

Family-Centered Care in Pediatric Intensive Care Units

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Abstract

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Background: Parents of children admitted to the ICU can experience long-lasting distress associated with communication problems and parental role disturbance. Family-centered care (FCC) is a partnership approach to care that is proposed to improve outcomes. Palliative care (PC) is a FCC approach that supports quality of life consistent with patient and family values. **Purpose:** This study examined FCC in pediatric critical care settings with the goal of making recommendations to improve its implementation.

Methods: The first part is a systematic search and thematic analysis of 33 qualitative articles. The second and third parts analyzed semi-structured interviews with 22 physicians from neonatal, pediatric and cardiothoracic intensive care units in a single pediatric hospital. Transcripts were analyzed using content and thematic analysis. **Results:** Parental preferences for involvement differ in the domains of information sharing, decision making, and power-sharing across a spectrum of parental roles, from parents as care providers to parents as care recipients. Families want to be included in discussions, decisions and actions related to their child's care, but system and clinician level factors create barriers to their participation. System factors include competing priorities, fragmentation of care, and continuity issues. Clinician factors include skill needs for exploring family role preferences, hopes and goals, beliefs about quality of life, and

preferences for acute vs. chronic care. These factors contribute to unmet PC needs for patients with longer stays and greater medical complexity. PC consultation teams can help meet these needs but system factors also limit their participation. **Conclusions:** Including PC needs checklists may stimulate earlier and more frequent goals of care discussions and identify unmet needs to trigger consultation with the PC team. Interventions to improve coordination of care and continuity include maintaining a list of the roles and names of all clinicians involved in a child's care and standardizing the format of a weekly report with families to assure consistency in information sharing. Families want to be involved in their child's ICU care, which will require system- and clinician-level changes in practice given competing demands and skills. Palliative care teams offer additional support and can facilitate family-centered care in pediatric ICUs.

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DEDICATION

This is dedicated to my son Paxton Harvey Richards, born during in the midst of my dissertation work.

“Happy toot toot!”

You made me a mother and have brought me joy I never imagined possible.

“Every single life is lived in the shadow of our mortality, which means all those things we cherish are not just part of life, they’re ultimately part of our death” –Nina Riggs

“We are certain only that there is so much of what we are uncertain” – Nina Riggs

“Palliative care is a work-around, not a solution. Radical system change is needed that includes a fundamentally new alliance among patients, families, and professionals.” – Stu Farber

Chapter 1. Introduction

1.1 The Problem

Estimates of pediatric death each year range from 43,000 to 55,000, including children from birth to 19 years old.^{1,2} Children die most often die in the ICU, usually following the decision to withdraw or limit life-sustaining treatments (LST).^{1,3-5} Advancements in medical technology have improved survival, along with a concomitant increase in the number of children with chronic conditions and disability.⁶ Following a hospitalization in the ICU, many parents and children report symptoms of post-traumatic intensive care syndrome, regardless of the outcome.⁷⁻¹¹ Parental role disturbance and communication with the clinical team are contributing factors to psychological distress in parents.^{9,12-16} Family-centered care (FCC) is considered an approach to care that supports the parental role and involvement of family in the care of the child,¹⁷⁻²⁰ and may be an important way to improve psychological outcomes of parents as well as children.

Family-centered care is defined as an “equal partnership” where the treatment plan is “mutually developed” by clinicians and families.¹⁸ However, conceptual work has brought up questions about the nature of FCC because there is a lack of agreement between practice and theory.²⁰ Problems with implementing FCC in practice suggests that FCC is more of a theory of change rather than a theory that reflects actual practice: “... *a change in practice is required* to support the family’s understanding and ability to actively participate in their child’s care.”²¹

1.2 Evolution of FCC

Between the 1920s and 1940s, hospitals had severely restrictive visitation policies for families of admitted children.^{22,23} Reasons for these restrictive visitation policies included fear of infectious disease outbreaks and concern that the children were distressed when their parents visited.^{22,23} Policies began to change in the 1950s when researchers such as John Bowlby identified the negative effect of child separation on the psychological wellbeing and development of the child^{22,23} and the Platt Report identified the importance of family participation in the care of a hospitalized child.²⁴ The Association for the Care of Children’s Health (ACCH) was formed in 1965 to respond to concerns about hospital policies and worked

on initiatives for families with chronically ill children, collaborating with families including those with special health care needs.²³ The effect was slow and clinicians remained ambivalent about the involvement of families in the care of hospitalized children, with clinicians continuing to label the presence of mothers as distressing throughout the 1960s and 1970s.²⁵ Families of children and youth with special health needs (CYSHCN) collaborated with organizations such as the federal Maternal and Child Health Board (MCHB) in the 1980s and Family Voices in the 1990s to develop a variety of programs in the community and partnerships with professional organizations, with a particular focus on clinician/family partnerships.²⁶ In 1992, the Institute for Family-Centered Care (IFCC) took over the role of the ACCH,²⁷ developing position papers and publications and advocating on a policy level for the development of children's health initiatives, in particular FCC.²²

The slow implementation of FCC in critical care is considered to be due to the prioritization of technical aspects of care over the psychosocial needs of the child and family.²³ This has also been attributed to the beliefs and traditions of nursing, and a culture in which nurses understood they were not to ask critical questions or form or express clinical opinions.²⁵ However, knowledge produced by nursing research and other disciplines has been viewed as essential for providing a theoretical base to guide practice, through the development of the concept of FCC.²⁵ With increasing acceptance of family presence and involvement in the care of hospitalized children, research on families became less focused on the stress and dysfunction of families, and more on identifying the strengths and needs of families.²⁵

As a result of medical technology, children who survived the ICU after being on positive-pressure ventilation, went on to develop chronic pulmonary diseases requiring ongoing care. FCC changed from a focus on open visiting in the 1960s to involving several important elements by the 1990s.²⁵ The IFCC was renamed as the Institute for Patient- and Family-Centered Care in 2010 to explicitly include the role of the child.²⁸ The term *patient- and family-centered care* (PFCC) is a newer term that appears in the literature after the year 2000, although it is not differentiated from the term *family-centered care* (FCC) and the two terms are used to describe the same concept. The term FCC is used more frequently than PFCC in the literature and so this term is used throughout this dissertation.

In 2001, the Institute of Medicine published *Crossing the Quality Chasm: A New Health System for the 21st Century*, declaring patient-centered care as a domain of health care quality.²⁹ Hospitals were

encouraged by a joint policy statement from the American Academy of Pediatrics and the Institute for Family-Centered Care in 2003 to establish policies for patient- and family-centered rounds.^{30,31} Prior to this time, physicians conducted rounds, informed staff to implement the orders, and then informed family later.³¹ The shift to patient and family-centered rounds was intended to bring the patient and family “back to the center,” by becoming more transparent and allowing for patients and families to participate in decisions during rounds.^{21,31}

FCC is now considered the gold standard of care delivery in pediatrics,³² and there has been growing momentum to apply the principles of FCC across both primary and critical care, and both adult and pediatric settings,³³ FCC is used widely by pediatric health care practitioners around the world,²² and is endorsed by many professional associations including the American Association for Critical Care Nurses,³⁴ the Society of Pediatric Nurses,³⁵ and the American Academy of Pediatrics,³⁰ among others.

1.3 Definition of FCC

Despite general acceptance of the benefits of FCC, empirical evidence about its use and related outcomes is lacking.²⁷ Studying FCC is made more difficult by the fact that the concept of FCC is highly abstract and there is disagreement about the definition of what constitutes FCC.³⁶ A lack of conceptual clarity of FCC is thought to be a key challenge to the implementation of FCC in practice across settings.³⁷ The scope of the term FCC is sometimes very broad and used to describe collaboration with families inclusive of both the level of the health care system and the point of care delivery,^{17,33,38,39} and other times used to describe only elements of care at the level of care delivery.^{18,20,32,40,41} Definitions of FCC have been found to differ in that they range from viewing the family as a care provider, in equal partnership with the clinical team, to a care recipient, for whom decisions are made in their best interest.²⁰

Despite differences, there are several thematic similarities in the attributes of FCC in the pediatric intensive care unit including facilitating family presence and participation in care, communication of compassion and caring, sharing of information with family, inclusion of parental expertise, negotiation and flexibility, and sharing goals (see Table 1.1)

Table 1.1 Attributes of FCC in the Pediatric Intensive Care Unit (PICU)

<p>Facilitation of family presence. Family is made to feel welcome and their presence is facilitated, including at the bedside, rounds, procedures, and invasive procedures.^{13,24,42-49}</p>
<p>Facilitation of family participation in care. Clinicians encourage and facilitate parental participation in physical and emotional care for child according to parents' preferences.^{24,42,44,50}</p>
<p>Communication of compassion and caring. Compassion and caring communicated by clinicians to family both verbally and non-verbally. Non-verbal communication of compassion and caring includes supportive actions such as being present, attentive, and addressing basic needs.^{45,46,48,51-58}</p>
<p>Sharing of information with family. Clinicians share clear, honest, accurate, sensitive, and timely information in a language family can understand and on an ongoing basis that allows parents to fully participate.^{46,48,50-52,54,57-66}</p>
<p>Inclusion of parental expertise. Family expertise is valued and included in development of daily care plans and decisions to provide higher quality care to the child.^{47,49,53,61,63,67}</p>
<p>Flexibility and Negotiation. Clinicians are flexible and responsive to the needs, preferences and circumstances of family and are willing to negotiate roles, such that family participation and presence is individualized and not dictated by cultural and institutional norms.^{24,44,49,50,54,55,61,68}</p>
<p>Sharing Goals. Shared or mutually agreed upon goals are developed between family and clinician in a process of decision-making about daily care plans, treatments, and interventions.^{45,47,55,66,67,69}</p>

All attributes of FCC may be viewed as supporting the parent in fulfilling the parental role to protect their child. However, three of the attributes specifically address including the parents voice at the level of care delivery. These three attributes are: Inclusion of Parental expertise, Negotiation and flexibility, and Sharing Goals. See Figure 1.1

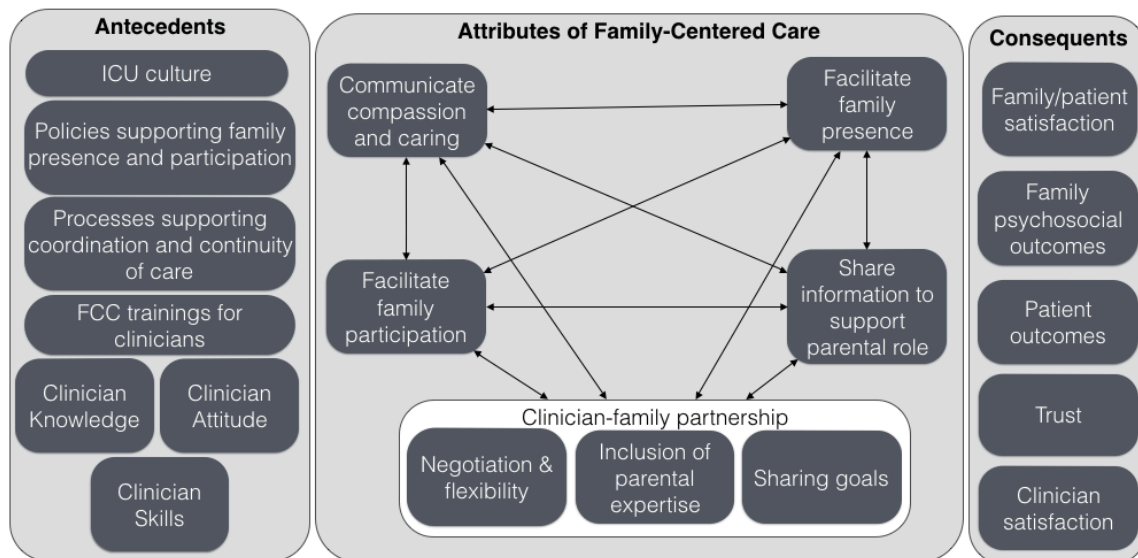


Figure 1.1 Conceptual Model of Family-Centered Care

1.4 Antecedents of FCC

Organizational factors influence the capacity for clinicians to deliver FCC. These organizational factors include the culture of the ICU^{55,60,64,70} and policies and protocols that guide family visitation and presence during rounds and resuscitation, and policies for implementing family meetings, such as during admissions or after discharge.^{13,43,45,49,50,52,54,58,61,63,64,67} Additionally, unit processes that support coordination and continuity of care through communication among the clinical team and between clinicians and families on a consistent basis are needed for FCC.^{24,43,44,58,60,71} Provision of trainings including communication skills and knowledge about unit level practices and benefits of FCC also support the implementation of FCC at the level of care delivery.^{13,43,48,52,54,57,58,72}

Clinician knowledge, attitudes, and skills are required for the implementation of FCC. These include knowledge that the parent has an important role in the child's life, and that parental involvement, presence, and knowledge of their child's needs is beneficial for the child's care.^{24,48,51,57,58,73,74 49,74} Additionally, family-centered attitudes include a willingness to listen to the opinions of families and incorporate their expertise into care and treatment plans, and respect for diversity in regards to beliefs, individuality, and methods of coping.^{43,57,64,73} Lastly, clinicians should possess communication skills, including assessing parental needs, being compassionate, sensitive, self-aware, empathetic, in addition to having technical competence, and sharing information with families, even in crisis or emotionally charged situations^{43,46,51,52,54,56,58,66,69,71}

1.5 Consequents of FCC

FCC offers several benefits to the child-patient, family, clinician, and clinician-family relationship. FCC is proposed to increase patient and family satisfaction with care and communication,^{13,24,44,45,47-49,51,52,56,58,61,63,66,71,75,76} improve psychosocial outcomes, such as reduce anxiety and distress, improve coping, and facilitate bereavement and reduce grief.^{13,24,41,45,46,49,51,54,56,60,66,70,71,77} The parental role and relationships within the family are also supported and maintained.^{24,44-46,49,56,62,70,77} FCC improves relationships between clinicians and families by helping build and maintain trust with families, which results in less conflict.^{47,66,69,71,73-76} Lastly, FCC supports clinician satisfaction in their roles.^{13,74}

1.6 Barriers to FCC

There are particular challenges to the implementation of family-centered communication in the PICU, in part because of the lack of knowledge, attitudes, and skills of clinicians (nested within organizational factors) congruent with family-centered care. Both medical⁶⁷ and nursing^{50,51,78} literature note that efficiency is in conflict with the needs of the family to be present and involved in the child's care, and the need for efficiency is viewed as an obstacle to including family in rounds or other processes. Additionally, concerns about the implementation of family-centered rounds commonly include the perception that when a clinician or trainee asks a question, family members will have less confidence in the clinical team and may challenge the authority of the clinician or trainee.⁶⁷ This suggests a tendency in PICU culture for clinicians to maintain their status as *the* expert, which contradicts the premise of FCC acknowledges and includes the expertise of the family.

Furthermore, conflict is reported between clinicians and family as a result of "gatekeeping" behaviors, in which clinicians attempt to limit the presence and participation of family and effectively distances the family from the child.⁵⁷ These gatekeeping behaviors are used to either maintain a professional role or to prevent interference from the family.²⁴ The term "gatekeeping" is used specifically in the nursing literature, although attitudes that fit under this concept are also reported in the medical literature. For example, clinicians are reportedly concerned that presence of family at rounds and resuscitation would cause interference with care delivery, result in increases in litigation, reduced teaching opportunities for residents and staff, and reduced authority for clinicians who ask questions.^{13,47,49,61,63,67,72} Despite the assertion of these concerns, there is very little evidence to substantiate them.^{55,61,79}

1.7 Conflict

Gatekeeping behaviors and attitudes contribute to clinician-family power struggles and conflict. The nursing literature describes these power struggles that result when rules are prioritized over family needs,^{42,44} or staff is authoritarian and paternalistic.^{43,44,51} Within the medical literature, Coleman & Pon state that if boundaries are not maintained when collaborating with family, family-centered care will turn into family-dictated or family-directed care, creating an "uncomfortable environment."⁴⁷ Page & Boeing⁴³

write that power struggles between nurses and family can be avoided by mutually defining goals rather than defining goals for family while the family maintains a more passive role. Similarly, Lewis-Newby & Curtis argue that “effective communication” would usually allow for the development of shared goals between clinicians and family.⁵⁵

1.8 Sharing power

The sharing of power between HCPs and families arises out of a confluence of other attributes of FCC. Both compassionate communication and information sharing support the family’s ability to participate in decision-making. However, communication practices are generally clinician driven and often fail to include family’s needs or interests. For example, during rounds or on follow up visits with families at the bedside, the type of information clinicians typically share tends to focus on clinical team priorities, such as clinical indicators, and to a lesser extent on the priorities of families, such as the patient’s quality of life.⁷¹ This suggests that agenda setting is not consistently negotiated, and that the topics of discussion are based on the priorities of the clinical team and not those of the family. This may interfere with the development of shared goals because parents do not have the information that is meaningful to them to fully participate in decisions.

Decision-making on a daily basis, involving both daily care plans and complex discussions about medical treatments, is viewed as an important part of FCC. However, it remains unclear if there is a particular approach to decision-making that is viewed as congruent with FCC attributes or if parents are asked about their preferred role in decision-making. Decision-making models can range from paternalism to informed choice and the type of decision-making model used may also be negotiated based on family needs and preferences.⁸⁰ For example, some families may prefer to make an informed choice while others may prefer to let the clinical team decide. This decision making preference may vary across the type of decision being made. Several authors identify improved decision-making as an outcome of FCC,^{51,60,71} but it is unclear how this occurs. Others suggest that a particular model of decision-making, called shared decision-making,^{13,81} is an attribute of FCC. In contrast, Foster et al. notes that paternalistic decision-making models may be acceptable to some families when they feel informed.⁵¹

In order to make recommendations to support the parental role and improve outcomes, there is a need to first understand *how* FCC is implemented in practice, in particular how power is shared and how shared goals are developed within the local context of pediatric critical care and the complex challenges that the setting presents. In the next chapters of this dissertation, I examine FCC in pediatric critical care settings on individual and organizational levels, with the goal of making recommendations to improve its implementation.

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Chapter 2. Elements of Family-Centered Care in the Pediatric Intensive Care Unit: An Integrative Review

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Elements of family-centered care in the pediatric intensive care unit: an integrative review. *J Hosp Palliat Nurs.* 2017;19(3):238-246

2.1 Abstract

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

2.3 Background

A child's admission to a pediatric intensive care unit (PICU) is an overwhelming time for the patient and family because of the emotional intensity they experience and the medical complexity of the care being given.¹ Most deaths of pediatric patients in the hospital occur in the PICU² and, regardless of the outcome, families may experience feelings of uncertainty and fear of a poor outcome or the death of the child.³ Additional causes of psychological distress in parents include parental role disturbance and poor communication experiences with health care teams.⁴⁻⁶ Psychological effects can be long-lasting,⁷ and there is an association between the distress parents experience and the long-term psychological well-being of the child.⁸ Family-centered care (FCC) is a partnership approach to care that supports the

parental role and involvement of parents in the care of their child.⁹⁻¹² FCC promotes dialogic communication between families and clinicians that aims to support “more effective, efficient, and empathic pediatric health care”¹³ and is proposed as an important contributor to addressing family distress and improving long-term outcomes of children and their families.

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

2.4 Methods

We conducted a comprehensive review of qualitative and mixed methods empirical research on nurse and physician communication with parents of critically ill children in the PICU, using a systematic approach. We limited the search to studies that reported using qualitative and mixed methods research to examine how FCC was being framed and to further refine the concepts and definitions of FCC as it applies in pediatrics. Searches were performed using PubMed and CINAHL databases and included publications for all articles up to April 2015. We used a broad range of search terms relevant to FCC (see

Table 1) because previous research only using the search term “family-centered care” missed articles that report on elements of FCC due to the limited search strategy.¹⁵ In preparation for this systematic literature review, a concept analysis was first performed to define FCC in the PICU and inform the search strategy. For this review, FCC is defined as including some or all of the following elements:

1. the mutual exchange or sharing of information and goals between clinicians and parents, including advocacy by parents for their child²¹⁻²⁶
2. decision-making about day-to-day caregiving, medical care, or withdrawal or limiting of life-sustaining treatment^{24,27-30} and
3. negotiation of roles in providing care to the child or the negotiation of presence during interventions and medical communication events^{22,26,30-35}

This search strategy identified an initial set of 780 articles, including 231 duplicates which were removed. The titles and abstracts of the 549 articles were then evaluated for the inclusion and exclusion criteria (see Table 1 for criteria). After this review, another 481 articles were omitted; the remaining 68 full-text articles were read and an additional 35 articles were excluded because they did not meet the inclusion criteria, leaving a final set of 33 articles published between 1990-2015 (see Figure 2.1 PRISMA diagram).³⁶

The full texts of the 33 articles meeting inclusion criteria were then further evaluated to determine if there was any discussion about including the voice of parents as described in Table 1. For example, the unidirectional sharing of information from clinician to family alone did not meet the inclusion criteria; we also required there be some description of the family sharing information with clinicians, participating in decisions, negotiating their role or presence at the bedside, or advocating for the child. Once selected for inclusion, each article was read at least once to get a sense of the whole and then reviewed again to abstract the following structured data elements: the country of origin; research question and design; theoretical or conceptual frameworks used to guide the project; methodological orientation; methods of sampling, data collection and analysis; and key findings related to family-centered care including information-sharing, parental advocacy or expertise, negotiation, how mutual goals or needs/expectations were defined, and support of family participation. The findings were then read across studies to identify and group similar themes.³⁷

Table 2.1 Search Strategy

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

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

* indicates "wild card" to include all possible endings

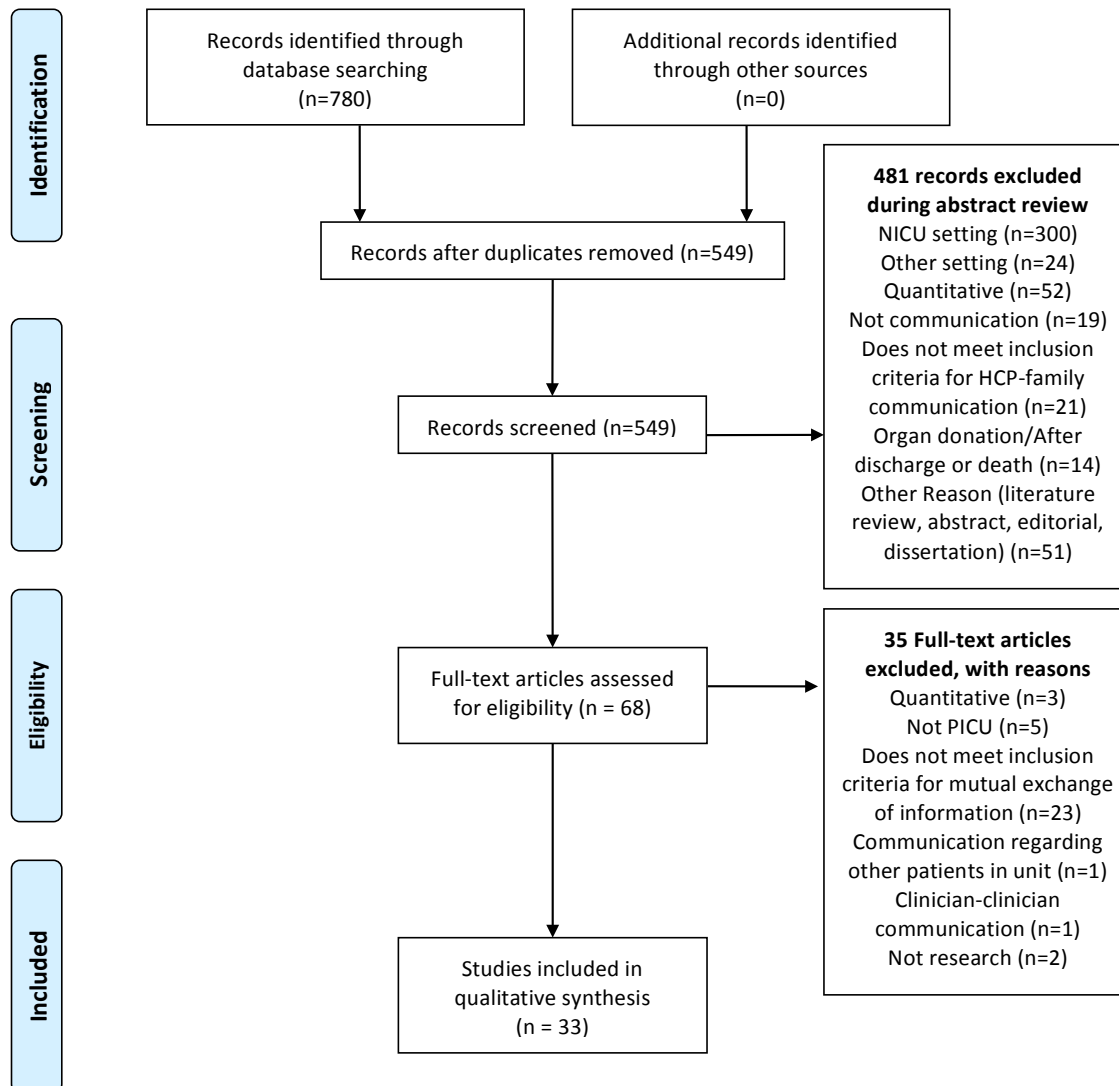


Figure 2.1 PRISMA Diagram

2.5 Results

Overview of the articles. Of the 33 articles included in this synthesis, 29 used only qualitative methods and four used mixed methods (see supplementary materials). The majority of studies were performed either in the United States or in Europe. The majority of data (81% of the studies) were collected through focus groups and interviews, or open-ended survey questions; 19% of the studies involved direct or indirect observation (e.g., either as ethnographic studies or audio-recording of actual communication events). Study designs were mostly cross-sectional; 19% used longitudinal designs, of

which 6% collected longitudinal data but did not analyze those data over time. Parental views were included in 30 of the 33 studies.

Diversity. All of the studies reported demographic information about study participants' gender. Of the 30 articles that included parents as participants, only 12 articles (36%) included information about race, ethnicity, or nationality, all of which were performed in the United States except one from the Netherlands³⁸ and one from Italy.³⁹ Five of the 10 articles in the United States that include demographic information describe samples with 75% or more White participants. There were 17 articles that include clinicians as participants, of which only 4 articles (24%) describe the ethnicity, race or nationality of the clinicians.^{38,40-42} Only four articles (12%), all from the United States, discuss any influence of cultural or language differences or socioeconomic status indicators (such as race and class) in relation to biases and their effects on communication.⁴¹⁻⁴⁴

2.6 Synthesis of Findings

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

Sharing information with parents

Parents seek honest, clear, and complete information^{43,45-51} to be able to actively participate in decision-making^{48,52} and in the physical care and comfort to their child,^{44,45,48} as well as to cope with uncertainty and fear of a poor outcome..^{43,50,53} Access to information can make parents feel more prepared, less helpless, and give them a sense of control.^{43,45,50,53} Parents reported that they wanted to receive information even when it was potentially distressing^{43,44,54} and wanted to be informed about decisions even when clinicians are the primary decision-makers.^{44,52,53,55} Two articles by Carnevale et al (2006; 2007) suggest that improved coping may help parents feel less fear and regret, and facilitate closure and grieving if the child dies.

Despite parental desires for clear, complete and honest information, several studies found that

clinician communication often entailed use of medical terminology, euphemisms and complex speech that was difficult for parents to understand.^{41,44,55-57} Other studies reported that some clinicians withhold information,⁵³ avoid being transparent with the intention of protecting families from distressing information,⁵⁷ and manage the timing and kind of information that parents receive. For example, clinicians are reportedly more reserved about what they say during rounds when parents are present, such as information about poor care at other facilities or medical errors.⁵⁸ However, withholding information can lead to parental distress⁵⁹ and contribute to a sense of powerlessness⁵⁹ and fear,⁵³ insecurity and anxiety,⁵⁹ a stressful search for information,⁵⁰ and an erosion of trust in clinicians.⁵⁷

Clinicians report that they attempt to balance hope with realism in the information they give families.^{47,60} Gordon et al.⁶¹ describes a balance of hope and realism as an outcome of parental understanding of both prognostic uncertainty and the reasons and implications of tests and procedures. However, uncertain information may conflict with families' preferences for clear information and may make parents wonder if they can trust the clinician's competence, commitment, or transparency⁴⁶ and put clinicians in a difficult situation.

Hearing parental voices

Parents report wanting clinicians to listen to them, answer questions, address their concerns and incorporate their knowledge into the treatment plan. They want to be involved to improve the child's quality of care by sharing important information, correcting misinformation, helping to avoid medical errors, and preventing infections^{43-46,49,54,62}. Similarly, parents want to share their specialist knowledge of the child,^{46,54} including cues and indicators of pain,^{45,53} and physical, emotional and spiritual needs.⁴⁸ Yet some parents report that their medical knowledge is often either not solicited or disregarded,^{39,63} and their questions and concerns are left unaddressed.^{40,53,56} A study by de Vos et al.³⁸ found that only a third of clinicians invited families to share their observations about the child's ability to interact or their perceptions of the child's level of comfort. Both Van Cleave et al.⁴¹ and de Vos et al.³⁸ found that in family conferences clinicians spoke a disproportionate amount of time.

The unequal power and authority to direct care between parents and clinicians makes it difficult for parents to speak up about concerns they have, ask questions, or challenge a clinician's decision because of concerns that this behavior would jeopardize their relationship with providers upon whom they

depend for their child's care.⁶⁴⁻⁶⁶ Clinicians have also described power differentials that reduced parental involvement, citing parental concerns about "rock[ing] the boat" by asking questions.⁵⁸ One observational study found that nurses labeled parents who advocated and asked questions as "difficult" with negative impacts on subsequent interactions.⁴⁰

Listening to parents is essential in order for parents to be in partnership with clinicians⁶³ and to establish a trusting relationship.⁴⁵ However, clinician biases may prohibit the development of a partnership with parents of minority ethnic and racial backgrounds. One study in the United States found that parents were less likely to communicate concerns if they felt they were viewed negatively.⁴³ Furthermore, racial and ethnic minority parents were more likely to report, unsolicited, that clinicians did not listen to them. Racial and ethnic minority parents gave accounts of events in which they perceived that clinicians were discriminating against them and making assumptions based upon race, language, and insurance status, which made communication difficult. In combination, this information suggests that racial and ethnic minority families may feel less comfortable communicating concerns and being in partnership with clinicians than non-Hispanic White families. It is unclear to what extent clinicians were aware of the influence of biases on communication. In another study in the United States, Bartel et al.⁴² describe how physicians did not discuss how differences in race or socioeconomic status may have influenced communication with families and may not have wanted to admit to failures in communication. Open dialogue about the role of biases in communication may facilitate greater self-awareness and improved patient and family experiences.

Making decisions for or with parents

Studies based in France, Italy, Turkey, and the Netherlands described an ethical and legal norm called "beneficent paternalism" in which the role of the physician is to make treatment decisions for critically ill children,^{38,49,51,55} and then parents are given the option to assent or dissent to the decision. In contrast, in the United States and Canada, the ethical and legal norm is for parents to make decisions for critically ill pediatric patients based on a best interest standard in which an attempt to balance benefit and harm is made.^{13,49} Across countries, however, studies report beliefs that physicians make decisions for parents because they believe that parents do not have the necessary knowledge to participate in such complex decision-making and that parents would otherwise be burdened with feeling culpable and

responsible if the child were to die.^{38,47,49} While Bartel et al.⁴² and Michelson et al.⁴⁷ in the United States describe parents as being ultimately legally responsible for end-of-life decisions, Michelson, Patel, Haber-Barker, Emanuel, Frader⁴⁷ also describe a process of secondary decision-making in which clinicians influence the decisions parents make by limiting the choices available or how information is delivered, with the goal to reduce the burden of decision-making for parents. In a longitudinal observational study in the Netherlands, de Vos et al.³⁸ describe a decision-making process in which parents were more involved earlier in the hospital stay with sharing information and preferences. However, decisions to withdraw LST were ultimately made by clinicians who would allow time for parents to adapt to this decision if they disagreed. These authors also report that clinicians wanted to protect parents from decisional regret by taking responsibility for the decisions and not including parents, yet parents were found to be capable of participating in difficult decisions despite feeling intense emotions. Furthermore, in a comparison of practices in France and Quebec, there was no pattern between parental involvement in life-support or surgical treatment decision-making and subsequent feelings of regret or guilt.⁴⁹

Individualizing communication

The literature reports a range of parental preferences for communication, such as level of participation in decision-making or type and degree of information that is shared. Some parents want to defer decisions to physicians and other parents want to be more involved and have physicians support their decisions.^{39,49,51,52,55,59,67} Some parents have reported that they wanted only basic information about the care being provided to their child⁴⁵ and that they did not want to be informed until care plans were certain⁴³ because hearing varying perspectives on potential diagnoses and their child's medical history increased their anxiety and confusion.^{63,68} However, other parents reported that they wanted to be informed about the different aspects of the care plan that clinicians were considering⁴³ and to know as much as possible to better understand their child's condition.^{45,63} For example, Meyer, Ritholz, Burns, Truog⁵⁰ found that parents had different levels of tolerance for uncertainty and complexity and that some parents preferred to know all the viewpoints when there were conflicting perspectives among the health care team, while others preferred talking with just one spokesperson. Greater comfort levels with differing perspectives may have been because they experienced greater cohesion overall in the information from their clinical team⁵⁰ and not because of fundamental differences in communication styles.

Negotiating roles

Role negotiation is defined as collaborating with parents in deciding the level of involvement on the part of parents in providing care to the child, including presence at the bedside and participation in decisions. Overall, there was little discussion about negotiation of roles in this literature. In one study, clinicians indicated that they should have the authority to determine if parents can be present during resuscitation events.⁶⁴ The common practice was for clinicians to ask parents to leave during resuscitation events without inquiring about parental preferences or consulting with other clinicians. In regards to negotiating the level of parental involvement in decisions, Carnevale et al.⁴⁶ report that clinicians were unclear as to how to determine decisional-authority in different circumstances, and de Vos et al.³⁸ found that none of the physicians in their study assessed parental preferences for level of decision-making involvement.

There was some indication that barriers to role negotiation include power differentials and differing priorities. de Vos et al.³⁸ found that some parents expressed strong objections to decisions made by clinicians while others complied, resulting in differences in parental influence on the ultimate decision. Because clinicians did not actively solicit parental preferences for participation in decision-making, it is unclear if different behavior is a result of preferences for participation or different comfort levels or cultural norms about challenging power differentials between clinicians and families. Baird et al.⁴⁰ found that parental behaviors to seek individualized care were perceived by nurses as problematic and challenging. DeLemos found that some parents were less likely to communicate concerns if they felt they were viewed negatively.⁴³ Additionally, racial and ethnic minority parents were more likely to report, unsolicited, that clinicians did not listen to them. This suggests that power differentials present in relationships between clinicians and parents may impede negotiation and are of particular concern for parents racial and ethnic minority parents.

A few studies report that clinicians prioritize efficiency, rules, and norms over family needs and participation. Jefferson and Paterson⁶⁴ reported that clinicians' made decisions regarding parental presence during resuscitation events based on their personal goals for either an efficient procedure or to maintain the child-parent relationship.. Baird reported that clinicians are challenged to respond to competing priorities to both deliver safe and efficient care while also giving patient and families a

satisfying experience. These goals are often in tension with each other because clinicians have come to prioritize rules and norms that do not necessarily meet the needs of individual patients and families. Macdonald et al.⁶⁹ also found that there was a conflict between the interests of families and clinicians, and rules regarding behavior and noise levels were applied to parents and not to PICU staff. These different standards for behavior are attributed to whether parents are viewed as (and made to feel like) guests or visitors^{39,69} or members of the health care team.⁴⁰

2.7 Discussion

FCC has been described as existing along a continuum of clinician-family partnership.¹² This continuum ranges on one end from emphasizing the role of parents as care providers, actively contributing their knowledge, observations, and expertise about their child to the plan of care along *with* clinicians, to the other end in which parents are viewed as care recipients, who are being cared *for* by clinicians who take responsibility for distressing decisions and procedures.¹⁵ The literature highlights three domains of the clinician-family partnership in the PICU with varying levels of family involvement: information sharing, power sharing, and goal sharing (see Figure 2.2). The continuum includes variation across these three domains such that families may be at one end or the other, or some combination of both providing and receiving care. These are three domains in which parental roles may be negotiated. FCC in pediatric critical care is a dynamic construct that is unique to different families and that may vary over time.

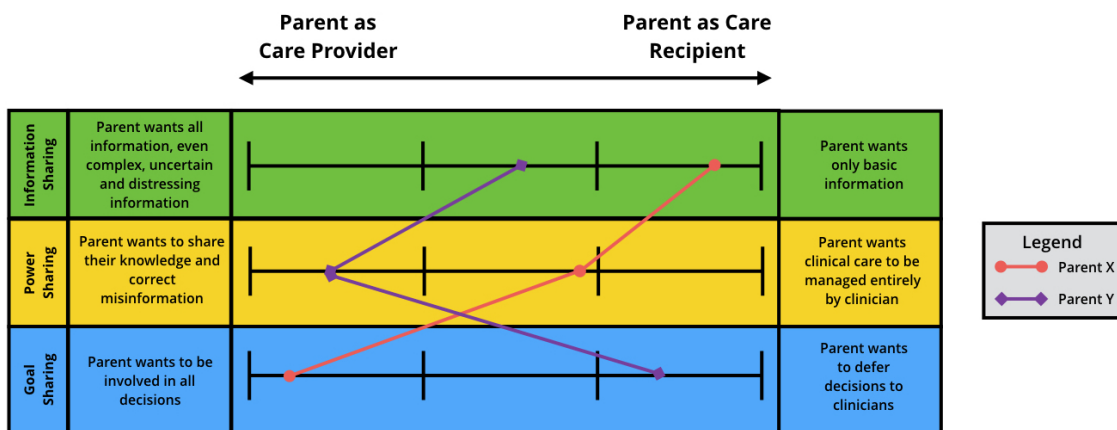


Figure 2.2 Continuum of Family-Centered Care

** Parent X and Y are examples and not based on data

Our review suggests that in general, clinicians in the PICU are still the ones who determine the level of parental access to information, participation in decisions, and presence during procedures.^{38,47,49,53,57,58,64} Exercising this authority may be done to achieve the well-intentioned goal of alleviating family distress, but it also serves the medical-centered goals of efficiency and the enforcement of rules and norms.^{40,64,69} In contrast, parents reported a wish to have a more active role in their child's care, in which they had greater access to information,^{43,44,47-51,54} more participation in the development of treatment plans,^{43-45,54,62} and more recognition and inclusion of their knowledge and concerns about the child.^{45,52,63} This involvement may reduce parental emotional distress by allowing them to fulfill a parental role to protect their child's life and ensure higher quality of care.

Family preferences and needs for their roles as care recipient and care provider may vary depending on the clinical situation and personal characteristics of families, such as the nature of the patient's diagnosis or a family's ability to manage uncertain and complex information. Thus, it is not possible to deliver FCC in a one-size-fits-all approach. It is necessary to negotiate with parents the level of involvement they have by inquiring into their preferences and tailoring communication to their needs. While it has been recommended that communication and decision-making involvement be individualized for the preferences and needs of families,^{39,43,50} parental roles are not often negotiated and there is a lack of specific guidance for how clinicians can do so.

There are specific challenges to clinician-family partnership in the PICU setting, such as the high level of technology, complexity of care, and uncertainty of prognosis, that may place clinicians in a double bind in multiple ways. Clinicians feel responsible for protecting parents from experiencing emotional distress related to participating in treatment decisions that parents may later regret,^{47,49} receiving uncertain or distressing information,^{53,57,58} or being witness to stressful events.⁶⁴ Clinicians may view the selection, modification, or obfuscation of information that parents receive and the limitation of the degree of parental involvement in decisions as therapeutic communication strategies to protect parents from experiencing psychological distress. However, some parents report distress when they do not have access to complete information or when they feel unable to advocate for their child's best interest.^{43,50,53,57,59} Clinicians may inadvertently increase parental distress by not giving complete information or not involving parents in care to the degree that they prefer. Furthermore, clinicians may

have difficulty balancing the goals for physiological endpoints and patient and family satisfaction with communication and involvement, and view these in tension with each other. This results in a reliance on rules and norms that become prioritized at the expense of family participation in care and perpetuate power differentials that impede partnership.

With few exceptions, this body of research does not include a critical lens to power dynamics and status, which may influence the communication between clinicians and families. There is a lack of demographic information given in articles, with mostly homogenous samples of non-Hispanic White participants (see supplementary materials), and little discussion of the influence of socioeconomic status or differences between clinicians and families in regards to ethnicity, race, or nationality on communication. Results from the study by DeLemos⁴³ suggests that racial and ethnic minority families may feel less comfortable communicating concerns and being in partnership with clinicians than non-Hispanic White families. This is important because racial or ethnic minority families and those with lower literacy and education levels and/or who do not speak English, may not be able to participate in the child's care to the same extent as other families with different societal privileges. Parental participation gives parents a sense of control that may allow them to cope and could potentially alleviate the long-term impact of critical illness on the parents, family, and child. A decrease in parental involvement for subgroups of parents could contribute to health disparities. More research is needed in regards to the influence of biases on communication and the parental role in the PICU as well how communication may be modified to better accommodate families from different cultural backgrounds.

2.8 Conclusions

This review synthesized 33 qualitative and mixed methods studies with the purpose of identifying FCC behaviors and communication skills that support the parental role and improve patient and family outcomes. This review adds to the literature in three ways: 1) it provides details about the varying needs and preferences for parental roles across the continuum of family-centered care; 2) it provides evidence of the gap between how parents generally wish to be involved and how clinicians involve them and highlights that parents are rarely asked about their preferences for participation; and 3) it describes some of the specific challenges to implementing family-centered care in the PICU setting. Asking parents about

their preferences for communication and participation may improve clinician-family relationships, improve the care of children, reduce conflict, and alleviate the emotional distress often experienced by parents due to parental role disturbance and poor communication. Further study is needed to understand how clinicians modify their communication with families, as well as the role of biases, cultural differences, and power differentials in communication, in order to develop effective interventions.

Table 2.2 Supplementary Information. Descriptive summary of qualitative studies (n = 33)

Characteristic	n	(%)	References
Participants			
Parents only	16	(48)	(Abib El Halal et al., 2013; Ames et al., 2011; Carnevale, 1990; Carnevale et al., 2006; DeLemos et al., 2010; Gilmer et al., 2013; Gordon et al., 2009; Graham et al., 2009; Lamiani et al., 2013; Latour et al., 2011; Maxton, 2008; McGraw et al., 2012; Meyer et al., 2006; October et al., 2014; Orioles et al., 2013; Tomlinson et al., 1999)
Parents and nurses only	1	(3)	(Baird et al., 2015)
Parents and physicians only	2	(6)	(de Vos et al., 2015; Van Cleave et al., 2014)
Parents and multiple clinicians (including nurses and physicians)	11	(33)	(Cameron et al., 2009; Carnevale et al., 2011; Carnevale et al., 2007; Carnevale et al., 2014; Kahveci et al., 2014; Macdonald et al., 2012; McPherson et al., 2011; Michelson et al., 2011; Michelson et al., 2013; Stickney et al., 2014; Vasli, Dehghan-Nayeri, Borim-Nezhad, & Vedadhir, 2015)
Nurses and/or Physicians	3	(9)	(Bartel et al., 2000; Jefferson & Paterson, 2001; Mattsson, Forsner, Castren, & Arman, 2013)
Child status during data collection			
Admitted to PICU (critical)	13	(39)	(Baird et al., 2015; Cameron et al., 2009; de Vos et al., 2015; DeLemos et al., 2010; Macdonald et al., 2012; McPherson et al., 2011; Michelson et al., 2011; Michelson et al., 2013; Orioles et al., 2013; Stickney et al., 2014; Tomlinson et al., 1999; Van Cleave et al., 2014; Vasli et al., 2015)
Preparing for discharge from PICU	1	(3)	(Ames et al., 2011)
After transfer from PICU	1	(3)	(Carnevale, 1990)
Deceased	7	(21)	(Abib El Halal et al., 2013; Gilmer et al., 2013; Gordon et al., 2009; Lamiani et al., 2013; McGraw et al., 2012; Meyer et al., 2006; October et al., 2014)
Discharged	2	(6)	(Graham et al., 2009; Latour et al., 2011)
Deceased and discharged	5	(15)	(Carnevale et al., 2011; Carnevale et al., 2007; Carnevale et al., 2006; Carnevale et al., 2014; Kahveci et al., 2014)
Deceased and admitted to PICU	1	(3)	(Maxton, 2008)
No child enrolled	3	(9)	(Bartel et al., 2000; Jefferson & Paterson, 2001; Mattsson et al., 2013)

Supplementary Information. Descriptive summary of qualitative studies (n = 33) (continued)

Characteristic	n	(%)	References
Context of communication			
Bedside care (overall)	12	(36)	(Ames et al., 2011; Baird et al., 2015; Bartel et al., 2000; Carnevale, 1990; DeLemos et al., 2010; Gordon et al., 2009; Graham et al., 2009; Latour et al., 2011; Macdonald et al., 2012; Mattsson et al., 2013; Tomlinson et al., 1999; Vasli et al., 2015)
Deliver bad news	1	(3)	(Orioles et al., 2013)
End of life care	5	(15)	(Abib El Halal et al., 2013; Gilmer et al., 2013; Lamiani et al., 2013; McGraw et al., 2012; Meyer et al., 2006)
Family conference	3	(9)	(de Vos et al., 2015; Michelson et al., 2011; Van Cleave et al., 2014)
Invasive Procedures	1	(3)	(Jefferson & Paterson, 2001)
Resuscitation	1	(3)	(Maxton, 2008)
Rounds	3	(9)	(Cameron et al., 2009; McPherson et al., 2011; Stickney et al., 2014)
Treatment decisions (life support or clinical management)	7	(21)	(Carnevale et al., 2011; Carnevale et al., 2007; Carnevale et al., 2006; Carnevale et al., 2014; Kahveci et al., 2014; Michelson et al., 2013; October et al., 2014)
Data collection			
Focus groups and in- person interviews	5	(15)	(Bartel et al., 2000; Carnevale et al., 2011; Michelson et al., 2011; Michelson et al., 2013; Stickney et al., 2014)
In-person interviews	17	(52)	(Abib El Halal et al., 2013; Ames et al., 2011; Carnevale, 1990; Carnevale et al., 2007; Carnevale et al., 2006; Carnevale et al., 2014; DeLemos et al., 2010; Graham et al., 2009; Jefferson & Paterson, 2001; Kahveci et al., 2014; Lamiani et al., 2013; Latour et al., 2011; Maxton, 2008; McPherson et al., 2011; October et al., 2014; Orioles et al., 2013; Tomlinson et al., 1999)
Observation	2	(6)	(de Vos et al., 2015; Van Cleave et al., 2014)
Observation and in- person interviews	5	(15)	(Baird et al., 2015; Cameron et al., 2009*; Macdonald et al., 2012; Mattsson et al., 2013; Vasli et al., 2015)
Survey (open-ended questions)	1	(3)	(Meyer et al., 2006)
Telephone interviews	3	(9)	(Gilmer et al., 2013; Gordon et al., 2009; McGraw et al., 2012)

Supplementary Information. Descriptive summary of qualitative studies (n = 33) (continued)

Characteristic	n (%)	References
Study design I		
Cross-sectional	26 (79)	(Abib El Halal et al., 2013; Ames et al., 2011; Cameron et al., 2009; Carnevale, 1990; Carnevale et al., 2011; Carnevale et al., 2007; Carnevale et al., 2006; Carnevale et al., 2014; DeLemos et al., 2010; Gilmer et al., 2013; Gordon et al., 2009; Graham et al., 2009; Jefferson & Paterson, 2001; Kahveci et al., 2014; Lamiani et al., 2013; Latour et al., 2011; Maxton, 2008; McGraw et al., 2012; McPherson et al., 2011; Meyer et al., 2006; Michelson et al., 2011; Michelson et al., 2013; October et al., 2014; Orioles et al., 2013; Stickney et al., 2014; Tomlinson et al., 1999)
Longitudinal	5 (15)	(Baird et al., 2015; de Vos et al., 2015; Macdonald et al., 2012; Mattsson et al., 2013; Vasli et al., 2015)
Mix (primarily cross-se	2 (6)	(Cameron et al., 2009; Van Cleave et al., 2014)
Study design II		
Qualitative	29 (88)	(Abib El Halal et al., 2013; Ames et al., 2011; Baird et al., 2015; Bartel et al., 2000; Carnevale, 1990; Carnevale et al., 2011; Carnevale et al., 2007; Carnevale et al., 2006; Carnevale et al., 2014; de Vos et al., 2015; DeLemos et al., 2010; Gordon et al., 2009; Graham et al., 2009; Jefferson & Paterson, 2001; Kahveci et al., 2014; Lamiani et al., 2013; Latour et al., 2011; Macdonald et al., 2012; Mattsson et al., 2013; Maxton, 2008; McGraw et al., 2012; Meyer et al., 2006; Michelson et al., 2011; Michelson et al., 2013; October et al., 2014; Orioles et al., 2013; Stickney et al., 2014; Tomlinson et al., 1999; Vasli et al., 2015)
Mixed Methods **	4 (12)	(Cameron et al., 2009; Gilmer et al., 2013; McPherson et al., 2011; Van Cleave et al., 2014)
Country		
Australia	1 (3)	(Maxton, 2008)
Brazil	1 (3)	(Abib El Halal et al., 2013)
Canada	5 (15)	(Ames et al., 2011; Carnevale, 1990; Jefferson & Paterson, 2001; Macdonald et al., 2012; McPherson et al., 2011)
France	1 (3)	(Carnevale et al., 2006)
France and Quebec, Canada	2 (6)	(Carnevale et al., 2007; Carnevale et al., 2014)
Iran	1 (3)	(Vasli et al., 2015)
Italy	2 (6)	(Carnevale et al., 2011; Lamiani et al., 2013)
Sweden	1 (3)	(Mattsson et al., 2013)
The Netherlands	2 (6)	(de Vos et al., 2015; Latour et al., 2011)
Turkey	1 (3)	(Kahveci et al., 2014)
United States of America	16 (48)	(Baird et al., 2015; Bartel et al., 2000; Cameron et al., 2009; DeLemos et al., 2010; Gilmer et al., 2013; Gordon et al., 2009; Graham et al., 2009; McGraw et al., 2012; Meyer et al., 2006; Michelson et al., 2011; Michelson et al., 2013; October et al., 2014; Orioles et al., 2013; Stickney et al., 2014; Tomlinson et al., 1999; Van Cleave et al., 2014)

*Observational data collected is purely quantitative.

**Only qualitative data collection for mixed methods studies included here

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Chapter 3. Shared Decision-Making in the NICU and PICU: Who Determines the Child's Best Interest?

3.1 Abstract

Background: Most neonatal and pediatric deaths in the intensive care unit occur after decisions are made to withdraw or withhold life-sustaining treatment. These decisions can be challenging especially when there are different views about the child's best interest and when there is lack of clarity about when the interests of the family should be considered as well. **Objective:** To understand how neonatal and pediatric critical care physicians balance and integrate the interests of the child and family in decisions about life sustaining treatment. **Design:** This was a qualitative study; Semi-structured interviews were conducted, transcribed, and analyzed using content and thematic analysis. **Setting and participants:** A total of 22 physicians from neonatal, pediatric and cardiothoracic intensive care units in a single quaternary care pediatric hospital. **Measurements:** Themes identified from content analysis. **Results:** We identified three main themes: 1) beliefs about best interests; 2) disagreement about best interests; and 3) decision-making strategies, including physicians using their authority in decision-making, limiting what options are offered, staying neutral, and allowing parents to come to their own conclusions about outcomes. **Conclusions:** Physicians described several challenges to implementing shared decision making in pediatric critical care, including unequal power and authority, clinical uncertainty, and complexity of care. Families may be excluded from discussions about goals of care and thus, their values and preferences may not be integrated in decisions. Asking parents about their preferences for how to receive information and hopes and goals for the child could promote earlier and more frequent shared decision making during the hospitalization.

3.2 Background

While most children in the neonatal intensive care unit (NICU) and pediatric intensive care unit (PICU) survive, some don't: 3 to 29% of NICU patients and about 2% of PICU patients die in these settings.^{1,2} Death most commonly occurs after making decisions to withhold or withdraw life-sustaining treatment (LST), failed cardiopulmonary resuscitation (CPR), or brain death.^{2,3} Furthermore, due to improved survival as a result of advances in medical technology, there are an increasing number of

children with chronic conditions and disability.⁴ Families of critical care patients often report symptoms of post-intensive care syndrome⁵⁻⁹ that are associated with communication problems¹⁰⁻¹² and impede their ability to make decisions.¹³ Family-centered care (FCC), a partnership approach that supports and engages the family in the care of their hospitalized child, is endorsed by professional organizations as a practice that improves outcomes for both children and families as a whole.¹⁴⁻¹⁸

Shared decision-making (SDM), a key part of FCC, involves developing a shared understanding of the patient's condition and agreement on a treatment plan that is consistent, whenever possible, with patient and family preferences, values, and goals.¹⁹ SDM entreats physicians in pediatric ICUs to invite parents to share in decisions about LST to promote both the child's and family's interests and as a way to help families manage distress.²⁰⁻²³ Studies have shown, however, that NICU and PICU physicians vary in the extent to which they engage parents in decision-making and how they integrate families' values and preferences into clinical decisions.^{15,24-29} This is due in part to the challenges of implementing SDM within the fast-paced and clinician-driven environment of pediatric critical care and the ethical complexity of determining a child's best interest.

Pediatric SDM relies on the best-interest standard, given that children generally lack capacity to give informed consent until adolescence, and/or have not developed or expressed preferences that could guide decision-makers.^{30,31} While there is general agreement about best interests as a guiding standard, there is often disagreement about how a child's best interest is defined and who has the authority to make decisions at the end of life.³² Physicians' obligations to involve parents in decisions are sometimes in conflict with their obligations to the child, especially when physicians perceive parental preferences to be at odds with their own view of the child's best interest.^{20,22} While the child's best interests are intended to be the overriding factor, most physicians also consider the interests of the family as a whole.²⁰ At times, this leads physicians to assume responsibility for LST decisions and limit parental participation in SDM to reduce parental guilt or regret.^{15,25,28,33}

It is not clear how NICU and PICU physicians balance the interests of the child and family, nor how they engage parents in LST decisions when they perceive tensions between the child's and family's interests. We used qualitative methods to explore: (1) physicians' perspectives about best interests; and

(2) what factors about the clinical situation, family interests, and past experiences inform how physicians choose from a range of decision-making approaches regarding decisions about LSTs.

3.3 Methods

Study design and participants

We contacted 22 critical care physicians at a quaternary care pediatric hospital in the Pacific Northwest. All consented and enrolled in the study, including 4 from the NICU, 14 from the PICU and 4 from the pediatric cardiothoracic ICU (CICU). In-person, semi-structured interviews were conducted. The interviews averaged 47 minutes (range 20-76) and were recorded, transcribed, and entered in Dedoose (software used for qualitative data management and analysis).³⁴

Data Analysis

We used content and thematic analysis to examine physicians' descriptions of how they established relationships with families, modified communication for different families or in different clinical situations across a range of certain or uncertain outcomes, and how they typically responded when families and the clinical team disagreed about care.^{35,36} We coded the transcripts looking for examples of decision processes, values, attitudes, and beliefs about communication and decision-making from both clinicians and families (as conveyed by the physicians).³⁷ This was followed by identifying specific decision-making strategies that were described, including whether parents were invited to participate in decisions, whether and how they gave recommendations for treatment decisions, and what contextual features (such as time, the child's suffering, and the physician relationship with the family) contributed to choosing different strategies.³⁸

3.4 Results

We identified three main themes that relate to: 1) beliefs about best interests; 2) disagreements about best interests; and 3) decision-making strategies. Each of these broader themes comprise a range of decision-making strategies and considerations of when to use them, described below.

1. Beliefs About Best Interests

Physicians said it was difficult to separate the interests of the child from those of the parents and family. Physicians often described the child's best interest as a balance between the expected benefits and burdens of LST, especially when prognosis was poor and LST contributed to the child's suffering.

I hope that she gets better too, but I honestly don't think that she will, and I think that it's really possible that she could go on to have her heart stop... and I don't wanna harm her in any way by doing something that I don't think will help her. (PICU-06)

In these situations, multiple parental interests were described, including wanting a sense of control over the decisions made so they can have a sense of peace about them; needing time to adjust to or accept a poor outcome prior to making end of life (EOL) decisions, and/or to say goodbye and interact with their child prior to the child's death. When physicians expected that a child would survive and have significant cognitive and/or physical impairments and ongoing health care needs, physicians described best interests for both the child and family as they related to quality of life (QOL) and the future potential that families wanted for both their child and themselves.

...it really does change how they think about things; like, "Oh, I wouldn't want my child to live if they can't participate in their activities," and some people are like, "Doesn't matter. As long as they have a heartbeat, that's enough for me...". (CICU-01)

Physicians also spoke of wanting families to consider future best interests and be aware of potential burdens and long-term stressors due to the child's future health care needs that could result in financial strain, divorce, or reduced parental attention for other children.

...the worst for me is to see a family like a year later, and they've just been devastated by some intervention that we've done, and they didn't realize the weight of it in their family and the family's fallin' apart or the parents get divorced... (PICU-05)

2. Disagreements About Best Interests

Physicians described several scenarios involving disagreements between the clinical team and family regarding whether LST was in the child's best interest. One physician described a family wanting to stop LST when he was still uncertain about the outcome. It was more common that parents were described as having biases towards initiating more interventions rather than focusing on comfort: "Many of our families come here wanting that bias because that's why they chose to come here. They want everything possible to be done." (NICU-02)

Often physicians had developed a sense of confidence that the child would inevitably die or have severe neurological impairment, while the family was still uncertain and hopeful for a different outcome.

Some physicians described parents as not accepting or believing the poor prognosis and “pushing” for more quantity rather than quality of life.

Some of the patients that we take care of are sort of frustrating; I look at them and I honestly wonder, “What sort of quality of life do you have? What is going on within you that is so satisfying? Are we doing this for the family or are we really still focusing on our patient?” (PICU-05)

However, other physicians were skeptical of their own and other clinicians’ assessments of suffering as the basis for reframing goals and recommending withdrawal/withholding of LST. These physicians thought that their perceptions of suffering varied over time and became more acute when they recognized their own inability to effect change given the child’s clinical status. One of these physicians described parents as being the most capable of assessing whether or not the child was suffering: “Who knows what suffering is? The best that I can say for a child that can’t speak for themselves as to whether they’re suffering is the parents are the best assessors of suffering.” (CICU-01)

3. Decision-Making Approaches

Using one’s authority in decision-making. When physicians were still hopeful that the child could survive, they described making decisions to initiate LST such as extra-corporeal membranous oxygenation (ECMO) or cardiopulmonary resuscitation (CPR) without including parents in the decision. While physicians generally did not make withdrawal decisions for families, one physician described making an exception if parents were unable to make a decision because of their religion *and* the parents thought that the child was suffering: “... they felt that their child was suffering, but they felt because of their religion that they couldn’t stop life support, even though they thought that that is what should happen.” (CICU-01) This physician perceived that these parents were in a double bind because their moral convictions prohibited them from explicitly consenting to LST withdrawal and so they were unable to relieve their child’s suffering. In cases like this, she would tell the parents that she was going to assume the burden of decision-making, as long as the parents did not disagree: “I told them outright, I’m taking the moral burden and I’m telling you it’s time to stop.”

Some physicians described being more direct, clear, or blunt and increasing the strength of their recommendation to withdraw or withhold LST when they were certain that the child would die or have severe neurological impairment.

“It’s the ones that are... not interactive, they’re basically on a ventilator, sedated, muscle relaxer, whatever, that it’s sort of hard in that case to justify an existence. In those cases we’re more heavy handed in pushing families.” (CICU-03)

This approach was considered when physicians thought that their recommendations would give parents permission to make difficult choices. In some cases, physicians framed their recommendations as a decision.

“I’ll just be more firm with what I say. If I’ve had that rapport with them, they’ll respect that. They’re gonna say, ‘Okay.’ Maybe they actually needed to hear it from someone they’ve trusted and come to respect as the doctor.” (NICU-03)

Limiting what options are offered. Physicians also described not discussing with families certain types of LST, such as ECMO or renal replacement therapies, on the basis of futility. Physicians reasoned that they should not discuss therapies that are not a standard of care and are not “indicated” or “appropriate” unless families asked about them.

“...we don’t talk about bringing up whether you should use antibiotics or not in someone that has a neurological process that’s not an infection. I see [ECMO] as a different category of therapy that doesn’t really apply in this situation” (PICU-02)

In addition, physicians described parents having a harder time withdrawing than withholding LST and that offering these treatments was unfair because it gave parents unrealistic expectations: “Should they go on ECMO? Is it fair to ask the family that? Cuz all the family hears is, ‘There’s something more that can be done.’” (PICU-14)

Another physician told a story about starting LST emergently and then getting “stuck” there. Some physicians thought it was their professional obligation to stop offering parents the option of treatments such as antibiotics, vasopressors, or mechanical ventilation when they knew it would not change the outcome. Other physicians viewed these treatments as “benign” and as such, it was ultimately up to the family to decide about their use.

Staying neutral. Another strategy was the importance of not making any recommendations about LST, even when asked to do so by parents, because the physicians did not want to influence value-laden decisions that most impacted the interests of the family, and did not want parents to feel judged or create mistrust. Physicians offered options by saying that there was no right or wrong choice and that different families make different decisions, without any being better than others. Some physicians additionally described making emotionally supportive statements, such as: “Some families choose to do

this, and other families choose to do that, and neither one is better than the other. Everybody has a different way of loving their child. We just wanna support you through this.” (PICU-06)

Allowing parents to come to their own conclusions. Physicians also described situations in which they were certain that the child was going to eventually decompensate. They described delaying the deliberation with families about LST because they believed that the parents needed an opportunity to witness the dying process and come to their own conclusions that death was the inevitable outcome: “There’s one thing to say we’ve done all we can, and there’s another thing ...for people to see that that is true.” (PICU-02) For example, one physician described postponing discussions about mechanical ventilation because the family had stated their goal was to interact with their child. He recognized that mechanical ventilation would conflict with that goal and so did not offer it until BiPAP could no longer provide sufficient breathing support. He believed that if they had offered mechanical ventilation earlier, the family would have felt pressured to intubate their child: “...we stretched our ability to utilize that modality based on a goal that the family had defined, but had not placed a limit on our care, because they weren’t at that point yet.” (PICU-04) As a result, the family was able to interact with the child until the child died and he thought that the child and family had a higher quality EOL experience.

3.5 Discussion

The objective of this study was to describe how NICU and PICU physicians balance the interests of critically ill children and their families when LST decisions are on the horizon. The participating physicians described a range of factors that influence how and when they engage parents in treatment decisions. When physicians expected a good outcome, they made decisions to initiate LST based on the child’s best interest, with the assumption that parents shared the same goals. When physicians expected a poor outcome but were uncertain about the correct course of action, physicians engaged more with families, recognizing that they needed to work together to elicit and integrate the family’s values into decision-making. However, when physicians expected a poor outcome but felt certain that LST was medically futile, they limited the options offered to parents or worked to convince parents of their perceived “correct” course of action. Other studies have found that ICU physicians are directive in how they provide recommendations or limit parental involvement in EOL decisions.^{28,39} Our results highlight

reasons when and why physicians choose to engage in SDM with parents (or not), reflecting broader challenges to implementing FCC in pediatric critical care settings, including unequal power and authority, complexity of care, and clinical uncertainty.¹⁵

Physicians have the authority to determine what goals are in the child's best interest because they are the ones to determine the level of uncertainty or certainty about the outcome. A study comparing decision-making practices between physicians in French and American NICUs found that French physicians sometimes transformed ambiguity into medical certainty, and thus limited the role of parents in decision-making.⁴⁰ In contrast, the American physicians evoked prognostic uncertainty to continue treatment and not offer limitations.⁴⁰ Our findings were similar: when physicians were uncertain about outcomes, they presumed that families shared their goals for the child and initiated LST or curative treatments without offering limitations. However, we also found that physicians justified limiting parental involvement or being directive in decision-making by evoking prognostic certainty in the form of futility arguments although scholars agree that futility arguments are subjective and based more on values than facts.^{40,41}

Physicians described their own desires to "move the case along" once their view of the endpoint was clear, such as when a patient's clinical situation was not changing.⁴² Futility arguments were sometimes based on perceptions of suffering or that the child's anticipated QOL would be poor. This finding reflects concerns about QOL as an outcome of pediatric critical care due to an increasing proportion of patients admitted with preexisting chronic illness, who have longer hospital stays, higher mortality rates, and more dependence on medical technology.⁴³⁻⁴⁵ The outcome of QOL is more subjective than mortality⁴³ and requires more engagement to elicit parents' perspectives and match treatment decisions with their values about acceptable outcomes. Physicians commonly underestimate a child and family's QOL when a child survives with neurological impairment or chronic illness.^{43,46,47} Given the subjective nature of futility estimations, it is important for physicians to be clear about how and who is establishing the goals for the child, and to be self-reflective about their values.^{40,41,46}

This analysis is limited by the fact that this study was done only with physicians at one quaternary care pediatric hospital. The strategies and scenarios were prompted by questions about difficult communications and thus generally focused on when the physician and family disagreed about care.

Physicians described the most difficult and ethically complex decision-making processes that may not represent typical patterns of communication that occur on a more regular basis.

3.6 Conclusions

We have described several challenges to implementing SDM in pediatric critical care, including unequal power and authority, clinical uncertainty, and complexity of care. Families may be excluded from discussions about goals of care and thus, their values and preferences may not be integrated in decisions.^{40,48} One approach to including parents in decision-making earlier and according to their preferences might be the use of a checklist⁴⁹ that could include family-centered items such as parental preferences for roles in decision-making, information about prognosis and recommendations, and parental hopes for their child. Since parental preferences may change over time, regular reassessment should be performed.¹⁵

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Chapter 4. When and Why Do Physicians Consult Palliative Care in Pediatric ICUs?

4.1 Abstract

Background: Parents of children admitted to the PICU and NICU seek complete information and participate in their child's care to improve the quality of care and protect their child. These parents and children are at increased risk of experiencing post-intensive care syndrome symptoms. The integration of palliative care (PC) may improve child and family outcomes. However there remains a lack of information about indicators for specialty level PC involvement in this setting. **Objective:** To describe NICU and PICU physician perspectives on indicators for when and how to involving palliative care consultants. **Design:** Semi-structured interviews were conducted, transcribed, and analyzed using content and thematic analysis. **Setting and participants:** A total of 22 physicians from neonatal, pediatric and cardiothoracic intensive care units in a single quaternary care pediatric hospital. **Measurements:** Themes identified from content analysis. **Results:** We identified two main themes: 1) palliative care expertise including support and bridging communication, and 2) structural factors influencing communication in the ICU including competing priorities, fragmentation of care, and continuity issues. **Conclusions:** Palliative care involvement supports partnership between the clinical team and family and was most beneficial for families at risk of experiencing communication problems that resulted from competing priorities, fragmentation of care, and continuity issues. This patient population included those with long-lengths of ICU and/or hospital stay and medical complexity. The ability of PC consultants to bridge communication was limited by some of these same structural factors. These findings are concerning given the changing demographics of the PICU and an increasing number of patients with complex chronic conditions. We suggest a daily PC needs assessment to ensure that families have regular opportunities for goals of care discussions and to trigger PC involvement, standardization of weekly report to include contextual information about communication with families, and a formalized list of the patient's care team.

4.2 Background

Parents of children admitted to the neonatal (NICU) and pediatric intensive care unit (PICU) seek information to support participation in their child's care and treatment decisions to give their child the best

possible outcome.¹⁻⁶ Parents experience stress when they encounter barriers to their involvement, such as receiving incomplete or conflicting information or when their expertise about their child is not incorporated into the treatment plan.⁶⁻⁹ Additionally, parents often report feelings of uncertainty and fear about their child's outcome.¹⁰⁻¹² Improvements in technology have improved survival, but an increasing number of children survive the intensive care unit (ICU) with complex chronic conditions and disabilities.^{13,14} Stress during the ICU admission can persist even after the child leaves the hospital and impact family functioning and the psychological well being of the child.¹⁵⁻¹⁷

Improving communication by integrating palliative care (PC) in the ICU is proposed as one way to improve outcomes for children and families.¹⁸⁻²⁰ PC is a patient and family-centered approach that strives to achieve the “best quality of life for patients and their families, consistent with their values”²¹ and provides continuity that is more typical of a primary care setting.²² ICU physicians generally involve PC consultants in only the “most complex or difficult cases”^{23,24} that require “additional expertise and time.”²⁵ Because pediatric patients have varied illness trajectories and medical complexity that are not necessarily tied to a diagnosis, it can be difficult to identify patients whose palliative care needs exceed the capacity of the ICU clinical team.^{22,24} The purpose of this study was to describe NICU and PICU physician perspectives on indicators for when and why to involve PC consultants, in order to make recommendations for integrating PC.

4.3 Methods

Study setting, design, and participants

This qualitative and descriptive study was part of a larger randomized controlled trial (RCT) of the impact of automatic involvement of the PC consultation team (called Pediatric Advanced Care Team or PACT) with children in the ICU for 8 days or more at Seattle Children's.²⁶ Many pediatric PC teams are called PACT or “supportive care” in order to make PC more acceptable to families and physicians.^{27,28} At the time of the study, PACT included 2 social workers, 3 chaplains, 2 nurses, 1 physician and a child life specialist who provided primarily communication and decisional support.

We invited 22 ICU attending physicians to participate in semi-structured interviews about a range of topics, including: how they perceived the added value of PACT involvement and what types of

situations usually prompted a referral to PACT (outside the RCT). All of the invited physicians consented and enrolled in the study: 14 from the PICU, 4 from the pediatric cardiothoracic ICU (CICU), and 4 from the NICU. The semi-structured interviews (averaging 47 minutes, range 20-76 minutes) were conducted, recorded, transcribed, and entered in Dedoose.²⁹

Data Analysis

We used content and thematic analysis to examine physicians' descriptions of PACT involvement across a range of clinical situations.^{30,31} We first coded the transcripts by looking for physician attitudes and beliefs about PACT and indicators for consulting PACT.³² Other codes were used to identify contextual information about the benefit from PACT involvement, including patient and family characteristics (e.g., chronic vs. acute patient condition, family coping and information preferences), provider characteristics (e.g. beliefs about their own skills and role), and health system factors (e.g., multiple providers, continuity, competing priorities). The analysis included examining the relationships within and between these factors to identify the perceived outcomes of communication processes (e.g., efficiency, quality of decision making, trust, conflict, and family stress level) that contributed to whether and when ICU physicians involved PACT.³³

4.4 Results

Indicators of the need for PC were related to two complementary themes: (1) physicians' self-identified needs for PACT's expertise in supporting families and bridging communication; and (2) health system factors such as competing priorities for clinicians' time, care fragmentation, and continuity issues. Parents of patients with greater medical complexity and uncertainty were described as needing PACT expertise and being susceptible to problems arising from health system factors. Resulting communication breakdowns were sometimes the indicators for consulting PACT, with the purpose of resolving disagreements and mediating the relationship between the family and primary clinical team.

1. Palliative care skills

Physicians described PACT as capable of establishing a trusting relationship with the family and negotiating a shared mental model of the problem and treatment plan between the family and clinical team that integrated the values, concerns, and perspectives of the family.

Support. Physicians said that PACT provided emotional, spiritual, and informational support that helped families cope with uncertainty and navigate a complex health care system. PACT was described as using a nonjudgmental approach and having more frequent communication with families. Physicians reported that families could be more open with PACT about their questions, concerns, and uncertainty. Additionally, PACT provided anticipatory guidance by putting the “hills” and “valleys” in context of the child’s illness trajectory and supporting their understanding of the big picture implications of decisions on the family as a whole:

PACT has time to sit down with them and talk about, ‘Well, this is what it means when we say we’re gonna trach your child,’ and talk about a lot of the long-term issues associated with that...because we’re intensivists, we tend to gloss over...the long-term repercussions (PICU-03)

PACT involvement was also beneficial for families that needed support during transitions from curative to comfort-focused care or from critical to chronic disease management. Patient factors for PACT involvement included long ICU and/or hospital stays, likelihood of readmission, medical complexity and care involving multiple subspecialists, and/or an expected death within weeks or months of the ICU admission.

Preparing for being out of the ICU or moving to a different kind of philosophy of the care where we’re maybe transitioning not into end of life, but we’re transitioning into just a different phase where the goals are going to become different. (PICU-02)

One physician said that the longer the stay, the more the family needed, yet the less support the clinical team provided. Physicians appreciated PACT support: “The families who are in an ICU for a long time really benefit from some other team helping them because people who go into ICU medicine are not good at chronic management.” (CICU-01) Physicians said that they were capable of providing end-of-life care when the process was “self-limited” and the child was dying imminently, although one said that not all physicians “took the time.”

Bridging communication. PACT bridged communication by relaying information on an individual basis or facilitating communication during care conferences. Physicians valued that PACT members listened during rounds, talked with the family afterwards, and then shared information about family concerns and/or organized a care conference: “She often finds out things that you don’t know, or changes things; or discovering like, “This family really does need an interpreter.” You’re like, “Who knew? They’ve been here for three weeks, how did you know that?” (PICU-05) When physicians expected a

poor outcome they often involved PACT because of the need to assure that families and the clinical team were communicating effectively.

Physicians reported that they lacked the capacity to explore family goals: “Sometimes we’re missing the goals of the family ‘cause either we’re not hearing it, or we’re too busy, or we’re just not trained maybe to hear these things.” (PICU-06) Additionally, physicians thought that families had difficulty asking questions due to feeling emotionally overwhelmed or uncomfortable, or because they didn’t have the necessary knowledge. Physicians valued that PACT asked or rephrased clarifying questions on the behalf of families, thus facilitating the connection between family values and goals and the big picture implications of the treatment plan. PACT helped physicians identify “alternative” options that integrated the family’s goals, especially in situations of clinical equipoise when there was no obvious best course of action.

Disagreements between the clinical team and family about expectations was another indicator for PACT who could “bring the family around” and/or share information that helped the clinical team understand the family perspective and/or address concerns: “They can sometimes get a lot of the background and what’s leading to the family’s decisions or wishes...so that can be eye-opening.” (PICU-11) Physicians also described PACT as encouraging the clinical team to continue to communicate even when it was taking more time to come to agreement: “It was maybe the PACT team just saying, ‘All right, I know we’ve done this three times already, but we gotta do it again.’” (PICU-12)

2. Health system factors

Physicians described ICU system factors as additional reasons for involving PACT, including competing priorities for their time, fragmentation of care, and continuity issues. PACT was instrumental in addressing communication needs that arose from these factors.

Competing priorities. Physicians said that their paramount responsibility was to address the physiological needs of their patients. Because of a high census they often lacked time for in-depth conversations with families and they relied on PACT expertise and availability to fill this gap: “They have the time; they make the effort to understand families in a way that I don’t have the time to do- so we are dependent on it.” (CICU-04) PACT was valuable because they identified communication needs for

families that otherwise may have been overlooked, thereby preventing or resolving disagreements and making communication more efficient.

Competing priorities meant that bigger picture discussions with families were deferred in favor of acute management decisions. Physicians reported that while parental presence during daily rounds was invited, rounds were not the appropriate place to discuss goals of care because the nature of such discussions could be sensitive and they needed to “start the day.” Physicians often intended to return to the family later in the day to translate medical information or address concerns, yet that frequently did not happen: “If there's then five admissions and procedures to do and then all those things have to take priority...then some work will be undone.” (PICU-07) While care conferences were often described as the appropriate place to discuss goals of care, one physician said that she (and other physicians) avoided consulting PACT because they dreaded the “painful and life-sucking” family conferences, when they had other pressing responsibilities.

Physicians also noted that some families of patients with longer stays were less likely to communicate directly with physicians because they had to return to work or household responsibilities and weren't available for spontaneous bedside conversations. Physicians said that they did not have time to call families at the end of the day either. The updates these families received were incomplete: “When they do, they get updates by their nurse and sometimes by the resident, but it's not big picture, ‘Here's what we know and don't know.’” (NICU-01). PACT was instrumental in ensuring that these families were informed.

Fragmentation of care. ICU physicians said that each subspecialty team (i.e. pulmonology, cardiology) viewed the child through their discipline-specific perspective. Because these teams worked in parallel, they often missed a holistic perspective and communicated differently with families, infusing different degrees of optimism or pessimism based on which organ system they were managing. Physicians said some families wondered if members of the clinical team weren't communicating with each other and if they were trustworthy, causing increased stress for the family: “The family is just totally at wit's end. They have no idea who to believe, who to trust, and they hear both ends of spectrums on multiple organs that are or are not failing...They totally fall apart.” (PICU-07) PACT managed or prevented problems by getting everyone on the “same page.”

Continuity issues. Continuity issues exacerbated problems with fragmentation of care. Both ICU and subspecialist physicians are scheduled for weeklong rotations, which might end before they can fully accomplish communication goals with long-stay patients, such as resolving disagreements with families about expectations for a child's outcome and treatment plan. Departing physicians then hoped that the oncoming physician would continue to make progress. Physicians described losing contextual information during sign-out that could facilitate progress: "I can guarantee you that a lot of the more subtle decision-making stuff gets lost." (CICU-01) As a result, physicians described PACT as being particularly helpful for patients with long ICU/hospital stays and/or repeat admissions due to chronic illness.

PACT facilitated communication by serving as point persons that had continuity with the family. PACT members had regular schedules and were available throughout the hospital and so were available to establish and maintain relationships with families during the entire hospital stay and any subsequent admissions. PACT presence during past conversations with the family allowed them to facilitate communication between the different clinicians involved in the patient's care and with the family. PACT became like the rim of a wheel, reducing the fragmentation of care by connecting all the "spokes":

Palliative care has helped to...be the go-between for the families at the center of the circle, and all the different people who are caring for their spokes from them to the family... Creating a connection between all those spokes, and helping to make it a little bit easier. (PICU-01)

However, physicians reported that PACT's method of communication sometimes contributed to fragmentation. Several physicians said that while on service, they relied primarily on verbal communication and went "digging through the chart" for background. PACT notes include a comprehensive assessment of the medical indications, family context, preferences for treatment, and quality of life considerations.²⁶ However, some physicians perceived this method of communication as making PACT yet another "spoke" in the wheel.

It's the same communication issue that we have with all of our subspecialists. I really would like to know directly what they're thinking and what they're saying and what they're hearing...Sometimes I'll find a note that I'm shocked at the content and didn't know that there was this concern. (NICU-04)

4.5 Discussion

The purpose of this study was to describe pediatric ICU physician perspectives on indicators for why and when to involve palliative care. Physicians described how PACT expertise and longitudinal

availability helped address system factors including competing priorities, fragmentation of care, and continuity issues. System factors contributed to PC needs for some patients and families because it was difficult for physicians to find time for goals of care conversations with families, and to gain contextual knowledge about family perspectives, and past conversations and decisions. This information was important for building and maintaining trust and the prevention and resolution of conflicts. Furthermore, treatment choices that are made without a big picture discussion may be discordant with patient and family values and goals.¹⁸ A checklist strategy can be implemented upon admission and on a daily basis throughout the hospital and help physicians become aware of unmet PC needs.³⁴ When the clinical team is unable to meet these needs, then they can consult PACT.³⁴

PACT involvement was indicated for children with greater medical complexity, longer ICU or hospital stays, and when poor outcomes were expected and there was uncertainty related to the “right” course of action.¹⁴ Physicians in a different study were less likely to involve palliative care in caring for imminently dying children, possibly because they perceived less uncertainty.³⁵ Additionally, some physicians consulted PACT when they were unsuccessful in convincing families of what they perceived to be the “right” course of action. As others have noted, these discussions often happen later in the illness trajectory or hospital stay,³⁶ after physicians become more certain of the outcome and treatment plan.

Patients with prolonged stays were described as medically complex and susceptible to system problems because their care involved more: 1) subspecialty teams; 2) clinical history and contextual information; 3) sign-outs and opportunities to lose information; and 4) planning to communicate about goals of care. Furthermore, physicians said that the clinical team preferred acute over chronic care and provided less support to these families while reframing goals on the basis of suffering.¹⁴ One study found that nurses reported moral distress when caring for medically complex children, resulting in less provision of support to families.³⁷ The combination of system problems and less support provided by the clinical team may partially explain why conflict has been found in the care of half of patients in the PICU with stays longer than a week.³⁸

The changing demographic of the PICU makes the problems experienced by patients with longer stays more problematic. The number of pediatric patients with complex chronic conditions (CCC) has increased and more than half of PICU patients have a CCC.^{13,39-41} The capacity for the clinical team to

build and sustain trusting relationships with families of patients with CCC is critical since it is not feasible for PACT to be consulted for them all. Patients with CCC tend to have longer hospital stays that are characterized by higher costs, intensity of care, morbidity and mortality than patients with non-complex chronic conditions or no chronic condition.^{39,42} Parents of CCC patients are often exhausted by the care that they provide at home,⁴³ and remain vigilant at the child's bedside in the ICU because they are concerned about ensuring continuity of care and the potential for errors in care.^{6,7,44,45} Thus, while these families may be more likely to experience problems as a result of health system factors, they may also be more stressed by them. There is a need for ICU clinician training to incorporate skills related to chronic care and partnership with families of patients with chronic conditions and disabilities.¹⁸

4.6 Conclusions

We've described how structural factors related to multidisciplinary teamwork in the ICU setting necessitated PACT facilitation of care coordination and clinical team-family partnership. Those same factors also hindered the benefit of PACT. We suggest preliminary steps to improve the capacity of the clinical team to coordinate care, including: 1) ensuring that families have regular opportunities for goals of care discussions with physicians by using a checklist strategy,^{14,34} 2) systematic inclusion of information about communication with families in weekly report, and 3) ensuring that the family and clinical team know the roles and names of all clinicians involved in a child's care with a formalized list that is consistently maintained. A long-term strategy is to improve readability and accessibility of electronic medical records so that patient and family-centered information can be found efficiently.

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Chapter 5. Conclusions

The purpose of this study was to examine how FCC is practiced in pediatric ICUs on individual and organizational levels with the goal of making recommendations to improve its implementation. We have described several barriers to the practice of FCC on both system and individual levels. Structural factors such as competing priorities, fragmentation of care, and continuity issues impede the implementation of FCC. These factors make it difficult to build and maintain trust, which contributes to conflict, and makes conflict more difficult to resolve. Individual level clinician skills in exploring family goals, preferences, and hopes are an additional barrier to FCC.

There are several implications for research, education, and practice described in Table 5.1. Continued work in these areas will promote FCC by facilitating the inclusion of patients and families in care while also providing them additional support tailored to their specific needs.

Table 5.1 Implications

Future Research	Education	Practice
Explore the role of biases, cultural differences, and power differentials on communication to develop effective interventions.	Provide education on tailoring information and decision-making to the needs of families.	Asking families about their preferred role in decision-making, information and participation may improve clinician-family relationships.
Test effectiveness of checklists on proposed outcomes from FCC including psychological outcomes and quality of care measures such as medical errors, length of stay, or location of death.	Provide skill development opportunities for clinicians include exploring family hopes, goals, preferences & values and providing recommendations.	Including palliative care needs checklists may stimulate earlier and more frequent goals of care discussions on a consistent basis and identify unmet needs to trigger consultation with the palliative care team.
Identify needs and outcomes specific to patients with complex chronic conditions and their families.	Include needs of patients with complex chronic conditions in critical care and palliative care curriculum and in hospital based trainings.	Systematic inclusion of information about communication with families in weekly report can facilitate continuity.
Identify ways to improve team based care such as improving coordination across subspecialty teams, while also including the patient and family as a member of the care team.		Ensuring that the family and clinical team know the roles and names of all clinicians involved in a child's care with a formalized list that is consistently maintained can facilitate coordination of care.