Sasha had a tracheostomy and gastrostomy tube (GT) placed on DOL 263 and continued on mechanical ventilation. She was eventually discharged to home from the PICU on DOL 315 and at the end of her family's involvement in the study was being cared for at home but ventilator, tracheostomy, and GT dependent.

Social history. Sasha's married parents Sally and Roland are college-educated professionals who describe themselves as being Christians. They have a healthy 3 year old son. The parents experienced multiple changes in their living situation due to parent schooling, employment, and the child's medical condition. Prior to the initial cardiac diagnosis, the family had relocated for the mother to attend graduate school and the father had yet to find employment. Upon learning of their unborn child's complex cardiac anomaly and considering their lack of an established social support network in their graduate school location, this family moved again to be closer to appropriate medical care and extended family. Throughout the first months of the child's life the family lived with Sally's parents. Soon after the second open heart surgery, Roland moved out of state for a job opportunity while Sally stayed behind and the infant's parents lived apart for many months. At DOL 315 upon Sasha's discharge from the hospital, the family re-united to live under the same roof close to the father's job. Sasha's extensive outpatient medical care was transferred to a medical institution in the family's new state.

Previously identified good parent themes. Many of the good parent themes previously described by Hinds et al. (2009) and October et al. (2014) were evidenced in this case, including: being an advocate for my child, being there for my child, doing right by my child, and letting the lord lead.

Being an advocate for my child. Being an advocate for my child was a major theme in Case 1, particularly for Sasha's mother Sally as she was the primary parent at bedside. How the parents in this case advocated for their child evolved over the study year beginning with the very first interview when Sasha was days old. The first interviews provided no evidence of this theme; regarding any decision making in those early days the father says they relied entirely on the physicians, "I was confident that all of them were competent enough to speak on her (Sasha's) behalf". As early as the second month, however, Sally showed evidence of being an advocate for Sasha as she recalled her recent re-admission for a surgical wound infection. Sally discussed how she was able to speak up and ask for care to be clustered so that the child could have more periods of rest between exams and procedures. She also discussed an instance where Sasha was subjected to multiple venous punctures and, looking back, wished she had advocated for stopping after a certain number of attempts. At this early stage, Sally was confident enough as Sasha's parent to advocate for some things but lamented her inability to advocate for other items related to her care.

Over time, Sally became very comfortable advocating for Sasha with regards to major decisions and medical procedures. After Sasha's second planned open heart surgery, she stated

when she had her first surgery...at first you still aren't really comfortable with just sticking your opinion in there, you just don't really know... and through this process, I can honestly say that ... for me in my journey is to the point that I can say how I feel about something and I see results from that...I've been really fortunate to have a voice and to be able to advocate for her.

Also after this surgery, Sally comfortably and confidently advocated for changes in medications and feeding schedules, for and against specific procedures, and for clinical attention when she noticed subtle changes in her child's condition. She described feeling listened to as an important member of the health care team.

Being there for my child. In Case 1, the mother was an almost constant presence when her child was hospitalized in the PICU and continued as the primary caregiver at home. Sally expressed the critical importance of a parent being present at bedside in the PICU in terms of the consistency offered. She also expressed her belief that parental presence was crucial to the quality of care provided and explained the importance of a consistent presence at bedside: “you’re the one consistency, the attendings change every week, the nurses change every day, the respiratory therapists are different, you’re the only thing that’s consistent that’s there every single day”. In addition to Sally’s impression that the quality of Sasha’s clinical care was improved by maternal presence at the bedside, Sally expressed that when not at the bedside she felt guilty not being present. Sally felt that although Sasha was in the PICU, it was important for her to be present for Sasha’s “milestones” that were not those of a healthy infant at home but rather corresponded to her clinical progress and ability to be discharged from the PICU (e.g., meeting GT feeding goals, weaning from the ventilator and sedation).

Doing right by my child. As previously stated, in the days following her birth Sasha’s parents relied heavily on the medical team to make decisions regarding Sasha’s care. For example, when asked about how he decided that Sasha should have her first heart surgery, her father stated, “when you talk to different people and they say that she’s being operated on by the best pediatric heart surgeons in the country, I mean who are you to question”. As Sasha grew older and the parents became more familiar with her behaviors and needs, they became more active in decision making, especially her mother. Sally gave multiple examples of contributing to medical decisions regarding feeding, medications, treatments, and surgeries with the physicians, including instances where she voiced an opinion that was contrary to that of the medical team. Sally drew on her growing maternal knowledge of Sasha from the short time she cared for her at home and the prolonged time she was the constant presence at the PICU bedside. She frequently expressed that she felt her opinions were listened to and that she participated in constructive discussions that resulted in decisions made in collaboration with the team regarding Sasha’s care.

In our analysis, the equivalent October et al. (2014) theme *putting my child’s needs above my own* applied more to basic lifestyle decisions and needs rather than medical decision making. In this case,

parents provided multiple examples of putting Sasha's needs above their own that began even prior to her birth. For example, Sally suspended her graduate-level education to move back to a state where there was better medical care for Sasha's future needs and a stronger family support system. While in the PICU, if Sasha experienced a clinical setback or was having a rough night, Sally would often stay at bedside around the clock to see Sasha through these difficult times. Months into the study, the father took a job in another state while Sally remained behind so she could participate in the daily care and decision making for Sasha. As the months followed and Sasha remained in the PICU, the family remained separated so that Roland could continue his new job out of state and Sally could be present for Sasha. Although Sally expressed that she missed her husband and older child terribly, she wouldn't consider moving until Sasha was healthy enough to leave the hospital and move with her.

Letting the lord lead. Faith was very important to this family; from the very first interview soon after Sasha was born, both parents expressed that they maintained their faith by routinely praying for guidance and for Sasha to be healed. This faith and prayer continued throughout their participation in the study. In his final interview Roland stated that their faith had become stronger as a result of their experience with Sasha.

Our faith has gotten stronger... In those moments where we're sitting at home and Sasha's struggling to breathe and we don't know anything to do but stand there and pray. So it's not only been a spiritual benefit for both of us but has helped our relationship as well. Brought us to the point where we had to pray but after we prayed we still have to do something about it and to decide whether to go to the ER or stay at home, or to call the nurse to come by and look at her.

Roland indicated that faith was "the most important thing for them", and their faith gave them confidence that everything would turn out as God had planned.

Case 1 additional good parent themes identified in the analysis. In addition to the themes discussed above present in the existing good parent research literature there were three new themes discovered in Case 1. *Knowing your child* is defined as: the parent comes to recognize and understand the physical and behavioral cues of their child and in turn is able to make judgments as to the wants and needs of the child. *Developing relationships with other PICU infants and families* is defined as: the parent develops relationships with infants and/or their family members who are experiencing trajectories

that are similar to that of their own child. *Developing a trusting relationship with the members of my child's team* is defined as: the parents develop a relationship with the members of their child's health care team that is built on trust.

Knowing your child. Getting to know your baby through the baby's behavioral cues and responses to parents' behaviors is part of the parental role attainment process. When Sasha was prenatally diagnosed with her complex cardiac anomaly, her parents knew that she would need complex medical intervention and intensive supportive care in the PICU soon after birth. In her first interview, Sally discussed Sasha's birth and how she verbalized her wishes to at least see and preferably hold Sasha prior to her being taken to the PICU. Immediately after the delivery, the baby was taken to the PICU and Sally was unable to see or hold her. She was distressed by this and felt that her bonding with Sasha was delayed as a result of the immediate need for medical intervention. Over the course of the next weeks as Sasha recovered in the PICU from her first open heart surgery, Sally discusses her lack of "knowing" her child and how difficult it was to feel like a mom to Sasha or her older child, "it's just the mother in you and not being able to mother even one of your children is just, it was just really hard". In those early weeks Sally viewed participation as a way to get to know her child and took cues from the nurses for how and when she could be active in care, "it would be really nice if the nurse decides that you can play a part in your baby's care". She was thrilled when a nurse told her she could change a diaper or help with a bath because she had yet to perform these basic caregiving tasks. Upon returning to the PICU for subsequent admissions, Sally reported she had a much better understanding of Sasha's wants and needs believing that being there for her at home had helped form those connections. Additionally, Sally believed a consistent parent presence both at home and at the bedside was beneficial to Sasha's care, stating "for these four months (in the PICU) I've watched her and I know her patterns and I know what makes her uncomfortable and what she doesn't like, what side she likes the best and what side she doesn't". Sally also used her knowledge of Sasha's behaviors to communicate with other team members when she recognized almost imperceptible changes in Sasha's condition. Over the study year, Sally became an expert in Sasha's condition and care. As Sasha's outpatient care was transferred to their new home state,

Sally was relied upon to be the expert historian and information source for her new medical team. This led Sally to realize her new responsibility of being a parent to a child with special health care needs,

They were asking me all this information and the doctor would come in and say ‘well mom what do you think we should do?’ and at that moment I realized that I always have to be on top of knowing this child really, really well. Because at that moment I realized that I am the go-to person, I’m who they’re going to get information from.

Sally described how *knowing her child* contributed to her ability to advocate for Sasha with health care staff and share her experiences as someone who had been consistently caring for her both inside and outside of the PICU.

Developing relationships with other PICU infants and families. In addition to *knowing your child*, this case contained the new theme *developing relationships with other PICU infants and families*. As it relates to being a good parent to a child in the PICU, this theme is manifested in a variety of ways. In this case, the development of relationships with other infants and families gave this mother examples by which to measure the progress or deterioration of her own infant thereby giving this mother hope for her child’s future. From her study entry interview through to her final interview, Sally frequently discussed how she interacted with and was impacted by other children and their parents in the PICU. When comparing her child to others, she often used this as a way to indicate that “it could always be worse” or “my child is not as sick as that child”. Through these comparisons, she found hope that her own child might have a better outcome, which seemed to enable Sally to remain persistent and determined to be a good parent under difficult circumstances. Whether it was another family in the PICU that she knew well through their long-term stay or one with which she barely interacted, Sally consistently described herself as emotionally impacted by those parents she met or merely observed. She often expressed the belief that multiple other families had it much worse than hers, and that Sasha could be so much worse, too. As the study progressed, both Sally and Roland commented that witnessing other children have emergencies struck them as they thought “please just don’t let me have to go through that”. As Sasha became more ill and experienced more complications, Sally reasoned that at least she was able

to “take her home and enjoy her, watch her grow...I got that experience” when comparing herself to parents who had yet to take their infant home.

Throughout the study Sally discussed her interactions and relationships with other families in the PICU; she described these relationships as “invaluable to me”. Sally saw these relationships as a “double edged sword” because she was often reminded of the “worst-case scenario”. Sally struggled with feelings of needing to support fellow cardiac PICU parents versus her need for self-preservation when other children were doing poorly and her focus needed to be on Sasha. On the day that Sasha was to be discharged from the PICU and transported to their new home in another state, Sally spent a large portion of the morning in the PICU with another mother whose son had died moments before

I was just really blown away by it, and so when I left them at the same time, I could not get out of that hospital soon enough, because it just was a feeling of although I had just witnessed such a beautiful thing with this mom and her child I still, there was just almost a fear that came over me of... I have to get out of this hospital, I have to get her out of this hospital like now.

When faced with the death of a child very medically similar to Sasha, Sally’s desire to interact with and comfort a fellow mother was overcome by the urgency to retain hope for her own child and protect Sasha from a similar fate.

Developing a trusting relationship with members of my child’s team. Considering infants are unable to self-report and actively participate in relationships with their health care team members, parents are responsible for developing these relationships on the child’s behalf. In the first weeks of Sasha’s life, her parents relied heavily on the medical team to make decisions regarding appropriate treatments and surgery for her complex cardiac anomaly. Her father stated, “I was confident that all of them were competent enough to speak on her behalf”, and “when you talk to different people and they say that she’s being operated on by the best pediatric heart surgeons in the country I mean who are you to question?”. These quotes illustrate an unquestioning trust in the medical team caring for their daughter. As time progressed and Sasha spent a large portion of time in the PICU, Sally commented that she frequently had constructive, collaborative conversations with members of the care team regarding the day to day and

long-term care goals for Sasha. Sally described feeling as though she was a valued and heard member of her child's team, thus promoting her trust in the members of Sasha's health care team.

Summary. Sasha's complex cardiac anomaly necessitated planned and immediate critical care intervention. Even with her complex condition, within one month of life she was able to be discharged from the PICU and was cared for at home briefly. At this early time, both parents relied heavily on the health care team for guidance in making medical decisions and for cues on how to participate in their child's care while Sasha was in the PICU. Sally in particular was committed to forming a connection with Sasha and perceived the PICU nurses as the gatekeepers to participation in care; in the first month of Sasha's life Sally felt she didn't know her child but expressed that "I cannot wait to learn her". Despite a few early complications, Sasha remained at home for months prior to a second planned surgery and subsequent prolonged PICU stay that would transform her into a technology dependent child. The time spent at home prior to her second surgery improved both parents' early sense of knowing their child. As her stay in the PICU grew longer and complications grew, Sally was able to further "know" her child, this time as a child who was now dependent on technology rather than the relatively healthy infant she cared for at home in the early months. In Case 1, being there (both at home during early life and at bedside while in the PICU) allowed for Sasha's parents to get a sense of knowing their child. By knowing their child, they felt they knew what would be appropriate for Sasha's care and in turn were empowered to advocate for her and do right by their child by making informed medical care decisions. Sally often voiced her opinion as a member of the health care team and participated in collaborative discussions regarding care, thus developing a trusting relationship with the members of the team. This empowerment continued once Sasha was discharged from the PICU and was cared for at home. While Sally was the primary parental caregiver both at home and while in the PICU, she took on the role of primary advocate and decision maker while father Roland assumed the role of provider and was minimally involved in hands-on care. Sasha's parents developed close relationships with fellow PICU parents and often used the acuity of other infants to express their hopes for their own child. Sally was impacted greatly by other parents and children, but ultimately remained committed to the hope she felt for Sasha. Undeterred by

hardships including physical separation, financial strain, and multiple medical complications, the parent dyad remained intact and worked together as a team once Sasha was discharged from the PICU and cared for at home. This case is one of teamwork, within the family unit and those working to care for Sasha in the PICU.

Table 4.3: Case 1 summary template

Good Parent Theme	Early	Middle	Late
Being an advocate for my child	M: advocated for rest, clustering care. Wishes she had advocated more strongly for limitation of painful procedures F: “physicians are competent enough to speak on Sasha’s behalf”	M: becoming comfortable as an advocate. Routinely advocates on Sasha’s behalf with the care team	M: continues to be a strong advocate in new setting and while child is cared for at home
Being there for my child	M: wanted to be more involved, “would be nice if the nurses let you play a part in your baby’s care”	M: constant parental presence at bedside is crucial to quality of care F: returns to work in another state, rarely able to be at bedside	M: continues to be the constant presence as the child is cared for at home and when interacting with medical team F: becoming more active in care now that child is cared for at home
Doing right by my child	M: put education on hold to move closer to support system and medical care P: relied heavily on the medical team for care decisions	M: became active participant in medical decisions. Drew on her growing knowledge of child to express opinions and preferences for care P: family chose to live apart so that father could start new job and mother could stay at bedside	M: continued to put off her career and school to care for child at home P: as child was cared for at home, parents had to make more decisions at home related to her care and when to seek medical attention
Letting the lord lead	P: routinely prayed for guidance and for child to be healed	P: continued to pray for guidance and healing for the child	F: “our faith has gotten stronger”
Knowing your child	M: “I cannot wait to learn her”. Time spent at home with child was very important to helping mother learn what child liked/disliked	M: spending continued time at bedside in PICU allowed for mother to read the child’s behavioral cues. “you are the one consistency”	M: “I realized I am the go-to person”, “I always have to be on top of knowing this child really, really well” F: my wife has a mommy sense of what the child needs

Good Parent Theme	Early	Middle	Late
Developing relationships with other PICU infants and families	M: talking with other families is a “double edged sword” because there are best and worst case scenarios shared	M: continues to compare her child to others, “it could be much worse”. Develops relationships with multiple families, struggles with whether to attend funerals	M: relationships with other families were “invaluable” and a big “highlight” from time in PICU. Wanted to be sure that she took child home before something bad happened since she had recently seen other children die in the PICU
Developing a trusting relationship with members of my child’s team	P: parents trusted the medical team to make the appropriate decisions regarding surgery and care	M: became a member of the team, actively contributed to discussions and decisions. Felt listened to by the team	M: feels like the “expert” on her child’s care. Must be the information provider for the new team

M: mother, F: father, P: parent dyad. Early, middle, late refers to the timing of the parents’ participation in the study.

Case 2

The results for Case 2 are based on 11 interviews with the mother and 12 interviews with the father, conducted approximately every month from DOL 8 to Calista’s death (note: her father was interviewed 6 weeks following her death, and both parents were interviewed 6 months following death).

Medical history/case events. Calista was born at 38 weeks gestation to married, first time parents Janice and Peter. On DOL 2, Calista exhibited signs of peripheral cyanosis and poor circulation in the newborn nursery and thus a cardiac defect was suspected. Calista was transferred to a children’s hospital hours away where she was admitted to the PICU and subsequently diagnosed with a complex congenital cardiac anomaly requiring surgical intervention. Calista underwent her first open heart surgery at DOL 6 which led to numerous complications, escalations in care, and code events requiring cardiopulmonary resuscitation (CPR). Calista’s prolonged and complex PICU course resulted in a series of major conflicts between parents Janice and Peter and the PICU health care team which will be discussed further. She remained in the PICU from admission on DOL 2 until her death on DOL 310, dependent on mechanical ventilation for the entire time period.

Social history. Calista’s mother Janice is a college graduate and was professionally employed at the time of Calista’s birth; father Peter completed high school and was an active duty military member. Similar to Case 1, the parents in Case 2 also experienced changes in the family’s living situation as a

result of the child's medical condition and the father's employment. At the time of her birth, Calista's father was deployed and unable to join his wife and child in the PICU until DOL 4. Additionally, the military required Peter to return to work several weeks into Calista's PICU course and subsequently re-assigned him to a military base in another state while Janice remained close to the hospital to participate in Calista's care.

Previously identified good parent themes. Many of the good parent themes previously described in the literature were evidenced in Case 2, including: being an advocate for my child, making my child healthy, being there for my child, doing right by my child, letting the lord lead, and having a legacy.

Being an advocate for my child. Being an advocate for my child was a dominant theme in Case 2. Calista's parents advocated for their child, both individually and as a team. However, as her PICU stay stretched into months, how they advocated often resulted in conflict with other members of Calista's health care team. As the primary bedside presence, Janice exhibited the most advocating behaviors for her child, beginning on DOL 1 when Janice recalled feeling something was wrong when Calista's feet felt cold to touch and appeared to be turning purple in color. She reported efforts to alert the nurses to her concerns stating, "I kept fussing about it" and feeling ignored and dismissed when they seemed to disregard her concerns. In the following months as Calista experienced more complications, Janice reported that as Calista's mother, she was the "ultimate authority" for determining what was best for her daughter. Throughout her time in the PICU including at end of life, both parents repeatedly advocated for less liberal use of sedation and pain medication for Calista. Janice and Peter tended to advocate for their child in a manner that was adversarial and included expressions of anger- particularly from Peter. In his interviews, he frequently used language like "I was mad at (staff members)", "I had to confront (staff members)", "I've fought everyone", and "I'll step on anybody's toes". Both parents also described advocacy efforts to prevent certain staff members from being involved in Calista's care. As early as her month 1 interview, Janice identified one nurse that she felt was "neglectful" in caring for Calista and stated, "I'm probably going to say she can't be Calista's nurse anymore". This form of advocacy

continued into month six when both parents decided that one of the attending physicians could no longer be involved in Calista's care. Janice stated, "My goal was she's never taking care of my child again". In his interview six weeks after Calista's death, Peter expressed regret that he and his wife had not been stronger advocates for their daughter, stating, "some things that we think we would have done a little different; we would have been much more forceful early on in Calista's treatment had we known then what we know now". Janice and Peter appeared to be both strong and forceful advocates for Calista from early in her care.

Making my child healthy. Calista's parents recognized the complexity and critical nature of their daughter's condition; they insisted that everything possible be done to improve her immediate health and prospects for longer-term survival. In her month 2 interview, Janice stated, "I would never have thought I would have a disabled child or a special needs child or whatever you want to call her but here I am with one...whether with special needs or not, she goes home with equipment or not, you know, I just keep going". Much of the conflict that occurred in this case stemmed from the parent's wish to make their child healthy and the perception that members of the health care team had given up on Calista or did not see a chance for her to make a meaningful recovery. This was evident early in Calista's PICU hospitalization when Janice stated, "our problem was that they weren't giving us any more long-term goals; they weren't talking future". At this point, Calista's PICU trajectory was early on and a multitude of complications had yet to occur. As her condition deteriorated, the health care team continued to offer supportive care but indicated they had no treatments remaining that could significantly improve Calista's condition and the topic of withdrawal of intensive care was approached with Janice and Peter. The parents perceived this as "giving up" on Calista and remained steadfast in their belief that Calista could be healed and live a "productive" life, Janice stated, "number one you're never going to get me to sign DNR ever 'cause I'm not giving up on my child" and Peter stated "maybe the chance to win the lottery is one in seven million, but still people win the lottery. And maybe her chance of survival is one in seven million but I'm going to give her that chance". As mentioned previously, Janice and Peter advocated that one of the attending physicians be removed from Calista's case. This physician strongly voiced her concern that

Calista was suffering, nothing more could be done, and recommended a withdrawal of intensive care and a focus on comfort care. Janice and Peter believed that Calista's condition was not as dire as perceived by this physician and demanded she be removed from care, since she was seen as thwarting their commitment to giving their daughter a chance to live and be healthy. They continued to insist every possible treatment be attempted and pursued multiple second opinions at outside institutions with the goal of making Calista healthy as evidenced by the following language from both parents: "I want to give her every chance I can give her", "I don't want them to stop looking for a treatment", "I'd keep giving her every chance she's got", "she may still die but that doesn't mean I'm not going to try", and "if the chance exists and it's five percent I'll take that chance". This disconnect between parent and physician perception of making Calista healthy continued until her eventual death in the PICU.

Being there for my child. Calista's mother Janice was the primary parental bedside caregiver throughout her life in the PICU. In contrast to many parents of infants in the PICU who have no opportunity to engage in usual parenting behaviors, Janice's experience is unique in that she was able to deliver Calista and spend the first 36 hours of her life rooming in with her on a post-partum unit. Once the signs and symptoms of her complex congenital heart anomaly were appreciated and Calista was transferred to another hospital, Janice was unable to reunite with her newborn for several days. In her DOL 8 interview, Janice recalled the difficulty of being separated from Calista after their initial time together, "separations are very hard, it was frustrating not being able to go with her...they finally discharged me and got me up there but the separation was really hard not to be with her". Janice and Peter's primary residence was hours away from the hospital; they relied on the Ronald McDonald House for lodging throughout Calista's stay in the PICU. Her parents indicated they initially attempted to visit Calista for a few hours in the afternoon and often again in the evenings. Janice and Peter didn't always agree on how much time should be spent at Calista's bedside. For example, during his month 1 interview Peter said, "I don't think sitting by her bedside twenty four hours a day is the right thing to do"; at this time Peter believed that it was important to maintain a sense of normalcy for him and Janice outside of the PICU, this included going out to dinner and watching movies in the theater. Months into Calista's

stay following the parents' conflicts with the previously discussed physician, *being there for my child* began to resemble active vigilance and monitoring of staff behavior as well as being present for their daughter. At the height of the conflict with this physician, Janice made sure someone was always there: "my parents can stay at the bedside with the baby and protect the baby. I mean because it was to that point we've got to protect the baby. My mom was there that entire week after that, basically so somebody was with the baby all the time". Additionally, when they determined the previously mentioned physician would be on call in the PICU when Janice and Peter were planned to be at a weekend marriage retreat out of state, they cancelled their plans to remain at Calista's bedside.

Doing right by my child. As reflected in the above example of canceling a planned trip, Janice and Peter frequently placed Calista's needs above their own, both at the bedside and in their careers. From her first interview, Janice repeatedly lamented that she was unable to hold Calista because of her fragile condition. When Calista was finally well enough to be held, she was physically unable to tolerate that for long and was quickly returned to her crib. Janice continued to comment on this in multiple interviews and often weighed her perception of possible harm to Calista with her desire to hold her, stating, "We want to hold her, and that's for us, we want to hold her but we don't want her to hurt". As for Peter, he indicated that he felt obligated to return to work in a timely manner as to not jeopardize a promotion that would come with increased pay and allow him to stay in the military retaining military benefits including health insurance to cover the cost of the multiple surgeries that Calista would need as she matured.

Janice and Peter described themselves as "information-oriented" and "analytical" people when making medical care decisions. Peter indicated he based many of his care decisions for Calista on what the effect would be on her eventual quality of life; he emphasized the importance of quality of life throughout his interviews, often discussing his perception that Calista was "mentally intact", thus providing her with quality of life. In his study entry interview he based his decision on whether to provide consent for the primary cardiac repair as one based on "quality of life" and if the surgery will make her a "functional person" with a "full, normal life" or simply "prolong her for five years, she'll

never really get to start school”. In this early interview, Peter’s consent to surgery was linked to his belief that the outcome would enhance his daughter’s quality of life. As their time in the PICU progressed and the parents became increasingly wary of the perceived behaviors and motivations of the health care team, Peter described how his outlook on decision making changed

Back when we first got here, we walked in the door and we let the doctors and nurses do whatever they thought was best because we didn’t know better. And I think they get used to the fact that most parents will walk in the door and ‘whatever you think is best’ because they’ve got that ten year degree. Well you know after you get to know your child for so long you know what works and what doesn’t work. They get set in their little ways and they want what they want, and ‘this is the way we do it here’, well you can’t categorize every single child into these nice little square holes and say that this works for everybody. It doesn’t work!

Janice and Peter’s decision making evolution from one of unquestioning trust in professionals to perceiving themselves as having the ultimate decision making authority resulted in repeated conflicts with members of the health care team and many assertions from Peter that he would have to “confront”, “yell at”, or “threaten lawsuits” for the parents’ decisions to be respected. At her interview six months after Calista’s death, Janice reflected on how they made decisions for Calista saying, “We purposely tried to make decisions that Peter and I agreed on and that we could live with that we wouldn’t regret”, however in an interview after Calista’s death, Peter commented that he regretted not being more forceful and should have been a stronger advocate for his daughter.

Letting the lord lead. Janice and Peter self-identified as being Christians. Throughout Calista’s life in the PICU, both parents struggled with their perceptions that the health care team was pressuring them to withdraw intensive care; they believed a withdrawal of intensive care was “playing God” and were adamantly against this choice. Janice and Peter remained steadfast in their decision against withdrawal of intensive care up until the end of her life, when she died in the PICU despite attempts at cardiac resuscitation. Months after Calista’s death, Janice expressed relief that they didn’t make a decision about withdrawal of intensive care that was inconsistent with their faith beliefs, “the only decision I couldn’t have lived with was withdrawal of care which we ended up not having to do... she went on her own”. Janice believed that as a good parent to Calista, it was not her place to make a decision that could lead to the child’s death.

Having a legacy. Months into her life, Janice and Peter discussed the possibility that should Calista die, they would chose to have an autopsy performed in hopes that the information obtained might help future patients similar to Calista. Although they had hoped for her survival, when Calista died they consented to an autopsy hoping to gain information about Calista’s condition. Peter commented that if an autopsy had the potential to “help someone else’s child live, it’s a reasonable thing to do”. Additionally, Janice and Peter believed that Calista’s memory could live on if other children were impacted by the findings of her autopsy.

Case 2 additional good parent themes identified in the analysis. In addition to the good parent themes found in the research literature, Case 2 also contained the following newly identified themes related to being a good parent: knowing your child, developing relationships with other PICU infants and families, and developing a trusting relationship with the members of my child’s team.

Knowing your child. From their first month in the PICU, Janice and Peter felt they knew Calista and her needs better than members of the health care team. Throughout her life, Calista was reliant on mechanical ventilation which required that she be somewhat sedated to avoid respiratory distress due to “fighting” the machine. Delivery of pain medication and sedation to Calista by the health care team created ongoing conflict with her parents; Janice and Peter insisted they knew their child’s facial expressions and mannerisms and thus could better interpret her level of pain or discomfort than the professional staff caring for her. Her parents described how, more often than not, nurses would deliver bolus doses of pain medication and either Janice or Peter (or both) would disagree with the necessity of the bolus dosing based on their perception of Calista’s needs. Since Calista was unable to provide verbal cues and rarely made any physical movements, Janice and Peter determined her moods and needs based on their interpretations of her facial expressions. Janice reported in multiple interviews that what clinicians interpreted as “grimaces” she believed was Calista smiling. Staff members’ perceptions would lead them to increase pain or sedative medication and cause conflict when the parents believed no increase was needed. Calista’s mother described the situation saying

Some of the doctors are not used to her, they weren't at her bedside all day long. They come over at the bedside they see her grimace 'oh my gosh she's suffering I've got to shoot her up with narcotics'. No, she's not- not always. Sometimes she is and you can tell if you're around her enough you can tell the difference you just have to learn.

These differing perceptions about the need for medication resulted in ongoing conflicts with staff. Even Peter, who was rarely at the bedside, felt that he knew how to interpret Calista's needs better than the staff. He stated

I don't know baby-isms, I don't know what is generally right for a child. But I know the Calista-isms and I know what is right for Calista. And what she reacts to and what she doesn't react to and what helps her and what doesn't help her.

Janice and Peter's perceptions of knowing their child and their perception of knowing her better than the health care team coupled with the manner in which they asserted those perceptions was an almost constant source of tension between the parents and members of the team.

Developing relationships with other PICU infants and families. In Case 2, this theme was manifested in multiple ways. A product of her relationships with other PICU infants and families was that it gave Janice examples by which to measure the progress or deterioration of her own infant thereby giving her hope for her child, but also in demonstration of good parent behaviors not only on her own child, but for those children she had come to know and feel a relationship with in the PICU. During their time spent in the PICU, Janice and Peter developed relationships with many of the other parents in situations similar to their own, and came to believe that only fellow PICU parents could understand what they were going through. Both Janice and Peter repeated the statement "it takes a village to care for the kids in the ICU" when discussing their relationships with other parents and how they would frequently "watch over" or "keep an eye on" the other children when their parents were not able to be at bedside. They compared their relationships with fellow PICU parents as a "family" stating: "you bond with each other... I think we've kind of developed our own family but in doing that you bond with the other families, you bond with other children". In addition to parenting Calista, Janice described many PICU-related good parenting behaviors for other children, including advocating, being there, and knowing the child. Janice and Peter discussed many instances of vigilance for other children they felt were like family

and described notifying those parents of changes they witnessed in the child's condition when the parents were not at bedside. For example, Janice stated, "we've got a little network going on, we check up on each other's babies and we check up on each other". Janice reported she had formed close bonds with many other mothers in the PICU, and during the course of the interviews she frequently talked in detail about her relationships with them and their children. When asked, she was able to give detailed medical information about multiple infants in the PICU and described how she either gave counsel to their parents or maintained a presence at bedside while the actual parents were away. This good parent role modeling behavior can be seen as an extension of Janice's advocacy and vigilance with her own infant.

Underscoring the importance of their relationship with PICU families, Janice and Peter continued many of their relationships with other PICU families after Calista's death. In his interview six weeks after her death, Peter stated that "all of my positive memories (of the PICU) quite honestly are of the other patients there and their families". Janice used her perception of other infants and their condition as a benchmark for judging Calista's progress. She frequently commented on what surgeries other infants had and how long it took them to recover and transfer out of PICU. She verbalized that "Calista's turn would be next", indicating her hopes for Calista were based on what she observed in other children. Janice described being emotionally impacted when she perceived a lack of visitors or attention for other infants; she voiced a desire to interact with those infants to provide love, comfort, and stimulation- as a surrogate good parent. The many infant deaths in the PICU took an emotional toll on Janice, and at one point she commented, "In some ways you have to distance yourself from that and just focus on what really is going on with your own child", and then was quick to point out how Calista was "strong" and different from other children and would not have the same fate as others, illustrating hope for her child.

Developing a trusting relationship with the members of my child's team. As the parents of an infant in critical condition, Janice and Peter believed they were responsible for voicing Calista's needs and wants which required repeated communication with members of the health care team. Early in Calista's hospitalization, both parents discussed their trust of the health care team to know what was best regarding Calista's initial treatment and cardiac repair. As her stay in the PICU grew longer and the

complications multiplied, Janice and Peter began to frequently voice their frustration with some of the team members' perceived actions and decisions. The erosion of trust became a major theme beginning as early as month two and continued until Calista's death; however it is possible that the parents' trust in the health care team was impacted by the child's complex cardiac anomaly not being diagnosed on the pre-natal ultrasound and the inattention to Janice's concerns about her newborns' health. The month 6 interviews suggest that trust sharply deteriorated after a provider voiced concerns that Calista was suffering and, nothing more could be done medically, and broached the subject of withdrawal of intensive care with Janice and Peter. They described themselves as becoming very distrustful of this provider to the point of believing the provider would actively harm Calista stating, "I thought she was trying to kill my daughter", and "I really feel she intends harm... and she may justify it however in her own mind, but she intends harm". At this point in their daughter's PICU hospitalization, Janice and Peter described themselves as becoming very vocal about their eroding trust in the health care team and began to question any and all decisions made in relation to Calista's care and kept vigil at her bedside. Janice and Peter perceived that these behaviors caused conflict and negatively impacted their relationship with members of the health care team yet they remained steadfast for the sake of their daughter. They felt the PICU team had "given up" on Calista and their duty as her parents was to pursue every possible treatment or cure and to protect her from harm. Their extreme mistrust in the health care team led them to become stronger advocates, remain present at the bedside for large blocks of time (something Peter had not thought was necessary early in his daughter's hospitalization), attempt to make their child healthy, and make informed medical care decisions- all themes present in that of a "good parent".

Summary. In Case 2, many of the previously published good parent themes as well as newly discovered themes were interconnected to one another to produce a unique case of being a good parent. From the beginning, Janice and Peter were advocates for their infant and remained so throughout the PICU hospitalization. They advocated for medical decisions to be made that would improve Calista's condition, and to ultimately make their child healthy. They were able to be such strong advocates for Calista because they felt they knew her better than anyone as a result of being there and often putting her

needs above their own as individuals and a couple. Janice and Peter based their decisions for Calista on a combination of their faith and what “they could live with”. In addition to parenting Calista, Janice and Peter incorporated good parent behaviors into their relationships with other parents and infants in the PICU, exhibiting advocacy for, presence with, and intimate knowledge of those infants. Calista’s parents became so involved with other families in the PICU that, according to them, other parents looked to them for advice and information. As parents who had spent a considerable amount of time in the PICU, Janice and Peter became self-appointed ‘role models’ for being good parents to a child with a complex congenital cardiac anomaly in the PICU. Ultimately, Case 2 is one of escalating conflict and erosion of trust. Over the course of this case, Janice and Peter functioned in a manner that they felt was acting “as a good parent would” to their critically ill infant; however, the good parent themes were manifested in a way that repeatedly created conflict between the parents and health care team.

Table 4.4: Case 2 summary template

Good Parent Theme	Early	Middle	Late
Being an advocate for my child	M: advocated soon after birth that the infant had cold, purple feet. A: Advocates against “neglectful” nurse caring for infant F: everything should be done as long as she has good quality of life	M: “I am the ultimate authority” for infant. A: Advocated against a specific provider having access to infant P: continuously voice concerns regarding amount of medication given	F: “we should have been more forceful early on in the treatment” P: continue to want everything done for infant
Being there for my child	M: primary bedside parental presence F: “we don’t need to be at bedside 24/7”	M: continues as primary presence F: returns to work, visits infrequently P: insist on continuous family presence when “untrustworthy” physician is on call	M: present for infant death F: not present for infant death, arrives the next day
Doing right by my child	M: longs to hold infant and perform care F: must have quality of life and be “mentally intact” to undergo initial treatment P: trusts health care team to know what is best	P: no trust in providers to make decisions. Uses language including: “confront”, “yell”, “threaten lawsuits” in regard to care and decision making	M: “we purposely tried to make decisions that we could live with and wouldn’t regret”
Letting the lord lead		P: not appropriate for parents or health care team to “play God” and	M: thankful that infant died “on her own” and no withdrawal decision had

Good Parent Theme	Early	Middle	Late
		withdraw care	to be made
Making my child healthy	P: understood infant’s condition was critical and tenuous. Wanted every intervention performed to give opportunity of survival	M: even though infant may be “special needs”, just keep going. “I’m not giving up on my child” P: health care team has given up on infant, parents will push for continued treatment and meaningful recovery	P: pursued every possible treatment, and initiated multiple second opinions. Despite dire prognosis, parents continued to push for care.
Having a legacy		P: discussed autopsy and believed it could provide information that might help someone else’s child live	P: consented to an autopsy. Autopsy was performed
Knowing your child	P: felt they knew the infant and were easily able to determine her needs	M: mother at bedside was a continuous presence and knew more about infant than caregivers	
Developing relationships with other PICU infants and families	P: begin to develop relationships with other families in PICU	M: frequent deaths in the PICU are difficult to deal with P: network of parents in the PICU who “watch out” for each other’s infants	P: continued relationships with PICU families after hospitalization ends
Developing a trusting relationship with the members of my child’s team	P: trust the health care team to know what treatments are appropriate	P: “physician wants to kill our daughter”. Parents admit to lack of trust in all providers	

M: mother, F: father, P: parent dyad. Early, middle, late refers to the timing of the parents’ participation in the study.

Case 3

The results for Case 3 are based on 10 interviews with the mother, and 9 interviews with the father. The interviews were conducted approximately every month from DOL 15 to 13 months later.

Medical history/case events. Benji was born at 39 weeks gestation to parents Misty and Andy. Benji was diagnosed prenatally via routine ultrasound with a complex cardiac anomaly, and upon further testing after birth was found to have a syndrome that included structural abnormalities of multiple internal organs. Benji was admitted to the PICU immediately after delivery and underwent his first open heart surgery at DOL 12, he also underwent an abdominal surgery at DOL 14 to repair intestinal damage caused by his recently diagnosed syndrome. Benji was discharged home on DOL 34 with an NG tube in place to support feeding and medication administration. He was cared for at home by his mother for 5

months prior to being admitted to the PICU for his planned second open heart surgery on DOL 177 and surgical placement of a feeding tube on DOL 184. He was discharged home from this hospitalization on DOL 190. Benji was re-admitted to the PICU twice after his second planned cardiac surgery, once for increased work of breathing and then for dehydration; each time he was discharged within 2 days of admission. The majority of Benji's health problems related to feeding; he remained almost exclusively tube fed throughout the study and his parents reported that he experienced almost constant vomiting and feeding intolerance for which he had numerous outpatient visits and diagnostic work-ups. At the end of his family's involvement in the study, Benji was cared for at home and remained dependent on a feeding tube for delivery of all nutrients. The parents voiced frustration with the coordination of care related to their son's feeding difficulties and were in the process of seeking second opinions at two outside institutions.

Social history. Benji's married parents, Misty and Andy are college-educated professionals with advanced degrees. They describe themselves as Christians and have a healthy 3 year old daughter at home. When told prenatally of their child's complex cardiac anomaly, Misty and Andy considered termination of the pregnancy. They worked proactively to gather information from pediatric cardiology professionals that would aid them in determining the eventual quality of life for their child and thus in making the decision about termination. Unlike Case 1 and Case 2, this family did not experience any changes in living arrangements or employment during their participation in the study. Benji's mother Misty did not work outside the home and was the primary caregiver; she was also the sole caregiver present for all outpatient medical visits. Benji's father Andy was employed outside of the home and was the primary caregiver for the couple's older child in the evenings and on weekends. The parents reported a strong family support system throughout their participation in the study.

Previously identified good parent themes. Previously identified good parent themes were also evidenced in Case 3, including: being an advocate for my child, focusing on my child's quality of life, doing right by my child, and being there for my child.

Being an advocate for my child. Being an advocate for my child was a prevalent theme in Case 3 and showed an evolution as study participation progressed. Of Benji's parents, his mother showed the greatest evidence of being an advocate as she was the primary caregiver both while in the hospital and at home. In her first interview, Misty discussed how she arrived at the decision to consent to their son's first open heart surgery, she stated

I do like to know the options and understand the facts...and understand the possible ramifications of whatever decision is being made but I'm not going to question their decision, I mean not really. Unless I feel like they're not being frank or honest you know. So my place is never really to question anything more than in a way that would expand my understanding of what was going to go down.

Once he was discharged from the hospital to home, Misty remained Benji's primary advocate and routinely recognized changes in her child and alerted the medical team to those changes. As previously stated, Benji experienced feeding difficulties from early in his life; once discharged from the hospital, Misty recognized the need to be followed by a pediatric gastroenterologist (GI) and advocated for follow up by this service when none had previously been arranged. As is often the case with infants needing multi-stage cardiac reconstruction, the timing of Benji's surgeries was based on his reaching weight milestones set by the cardiothoracic surgeons. Misty was extremely cognizant of this and frequently initiated contact with the GI physicians, cardiac physicians, nutritionists, and feeding therapists to ensure that her son had all the support he needed to continue progressing toward the weight targets for each surgery. As Benji's feeding difficulties continued, Misty and Andy began to look beyond the team of physicians caring for their son and actively sought second opinions from two outside academic medical institutions. About this decision Misty stated: "we just wouldn't be doing due diligence as Benji's advocate if... you know as his advocates if we hadn't said 'this little boy is, this is not normal. What can we do to improve the situation?'" Over the course of their participation in the primary study, Benji's parents felt as though they had to coordinate care for their son. Both parents repeatedly used the analogy of "being the quarterback" of their son's care by having to organize and lead his care team. In her last interview, Misty reflected on how her thoughts on advocating for her son had changed over time:

It would not be due diligence as parents if we did not pursue this (second opinions). You know there's –and I'm not sure that we would have had the confidence to say something like that, about something similar thirteen months ago. I mean I think the last year has shown us that it's a good system, there are some shortcomings in the system and it's our responsibility to make up for them when we encounter them.

Over his first year of life, Misty had evolved into a strong advocate for Benji and made it her goal to be his voice when navigating complicated outpatient care.

Focusing on my child's quality of life. In Case 3, Misty and Andy were focused on their child's quality of life even prior to his birth. Upon learning of his complex cardiac anomaly, both parents were concerned about the severity of the diagnosis and how it might impact his quality of life. Misty and Andy met with a pediatric cardiologist and cardiothoracic surgeon during the pregnancy to initiate further diagnostic testing and discuss options; at this time termination of the pregnancy was considered. In his first interview, Andy stated that “more decisions were made during the pregnancy than in the first few weeks of Benji's life”. Misty indicated that their son's eventual quality of life impacted their decision-making during the pregnancy

I think for us in the decision-making process it was really a quality of life for him, when we looked down the road our decisions that we're going to make whether it's to keep the baby or to go with um...is that going to enhance his quality of life to the point where we're happy or we feel like we'll be happy with that. So um... along the decision-making tree, it was 'can we repair it, can we feel like he's going to be okay' and even if he's not perfect, is he going to be better off than not moving forward?

Benji's parents continued to focus on his quality of life as he recovered from his initial open heart surgery and struggled with feeding. When first discharged home from the hospital, Benji had an NG tube that was his primary source of nutrition. To prevent him from exploring and inadvertently dislodging or completely removing his NG tube, Misty kept Benji swaddled for extended periods of time. She became concerned that her efforts to decrease the likelihood of NG tube dislodgement were impacting Benji's quality of life and negatively influencing his development. As it became clear that his dependence on a feeding tube would be long-term, Misty stated

I just can't imagine going on for months and months and months like this with this NG tube—we're going to hit a wall at some point, and if it's not a nutritional wall, we're going to hit a developmental wall because he's at the point where he wants to start playing and rolling over and we still got him swaddled like he's a month old!

As the discussions turned to the need for surgical placement of an abdominal feeding tube, Misty reasoned that the surgically-placed feeding tube would improve Benji's quality of life over what it was with an NG tube. She stated, "Not that we were looking for any kind of tube in Benji, but we're just looking for his daily quality of life to improve."

Throughout their participation in the study, one of Misty and Andy's primary concerns was Benji's quality of life which they worked to enhance by enrolling him with both feeding and physical therapists to ameliorate perceived developmental delays and feeding difficulties. For his part, Andy found a published research study that indicated acupressure was beneficial for children suffering from feeding disturbances. With the blessing of their physicians, Misty and Andy enrolled Benji in a weeks-long course of acupressure to alleviate his GI distress. In her final interview, Misty discussed the difficulty of focusing on Benji's long-term quality of life when there were many times his survival was in doubt. She stated

you forget to think forward about what your hopes are for this child, you just think 'oh I'm just hoping that they don't die'...I never really think about, 'oh I hope he tries golf someday', I think that's the difference between having a healthy child and having a child with medical concerns.

In this interview Misty began to discuss her hopes for the quality of the next few years of Benji's life; however, she only discussed those items related to his next cardiac repair and his feeding difficulties.

Doing right by my child. In Case 3, Benji's parents considered themselves to be information gatherers, with Misty even commenting that she "went into data collection mode" upon hearing of a possible congenital heart anomaly on a prenatal ultrasound and "needed to treat the whole thing like an algorithm" when attempting to understand the complex decisions being made regarding her son's care. As previously discussed, when making medical decisions in the first weeks of Benji's life, Misty and Andy relied heavily on his physicians. The parents indicated their role in this process was to ask specific questions and be sure they were informed of all options for testing, surgery, and other treatments. Misty indicated that a primary concern was that they might "miss a vital piece of information that would make a difference in Benji's life" and they hoped for a continued flow of information from providers that would aid them in making informed medical decisions for their son.

As the primary caregiver at home, Misty discussed frequent care decisions that she made for Benji based on her knowledge of his medical history, physical condition, and her assessment of his state of health. For example, Misty would adjust Benji's feeding schedule and amount, she titrated medications based on his physical symptoms, and she regularly communicated with multiple health care team members based on her daily/weekly assessment of Benji's perceived progress or lack thereof. While Misty reported fluency in the day to day management and decision making related to Benji's health care needs, her manner for making larger treatment decisions did not change. In her first interview she stated: "my place is never really to question anything". Similarly in her penultimate interview she stated "I mean this is what the surgeon does for a living, you know? Ma and Pa don't know anything about it other than what we read on the web. At the end of the day, they're the experts." Benji's parents continued to rely on the expertise and experience of the treating physicians when making decisions regarding his cardiac surgical care.

Being there for my child. While Benji was cared for in the PICU, Misty and Andy were not a constant presence at his bedside. They do not elaborate in interviews on their perception of the visitation expectations or policies in the PICU. They state that when Benji was moved out of the PICU they stayed with him much more frequently. Both parents went home immediately after Benji was out of the operating room from his initial cardiac repair at DOL 12, "we went home after the surgery, he was having some bleeding issues but we just decided to stay out of their hair up in the ICU". Later that night when they were called because Benji was experiencing complications and was rushed back to the operating room, Andy opted to go back to the hospital while Misty stayed at home. Additionally, Misty commented on their visitation strategy and how it impacted when they would come to the PICU, stating,

Andy would call ahead before he headed out to make sure that they weren't in the middle of something that was going to take an hour and we weren't going to get there and not be able to see him anyway. Sometimes it was a difference between going in or getting two more hours of sleep or spending some time getting our older daughter situated for the whole day so that we could go in and know that we were going to need to be there all day.

In addition to their PICU visitation, Misty discussed their early impressions of spending time at Benji's bedside in the PICU. She stated: "there was a part of Andy and I that were kind of really intellectually

curious about what lines did what, and in a way that maybe helped a little stay just detached enough to... certainly helped knowing that he wasn't in pain, like those days when he was sedated were comforting to me." This detachment noted by the parents while Benji was in the PICU was never mentioned once he was moved out of the ICU and then cared for at home. The interview data suggests that Misty was a near constant presence in the step-down unit and then, as the primary home-caregiver was rarely apart from her son.

Case 3 additional good parent themes identified in the analysis. In addition to the themes discussed above present in the existing good parent research literature, the following newly identified themes were also evidenced in Case 3: knowing your child, developing relationships with other PICU infants and families, and developing a trusting relationship with members of your child's team.

Knowing your child. In her first interview, Misty indicated that she did not feel like a mother to Benji during her son's initial stay in the PICU: "I'm just not sure I feel like Benji's mom", but instead knew him "on a medical-patient level". It wasn't until Benji was moved to the step-down unit and Misty became his frequent caregiver that she began to develop a sense of knowing her son, stating: "having spent so much time in step-down was huge because you know I kind of feel like Benji and I had had a feel for each other."

After his initial hospital discharge and over the months of caring for Benji at home, Misty continued to build familiarity with her son, from his burgeoning personality to his complicated outpatient medical care. She frequently commented on her "gut instinct" regarding how Benji would tolerate the introduction of new medications and changes to his feeding schedule. Andy described Misty as the "quarterback" of Benji's health care team; he felt she was responsible for coordinating every aspect of their son's care. Misty frequently commented on her role as a care coordinator or the "quarterback" for her son and recognized the weight of this responsibility, although some of her comments indicate this was a role she wasn't entirely comfortable in. Misty stated: "but you know, at times it's a little unnerving that I'm the only common denominator between all these different treatment providers", and "I mean there are just so many moving pieces with managing Benji and really the only common denominator is... is a

parent.” Misty indicated that during Benji’s numerous outpatient visits she was frequently asked to weigh in on her son’s condition and give insight into his reaction to medications and treatments. Misty commented that she felt this was a “dangerous model” in that the medical professionals should be forming their own opinions rather than relying so heavily on parents’ opinions. While Misty was a strong advocate, caregiver, and historian for Benji and often performed these roles simultaneously, her comments indicate that she might have perceived herself as being under qualified for the responsibilities entailed.

Developing relationships with other PICU infants and families. Prior to Benji’s birth, Misty and Andy were offered the opportunity to meet other parents of children with complex cardiac anomalies similar to their son’s condition. In her first interview, Misty explained that initially she had no interest in this, she stated “for somebody who likes to gather information, I sort of shut down there for a while...I just wasn’t ready to talk to other families.” She eventually spoke to these other parents but indicated the conversations were only helpful in giving information about the logistics of having a child in the PICU. Regardless of what she heard about quality of life or prognosis from other parents, Misty pointed out reasons that those children were different from her son, commenting “I did talk to a couple of families and it was helpful but you know there’s a part of me that didn’t really apply much of what they had said because I knew that the cases weren’t going to be the same.”

In contrast to how she felt early on about meeting with other families, Misty shared that she had a very different outlook as Benji grew and she became more hopeful. In addition to her willingness to interact with her experiential peers, she described a kinship with them. Misty stated,

I’m more than happy and I’m almost eager to talk to people now, and I’m thrilled for them to meet Benji. And truly when I run into people in the waiting room and I find out that we both see Dr. D or their child is getting ready to go in for the second-stage surgery, like the other mom and I, we almost get giddy. We almost get goose bumps because you know you’re like ‘oh my gosh I’m talking to somebody who also speaks this language’. You know it surprises me when, I mean, I almost get like a sort of high from meeting another parent who’s dealt with these issues not because I’m glad to meet another child that has this unfortunate condition, but because there aren’t that many of us walking around, and you know, it is nice to genuinely share a sense of hope. I mean it always feels good to share hope.

Misty gained hope from her relationships with other PICU infants and family members; this was used as both a way to measure of her son's progress and as a way to give her a sense of fellowship with other parents going through the same events. In an effort to contribute and in celebration of Benji's first birthday, Misty and Andy threw a party and invited many families they had encountered during the past year in the PICU and step-down unit. They also used this opportunity to raise funds to donate developmentally appropriate toys to the unit where Benji received his care.

While not directly developing relationships with other families in the PICU, Andy began reaching out to other families very early in Benji's life. Andy discussed Benji's prognosis with parents who had children with a similar diagnosis and joined online forums for parents of children with Benji's specific syndrome and cardiac anomaly. He commented that "Misty doesn't like to read (the forum) because it bums her out", but he indicated he found the camaraderie and information exchange to be very helpful. Andy behaved as a "good parent" would by joining these forums and reaching out to similar families in order to gain information that might benefit his son.

Developing a trusting relationship with members of my child's team. Early in their relationship with members of the health care team, Misty and Andy went to great lengths to gather information about their son's condition but ultimately relied on the physicians and surgeons to decide the appropriate course of action. As time progressed and their child was cared for at home by Misty, she became comfortable voicing her opinion about Benji's needs. Misty was a constant contributor to health care decisions and the coordinator of his outpatient team. Here she discusses how she perceived trust in the members of Benji's health care team: "when it comes to medical providers I feel like if you feel like you can believe in the treatment recommendations that they're providing then, that's sort of the level of trust I'm hoping for". She also stated, "I felt like he (physician) actually listened to my concerns about Benji. So I think, trust, you do have to know that you're being heard... you know I cannot trust somebody who will not listen, because I can't be sure that they are ruling based upon facts". Misty also discussed that she was more willing to trust members of the health care team that admitted "I don't know", stating: "admitting that you don't know engenders trust". A trusting relationship was developing between the parents and the

members of their child's team; Misty and Andy reported feeling listened to and that physicians readily admitted to the limits of their knowledge and encouraged the pursuit of second opinions that might, in turn, improve Benji's quality of life.

Summary. Despite his complex cardiac anomaly and subsequent diagnosis with a complicated syndrome, Benji spent minimal time in the PICU and was cared for primarily at home during the first year of his life. Case 3 demonstrates how many of the previously published good parent themes are applicable to the PICU environment, but can also apply when an infant is discharged home from the PICU and cared for at home by parents striving to be good parents to a medically complex child. As with previous cases, Misty and Andy relied on the medical team for decision making related to Benji's initial need for cardiac surgery yet they participated and advocated for their child by gathering as much information as possible. Over Benji's first weeks of life, Misty slowly came to know her son and overcame her initial feelings that she didn't feel like his mother. Misty exhibited an evolution in her thinking as a parent, from her initial thoughts of possible termination due to the severity of Benji's prenatal diagnosis to her last interview when she describes recently reading about her son's cardiac diagnosis and syndrome on the internet.

Misty stated,

We read this paragraph and we thought 'oh gosh' it caused us to step back because it was just a very scientific explanation. And had I read it about somebody else's child, I would have been like 'oh my God, I could never do that, I could never deal with something like that.'... And I mean it just looks so daunting on paper and I thought 'well you know, I guess it's not that big of a deal because we've done it!'

As his primary caregiver, Misty served as his strongest advocate and care coordinator. Prior to his birth, Misty and Andy contemplated Benji's quality of life; they continued to use it as a driving force in how they advocated for him, specifically regarding his feeding difficulties. Misty's sense of knowing her son as well as the parents' focus on quality of life empowered Benji's parents to advocate for him with his extensive outpatient care team. Case 3 is a case of parents taking the lead and coordinating the care of their medically complex child, in other words, "quarterbacking" his care. Throughout their study participation, Misty and Andy focused on providing Benji with care that would promote his quality of life. When not satisfied by the level of support received from specialty services, they pursued second

opinions from institutions that cared for children similar to their son. Perhaps Misty best described her interpretation of being a good parent when she said “I’m a mom! You know, more than anything I just don’t want to fail my children in parenting them. I have a lot of work to do if I want to be a good mom for them”.

Table 4.5: Case 3 summary template

Good Parent Theme	Early	Middle	Late
Being an advocate	M: “I’m not going to question their decision” and “my place is never really to question anything”	M: consistently coordinated care as an outpatient. Recognized need for GI follow up F: initiated discussions of needing second opinions	M: continued to coordinate care as an outpatient and advocate for attention to feeding difficulties
Focusing on my child’s quality of life	P: considered quality of life as primary indicator of continuation or termination of pregnancy	M: concerned about possible impact of feeding difficulties and NG tube on quality of life and developmental milestones F: recognizes delay in developmental milestones	M: “I worry that he will never be able to eat normally” and “he is doing amazingly well” F: “he’s got a lot going on but he never bitches about it” P: feel son is delayed in his gross motor functions but is overall very happy
Being there for my child Staying at my child’s side	P: infrequent visitors to the PICU. More of a constant presence when moved out of PICU	M: primary caregiver at home	M: primary caregiver at home
Doing right by my child Putting my child’s needs above my own Making informed medical care decisions	P: gathered as much information as possible to understand their son’s condition. Relied on the expertise of the medical team for decision making	M: makes decisions at home with minimal help from the medical team P: seeking second opinions at two other institutions that care for children like Benji	M: continues to make decisions at home with minimal help from the medical team
Knowing your child	M: “I’m just not sure I feel like his mom”	M: developing “gut instincts” about his care and reaction to treatments. Becoming the “quarterback” of the health care team	M: “the common denominator” on his care team
Developing relationships with other PICU infants and families	M: reluctant to speak with other families- not all cases are similar. Prior to birth decides to speak to two similar families	F: joins online forums specific to Benji’s diagnoses	M: finding other parents in similar situations gives mom hope. Other parents “speak the same language” P: invite fellow PICU families to celebration. Donate money to improve

Good Parent Theme	Early	Middle	Late
			toys available in PICU/step-down
Developing a trusting relationship with members of my child's team	P: unquestioning trust of the doctors to make medical/surgical decisions for their child	M: became a member of the health care team. Actively participated in medical decisions	M: continued to be involved in the health care team as an active member

M: mother, F: father, P: parent dyad. Early, middle, late refers to the timing of the parents' participation in the study.

Across-Cases Comparison

Multiple previously identified and three newly discovered good parent themes were evidenced in the cases analyzed for this study. An across-case analysis of selected themes is presented below. Table 4.6 presents all good parent themes and how they were demonstrated across each case.

By far the most prevalent previously identified theme (based on quantity of coded segments) present in each of the three cases was *being an advocate for my child*. The parents in each case analyzed showed evidence of being strong advocates for their children, and for what they perceived their child did or did not need. In Cases 1 and 3, advocacy developed relatively slowly, with initial evidence within 1-2 months of birth and culminating in parent report of frequent and continued advocacy for their child. In comparison, the mother in Case 2 began advocating for her infant as early as DOL 2, and both parents in this case continued to be strong and vocal advocates for their child until her death in the PICU. While parents in all three cases felt that advocating for their child was part of their responsibility as a good parent, it was apparent that in Case 2, the manifestation of this advocacy resulted in repeated conflict with the health care team. This finding illustrates that while being an advocate for one's child is an important part of being a good parent to an infant in the PICU, how that advocacy is manifested can be crucial to the development of trusting relationships with the members of the child's health care team, which are also essential.

A newly discovered good parent theme that was evidenced in all three cases was *developing a trusting relationship with the members of my child's team*. Over time, parents in each case developed working relationships with the many health care team members treating their infants. In Cases 1 and 3, the parents unquestioningly trusted the medical team to make decisions related to initial cardiac surgeries

as evidenced by the father in Case 1 stating: “when you talk to different people and they say that she’s being operated on by the best pediatric heart surgeons in the country, I mean who are you to question”, and the mother in Case 3 stating: “so my place is never really to question anything”. Over the course of their interaction with the health care team, both families in Case 1 and 3 came to be more active in decision making and formed relationships with the health care team members that were built on trust; the parents voiced that this trust was developed as they were recognized as part of their child’s care team and that their voice was listened to and valued by the other members of that team. In contrast, the parents in Case 2 repeatedly spoke of their lack of trust in the health care team. The lack of a trusting relationship was apparent within the first weeks of their child’s life as the parents began to question and disagree with many actions and decisions of the health care team; however, it is possible that the foundation for a lack of trust was present much earlier as this was the lone analyzed case with a post-natal diagnosis. This family may have been impacted by having a child with an undiagnosed complex cardiac anomaly despite multiple prenatal ultrasounds and in the delay in diagnosing a life-threatening condition in their newborn even with repeated assertions by her mother that “something wasn’t right” in the hours after birth.

Each family in this study built a relationship with the members of their child’s health care team; Cases 1 and 3 indicated that their relationships were built on trust and respect that allowed them to voice their thoughts on the care of their child. The parents in Case 2 frequently and passionately asserted their lack of trust in those caring for their child, leading to conflict and dysfunction. Often at the forefront of concern was the parents’ insistence that they knew their child best and the actions of the health care team did not reflect respect for this parental knowledge.

Knowing your child was another newly discovered theme present in all three cases analyzed for this study; this theme was found to draw upon the previously identified good parent theme *being there for my child*. Each parent, particularly the mothers of each case, reported that as they spent time with their child (and were there for their child) they developed a sense of knowing their child. In Cases 1 and 3, the mothers indicated that their ability to care for their child at home post-discharge from each child’s initial cardiac surgery allowed them to gain an intimate knowledge of their child’s personality as well as their

behavioral cues. The parents in Case 2 did not have an opportunity to take their child home and developed their sense of knowing their child through their frequent presence at her bedside in the PICU. The theme *being there for my child* was confirmed by the importance parents placed on a consistent presence at bedside and/or at home, the mother in Case 1 stated: “you’re the only thing that’s consistent” and the mother in Case 3 stated: “I’m the only common denominator”. Over time, the theme of *knowing your child* was manifested differently across cases. In Case 1, the mother used her gained knowledge of her child to advocate, notify of slight changes in condition, and to actively participate in care. This mother also noted that when she disagreed with the health care team members, they were able to have constructive discussions to come to a consensus regarding care. Similarly, in Case 3, this mother drew upon her knowledge of her son to advocate for him with outpatient services, to improve his quality of life, and to coordinate his care with multiple providers and specialties. Likewise, in Case 2, the parents quickly developed a sense of *knowing their child* and used this understanding to voice their preferences related to medications and treatments. However, unlike Cases 1 and 3, the manifestation of this theme in Case 2 was the emphasis that their parental knowledge of the child superseded any other information available and inhibited the development of a trusting relationship with members of the health care team.

The parents in each case *developed relationships with other PICU infants and families*, the intentions and functions of those relationships varied between cases. In all cases, the mothers of those infants frequently used other infants as a measure of how well their child was progressing in turn providing them with hope. Even as it seemed that the infants in those cases were doing poorly medically, developmentally, or in their prognosis, the mothers made comments like “you know, in the spectrum of these kids, he’s doing well” or “you kind of go ‘like okay I haven’t really been through anything’ you know compared to what you’ve been through”. In Case 2, the parents developed multiple, close relationships with parents they met while in the PICU. In this case, the mother became a “surrogate” parent to the other infants in the PICU while their own parents were not present. This mother demonstrated behaviors similar to those she exhibited with her own infant, such as being there and advocacy. Additionally, the mother in Case 2 indicated that she was part of a network of parents in the

PICU that had banded together to maintain a vigilant presence to protect the children cared for in the PICU, perhaps another extension of her difficulty in developing a trusting relationship with members of the health care team.

Table 4.6: Across case comparison

Good Parent Theme	Case 1	Case 2	Case 3
Being an advocate	Became comfortable advocating for child early on, this was helped along by time at home and getting to know the child. Comfortable advocating to PICU health care team about medications, feeding schedules, procedures, changes in child's condition. Continued to be an advocate after child was discharged to home.	Mother advocated for child from DOL 1. As the child's time in the PICU progressed, mother called herself the "ultimate authority" for determining what was best for the child. Parents felt a strong responsibility to advocate regarding medications, treatments, nursing care, and physician involvement. The manner in which the parents advocated often resulted in conflict with the health care team. The parents pursued second opinions at other medical institutions.	Became comfortable advocating for child once discharged home from the PICU. Mother became primary caregiver and advocate. Mother frequently recognized changes in her child and informed appropriate health care team members. Mother coordinated care; felt it was her responsibility to do her "due diligence" regarding her son's care. Parents pursued second opinions at two other medical institutions.
Focusing on my child's quality of life		Father initially made medical decisions based on the child's perceived quality of life.	Parents focused on quality of life even prior to birth. Quality of life was the main factor in determining if they would continue this pregnancy. Once home from the PICU, parents focus on quality of life led them to repeatedly seek help for feeding difficulties. Parents pursued acupuncture to alleviate GI symptoms.
Being there for my child Staying at my child's side	Mother was a constant presence at bedside in PICU and primary caregiver in the home. Believed parental presence was crucial to quality of care provided. Parents at bedside were the "one consistency".	Mother was able to be with child for 2 days prior to diagnosis of cardiac anomaly. Parents were a frequent presence at bedside in the PICU, with mother as the primary presence. Parents became vigilant at bedside as their conflict with and trust of health care team	While child was in PICU, parents visited daily but only for a few hours. Mother indicates that she was detached from child while he was in PICU. Once discharged, mother is primary caregiver and a constant presence at home.

Good Parent Theme	Case 1	Case 2	Case 3
		decreased.	
<p>Doing right by my child</p> <p>Putting my child’s needs above my own</p> <p>Making informed medical care decisions</p>	Initially relied on the medical team for decision making. As the mother grew to know the child she was an active contributor to medical decision making along with the health care team. The parents put the child’s needs first by moving their household to seek better medical treatment and better family support. Mother put law school on hold to stay at bedside and become primary caregiver.	Parents frequently placed the needs of the child above their own. Father returned to work early to secure medical insurance and future promotions. Parents based many medical decisions on quality of life. Parents considered themselves to be “information-oriented” and “analytical”. The parents considered themselves to have ultimate decision making authority which caused repeated conflicts with health care team.	Parents considered themselves to be information gatherers. They felt it was their responsibility to ask as many questions and gather all information as possible. Parents relied on medical team for decision making related to cardiac surgeries. At home, mother made frequent decisions regarding medications and feedings with minimal input from the health care team.
Letting the lord lead	Self-identified as Christians. The parents prayed for guidance and for the child to be healed. Faith was “the most important thing for them”.	Self-identified as Christians. Parents were opposed to any type of withdrawal of intensive care/life support because they felt this was “playing God”.	Self-identified as Christians.
Making my child healthy		Parents insisted that everything be done to ensure survival and long-term health. The parents perceived that the health care team had “given up” on the child causing continued conflict between parents and staff. Multiple heated discussions between parents and staff regarding withdrawal of care. Staff perceived that child was suffering, parents did not agree. The parents pursued second opinions at other institutions.	
Having a legacy		Parents chose to have an autopsy performed in hopes that information obtained might help other children with symptoms similar to their child.	
Knowing your child	Mother felt that bonding was delayed and that she didn’t feel like a mother to her child due to critical	Mother was able to bond with child prior to diagnosis. Parents believed from the first	Mother did not feel like child’s mom during initial PICU stay. Upon discharge, mother was

Good Parent Theme	Case 1	Case 2	Case 3
	<p>illness and PICU environment. Mother felt that time at home (post-primary cardiac surgery) helped her to understand the child's wants and needs. Being a near constant presence at bedside in the PICU (post-second cardiac surgery) helped mom recognize changes in child's condition and advocate for her with staff. Post-PICU discharge, mom realized she was now the "go-to" person for relaying all information regarding the child.</p>	<p>month that they knew the child better than the health care team and could interpret her needs more accurately. Parents strongly disagreed with health care team members assessment that child was in pain or suffering. Almost constant conflict between staff and parents regarding child's needs based on her physical cues.</p>	<p>primary caregiver and came to be the care coordinator or "quarterback" for her son's care. Mother recognized the responsibility of being the only "common denominator" in her son's care. She indicated that she didn't always feel qualified to be the expert of her child.</p>
<p>Developing relationships with other PICU infants and families</p>	<p>Mother frequently indicated "it could be worse" or "that child is so much sicker than my child". Mother had to strike a balance of self-preservation and supporting other parents. She developed close relationships with multiple parents.</p>	<p>Parents developed relationships with multiple families in the PICU. The parents often watched over or "kept an eye on" other children in the PICU and would report back to those parents. Felt they had a "network of parents" that would look out for and check up on each other. The parents continued their relationships with multiple other families even after their child died. Mother described wanting to provide love, comfort, and stimulation to children in the PICU with infrequent visitors.</p>	<p>Mother did not want to speak to other families during her pregnancy. Mother eventually spoke with other families but indicated that each child was different and perhaps comparing the children was not useful. She would comment that other similar children were "sicker" and her son was doing well and had minimal issues. As her child grew, mother was excited to meet similar parents because they "spoke the same language". Meeting similar parents and children gave her hope.</p>
<p>Developing a trusting relationship with the members of my child's team</p>	<p>Early on the parents trusted the health care team to know what was best for the child; they did not question medical decisions.</p> <p>Mother became comfortable voicing her opinion regarding care in the PICU and was made to feel like she was a valued member of the team, promoting her trust</p>	<p>Early on the parents trusted the health care team to know what was best for the child. As PICU stay progressed, parents voiced frequent frustration with perceived actions of the health care team. Parents each voiced that they no longer trusted the health care team and believed some members were actively trying to harm their child.</p>	<p>Early on the parents trusted the health care team to know what was best for the child; they did not question medical decisions.</p> <p>As time progressed and the child was cared for at home consistently, the mother became comfortable voicing her opinion about the needs of her child. She was a</p>

Good Parent Theme	Case 1	Case 2	Case 3
	in the health care team.	Parents kept vigil at PICU bedside to prevent members of the team from harming their child.	constant contributor to health care decisions and the coordinator of his outpatient team.

Discussion

This study examined parent perception of the construct ‘being a good parent’ to an infant requiring hospitalization in the PICU from a within-case and across-cases perspective. This is the first study examining the good parent construct specifically in parents of infants with complex congenital heart anomalies. Additionally, the longitudinal nature of the data contained herein allowed for the examination of how parent perception of the good parent construct evolved over time. Good parent themes previously discussed in the literature (Hinds et al., 2009; October et al., 2014) were present in the current study data, however, the themes *knowing your child*, *developing relationships with other PICU infants and families*, and *developing trusting relationships with members of my child’s team* were discovered in this study and are, so far, good parent themes that are unique to this study population.

The mothers in this study whose infants were transferred to the PICU immediately after birth indicated an initial lack of “knowing” or “bonding” with their infant caused by an inability to spend quality time with the child in the immediate postpartum period as well as the technology and equipment burden required in the PICU. This phenomenon is seen in the research literature on mothers of infants with congenital heart disease; they report “bonding difficulties” with their infants, these difficulties are impacted by the separation at birth, medical equipment, and lack of ability to perform traditional caregiving (Jordan et al., 2014). Regardless of timing of diagnosis, the parents in this study evolved from this initial feeling of not knowing their child to perceiving themselves as experts on their child. The parents who cared for their child at home frequently commented that they were considered the expert in their child’s care by outpatient providers. The parents in Case 3 used the term “being a quarterback” in relation to coordinating their son’s extensive care. Perhaps serving as a validation of this belief, this term has been used in the research literature on parent participation in care, “parents of pediatric cardiology

patients can play a significant role in their children's care and often act as quarterbacks by coordinating multiple specialists and treatments in a system that can be fraught with hazards and poor communication" (Haskell, Mannix, James, & Mayer, 2012, p. 67). This research group concluded that parents of children with serious medical conditions are "a rich source of information" and their particular knowledge of their child is valuable to the health care team.

The development of trust in the parent-health care team member relationship has been reported as a critical component of an effective health care relationship (Lynn-McHale & Deatrck, 2000). Early in this study, the parents in all cases had a naïve trust with the members of their child's health care team as described by Thorne and Robinson (1988); they relied on the team to make early medical and surgical decisions for their children and assumed these decisions would be made in the best interest of their children. The parents in Cases 1 and 3 were able to carry forward trusting relationships with their child's team; they frequently reported how they were part of the team and also trusted the team to listen to their opinions when considering the child's treatment course. The relationship between providers and the parents in Case 2 did not evolve into a trusting relationship; in fact, they reported an active distrust of those caring for their child. Thorne and Robinson (1988) described this relationship phase as "disenchantment", characterized by "dissatisfaction with care, frustration, and fear, and often expressed as anger" (p. 297). The parents in Case 2 remained in this relationship phase for the course of this study and were unable to regain a trusting relationship with the health care team.

The parents in this study were greatly impacted by their relationships with other infants and parents. This study found that each parent dyad developed relationships with other families going through similar experiences. When the parents in this study witnessed events perceived as either good or bad, they discussed how this made them feel about being a parent to their own child. In Case 2, this family began to exhibit parenting behaviors toward other infants on the unit when those parents were unavailable, acting as "surrogate good parents" to those parentless children. The literature shows that parents of critically and chronically ill children can benefit from support from their experiential peers (Foreman, Willis, & Goodenough, 2006; Hall, Ryan, Beatty, & Grubbs, 2015). In this study, the parents

in Case 2 acted as the veteran parents on the unit and used their knowledge and experience to encourage other parents to advocate for their own children. Additionally, the parents in all three cases used their relationships with their experiential peers as an indicator of hope for their own child. Parents of children diagnosed with cancer indicate that developing relationships with other families was an important factor in their ability to maintain hope for their child (Barrera et al., 2013); the parents in our study indicated that having a sense of hope for their children was an important part of their parental role.

Conclusions

Being a parent to a critically ill infant is a stressful and sensitive time that can impact the family long after the child is discharged from the PICU. Parents of hospitalized children have indicated that when they behave as a “good parent” would, they are better able to cope with their child’s illness (Hinds et al., 2009; October et al., 2014). Our findings indicate that parents of infants cared for in a PICU are strong advocates as a result of believing they have gotten to know their child as a good parent would, whether this was as a critically ill infant in the PICU or as a medically fragile infant at home. Relationships, both with the team and with fellow PICU parents are important and can impact how the parents perceive their child’s condition and the care their child receives. The results of this study have many implications for practice in the PICU. The health care team caring for critically ill infants must be mindful of the delicate transition that many families are making as their newborn infant is being treated for a congenital cardiac anomaly in the PICU. Nurses and physicians should recognize the unique challenges facing parents as they transition into their role as parent of a critically ill child, keeping in mind that parent behavior they may interpret as “difficult” or “disruptive” is often the individualized manifestation of how parents believe a good parent would behave. Nurses and physicians should recognize this behavior as parents trying to be good parents to their ill child; from there partnerships can be created with parents where individualized plans for care and participation are implemented based on parent perception of their role in caring for their critically ill infant.

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CHAPTER 5. THE IMPACT OF FAMILY-CENTERED CARE PRACTICES ON PARENTS OF CHILDREN HOSPITALIZED IN A PICU

Synthesis of Findings

This dissertation aimed to (a) investigate how parents of children hospitalized in the PICU experience FCC, (b) examine parents' perceptions of how the physical and cultural environment of the PICU impacts the implementation of FCC, (c) further develop the model of FCC in the PICU as described by Hill et al. (in press), and (d) examine parents' perceptions of being a good parent to an infant in the PICU and how their perceptions changed over the first year or until the end of the child's life, whichever came first. Taken as a whole, this dissertation revealed much about parents' experiences with FCC and parenting a critically ill child including the importance of environmental factors, the uncertainties inherent in being the parent of a child in the PICU, and how parenting a critically ill child evolves over time as the parent's knowledge and skills develop and the child's condition evolves. Below, I discuss how these findings advance this area of research and implications for nursing practice, education and future research.

Study 1

Multiple professional organizations have called for the delivery of pediatric care to be family-centered, maintaining that as the main constant and legally responsible adults in a child's life parents should be included in the care of their hospitalized child to the level they chose. Additionally, systematic reviews of FCC practices revealed how health care clinicians perceived the delivery of care in hospitalized pediatric patients (Kuo et al, 2012), chronically ill patients (Kuhlthau et al, 2011), and critically ill children in the PICU (Foster, Whitehead, Maybee & Cullens, 2013; Foster, Whitehead & Maybee, 2016). Based on clinical observations of FCC in a PICU, I became interested in how parents, who are key stakeholders in the FCC of their children, perceived the delivery of FCC in the PICU. After

consulting the research literature, I determined that no literature synthesis existed focusing specifically on parent report of their experiences with FCC as outlined by the IPFCC; therefore an integrative review was completed to address this knowledge gap (Hill et al., in press). The investigation revealed evidence of three of the four FCC core concepts: respect and dignity, information sharing, and participation (Table 5.1).

Table 5.1: Subthemes identified in Hill et al., (in press)

Core Concept	Subtheme found in literature
Respect and Dignity	Perceptions of the PICU physical and cultural environment
	Expressions of compassion and support from providers
Information Sharing	Using understandable language
	Medical rounds
	Amount/type of communication
	Satisfaction with communication
Participation	Parents as experts
	How parents participated
	Impact of environment/providers on parent participation
	Medical rounds
Collaboration	No evidence found

However I found no evidence of collaboration as defined at the time by the IPFCC (i.e., collaboration between patients, families and the healthcare team, institution-wide at a programmatic and policy level) (Institute for Patient and Family Centered Care, 2017). Figure 5.1 depicts the conceptual model of FCC in the PICU that I derived from the results of this integrative review.



Figure 5.1: Conceptualization of FCC in the PICU

Parent participants in the studies included in the literature review reported that their needs were both met and unmet with regard to how FCC was implemented by clinicians. That is, despite the Institute of Medicine’s 2001 call for implementation of FCC in the pediatric hospital environment, parents still reported that they did not experience FCC as conceptualized by the IPFCC. In an effort to identify factors that could explain the results of study 1, I explored the literature for results addressing barriers to implementation of the delivery of FCC in the PICU. In their systematic review of FCC in the PICU, Richards, Starks, O’Connor, and Doorenbos (2017) found that parents wanted to be involved in their child’s care but were often negatively impacted by whether and if so, how clinicians allowed them to participate in care; parents were also rarely questioned as to their preferences for participation. In a study examining pediatric nurses perceptions of barriers to implementing FCC, Boztepe and Kerimoglu-Yildiz (2017) found that, while nurses were aware of the principles of FCC and believed that parental presence at bedside was important, pediatric nurses were concerned about parent interference in their nursing practice and that implementing FCC would increase their workload and could lead to an increase in stress and anxiety in nurses. Coats et al. (2018) interviewed pediatric critical care nurses and found that these nurses also recognized benefits of FCC for families in the PICU but expressed how implementing FCC required a “balancing act” (p. 54) that challenged how they delivered nursing care, for instance nurses reported that changes to ICU visitation resulted in an increase in family presence at bedside that left

nurses “exhausted” (p.55) and struggling to juggle the demands of caring for a critically ill child while being attentive to family members at bedside.

In addition to parent report of met and unmet needs regarding FCC and the importance of clinicians, a major discovery from study 1 was the influence of the PICU physical and cultural environment on FCC delivery. The culture of the PICU, or the attitudes and beliefs of clinicians providing care, has historically been one of limited visitation and family involvement (Baird, Davies, Hinds, Baggott, & Rehm, 2015); the results of study 1 taken with the discussed literature indicate the importance of clinician buy-in in the implementation of FCC in the PICU.

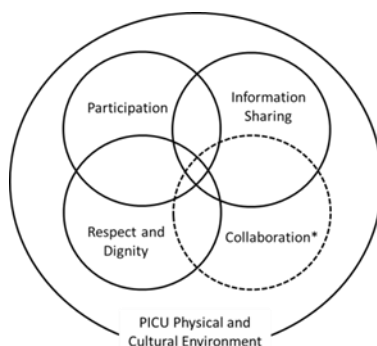


Figure 5.2: Further conceptualization of FCC in the PICU.

*Collaboration is tentatively present pending further investigation and development.

Study 2

Given the findings of study 1, I initiated study 2 to investigate parent perception of how the physical and cultural environment of the PICU influenced FCC, while also further developing the conceptual model that was the outcome of study 1. Figure 5.2 shows the refined conceptual model that resulted from study 2. Specifically, I found that the physical and cultural environment of the PICU greatly influenced parent perceptions of FCC; the core concepts of respect and dignity, information sharing, and participation were interconnected within the physical and cultural environment in the delivery of care that was perceived by parents to be at times both supportive and non-supportive of FCC. In recent years, studies have investigated nurse perceptions of the impact of the PICU physical and

cultural environment in the delivery of FCC. Butler, Willetts, and Copnell (2015) found that PICU nurses appreciated having secured unit where parents needed to request access from staff, they did not feel this inhibited family presence or participation; the nurses believed that limiting access promoted their control over their environment and visitors (including parents). Parents in study 2 commented that having to repeatedly request access to the PICU from the waiting room was a negative. In a study by Butler, Copnell, and Hall (in press), parents of children dying in the PICU indicated that FCC and the environment impacted their relationships with health care clinicians. Parents commented that whether or not they felt welcome on the unit by clinicians indicated a level of respect for them as parents that fostered an improved relationship. Parents were able to develop a positive, collaborative relationship with clinicians when they felt welcomed into the unit and room environment by clinician behaviors, when clinicians demonstrated concern for their physical comfort, and when parents perceived themselves as having “unrestricted access” (p. e4) to their child. Parents reported that when they experienced the physical and cultural environment of the PICU as unwelcoming, they were simply “visitors” and “watchers” rather than parents and active participants in their child’s care.

Although conducted in an adult ICU environment, a Swedish hospital designed an evidence-based ICU patient room to determine how this environmental change might impact nurse perception of care delivery (Sundberg, Olausson, Fridh, & Lindahl, 2017). The newly designed room included soothing colors, sound-proofing materials, access to a private patio, and medical equipment within the room was relocated. Nurses in this study expressed that the newly-designed room improved their perception of their delivery of caring behaviors and felt they were better able to communicate with their patients. The nurses also felt an overall emotional improvement in themselves as nurses and perceived the same in their patients from the newly-designed patient room. Missing an important opportunity to engage other key stakeholders in FCC, this study did not investigate the patient and/or family perception of this environmental modification.

As medical interventions and supportive care technologies advance, the number of children with chronic critical conditions (e.g., chronic ventilator dependence) increases. When entering the hospital,

these children are often cared for in a PICU environment due to their dependence on technology, regardless of if their current condition is considered critical. One of the infants in my study sample could be classified as having a chronic critical condition; this infant was hospitalized in a PICU on multiple occasions because of her ventilator dependence despite not being acutely critically ill. PICU nurses and physicians caring for chronically ill children identify the PICU as being sub-optimal for meeting FCC needs due to inherent visitation restrictions, lack of consistent nurses, and lack of comfort and privacy that would allow respite for parents (Henderson et al., 2017). As the number of children with chronic critical conditions who will be cared for in a PICU increases, the need to incorporate FCC values into the PICU culture becomes even more relevant as parents of these children make valuable contributions to their child's care.

The results of study 2 indicated that parents who comprised the study sample experienced a great deal of uncertainty about their child's condition, the treatment plan, and communication within the PICU that impacted their parenting and how they perceived FCC. Turner, Tomlinson, and Harbaugh (1990) examined parental uncertainty in the PICU and found that parents' uncertainty was related to the technology-laden environment, their child's current illness status, the competency and empathy of their child's clinical caregivers, and the consequences of the child's illness for the family system. The results of my dissertation study indicate that nearly three decades later parents are still experiencing uncertainty in relation to all four dimensions identified by Turner et al. (1990), which resemble the four factors of uncertainty (e.g., ambiguity, lack of clarity, lack of information, and unpredictability) identified by Mishel (1983) regarding parents of hospitalized children. In study 2, parents discussed how the changing plan of care and the lack of a consistent message from the clinicians caring for their child contributed to parental uncertainty about the state of their child's illness and the plan for care going forward. Similar to these findings and indicating the roles that communication plays in generating and sustaining parent uncertainty, Al-Yateem et al. (2017) found that parents of hospitalized children reported moderate to high levels of uncertainty surrounding their child's illness, especially in the lack of information domain.

Performed in the United Arab Emirates at government and independently run hospitals, these researchers found that hospital culture (e.g., policies and guidelines) also contributed to parental uncertainty.

One means through which parents can mitigate uncertainty about their child's illness is through the development of trusting relationships with pediatric nurses, which can be built over time through consistent supportive interactions. The parents in study 2 also commented on the lack of consistent nurses caring for their child and how this negatively impacted parents' experience in the PICU. While the literature focusing specifically on consistent professional caregivers in the PICU is scarce, investigators addressing FCC discuss this theme. Bowman (2010) discussed the trepidation that change of shift and nursing handoff can create in families in the ICU. She acknowledged that the changeover from nurse to nurse could result in inconsistencies in how the oncoming nurse enforced policies or delivered nursing care, resulting in confusion and possibly a decrease in confidence in the oncoming nurses' abilities and expertise. Baird et al. (2016) found that parents of children with complex chronic illnesses cared for in the PICU sought consistency in caregivers but infrequently experienced this model of care. Parents described a sense of relief and relaxation when their child had consistent caregivers and reported a need to remain vigilant when they did not have consistent PICU caregivers. While nurses in this study recognized the benefits of consistent caregivers for parents of chronically ill children, they also identified factors like the need to acquire and maintain technical skills as well as the possibility of emotional attachment as factors that led them to prefer to vary the patients for whom they care rather than participate in consistent caregiving on their unit. Nurses in the Butler, Willetts, and Copnell (2015) study mirrored this by acknowledging that consistent caregivers benefitted parents in the PICU and would ultimately lead to a decrease in confusion and mistrust of clinicians, however, nurses stated that they preferred not to care for the same patients for multiple shifts. The results of the above studies indicate that despite nurses' awareness of the benefits of consistent caregivers to parents of children in the PICU, there are cultural factors and possibly unit factors (e.g., staffing patterns) that would need to be addressed that prevent the regular implementation of this model of caregiving.

Study 3

Building on the results of studies 1 and 2, and recognizing the importance of FCC and how normative parenting behaviors are impacted by having a child in the PICU, study 3 examined parents' experiences in the PICU to further expand the good parent construct. In utilizing three cases that were both similar (complex congenital cardiac anomaly, PICU stay, complications experienced, decisions made) and dissimilar (pre/post-natal diagnosis, length of stay, child outcomes), I examined the parenting experience of those with a critically ill infant over the first year of life. Table 5.2 contains good parent themes previously identified by Hinds et al. (2009) and October et al. (2014) that were found to be present in the parent data of study 3. Table 5.2 also links previously identified FCC concepts to the good parent themes identified in study 3.

Table 5.2: Linking good parent themes to FCC core concepts

Hinds et al. (2009)	October et al. (2014)	FCC concept link
Doing right by my child	Putting my child's needs above my own Making informed medical care decisions	Respect and dignity: Parents need to feel supported (by clinicians) in decision-making for their child. Information sharing: Parents need information that is in a language they can understand, parents seek to participate in medical rounds as a means of information exchange. Parents want as much information as possible, even though this is often overwhelming Participation: Over time, parents become the experts in their child's care by observing and being present. Having knowledge of their child gives them confidence to make decisions and discuss treatment plans/options with providers.
Being there for my child	Staying at my child's side	Respect and dignity: Environment not conducive to having parents overnight or a constant presence at bedside. Parents asked to leave during emergency situations. Information sharing: Being present at bedside allows for contact with clinicians and an exchange of information. Participation: Clinicians impact how much parents are involved. Parent presence is crucial to quality of care provided by clinicians.
Being an advocate for my child	Advocating for my child	Respect and dignity: Parents are trying to meet the needs of the child, how the clinicians treat the parents is integral to whether parents can achieve this goal. Information sharing: Parents need the latest information on their child's illness and treatment plan to be able to make informed decisions and advocate for the child's physical and emotional needs. Participation: For parents to be strong advocates for their child, they must be able to participate and learn their child's behaviors, needs, and wants. Clinicians directly impact parent ability to advocate by how they "allow" parents to participate in care.

Hinds et al. (2009)	October et al. (2014)	FCC concept link
Letting the lord lead	Maintaining faith	Respect and dignity: Clinicians respect parent faith practices. Participation: Clinicians enable parents to participate in preferred faith rituals at bedside.
Not allowing suffering	Focusing on my child's quality of life	Respect and dignity: Clinicians respect parent wishes for care that focus on minimizing suffering or focusing on quality of life. Information sharing: Clinicians keep parents informed on child's condition, including perceived amount of suffering and prognosis; information is honest and contains known treatment options. Information exchange is free of judgment. Participation: Parents make decisions that they can live with regarding treatment options for the child.
Making my child healthy	Focusing on my child's health and longevity	Respect and dignity: Clinicians respect parent choices for care of the child and treatment options. Information sharing: Clinicians exchange honest information with parents regarding treatment options for the child. Participation: Clinicians encourage parents to be involved in the care of the child to the level parents choose.

In addition to the previously identified themes, three newly identified good parent themes that focused on relationships were found in study 3. Table 5.3 lists the newly identified themes and illustrates how the FCC core concepts are linked to these newly identified good parent themes.

Table 5.3: Linking newly identified good parent themes to FCC concepts

Newly identified good parent theme	FCC concept link
Knowing your child	Respect and dignity: Clinicians provide compassionate support to parents and recognize the delicate role the new parents are transitioning into. Information sharing: Clinicians exchange honest and understandable information with parents in a language they can understand, allowing parents to learn as much as possible about their child, their condition, and the treatment plan. Participation: Clinicians have an important role in assisting parents to participate in care at the level they choose. As parents participate in the care of their child, they come to know their child and in turn are able to better make informed decisions and participate fully in care.
Developing relationships with other PICU infants and families	Respect and dignity: The environment of the PICU and waiting room impacts how parents interact with others and what they witness while on the unit and in the waiting room. Participation: Parents observe other parents and ill children on the unit and can adjust their own behavior based on their interaction with other families. Parents may decide to assimilate or avoid parenting behaviors they observe in other families on the unit.

Newly identified good parent theme	FCC concept link
<p align="center">Developing a trusting relationship with members of my child’s team</p>	<p>Respect and dignity: Clinician behaviors and their perceived treatment of parents and the ill child impacts parent ability to form trusting relationships with clinicians.</p> <p>Information sharing: Parent perception of the quality and thoroughness of information exchange impacts the formation of trusting relationships with clinicians.</p> <p>Participation: Parents who actively participate in the care of their child and perceive that they are a valued member of the health care team are able to form trusting relationships with clinicians.</p>

As an example of how the previously and newly identified good parent themes were impacted by the core concepts of FCC, I concluded that the implementation of FCC core concepts as envisioned by the IPFCC are the building blocks needed for parents of critically ill children to realize their vision of being a good parent to their child while in the PICU. One cannot *know their child* without spending time at bedside and participating in the physical, emotional, and administrative care of the child. *Doing right by my child* and *making informed medical care decisions* both require that parents are fully informed regarding their child’s condition and treatment and feel respected by their child’s health care team. To *advocate for one’s child*, parents must have relevant medical information and the ability to perceive and understand their child’s need and wants; the latter comes with time spent with the child and through participating in the child’s care. The *development of trusting relationships with members of the child’s team* hinges on open and honest information exchange, respect and dignity, and inclusion of parents in the care of their child. In conclusion, studying parents’ perceptions of the implementation of FCC as recommended as a model of care by multiple professional organizations is an essential foundation for parenting a critically ill child in accordance with parents’ subjective construct of being a good parent.

Strengths of the Dissertation

This dissertation examined data from parents regarding their perspectives of parenting in the context of the PICU. Until now, no identified literature synthesis had focused specifically on parents’ perceptions; their perceptions are important because parents and families in general are integral

stakeholders in the delivery of family-centered healthcare. Nurses and other clinicians should understand and utilize parent and family perceptions to initiate changes in the health care environment that promote FCC, tailor care to the needs and preferences of individual parents, and engage and empower parents and families. Additionally, the richness, quality, and longitudinal nature of the dataset were notable strengths of this dissertation as was the access to data from fathers, an underrepresented population in pediatric research (Phares, Lopez, Fields, Kamboukos, & Duhig, 2005). The longitudinal nature of the data in this dissertation allowed for analysis of change over time as I was able to follow the trajectory of each case and compare across cases how the parents were distinctively and similarly impacted by their experiences with a child in the PICU. Taking advantage of this longitudinal design, I was able to determine that parental perceptions of FCC, the PICU environment, and their ability to fulfill their vision of being a good parent to an infant in the PICU transformed over the course of a year. The analysis of parental perceptions of their experiences in the PICU over time is a considerable strength of this dissertation; these changes would not be detected in a cross-sectional study. Trustworthiness was enhanced in the analyses by utilizing a second author to perform coding checks on a portion of data used in studies 2 and 3, and two co-authors to validate the data extracted from the literature for use in study 1.

Limitations of the Dissertation

The three studies that comprise this dissertation have limitations. The data utilized in studies 2 and 3 were from an extant data set collected with the primary purpose of investigating decision-making for parents of infants who were critically ill. While utilizing these data and performing a secondary analysis limited the analytic lines I could pursue if I had performed primary analysis, this limitation was mitigated by first performing a feasibility study that indicated the data set was rich with themes consistent with my research aims. However, during the analysis, questions did arise that would have been pursued further with the participants if I had been simultaneously engaged in ongoing data collection and analysis. Additionally, it is important to remember that the results from studies 2 and 3 are from 3 parent dyads and as such, one should be cautious generalizing the results to all parents of children in the PICU.

Future Research and/or Clinical Implications

Through this dissertation I investigated FCC and parenting of critically ill children entirely from the parent perspective, but how do parent perspectives compare to those of the PICU clinicians and what are the consequences of parents and clinicians having shared versus discrepant perspectives? While the clinician research has been synthesized (Foster et al, 2013; 2016), no identified prior study has investigated why, despite the best efforts of child and family advocates, the dimensions of FCC are not always being implemented as recommended by multiple agencies and professional organizations concerned with the well-being of children and families. In light of these recommendations and building upon the findings of this dissertation, the goal of my program of research is to develop and implement interventions at multiple levels to improve FCC in the PICU.

Building upon the importance of FCC in the PICU, parent behaviors are often a manifestation of their beliefs about how a good parent would behave. Once parents leave the PICU and are either transferred to an acute care unit or discharged to home, they are responsible for the care and decision making for their child. One theme I identified in study 3 was the need for parents to become experts in their child's care and condition. The two parent dyads that eventually took their child home from the PICU frequently commented that they had to be the "expert" on their child; one dyad used the phrase "being the quarterback" for their child's care team. I believe this is an important analytic line to pursue given that many infants (specifically those with complex congenital heart anomalies) discharged from the PICU will need ongoing coordination of care involving multiple disciplines. The "parents as quarterback" concept was recently mentioned in the pediatric cardiology literature; the study indicated a need for families to partner with clinicians in the outpatient care of children with congenital heart defects (Haskell, Mannix, James, & Mayer, 2012). In a more recent study, Gaskin (2017) found that parents of infants with congenital heart defects experienced multiple unanticipated transitions and new uncertainties as they were discharged from the hospital to home. Research in the area of care coordination for parents of medically complex and/or chronically ill children has the possibility to inform the PICU and/or pediatric hospital discharge process by addressing which providers parents would contact for a concern

about their child's health and in turn, promote parent confidence upon their child's discharge, or at the very least acknowledge the uncertainty of bringing home a newly medically complex child by planning for some safety net.

Additionally, while this dissertation explored parental perspectives of FCC implementation in the PICU, parents have yet to be asked directly how clinicians and others might help them while their child is critically ill, during transitions in care and care goals, and during survivorship or bereavement. Efforts should be made to collaborate with parents in the improvement of FCC by empowering parents to be active stakeholders in their hospitalization experiences. Exploring FCC needs regarding respect and dignity, information sharing, and participation directly from parents themselves would promote collaboration and the engagement of parents for the improvement of care delivered in the PICU.

In future research, I plan to include data from the nurses and clinicians that care for children in the PICU as well as family members. Future work will focus on investigating the perceived facilitators and barriers to FCC implementation as recommended by the IPFCC and multiple agencies. We must determine whether nurses and clinicians truly understand FCC and its core concepts; barriers could include a lack of education or process issues such as a perceived increase in workload and/or stress in an already overworked and stressful care environment. Building on the findings of study 2, cultural barriers may be inherent in the PICU where unit leaders or other nurses/clinicians are resistant to implementation of FCC. Frost, Green, Gance-Cleveland, Kersten, and Irby (2010) included parents and their self-reported positive and negative experiences with FCC when implementing an educational program targeted at improving FCC on an acute care pediatric unit. When implementing family-integrated care in a NICU environment, Aloysius et al. (2018) involved parents in nursing education programs believing that nurses needed to hear parent stories to begin to understand and incorporate family into their practice. I agree with this initiative and believe that including parent perspective in education related to FCC would provide nurses with an understanding and perhaps appreciation of how FCC can be beneficial to parents and ultimately the children, too. Based on the findings of these proposed studies, an evidence-based

education program including parents targeted to PICU nurses, clinicians, and/or management (based on identified barriers) could be developed.

Another finding from this dissertation was the importance of consistent caregivers for children in the PICU. In study 3, parents reported satisfaction in having caregivers they recognized and that were familiar with their child. There is a scarcity of research investigating use of consistent nurses in the PICU and how this impacts parent and nurse satisfaction as well as outcomes for the hospitalized child. Future research directions could include a synthesis of the literature on consistent nurse caregivers and perhaps an exploratory study of multiple PICUs to determine the presence of this model of care, and if not practiced, what are perceived barriers (e.g., management, staff, scheduling) to this model. If consistent nurse caregiving is practiced, it would be valuable to explore when, how and why this practice was implemented and the perception of parents/staff.

As has been shown in this dissertation, FCC is important to parents of critically ill children and impacts their ability to be a good parent to their hospitalized child. I see no shortage of research paths going forward; all have the possibility of improving the experience for parents and families of critically ill children. This dissertation is only the first step in what will hopefully be a long program of research that positively impacts care delivered in the PICU and ultimately improves outcomes for critically ill children and their families.

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