

THE INFLUENCE OF NURSES' ATTITUDES, BELIEFS, AND BIASES TOWARD
FAMILIES ON FAMILY-CENTERED CARE DELIVERY IN A
NEONATAL INTENSIVE CARE UNIT:
A GROUNDED THEORY

A DISSERTATION IN
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ABSTRACT

The purpose of this study was to examine nurses' attitudes, beliefs, and biases toward families and the influence these views have on the implementation of family-centered care in the neonatal intensive care unit and to uncover social processes underlying practice. Straussian grounded theory method was used to achieve this purpose and develop a substantive theory. Ten registered nurses working at least one shift per week in the NICU were interviewed by phone or Zoom web conference. Data were analyzed using constant comparison methods, leading to the identification of categories, subcategories, and one core category that are integrated into the substantive theory displayed in the model *Nurse Appraisal of Families and Resulting Family-Centered Care Practice*.

APPROVAL PAGE

The faculty listed below, appointed by the Dean of the School of Nursing and Health Studies, have examined a dissertation titled “The Influence of Nurses’ Attitudes, Beliefs, and Biases Toward Families on Family-Centered Care Delivery in a Neonatal Intensive Care Unit: A Grounded Theory,” presented by Paula Marie Prouhet, candidate for the Doctor of Philosophy degree, and certify that in their opinion it is worthy of acceptance.

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CHAPTER 1

INTRODUCTION

Family-centered care (FCC) is currently considered the standard of practice in the neonatal intensive care unit (NICU). Common principles of FCC involve partnership and collaboration, respecting cultural differences, openly sharing information, and caring for the child within the context of family (Kuo et al., 2012). Implementation of these principles has demonstrated positive outcomes surrounding an admission to the NICU, including improved perinatal and neonatal outcomes, better parental mental health, parent-infant bonding and attachment, shorter length of stay, and increased parent satisfaction with care (Asai, 2011; Gooding et al., 2011).

Though nurses claim to understand the various elements of FCC and believe in its value, they are often unable or at times unwilling to put the concepts into practice when caring for children and families (Coyne et al., 2013; Follett, 2006; Petersen et al., 2004). Nurses cite several perceived barriers to implementing FCC, such as hospital design, inadequate facilities, inconsistencies in policy adherence, workload constraints, and a lack of resources and organizational support (Coyne et al., 2013; Follett, 2006). Negative encounters with families also adversely impact nurses' implementation of FCC practice (Follett, 2006).

In addition to perceived physical barriers in implementing FCC in the NICU, research has uncovered cognitive and psychological barriers in nurses as well. Nurses' perceived self-efficacy might be a significant factor related to the implementation of FCC in the NICU (Asai, 2011). Nurses may support FCC, but lack the confidence to practice its principles, particularly young and inexperienced nurses. Working in a highly stressful

environment with a vulnerable population can lead to feelings of futility (Asai, 2011). A lack of knowledge and education on FCC principles also decreases a nurse's perceived self-efficacy (Asai, 2011; Petersen et al., 2004). NICU nurses may even rate the importance of FCC implementation lower than their pediatric and PICU colleagues (Petersen et al., 2004).

Research Question and Specific Aims

While research has identified that inconsistencies exist in the provision of FCC, and has identified numerous physical and psychological factors involved, no published research to date has formally examined the processes existing between nurses' individual attitudes, beliefs, and biases toward different family types and their decision-making process related to delivering FCC. Considering this gap, and the difficulties nurses claim to have in implementing FCC in practice, the proposed research question is: How do nurses' attitudes, beliefs, and biases toward families influence the implementation of FCC principles by nurses in the NICU? The specific aims of this study are to:

1. Identify nurses' knowledge and existing practice of family-centered care principles.
2. Identify nurses' attitudes, beliefs, and biases toward different family types.
3. Explore relationships between nurses' attitudes, beliefs, and biases toward individual families and nurses' decision-making processes when implementing FCC principles.
4. Construct a substantive grounded theory of NICU nurses' decision-making processes during FCC implementation.

Choosing Qualitative Research and Grounded Theory

A qualitative research design using a grounded theory approach was chosen to answer the research question. Qualitative designs are useful when little research has been done in an area, when a complex problem needs to be explored, to identify variables not easily measured, and when a detailed understanding of the context of an issue is needed (Corbin & Strauss, 2015; Creswell, 2013). A grounded theory approach in particular uses structured procedures to examine basic social processes (Creswell, 2013; Strauss & Corbin, 1990). Grounded theory allows the researcher to move past general descriptions and inductively create a theory grounded in data that explains an observed problem (Corbin & Strauss, 2015; Patton, 2015). Theories generated from this approach can be either substantive or formal. Substantive theories are theoretical interpretations of a problem in a limited focus area (Charmaz, 2014). These theories evolve “from the study of a phenomenon situated in one particular situational context” (Strauss & Corbin, 1990, p. 174). Formal theories are more abstract than substantive theories and emerge from studies of phenomenon under “many different types of situations” (Strauss & Corbin, 1990, p. 174). This current study aims to examine and explain the processes involved when nurses implement FCC in the NICU, therefore a grounded theory method with a resulting substantive theory is a good fit. Additional history, background, and the specific methods of grounded theory are presented in chapter three.

Since the goal of grounded theory is to inductively create a theory grounded in the data and not to validate pre-existing theories, the researcher typically does not begin the research with a preselected theory or *a priori* assumptions (Glaser & Strauss, 1967). However, symbolic interactionism is closely tied with underlying assumptions in

grounded theory, particularly the grounded theory methods developed by Strauss and Corbin (1990; Corbin & Strauss, 2015). Based primarily on the works of sociologists Mead and Blumer, symbolic interactionism is a theoretical perspective in the social sciences, which assumes society is created through the actions and interactions of its individuals (Carter & Fuller, 2016; Musolf, 2003). Through this lens, symbolic interactionists interpret individuals' subjective viewpoints to understand how they "make sense of their world from their unique perspective" (Carter & Fuller, 2016, p. 932). The use of language and symbols by individuals in their communications with one another is central to symbolic interactionism (Carter & Fuller, 2016). Other basic tenets of symbolic interactionism include: (a) individuals act based on meanings they assign to objects; (b) interactions occur within social and cultural contexts that must be defined based on individual meanings; (c) meanings develop from interactions between individuals; and (d) meanings are created and recreated through interpreting those interactions (Blumer, 1969, as cited in Carter & Fuller, 2016). Symbolic interactionist thought can help the researcher better understand behavior by taking into account "...agency, process, interpretation, minded activity, role taking, social construction, meaning, situation, and context" (Musolf, 2003, p. 113). A more in-depth look into the background of symbolic interactionism, how symbolic interactionism is intertwined with Strauss and Corbin's grounded theory methods, and the assumptions that will underpin this study are discussed in chapter three.

Definition of Terms

The key terms used throughout this study include attitude, belief, bias, NICU and its levels, and family-centered care. Family-centered care has been historically difficult to

define, and no singular definition currently exists in the literature. Due to its complexity, the historical context of family-centered care and its varied definitions will be presented in chapter two.

Two challenges exist when using the terms attitude, belief, and bias. First, the terms are often used interchangeably in everyday language. While the concepts are interrelated, they are distinct in their meanings. Second, the terms are frequently associated with negative connotations. Individuals can hold both positive and negative attitudes, beliefs, and biases towards persons and events (Fishbein & Ajzen, 1975; Staats, Capatosto, Wright, & Contractor, 2015). The definitions of these concepts and aspects of favorability are presented here.

Attitude. Attitude is defined as “a psychological tendency that is expressed by evaluating a particular entity with some degree of favor or disfavor” (Eagly & Chaiken, 2007, p. 598). This evaluation can be categorized as cognitive, affective, and conative responses towards an object, person, institution, or event (Ajzen, 2005). Cognitive responses reflect perceptions and thoughts about an object. Affective responses include the evaluations and feelings toward an object. Conative responses “are behavioral inclinations, intentions, commitments, and actions with respect to” the object (Ajzen, 2005, p. 5). Since favorable and unfavorable attitudes cannot be directly observed, they must be inferred from verbal and nonverbal responses towards objects or events (Ajzen, 2005).

Belief. Belief is defined as “something that is accepted, considered to be true, or held as an opinion” (Belief, 2018). A person’s beliefs reflect their understanding of themselves in relation to their environment (Fishbein & Ajzen, 1975). Specifically,

Fishbein and Ajzen (1975) defined belief “as the subjective probability of a relation between the object of the belief and some other object, value, concept, or attribute” (p. 131). Beliefs may be formed when a person establishes links between two objects (Fishbein & Ajzen, 1975). Belief formation can be created through three processes: descriptive beliefs, inferential beliefs, and informational beliefs. Descriptive beliefs are formed through direct observation of an object or event. Inferential beliefs occur when a descriptive belief about one object leads to the formation of a belief about another object. Informational beliefs are shaped when information is accepted as true from outside sources, such as friends, family, or media (Fishbein & Ajzen, 1975). A person’s beliefs create the basis for attitude formation toward an object (Fishbein & Ajzen, 1975).

Bias. Bias is defined as a “prejudice in favor of or against one thing, person, or group compared with another, usually in a way considered to be unfair” (Bias, 2018). It is a “natural phenomenon” in which people form associations “...as a way to better and more efficiently understand the world...” (Staats et al., 2015, p. 14). Biases can be implicit, which are involuntary and unconscious, or explicit, which is perceived consciously (Staats et al., 2015). Biases affect “understanding, actions, and decisions”, and influence an individual’s behavior towards others (Staats et al., 2015, p. 14).

Neonatal intensive care unit and levels of care. A NICU provides specialized care for premature and ill newborns and is designated by the level of care it provides.

Level I: A Level 1 NICU, also known as a well newborn nursery, provides basic levels of care to low-risk neonates. Services include neonatal resuscitation, routine postnatal care to stable newborn infants, stabilizing and providing care for infants born between 35 to 37 weeks gestation, and stabilizing ill newborns and newborns born under

35 weeks of gestation until the newborn can be transferred to a higher level of care (AAP, 2012).

Level II: A Level II NICU, also known as a special care nursery, provides the same services as a Level 1 NICU, plus care for newborns born less than 32 weeks of gestation and weighing ≥ 1500 grams, infants “convalescing” after higher level care, and can stabilize newborns born less than 32 weeks gestation and weighing less than 1500 grams until transfer to a higher level of care. Level II NICUs can also provide mechanical ventilation or continuous positive pressure ventilation if required for less than 24 hours (AAP, 2012).

Level III: In addition to Level II care, a Level III NICU can provide sustained life support, comprehensive care for newborns of all gestational ages and weights with critical illness, access to pediatric medical and surgical specialties, pediatric anesthesiology, and pediatric ophthalmology. Level III NICUs also provide full respiratory support and advanced imaging with interpretation (AAP, 2012).

Level IV: The highest designation, a Level IV NICU provides Level III care plus medical and surgical specialties and subspecialties capable of caring for complex conditions. These NICUs can also provide facility transport and outreach education (AAP, 2012). The NICU selected for this study is a designated Level IV.

Chapter Organization

Chapter one introduces the study and presents the research question and specific aims. Background and significance of the research, grounded theory as the chosen methodology, and definitions of terms are presented.

Chapter two provides a literature review on the history and current state of family-centered care in the NICU, neonatal nurses' attitudes about providing FCC in the NICU, perceived barriers of implementing FCC, and disparities in FCC implementation.

Chapter three describes the methods used in the study, including background on the grounded theory approach and its appropriateness for this study, symbolic interactionism and assumptions, selected setting and sample, and recruitment efforts. Plans for individual interviews and observations are discussed.

Chapter four presents the final theory and discussion of the categories, subcategories and core category that emerged from the data. The subsequent substantive theoretical model is presented.

Chapter five provides a discussion of the findings in the context of the current literature, strengths and significance of the study, limitations, and recommendations for next steps.

CHAPTER 2

REVIEW OF LITERATURE

Historical Context of Family-Centered Care

Prior to World War I and advancements in industry and technology, births took place in the home (Gooding et al., 2011; Jolley & Shields, 2009). Family-centered care (FCC) was a natural part of childbirth and infant care (Gooding et al., 2011). Mothers and families cared for their newborns with little intervention from physicians (Williams, 2016). In the early decades of the 1900s, labor and delivery transitioned from home to the hospital (Gooding et al., 2011; Jolley & Shields, 2009; Williams, 2016). Infection and sterility concerns, stricter regulations, and advances in technology led to families turning over their child's care to hospital staff (Gooding et al., 2011; Jolley & Shields, 2009; Williams, 2016). During childbirth, mothers were separated from their families, and newborns were separated from their mothers (Gooding et al., 2011; Williams, 2016). Beyond infancy, children admitted to the hospital had little to no contact with their parents (Fegran et al., 2006; Jolley & Shields, 2009). Physicians were considered the authority, with nurses acting as gatekeepers, and families merely bystanders (Gooding et al., 2011; Williams, 2016). The primary medical focus at the time was on the basic physical needs of the child (Fegran et al., 2006).

By the 1940s and 1950s, recognition of family needs and ideas of FCC began to emerge (Gooding et al., 2011; Just, 2005; Williams, 2016). Many attribute this evolution in thinking to the works of British theorists John Bowlby and James Robertson (Darbyshire, 1993; Jolley & Shields, 2009). Bowlby studied the early relationships and interactions between children and primary caregivers (Smith, 2014). He reported that

those early patterns of interaction would have a life-long impact on an individual's development. Bowlby developed his findings into what is now known as attachment theory (Smith, 2014). Robertson and his wife filmed hospitalized children and recorded the dramatic effects of family separation and the "emotional disintegration of children" (Darbyshire, 1993, p. 1671). The Robertsons then presented the films to both medical professionals and the public, at hospitals, schools, and town hall meetings in the United States (U.S.), Australia, and Europe (Jolley & Shields, 2009).

Another impetus for change was the publication of the Platt Report in 1959 by the British government following inquiries into the conditions of children's hospitalizations (Darbyshire, 1993; Just, 2005; Ministry of Health, 1959). The appointed Committee on the Welfare of Children in Hospital stressed the importance of recognizing hospitalized children's emotional and psychological needs (Darbyshire, 1993; Ministry of Health, 1959). Major recommendations in the Platt Report included: paying greater attention to the emotional and mental needs of hospitalized children; recognizing the authority and responsibility of parents, the individuality of the child, and the importance of mitigating the effects of separation of the child from family and home; children should be cared for in children's hospitals or wards, not with adults; parents should be allowed to visit and provide care for the child whenever possible; doctors, nurses, and ancillary staff need training in meeting children's emotional needs; and children's developmental needs should be considered in hospital organization and design, staffing, and recreational activities (Ministry of Health, 1959).

Parents, consumers, health care professionals, and government agencies have been vital in improving the care of hospitalized children and promoting FCC. Starting in

1955, The Citizens Committee on Children of New York City began advocating for child-friendly hospitals and increased access for parents (Jolley & Shields, 2009). Health care professionals formed The Association for the Care of Children's Health in 1965 (Jolley & Shields, 2009). Allowing parents to join in 1978, the Association produced initiatives to improve the health services of children (Jolley & Shields, 2009). In the 1970s and 1980s, the federal Maternal and Child Health Bureau (MCHB) helped revolutionize concepts of family-centered, community based, coordinated care, and family and professional partnerships (Wells, 2011).

Beginning in 1987, Surgeon General Everett Koop worked with the MCHB to bring families, pediatric leaders, policy makers, and state agencies together to “define and describe a family centered care approach to policy, program, and practice” (Arango, 2011; Wells, 2011, p. 100). During President Clinton's health care reform efforts in 1992, families of children and youth with special health care need (CYSHCN) took the opportunity to educate the public of their needs (Wells, 2011). Family Voices, a national network of families, was created to provide a voice for families of CYSHCN. Family Voices supported, organized, and connected families of children with disabilities and helped to build partnerships with key organizations, such as the American Academy of Pediatrics (AAP) and the National Association of Children's Hospitals and Related Institutions (Wells, 2011).

Beverly Johnson, an original founder of the now disbanded Association for the Care of Children's Health Institute, helped create the Institute for Family-Centered Care in 1993 (now the Institute for Patient- and Family-Centered Care; IPFCC) (Gooding et al., 2011; Jolley & Shields, 2009; Williams, 2016). The IPFCC has been instrumental in

developing and defining FCC in health care. In the same year, Helen Harrison, another advocate of FCC, introduced the principles in the NICU (Gooding et al., 2011).

The beginning of the 21st century has seen much advancement in FCC and its adoption as an accepted standard in health care. Leading health organizations now actively voice support for FCC (Just, 2005). In 2001, The Institute of Medicine urged health care systems to become patient-centered rather than disease-centered (Williams, 2016). The AAP (2012) incorporated FCC into their policies, and provided a statement defining patient- and family-centered care, describing core principles, and offering specific recommendations for the integration of patient- and family-centered care in health care settings. Currently, Healthy People 2020 has an objective to “increase the proportion of children aged 0 to 11 years with special health care needs who receive their care in family-centered, comprehensive, and coordinated systems” (Healthy People 2020, 2019).

Over the past century, FCC has evolved to provide a voice for parents, caregivers, and children. No longer bystanders, parents are now collaborators with the health care team. Parents are accepted as advocates for their children and are active in the decision-making process (Fegran et al., 2006). Caregivers are increasingly involved in their hospitalized child’s care (Fegran et al., 2006). Recognizing and supporting the needs of the family is becoming an integral part of overall care.

Defining Family-Centered Care

Despite recent advances in identifying and providing for the needs of families and hospitalized children, a singular definition and description of FCC and its components remains elusive. Family-centered care has been described in the literature as a philosophy

(Asai, 2011; Hockenberry et al., 2017; Just, 2005; Malusky, 2005; Skene et al., 2018), a theory (Bamm & Rosenbaum, 2008), an approach to care (American Academy of Pediatrics [AAP], 2012; Gooding et al., 2011; Institute for Patient- and Family-Centered Care [IPFCC], 2017; Kuo et al., 2012; Maternal and Child Health Bureau [MCHB], 2013; Williams, 2106), a model of care (Arango, 2011; Gooding et al., 2011; Jolley & Shields, 2009), and a concept (Arango, 2011; Family Voices, 2018; Malusky, 2005). However, most authors, regardless of how they initially labeled FCC, appeared to operationalize FCC within their studies as an approach to care.

Definitions of FCC, while similar in their language, vary in their breadth and scope across health care organizations. Since the works of the AAP, Family Voices, IPFCC, and the MCHB are the most often cited in the literature, their definitions will be presented in this section. Full definitions per organization can be found in Table 1. Consistent ideas found within all four definitions include: supporting active participation and partnerships between families and providers; acknowledging families as decision makers in their child's care; and recognizing family values, customs, cultures, and traditions (AAP, 2012; Family Voices, 2018; IPFCC, 2017; MCHB, 2013).

Just as the definitions vary by organization, so do the principles within FCC. A full description of the principles of FCC by organization can be found in Table 2. Common threads in the principles include: listening to the child and family; encouraging participation and partnerships between professionals and families; being sensitive to values, customs, and cultures of families; and providing complete and accurate information (AAP, 2012; Family Voices, 2018; IPFCC, 2017; MCHB, 2013).

Table 1

Definitions of Family-Centered Care by Organization

Organization	Definition
MCHB (2013)	<p>Family-centered care is an approach to the planning, delivery, and evaluation of health care whose cornerstone is active participation between families and professionals. Family-centered care recognizes that families are the ultimate decision makers for their children, with children gradually taking on more and more of this decision-making themselves.</p> <p>When care is family-centered, services not only meet the physical, emotional, developmental, and social needs of children, but also support the family’s relationship with the child’s health care providers and recognize the family’s customs and values.</p>
Family Voices (2018)	<p>Family-centered care is a way of providing services that assures the health and well-being of children and their families through respectful family/professional partnerships. It honors the strengths, cultures, traditions, and expertise that families and professionals bring to this relationship.</p>
IPFCC (2017)	<p>Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care by placing an emphasis on collaborating with people of all ages, at all levels of care, and in all health care settings. In patient- and family-centered care, patients and families define their “family” and determine how they will participate in care and decision-making. A key goal is to promote the health and well-being of individuals and families and to maintain their control.</p> <p>This perspective is based on the recognition that patients and families are essential allies for quality and safety—not only in direct care interactions, but also in quality improvement, safety initiatives, education of health professionals, research, facility design, and policy development.</p>
AAP (2012)	<p>Patient- and family-centered care is grounded in collaboration among patients, families, physicians, nurses, and other professionals in clinical care as well as for the planning, delivery, and evaluation of health care, and in the education of health care professionals and in research, as well.</p>

Table 2

Principles of Family-Centered Care by Organization

MCHB (2013)	Family Voices (2018)	IPFCC (2017)	AAP (2012)
<ul style="list-style-type: none"> • The provider spends enough time with the family • The provider listens carefully to the parents • The providers make the parent feel like a partner in the child’s care • The provider is sensitive to the family’s values and customs • The provider provides the specific information that the parent needs 	<ul style="list-style-type: none"> • Acknowledges the family as the constant in a child’s life • Builds on family strengths • Supports the child in learning about and participating in his/her care and decision-making • Honors cultural diversity and family traditions • Recognizes the importance of community-based services • Promotes an individual and developmental approach • Encourages family-to-family and peer support • Supports youth as they transition to adulthood • Develops policies, practices, and systems that are family-friendly and family-centered in all settings • Celebrates successes • Families and professionals work together in the best interest of the child and the family. As the child grows, s/he assumes a partnership role 	<ul style="list-style-type: none"> • Dignity and Respect: Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care. • Information Sharing: Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision-making. • Participation: Patients and families are encouraged and supported in participating in care and decision-making at the level they choose. • Collaboration: Patients, families, health care practitioners, and health care leaders collaborate in policy and program development, 	<ul style="list-style-type: none"> • Listening to and respecting each child and his or her family. Honoring racial, ethnic, cultural, and socioeconomic background and patient and family experiences and incorporating them in accordance with patient and family preference in the planning and delivery of health care. • Ensuring flexibility in organizational policies, procedures, and provider practices so services can be tailored to the needs, beliefs, and cultural values of each child and family and facilitating choice for the child and family about approaches to care. • Sharing complete, honest, and unbiased information with patients and their families on an ongoing basis and in ways they find useful and affirming, so that they may effectively participate in care and decision-making

-
- Everyone respects the skills and expertise brought to the relationship
 - Trust is acknowledged as fundamental
 - Communication and information sharing are open and objective
 - Participants make decisions together
 - There is a willingness to negotiate
- implementation and evaluation; in research; in facility design; and in professional education, as well as in the delivery of care.
- to the level they choose. Health information for children and families should be available in the range of cultural and linguistic diversity in the community and take into account health literacy. In hospitals, conducting physician rounds in the patients' rooms with nursing staff and family present can enhance the exchange of information and encourage the involvement of the family in decision-making.
- Providing and/or ensuring formal and informal support for the child and family during each phase of the child's life. Such support is provided so that Health Insurance Portability and Accountability Act and other relevant ethical and legal guidelines are followed.
 - Collaborating with patients and families at all levels of health care: in the delivery of care to the individual child; in professional education, policymaking, program development, implementation, and evaluation; and in health
-

care facility design. As part of this collaboration, patients and families can serve as members of child or family advisory councils, committees, and task forces dealing, for example, with operational issues in health care facilities; as collaborators in improving patient safety; as participants in quality-improvement initiatives; and as leaders or co-leaders of peer-support programs. In the area of medical research, patients and families should have voices at all levels in shaping the research agenda, in determining how children and families participate in research, and in deciding how research findings will be shared with children and families.

- Recognizing and building on the strengths of individual children and families and empowering them to discover their own strengths, build confidence, and participate in making choices and decisions about their health care.
-

The Positive Impact of Family-Centered Care

Although the literature on the impact of FCC in the NICU is somewhat limited, interventions based on family-centered principles have demonstrated several positive outcomes for infants, families, and nurses. Generally, the interventions most often studied included increasing parent access and participation in infant care, along with parent education on infant cues and development, feeding methods, and skin-to-skin practices. The impact of both formal and informal training of nurses on FCC principles is also frequently included.

The biggest impact of FCC in the literature is focused on infant outcomes. Interventions in the NICU based on FCC have shown an increase in infant body weight at discharge (De Bernardo et al., 2017; Lv et al., 2019; O'Brien et al., 2013; Yu et al., 2017), an increase in the incidence of breastfeeding by discharge (Lv et al., 2019; O'Brien et al., 2013), decrease in the incidence of nosocomial infections in infants (O'Brien et al., 2013), improved nutritional outcomes (Lv et al., 2019; Yu et al., 2017), earlier discharge from the hospital (Bastani et al., 2015; Yu et al., 2017), reduced neonatal readmissions (Bastani et al., 2015), better neurobehavioral performance (Yu et al., 2017), and a decrease of higher stages of retinopathy of prematurity by discharge (O'Brien et al., 2013).

Family-centered care interventions have also proved beneficial for both parents and nurses. FCC has been shown to increase overall parent satisfaction and decrease parental stress (Bastani et al., 2015; Cooper et al., 2007; De Bernardo et al., 2017; O'Brien et al., 2013). Parents are more satisfied with their communication with the health care team and the information received (De Bernardo et al., 2017). Parent caregiving

activities and skin-to-skin opportunities are increased with FCC implementation (Skene et al., 2018). After training and implementation of FCC practices in the NICU, nurses often report more positive perceptions of FCC and view FCC as more important than before implementation (Cooper et al., 2007). Nurses may feel more competent in their FCC practices and have more positive perceptions of information sharing with parents (Skene et al., 2018).

Nurses' Experiences with Family-Centered Care and Families

Belief versus Practice

It is well noted in the literature that nurses claimed to believe in the principles of FCC. Nurses accepted the importance of the family's presence in their child's life and including families in the care of their child (Alabdulaziz et al., 2017; Boztepe & Kerimoğlu Yildiz, 2017). Nurses thought they should empathize with families and support families emotionally (Alabdulaziz et al., 2017; Boztepe & Kerimoğlu Yildiz, 2017; Bruce et al., 2002). Nurses also believed in recognizing a family's individuality, sharing information, and working in collaboration with families (Alabdulaziz et al., 2017). Family-centered care is acknowledged by nurses as having benefits, such as increasing the comfort of the child (Boztepe & Kerimoğlu Yildiz, 2017) and building nurse-family relationships (Coats et al., 2018).

And yet, while nurses have stated they value FCC, it has not necessarily been evident in their day-to-day practice. Several studies using the Family-Centered Care Questionnaire (FCCQ) consistently demonstrated that nurses scored the necessity of FCC elements as significantly higher than their actual daily practice of those elements (Alabdulaziz et al., 2017; Bruce et al., 2002; Dall'Oglio et al., 2018). Observations of

nurses have demonstrated a lack of information sharing and emotional support of families (Alabdulaziz et al., 2017; Boztepe & Kerimoğlu Yildiz, 2017). Nurses may perceive elements of FCC as tasks to be checked off a list, rather than a working model of care (Alabdulaziz et al., 2017).

Perceived Barriers

Throughout the literature, nurses have cited a variety of barriers that prevented them from fully implementing FCC in their practice. Physical barriers included hospital design and environment (Benzies et al., 2019; Coyne et al., 2011), difficulty accessing tools and resources (Benzies et al., 2019; Coyne et al., 2013), time constraints (Aein et al., 2011; Coyne et al., 2011), and lack of space (Turner et al., 2014). Mental and emotional barriers were also expressed. Nurses may not feel confident in their ability to practice FCC (Asai, 2011). Nurses often felt a lack of support from hospital management (Boztepe & Kerimoğlu Yildiz, 2017). Constant family presence at the bedside was considered “distracting” and “exhausting” by some nurses (Coats et al., 2018, p. 55). Families who asked “too many” questions were considered a stressor, with nurses feeling as if their workload was increased and their attention divided between caring for the child and dealing with the parents (Alabdulaziz et al., 2017; Boztepe & Kerimoğlu Yildiz, 2017; Coats et al., 2018).

“Difficult” Parents: Role Expectations and Labeling

True collaboration and negotiation between nurses and parents were frequently problematic. To reduce workload, nurses delegated some of their duties to families without taking the families’ wishes into account (Aein et al., 2011; Coyne et al., 2011).

Some nurses considered dictating activities to parents as effective communication (Jones et al., 2015). “Good” parents were those who were co-operative and did not complain (Coyne, 2008; Coyne & Cowley, 2007). If caregivers refused to complete assigned tasks, they were deemed “uncooperative” by nurses (Aein et al., 2010). On the other hand, if parents attempted to be involved in their child’s care, nurses felt as if they were “encroaching upon their domain” (Aein et al., 2011, p. 848). If parents asked too many questions or questioned treatments, they were considered as challenging the nurses’ authority (Coyne, 2008). Nurses expected parents to remain calm and keep their child “manageable” (Coyne, 2008, p. 3154). Parents were labeled as “nightmare families” if they behaved aggressively. Unspoken rules by the nurses were used to control parental activities, such as timing of parent visits and parent conduct (Coyne, 2008). And yet nurses have considered a lack of parent engagement an obstruction to providing care and support (Turner et al., 2014).

Avoidance was often used as a strategy when dealing with so-called problem parents (Coyne, 2008). Many nurses avoided problem parents due to feeling annoyed and frustrated (Coyne, 2008, p. 3155). Nurses felt the need to avoid difficult parents to “maintain their sanity and provide good care to other children and parents” (Coyne, 2008, p. 3155). Tactics to avoid parents included staying in staff-only areas and persuading parents to take breaks from the bedside (Coyne, 2008).

Disparities in Family-Centered Care

Although specific research and data on health disparities related to FCC is relatively sparse, particularly in the NICU, there is certainly evidence to indicate care is not equitable across families and children. For example, infant mortality rates are much

higher in minority populations, with Non-Hispanic black infant mortality rates more than doubling that of Non-Hispanic whites (Centers for Disease Control and Prevention [CDC], 2016) In 2016, the infant mortality rates by race and ethnicity per 1,000 live births were: Non-Hispanic black, 11.4; American Indian/Alaska Native, 9.4; Native Hawaiian or other Pacific Islander, 7.4; Hispanic, 5.0; Non-Hispanic white, 4.9; and Asian: 3.6 (CDC, 2016).

Disparities in the receipt of FCC by children and families have been documented across racial, ethnic, and socioeconomic variables. Minorities, (specifically Latino, Non-Hispanic black, and multiracial children), poor families, families with less educated parents, and families with public or no health insurance reportedly received lower quality FCC than Non-Hispanic white children (Azuine et al., 2015; Bleser et al., 2017; Coker et al., 2010; Guerrero et al., 2010; Ngui & Flores, 2006). Children with special health care needs (CSHCN) overall received less family-centered care, and parents of Latino and African American CSHCN were less likely to report being listened to or receiving needed information from providers (Coker et al., 2010). Black and Hispanic parents of CSHCN reported more dissatisfaction with care and less ease of use of health care services than white parents (Ngui & Flores, 2006).

Nurses may be consciously or subconsciously contributing to these disparities. Less attention has been paid to families who are perceived by nurses as having unrealistic needs (Sigurdson et al., 2018). Nurses have reported that communicating with certain parents is challenging, such as “younger mothers, drug affected mothers and mothers from different cultural or ethnic groups” (Jones et al., 2015, p. e77). The labeling of parents and families as mentioned previously in this chapter may also be a reflection of a

nurse's personal biases (Coyne, 2008). Judgmental care, when nurses evaluated a family's moral status, commonly occurred with black and non-English speaking families, as opposed to the privileged care given to white families (Sigurdson et al., 2018). In Coyne's (2008) study of parent participation in pediatric wards, she noted "the labeling of non-compliant parents revealed a social order that was markedly classist, racist and outdated with regard to changing family structure and working patterns (p. 3156). O'Haire and Blackford (2005) found similar results, with nurses' admitting to providing minimal care when encountering difficult families. Labeling of families and providing minimal care was considered to be a coping mechanism by nurses in order to deal with parents who disagreed with their actions. (O'Haire & Blackford, 2005).

Summary, Gaps, and Reason for Current Study

Family-centered care has come a long way since the early 1900s. There is a growing acceptance of family inclusion in the care of the hospitalized newborn and the broader pediatric population. However, what actually constitutes FCC remains difficult to pin down. Components of FCC have resulted in positive outcomes for infants, parents, and nurses alike. And though nurses claim to believe in FCC, their practice does not always reflect FCC principles. Nurses often cite physical, mental, and emotional barriers when providing care for families, which may be contributing to documented disparities in care. While there has been a growing body of literature on FCC in the past two decades, significant gaps do exist.

Of the articles reviewed for this chapter, little research was completed in NICUs located within the U.S. Of those studies, two were commentaries on the history and current state of FCC in the NICU (Gooding et al., 2011; Williams, 2016) and one was a

concept analysis of FCC in the NICU (Malusky, 2005). Three qualitative studies examined nurses' perceptions of the benefits and challenges of providing FCC in NICUs (Coats et al., 2018), the nurses' role in providing emotional support to families (Turner et al., 2014), and accounts of disparities in care (Sigurdson et al., 2018). In one quasi-experimental study, the authors evaluated the impact of the March of Dimes NICU Family Support Program on overall care (Cooper et al., 2007).

In order to gain more insight on FCC, the literature search was expanded to include NICUs outside of the U.S. Two studies used cross-sectional surveys to examine FCC practices (Italy) (Dall'Oglio et al., 2018) and predictors of nurses' FCC practices (Japan) (Asai, 2011). Randomized clinical trials were implemented to examine the impact of FCC on pre-term infant outcomes (Taiwan) (Yu et al., 2017) and maternal satisfaction and neonatal readmissions (Iran) (Bastani et al., 2015). Two pilot cohort studies were completed, one examining the feasibility and potential outcomes of a Family Integrated Care program (Canada) (O'Brien et al., 2013), and one comparing satisfaction and stress levels of parents and infant weight gain between an FCC group and standardized care group (Italy) (De Bernardo et al., 2017). Skene (2018) used a participatory action research approach to develop, implement, and evaluate FCC interventions in England. Several authors used qualitative designs to describe nurses' perspectives, including nurses' views on their role in the NICU (Australia) (Turner et al., 2014), communication with parents (Australia) (Jones et al., 2015), and experiences of providing care for NICU infants and families (Canada) (Benzies et al., 2019).

Much of the literature exploring nurses' experiences with families and FCC occurred in pediatric hospitals, not the NICU, and outside of the U.S. This includes

pediatric wards in Iran (Aein et al., 2011), Saudi Arabia (Alabdulaziz et al., 2017), Turkey (Boztepe & Kerimoğlu Yildiz, 2017), England (Coyne, 2008; Coyne & Cowley, 2007), Ireland (Coyne et al., 2013; Coyne et al., 2011), Canada (Bruce et al., 2002), and Italy (Dall'Oglio et al., 2018). Four studies (Coyne et al., 2011; Coyne et al., 2013; Bruce et al., 2002; Dall'Oglio et al., 2018) used the Family-Centered Care Questionnaire-Revised (FCCQ-R) to investigate FCC perceptions and practices of pediatric nurses. In a mixed methods study, Alabdulaziz, Moss, and Copnell (2017) used the FCCQ, interviews, and observations to explore FCC in a Saudi context from pediatric nurses' perspectives. A qualitative descriptive study by Boztepe and Kerimoğlu Yildiz (2017) explored pediatric nurses' views and perceived barriers of implementing FCC. Finally, three studies included a grounded theory approach. Aein, Alhani, Mohammadi, and Kazemnejad (2011) developed a substantive theory of nurse-mother interactions in the care of chronically ill children. Coyne (2008) and Coyne and Cowley (2007) used grounded theory to explore parent participation in pediatric hospitals.

The research on disparities in FCC care primarily focused on the general pediatric and CSHCN populations. Researchers reporting findings on nurses' use of labeling families and providing less than optimal care did not specifically set out to explore inequities in the deliverance of FCC. None of these studies were performed in the U.S.

Interest in FCC practices is growing; however, it is evident that few studies focus on FCC in the NICU. O'Brien et al. (2013) developed and tested a FIC program based on the Humane Neonatal Care model. Several studies have examined nurses' experiences from the view of nurse-parent collaboration. No studies have been found to date that specifically focus on the connection between nurses' perceptions of families and its

impact on their practice. With the exception of the grounded theory studies, almost all studies used family-centered care as the underlying conceptual framework. An overview of the relevant research found in this literature review can be found in Table 3. This current study aims to build on previous research by exploring the relationships between nurses' attitudes, beliefs, and biases toward families and the decision-making process related to delivering FCC.

Table 3*Overview of Family-Centered Care Research*

Author, Year, Country	Purpose/Aim	Method, Theory/ Conceptual Framework	Population, Sample Size (n), Setting	Key Findings
Aein et al. (2011) Iran	To develop a substantive grounded theory of nurse-mother interaction in the care of chronically ill children in a hospital setting	Method: Grounded theory (Glaser) Theory: N/A	Pediatric nurses (n = 17) Mothers of chronically ill children (n = 14) University pediatric hospitals	“Struggling to create new boundaries” was the core variable. Process manifested in three stages: facing up to and perceiving environmental pressures; balancing nurse’s duties; controlling the nurse-parent boundary within care.
Alabdulaziz et al. (2017) Saudi Arabia	To explore family-centered care in the Saudi context from the perspectives of pediatric nurses	Method: Mixed methods Instrument: FCCQ Theory: FCC	Pediatric nurses (observations: n = 14; interviews: n = 10; FCCQ: n = 219) Pediatric units in government hospitals	Participants identified most elements of FCC as necessary for practice, however, were less likely to actually implement those elements. Participants had a limited understanding of FCC as a model of care.
Asai (2011) Japan	To identify the predictors of nurses’ FCC practices in NICUs in Japan	Method: Quantitative cross-sectional survey Instruments: Facility-level questionnaire developed by author; MPOC-SP; MBP-FCS Theory: FCC	Nurse managers (n = 30) Staff nurses (n = 710) NICUs (n = 30) in Tokyo, Japan	Most significant predictor of nurses’ implementation of FCC was perceived self-efficacy. Nurses supported philosophy of FCC, but few were confident they could practice FCC. NICU experience, nursing support, and visiting policies also impacted FCC practice.

Azuine et al. (2015)	To estimate the prevalence of parent/family-reported receipt of FCC among children in various socioeconomic and demographic groups and across the US. To identify sociodemographic groups and states with lower receipt of FCC among US children.	Method: Complex survey design using the 2011-2012 National Survey of Children's Health Theory: FCC	Parents or guardians (n = 91,001)	Non-Hispanic Black and Hispanic children had higher odds of not receiving FCC than non-Hispanic White children. Children from non-English speaking, low-education, and low-income households had a higher likelihood of not receiving FCC.
Bastani et al. (2015)	To determine the effect of FCC including maternal participation, presence, and information about neonatal care, on maternal satisfaction and neonatal readmission	Method: Randomized clinical parallel trial with a prospective posttest two groups design Theory: FCC	Mothers (FCC group: n = 50; control group: n = 50) University maternity hospital in Tehran, Iran	Mothers in the FCC group reported increased satisfaction after program implementation. The number of neonatal readmissions and the mean duration of hospitalization was less in the FCC group.
Benzies et al. (2019)	To describe the perspectives of health care providers and hospital administrators on their experiences of providing care for infants in Level II NICUs and their families.	Method: Qualitative descriptive Theory: FCC	Staff nurse (n = 9) Nurse educator (n = 2) Allied health professional (n = 6) Physician (n = 4) Medical director (n = 4) Patient care manager (n = 9) Level II NICUs (n = 10)	Health care providers and administrators felt the health care system was making "too much noise" to provide FCC in ways that would benefit infants and families. Participants spoke about involving parents in care and decision-making but expressed challenges with operationalizing FCC in practice.

Bleser et al. (2017)	To gain a better understanding of disparities in the receipt of PFCC among the general population of US children	Method: Cross-sectional analysis using 2001-2013 Medical Expenditure Panel Survey (MEPS) pooled data Theory: PFCC	Children (n = 22,942)	Overall prevalence of high-quality PFCC was high. Lower prevalence of high-quality FCC was observed among children who were publicly insured and living in families below the poverty line.
United States				
Boztepe & Kerimoglu Yildiz (2017)	To obtain in-depth information from nurses on factors related to FCC and the barriers to its implementation	Method: Qualitative descriptive Theory: FCC	Nursing providing direct clinical nursing care (n = 18) PICU, pediatric surgery unit, and general pediatric unit at a children's hospital in Turkey	Most nurses agreed on the importance of FCC and the value of parental participation and continuity of family in the child's life. The majority of participants did not believe that FCC nursing rounds and parental participation in nursing bedside shift report were beneficial. Nurses sometimes felt families were a stressor or obstacle.
Turkey				
Bruce et al. (2002)	To determine the differences in health professionals' perceptions and practices of FCC and to examine factors that influence those perceptions.	Method: Multisite survey Instrument: FCCQ-R Theory: FCC	Health professionals (n = 483) Tertiary care children's hospitals (n = 3)	Participants had an understanding of the elements of FCC and rated the elements as necessary. However, these elements were not consistently incorporated into practice. The least agreed upon and least practiced element was parent/professional collaboration.
Canada				

Coats et al. (2018)	To describe nurses' perceptions of the benefits and challenges of providing FCC in pediatric intensive care units	Method: Qualitative descriptive Theory: FCC	PICU nurses (n = 10) PICU, cardiac ICU, and NICU in an urban children's hospital	All nurses viewed the transition to FCC as beneficial for families. Described benefits and challenges of providing quality FCC as a "balancing act." Having families at the bedside increased opportunities to build relationships and include families in their child's care. Nurses also reported having family at the bedside 24 hours a day could be "distracting" and "exhausting."
Coker et al. (2010)	To examine racial/ethnic and language disparities in FCC and in FCC components for children with special health care needs (CSHCN)	Method: Bivariate and multivariate logistic regression analysis of data from the 2005-2006 National Survey of CSHCN Theory: FCC	Parents of CSHCN (n = 38,902) US households across all 50 states	Sixty-six percent of children received FCC; Latino, African American, and children in households with non-English primary language had lower odds of receiving FCC than white children in English speaking homes.
Cooper et al. (2007)	To evaluate the impact of a national program [March of Dimes NICU Family Support (NFS)] designed to promote FCC in NICUs and to provide information and comfort to families during the NICU hospitalization of their newborn	Method: Quasi-experimental, post-only design Theory: FCC	NICU administrators (n = 11) NICU staff (n = 502) NICU families (n = 216) March of Dimes NFS sites (n = 8)	NICU administrators viewed NFS as benefiting families by changing NICU culture. Over half of NICU staff reported that NFS enhanced overall quality of care.

Coyne (2008)	To investigate parent participation in the hospitalized child's care from the perspectives of children, parents, and nurses	Method: Grounded theory Theory: N/A	Pediatric nurses (n = 12) Four pediatric wards in two hospitals	Nurses expected parents to provide emotional and nursing care for their child. Parents were expected to co-operate, help, and follow all instructions. Nurses resorted to inclusionary and exclusionary tactics to deal with noncompliant parents.
Coyne & Cowley (2007)	To explore children's, parents', and nurses' views on participation in care in the healthcare setting	Method: Grounded theory Theory: N/A	Nurses (n = 12) Parents (n = 10) Children (n = 11) Four medical/surgical pediatric wards in two hospitals	Nurses assumed parents would participate in care. Nurses were reliant on parents providing care, and cited inadequate staffing, patient acuity, and increased technical care as preventing them from being available to parents and children. Nurses controlled nature and extent of parent participation through positive and negative actions.
Coyne et al. (2013)	To investigate pediatric nurses' practices and perceptions of FCC and to examine the factors that influence those perceptions	Method: Nonexperimental survey Instrument: FCCQ-R FCC	Pediatric nurses (n = 250) Pediatric units (n = 7)	Participants' total mean score for the necessary practices scale was significantly higher than the total mean score for the current practice scale, suggesting that FCC elements were not consistently applied in practice.
Coyne et al. (2011)	To report nurses' perceptions and practices of FCC	Method: Descriptive survey design	Pediatric nurses (n = 250) Pediatric units (n = 7)	Nurses accepted FCC as an ideal philosophy, but implementation was a challenge. Nurses identified improved hospital facilities, support services for

		Instrument: FCCQ-R with two open questions		families, communication, appropriate staffing levels, and managerial support as requirements for enhancing FCC.
		Theory: FCC		
Dall'Oglio et al. (2018)	1. To investigate the extent to which FCC principles are currently applied in clinical practice by healthcare providers working in inpatient units 2. To evaluate the extent to which FCC principles are perceived as necessary 3. To examine the associations between FCC principles and socio- demographic and job characteristics of participants	Method: Cross- sectional study	Healthcare providers (n = 469)	Scores of each item of the Necessary activities of FCC were significantly higher than those of Current activities of FCC. Participants who were male, younger, and with work experience >20 years reported a significantly higher perception of Current activities. Older and more educated participants perceived a greater necessity of FCC activities. Female, older, and less experienced participants perceived a greater gap between Necessary and Current activities.
Italy		Instrument: FCCQ-R	Tertiary pediatric research hospital	
		Theory: FCC		
De Bernardo et al. (2017)	1. To compare satisfaction and stress levels between parents in an FCC group and a non-FCC group 2. To compare the satisfaction and stress levels of mothers and fathers within the FCC and NFCC groups and between the two groups	Method: Non- randomized, prospective cohort pilot study	FCC group: Parents (n = 48) Newborns (n = 24)	Parents in the FCC reported more satisfaction and less stress than those in the NFCC group. Infants in the FCC group had increased body weight 60 days after admission.
Italy		Theory: FCC	NFCC group: Parents (n = 48) Newborns (n = 24)	

	3. To evaluate newborn body weight gain at 60 days after admission in the two groups		NICU at the Santobono-Pausilipon Level III Hospital	
Guerrero et al. (2010)	To examine racial and ethnic disparities in the receipt of FCC amongst a general population of US children	Method: Bivariate analyses using a linked dataset of the Medical Expenditure Panel Survey (MEPS) and the National Health Interview Survey (NHIS)	Parents of children aged 0-17 (n = 10,278) US households across United States	Parents generally reported positive experiences of FCC. Latino children had lower odds of receiving all four components of FCC than white children. Black children had similar experiences as white children.
		Theory: FCC		
Jones et al. (2015)	To explore and describe parents' and nurses' perceptions of what constitutes effective communication in the nursery environment	Method: Qualitative experiential approach	Parents (n = 32) Nurses (n = 12)	Both parents and nurses believed it was important to share information. Both parents and nurses recognized that a lack of information could negatively impact interactions. Similarities and differences occurred between how parents and nurses considered a partnership should be enacted. Policies and procedures of the unit created communication conflicts.
Australia		Theory: FCC	Two hospitals: Tertiary neonatal Unit in a tertiary referral hospital Level II unit in a regional hospital	
Lv et al. (2019)	To implement and test an FCC intervention providing parental education and participation in care among parents with VLBW infants	Method: Quasi-experimental	Preterm infants: FCC group (n = 156) Standard care group (n = 163)	Infant weight at discharge was higher in the FCC group. Nutritional outcomes and rates of certain infant complications improved significantly. Length of stay, hospital expenses, and
China		Theory: FCC		

			Level 3 NICU at Hunan Children's Hospital	nosocomial infections did not differ between groups.
Ngui & Flores (2006)	To examine whether there are racial/ethnic disparities in parent-reported satisfaction with care and ease of using health care services among CSHCN and to identify factors that contribute to these disparities among parents of CSHCN	Method: Bivariate analyses and multivariate logistic regression modeling using analyzed data from the National Survey of CSHCN (NS-CSHCN) Theory: FCC	Parents of CSHCN (n = 36,238) US households across all 50 states	On FCC measures, minority parents of CSHCN were more likely than white parents to report being dissatisfied with care. Severity of child's condition, lack of insurance, and inadequate FCC was associated with dissatisfaction with care and less ease of using health care services.
O'Brien et al. (2013)	1. To explore the feasibility and safety of the Family Integrated Care (FIC) model in a Canadian NICU 2. Identify potential improvements in neonatal and parental outcomes	Method: Pilot cohort analytic study Instrument: PSS-NICU Theory: FIC program based on the Humane Neonatal Care model	Infants: FIC group (n = 31) Matched control group (n = 62) Mothers (n = 42) Canadian NICU	The rate of change in weight gain was significantly higher for the FIC group than the control group. There was an increase in the incidence of breastfeeding at discharge and a decrease in the incidence of retinopathy of prematurity in the FIC group. The mean parental stress score fell for FIC mothers with no significant change in the control group.
O'Haire & Blackford (2005)	1. To explore nurses' understanding of parental participation in care	Method: Grounded theory (Strauss)	Nurses (n = 9)	Moral agency was identified as the central phenomenon. Causal conditions that affected how

Australia	<p>2. To understand how nurses negotiate parental participation in care</p> <p>3. To identify what resources and strategies nurses use to facilitate parental participation</p> <p>4. To identify the barriers to parental participation in care</p>	Theory: N/A	Pediatric cardiac/renal unit	nurses enacted their moral agency and could lead to moral distress included the child's best interests, disputes about care, and nurses' expectations. Coping strategies included labeling parents providing minimum care.
Sigurdson et al. (2018)	To identify how family advocates and clinicians describe disparities in NICU quality of care in narrative accounts	Method: Grounded theory	VON attendees (n = 324)	Nearly all accounts described how families were treated differently and implied that disparate treatment resulted in suboptimal care. Three types of suboptimal care included neglectful care, judgmental care, and systemic barriers to care. Narratives demonstrated isolation of non-English speaking families, lack of empathy for drug-abusing mothers, lack of accommodation for cultural needs, and racist treatment of black families.
United States		Theory: N/A	Convenience sample of neonatal clinicians and family advocates during a plenary presentation at the 2016 Vermont Oxford Network (VON) Annual Quality Congress	
Skene et al. (2018)	To develop, implement, and evaluate FCC interventions to promote parental involvement in caregiving in the NICU	Method: Participatory action research study	Nurses: Phase 1 (n = 74) Phase 3 (n = 68)	In Phase 1, nurses were aware of need for parental participation, but unable to provide support because of workload, NICU culture, and restricted parental access to the NICU. Parents identified professional, cultural,
England		Theory: FCC	Parents (n = 80)	

			Regional NICU in England	and personal factors that impacted involvement. After FCC implementation, nurses had a more positive perspective of FCC and parents described more episodes of involvement.
Turner et al. (2014)	To explore the nurses' views of their role both in the NICU and in the provision of interacting with, and emotionally supporting, families	Method: Qualitative Theory: None stated	Nurses (n = 18) Tertiary teaching hospital	Nurses viewed their role as both enjoyable and challenging. Positive NICU environment and parent support groups fostered the provision of support for families. Obstructive elements included lack of space, lack of time, lack of parent engagement, lack of education and training, and language and cultural barriers.
Yu et al. (2017)	To examine whether a family-centered intervention program (FCIP) could improve the short-term medical and neurobehavioral outcomes in preterm infants with very low birth weight (VLBW) in Taiwan over the outcomes seen with a usual care program (UCP)	Method: Multicenter, single-blind, randomized controlled trial Theory: FCC	VLBW preterm infants: FCIP (n = 129) UCP (n = 140) Three medical centers	Earlier full enteral feedings, earlier hospital discharge, greater weight gain, and better neurobehavioral performance was noted in the FCIP compared to the UCP group.

Note. FCCQ = Family-Centered Care Questionnaire; MPOC-SP = The Measure of Processes of Care for Service Providers; MBP-FCS = Measure of Beliefs about Participation in Family-Centered Service; PFCC = Patient- and Family-Centered Care; FCCQ-R = Family-Centered Care Questionnaire Revised; PSS-NICU = Parental Stressor Scale: Neonatal Intensive Care Unit.

CHAPTER 3

METHODS

The purpose of this study was to examine nurses' attitudes, beliefs, and biases related to families and the influence these views have on the implementation of FCC in the NICU and to uncover social processes underlying practice. A grounded theory approach was used to achieve this purpose and to develop a substantive theory. Grounded theory is a systematic, yet flexible method of collecting and analyzing data and leads to the construction of a theory "grounded" in the data (Charmaz, 2014). The resulting theory can be either formative or substantive (Glaser & Strauss, 1967). Formal theories are more abstract and can be applied across multiple areas; substantive theories address a specific empirical area (Glaser & Strauss, 1967; Polit & Beck, 2021). Grounded theory is primarily inductive in its approach; concepts are derived from collected data and are not selected prior to the study (Corbin & Strauss, 2015; Glaser & Strauss, 1967). Through constant comparative methods, data are continuously compared throughout the research in order to identify emerging concepts and their relationships with one another (Artinian et al., 2009). The most common types of data collected are through interviews and observations, although written and recorded materials may be used (Corbin & Strauss, 2015).

Grounded theory is used to study social processes by uncovering "the beliefs and meanings that underlie action" (Corbin & Strauss, 2015, p. 11) and examining aspects of behavior, including the influence of logic and emotion on a person's response to life's events (Corbin & Strauss, 2015). This method of theory development provides a foundation for future studies, is culturally sensitive, and can be applied to individuals,

organizations, and societies (Corbin & Strauss, 2015). It offers new insights into phenomena and “enables persons to explain and take action to alter, contain, and change situations” (Corbin & Strauss, 2015, p.11). A strength of grounded theory over other designs is in its “ability to move data from the descriptive level to the conceptual level” (Artinian, Giske, & Cone, 2009, p. 6).

History of Grounded Theory

In the 1950s, the University of California, San Francisco (UCSF) recruited sociologist Anselm Strauss to start a doctoral program in nursing (Corbin & Strauss, 2015). Shortly after, he received a grant to study the interactions between medical staff and terminally ill patients using fieldwork methods. Strauss enlisted sociologist Barney Glaser as a co-researcher in the study (Corbin & Strauss, 2015). During their research, Strauss and Glaser became frustrated with the overemphasis in the social sciences of verifying theory instead of generating theory from data (Kenny & Fourie, 2014). At the time, qualitative research in sociology was fading in favor of quantitative methods (Charmaz, 2014). Mid-20th century positivists believed in an objective, absolute, and measurable reality that existed separate from human construction (Charmaz, 2014; Polit & Beck, 2021; Weaver & Olson, 2006). Researchers deductively arrived at theories through formal scientific testing of hypotheses. Emphasis was placed on replication, verification, and generalization of scientific predictions (Charmaz, 2014; Polit & Beck, 2021; Weaver & Olson, 2006).

At the same time, qualitative inquiry had shifted from life histories and case studies in the early decades of the 1900s to participant observations by the mid-century. However, these qualitative methods “had not been theorized, explicated, or codified in

accessible ways” (Charmaz, 2014, p. 5). Little of what qualitative researchers did in the field was well understood, and methodological texts at the time did not emphasize analytic strategies (Charmaz, 2014). In response, Strauss and Glaser developed an innovative and systematic way of collecting, coding, and analyzing qualitative data to inductively arrive at a theory grounded in that data. The results of their study were published in *Awareness of Dying* (1965). The pair went on to describe their new methodology in *The Discovery of Grounded Theory* (1967). This groundbreaking text offered researchers both a “rigorous methodology” (Kenney & Fourie, 2014, p. 3) that had been sorely missing in qualitative research, and a guidebook for using grounded theory to “build theory that is faithful to and illuminates the area under study” (Strauss & Corbin, 1990, p. 24).

The study on medical staff and dying patients would be the only major research Strauss and Glaser would perform together (Corbin & Strauss, 2015). Going their separate ways, Strauss would eventually partner with Juliet Corbin and begin evolving the original grounded theory methodology, publishing their ideas in *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* (1990) (Corbin & Strauss, 2015). Glaser went on to write numerous publications, by himself and with others, on grounded theory methods, most notably *Theoretical Sensitivity* (1978) and *Basics of Grounded Theory Analysis* (1992). It was Glaser’s *Basics of Grounded Theory Analysis* and his criticisms of Strauss and Corbin’s version of grounded theory in *Basics of Qualitative Research* (1990) that would begin the debate among researchers on who held true to the “classic” grounded theory founded in Glaser and Strauss’ (1967) original text.

Glaser versus Strauss

The Discovery of Grounded Theory (Glaser & Strauss, 1967) is often considered and used as the authoritative text on grounded theory methods. Since its publication, Glaser and Strauss have independently refined the methods first mentioned in the text. There has been ongoing discussion by researchers regarding which perspective was most consistent with original grounded theory methodology. Proponents of Glaser's work have considered his writings as true to the original approach, arguing Strauss' methods are an entirely different approach to grounded theory. Glaser himself considered Strauss' methods as merely a detailed description of concepts rather than actual theory development. However, Corbin and Strauss (2015) argued that Strauss "wasn't trying to develop ... a separate branch of the original grounded theory" (Corbin & Strauss, 2015, p. 21), rather, Straussian grounded theory still holds to the basic methods: comparative analysis, theoretical sampling, and conceptual saturation (Glaser & Strauss, 1967).

The debate surrounding Glaser and Strauss' separate works is often related to assumed differences in ontology, epistemology, and methodology. For decades, researchers have tried to pin down Glaser and his methods to specific paradigms and philosophies. Some authors claimed Glaser's classic grounded theory is aligned with a realist ontology, objectivist epistemology, and a positivist paradigm, pointing to Glaser's assumption that an external reality will emerge from data and his insistence on the researcher remaining independent from that data (Annells, 1997; Charmaz, 2014; Kelle, 2005). Other researchers assumed critical realist and post-positivist underpinnings in Glaser's work (Annells, 1997; Kenny & Fourie, 2015; Levers, 2013; McCann & Clark, 2003). Many researchers believed Glaser's grounded theory is married to symbolic

interactionism (Annells, 1997; Heath & Cowley, 2004; McCann & Clark, 2003).

However, Glaser (2005; Glaser & Holton, 2004) has rebuked all of these claims, stating that his grounded theory methodology is not tied to any philosophy and is nothing more than an “inductive model for research” (2005, p. 5) and “the quest for an ontology and epistemology for justifying GT is not necessary” (2005, p. 5).

Like Glaser, Strauss refuted the claim that the original method had its roots in symbolic interactionism, saying no theoretical or philosophical perspectives were recognized during grounded theory development, nor was it needed in a grounded theory study (Glaser and Strauss, 1967; Glaser, 2005; Strauss & Corbin; 1990; Corbin & Strauss, 2015). On the other hand, Strauss would later become comfortable admitting the influences of pragmatism and symbolic interactionism on his separate grounded theory methods (Corbin & Strauss, 2015). In speaking of Strauss, Corbin (2015) stated:

...when Glaser and Strauss (1967) wrote *The Discovery of Grounded Theory*, they were not thinking in terms of formulating a methodology based on a theoretical foundation, such as pragmatism or interactionism. However, these philosophies were deeply rooted in Strauss, and over time, they manifested themselves in how he thought about the world and his approach to doing analysis. (p. 21)

Choosing Straussian Grounded Theory

I chose Strauss and Corbin’s (1990; 2015) approach to grounded theory for the following reasons. First, being a novice researcher and new to grounded theory, I appreciated Strauss and Corbin’s (Corbin & Strauss; 2015; Strauss & Corbin, 1990) detailed explanations and guidelines for theoretical sampling, coding, memoing, and constant comparison analysis. Strauss and Corbin (1990; 2015) presented clear examples

and procedures to build a substantive theory. Although critics find Strauss and Corbin's methodology too structured, and inconsistent with the original intent of grounded theory methods, I found the details of their approach easier to follow than the more ambiguous language used by Glaser (1978; 1992; 2005).

Second, I believe Strauss and Corbin's (1990; 2015) grounded theory methods are more reflective of contemporary, social constructivist thinking than Glaser's (2005; Glaser & Holton, 2004) grounded theory. Both Strauss and Corbin embraced changes to the method with Strauss, in particular, recognizing the world as constantly in flux (Corbin & Strauss, 2015; Strauss & Corbin, 1990). Corbin also admitted to the influences that feminists, constructionists, and postmodernists have had on her work (Corbin & Strauss, 2015). Using a methodology that is open to change in contemporary thinking and a socially constructed world is certainly appealing.

Finally, Strauss and Corbin (1990; 2015) also recognized the active role the researcher has in relation to prior literature and data collection and analysis. Glaser's methodology holds more to positivist ideas that the researcher should remain independent from data analysis and interpretation (McCann & Clark, 2003). Strauss and Corbin (1990; 2015) allow for research questions from gaps in the literature and past experiences. The research question in this study evolved from my personal experiences as a bedside NICU nurse and watching the interactions of my colleagues with families on the unit. As Corbin (Corbin & Strauss, 2015) stated:

...it is not the event itself that is the issue in our studies; it is the meaning given to events as evidenced in the action – interaction that follows. Each person experiences and gives meaning to events in light of his or her own biography or

experiences, according to gender, time and place, and cultural, political, religious, and professional backgrounds. (p. 25)

Reality cannot be fully known, only interpreted within structural, contextual, symbolic, and interactional influences (Corbin & Strauss, 2015; McCann & Clark, 2003).

Philosophical Assumptions

In choosing Straussian grounded theory, pragmatism and symbolic interactionism and the inherent assumptions found in Strauss and Corbin's (1990; 2015) texts formed the basis for the current study.

Pragmatism and Symbolic Interactionism

Symbolic interactionism is a perspective in sociology that focuses on the creation of society through interactions between individuals (Carter & Fuller, 2016). It is primarily rooted in the pragmatist philosophies and works of George Herbert Mead, John Dewey, and Herbert Blumer during their time at the University of Chicago. While Blumer coined the term symbolic interactionism, Mead is often considered the true originator of the theoretical framework (Carter & Fuller, 2016; Reynold & Herman-Kinney, 2003). Some of Mead's pragmatist contributions to symbolic interactionism include:

- Human behavior is behavior in terms of what situations symbolize
- Through the development of common meanings, understandings, expectations, and objects, a common social world is formed
- Individuals actually share one another's behaviors rather than simply respond to them (Reynold & Herman-Kinney, 2003, p. 17).

Further assumptions of American pragmatism include:

- Human beings are active, creative agents
- The world people inhabit is one they had a hand in making. And it, in turn, shapes their behavior. They then remake it.
- Subjective behavior does not exist prior to experience but flows from it. Meaning and consciousness emerge from behavior. An object's meaning resides not in the object itself, but in the behavior directed toward it (Reynold & Herman-Kinney, 2003, pp. 45-46).

From these pragmatist ideas flow Blumer's basic tenets of symbolic interactionism and what is now known as The Chicago School of symbolic interactionism. Developed in the 1950s, symbolic interactionism departed from current positivistic thinking at the time, which examined society at a macro-level (Carter & Fuller, 2016). Instead, symbolic interactionism shifted to a micro-level approach, focusing on processes involved during individual's encounters with one another (Carter & Fuller, 2016). Blumer described three premises of symbolic interactionism: (a) human beings act toward things on the basis of the meanings that the things have for them; (b) the meanings of things is derived from, or arises out of, the social interaction that one has with others; and (c) meanings are handled in, and modified through, an interpretive process used by a person in dealing with the things he or she encounters (Blumer, 1969, as cited in Carter & Fuller, 2016; Reynold & Herman-Kinney, 2003).

Blumer contended that human behavior should be studied in forms of action, that each member of society acts independently within the group (Carter & Fuller, 2016). Carter and Fuller (2016) summarized Blumer's approach to research methodology: "an understanding of social life requires an understanding of the processes individuals use to

interpret situations and experiences, and how they construct their actions among other individuals in society” (pp. 934-935).

Assumptions from Straussian Methodology and the Current Study

Consistent with Corbin and Strauss’ (2015) methodology, the following assumptions were adopted for this study:

1. External worlds and internal worlds are created and recreated through interactions.
2. Humans develop their identities throughout their lifetime, and those identities enter all their actions and interactions.
3. Interactions generate new meanings as well as alter and maintain old ones.
4. Actions are embedded in interactions and also carry meanings.
5. Contingencies can arise during action-interaction that can change its duration, pace, and intent. This may alter interpretations as interaction proceeds.
6. Actions have emotional aspects. They are not necessarily rational.
7. An individual’s membership in social worlds affects their perspectives, and therefore their interactions (pp. 22-24).

While Corbin and Strauss (2015) emphasized it is not necessary to subscribe to the tenets of symbolic interactionism in order to use their methods to conduct research, I felt it was relatively impossible to separate the two. In my study’s purpose of examining nurses’ relationships and interactions with families in the NICU, symbolic interactionism was a valid theoretical perspective to take.

Personal Assumptions and Biases

In addition to the philosophical assumptions, my own personal assumptions and biases should be discussed. I believed that nurses were aware of the concept of FCC and recognized the importance of collaboration with families to support the best possible outcome for the infant. Within my professional experiences of FCC in the NICU as a staff nurse, I have witnessed and personally experienced both positive interactions and challenges with families. I have noticed some disparities in how FCC is implemented by staff in the NICU. I assumed there were implicit and known biases about families, which consciously or subconsciously direct the level of care by bedside nurses, whether positively or negatively.

Reflexivity

It is important for researchers to recognize how personal assumptions and biases impact research (Patton, 2015). Reflexivity requires critical reflection on personal cultural, political, and social contexts that might influence data collection and interpretation (Patton, 2015; Polit & Beck, 2021). In qualitative research, the researcher is the instrument. A bidirectional, reflexive relationship exists between interviewer and interviewee; each having an impact on the other (Patton, 2015). To be reflexive requires asking oneself, “how might my previous experiences, my values, my background, my prejudices be shaping my analysis and interpretations?” (Polit & Beck, 2021, p. 551).

Reflexive notes can serve several purposes. After each data collection session, I took notes of my own reactions, along with reactions of the participants. Methodological notes helped me reflect on strategies used during observations and informed how I moved forward with future interviews (Polit & Beck, 2021). By taking theoretical notes, I

documented how I attached meaning to observations, which served “as a starting point for subsequent analysis” (Polit & Beck, 2021, p. 407). Personal notes included comments about my own feelings and their influence during interviews (Polit & Beck, 2021). I also included any problems I encountered and how I handled those problems.

Setting

Nurses were recruited from an urban children’s hospital located in the central Midwestern United States between June 2020 and November 2020. The hospital serves a diverse population from across the Midwestern region. This children’s hospital has a close collaboration with a local university and participates in numerous research studies. The NICU located within the hospital is designated as Level IV, and can provide services for highly acute, critically ill infants. With 125 beds, the NICU admits roughly 1500 newborns each year and staffs approximately 150 nurses. The NICU located within the hospital is designated as Level IV, and registered nurses with high acuity expertise provide care for critically ill infants. This NICU was selected for its ease of accessibility, diversity of clientele, volume of patients, expert nursing staff, research orientation, and stated claims of promoting FCC.

Sample

In a grounded theory study, sample size cannot be predetermined (Artinian, Giske, & Cone, 2009). Data collection continues until no new information is obtained and the derived concepts are “saturated” (Artinian et al., 2009). I began with open sampling for initial interviews, followed by theoretical sampling as concepts and categories emerged. Inclusion criteria during open sampling included registered nurses involved in direct neonatal care and working a minimum of one shift per week. A conversational

approach, along with a semi-structured interview guide and prompts, was used during the interviews. Interview questions and prompts developed and changed throughout the study as concepts arose. The initial interview guide can be found in Appendix A.

Concepts and emerging theory from initial interviews informed the process for further interviews to explore the “fit” of the substantive level theory for nurses beyond those in the open sample, thus this is the theoretical sample. A total number of ten individual interviews were completed, with theoretical saturation guiding the total sample size. Participants were predominantly White females with an average age of 29 years old and an average of 2 years 3 months of nursing experience in the NICU. Demographics of participants are provided here in aggregate to protect the identity of participants.

Procedures

Approval for the study was obtained through the University of Missouri-Kansas City’s (UMKC) institutional review board (IRB). A letter of support for the study was obtained from the director of the NICU. Initial recruitment of study participants took place through a flyer posted throughout the unit and a recruitment email included in the NICU weekly email updates by the NICU’s administrative assistant in June 2020. Following completion of six interviews, a second recruitment email was sent in September 2020. Both the flyers and the email included a description of the study and my phone and email contact information. The recruitment flyer and email can be found in Appendices B and C, respectively. Interested participants contacted me through email.

Prior to scheduling interviews, I emailed potential participants information on the study and the voluntary nature of participation. As nurses agreed to participate, I obtained informal consent over email and then verbal consent prior to starting the interview. The

verbal consent script can be found at the beginning of the interview guide in Appendix A. Participants were again informed that participation in the study was voluntary and they could choose to end the interview at any time. I explained that anything they shared would be kept confidential, except in cases of apparent threats to themselves or others. All participants agreed to and completed the interviews. All identifying information was removed from transcription, notes, and the final manuscript. Recordings were deleted once transcribed. All physical materials related to the study were stored in a locked cabinet in a locked office that only I have access to. Electronic data was kept on a password secured desktop.

Due to Covid-19 visitor restrictions at the hospital, interviews were completed either by Zoom video conference or phone call. Individual interviews ranged in length from about 30 to 90 minutes. Participants were encouraged to share information without fear of judgment. Open lines of communication were established with participants to allow nurses to contact me with additional comments or concerns. \$25 gift cards were mailed to participants upon interview completion.

Audio recorded interviews were transcribed by a professional transcriptionist and double-checked by myself for accuracy. Data management and analysis were conducted using the NVivo for Mac software package. I used the NVivo software to store, code, and categorize all data, including my research journal. Initial plans for the study included obtaining documentation from the hospital on family-centered care materials, however, after unanswered requests from the unit, I was unable to obtain this documentation for review.

Data Analysis

Using the constant comparative method, analysis began at the start of data collection and continued until theoretical saturation was achieved. Open coding of raw data generated initial codes and informed further data collection. Conceptual categories were defined through comparison of data and codes, continued until categories were saturated and a core category emerged. I worked closely with my committee chair throughout the data analysis process.

Open Coding and Microanalysis

Open coding started after the first interview. “Open coding is the part of the analysis that pertains specifically to the naming and categorizing of phenomena through close examination of the data” (Strauss & Corbin, 1990, p. 62). The data was broken down into individual parts and compared for similarities and differences (Strauss & Corbin, 1990, p. 62). This process was interpretive, not just a description of the collected data (Charmaz, 2014). To interpret the data, I used both my background knowledge of the NICU and asked questions, such as what, who, how, when, why, for what reason, and by what means? (Böhm, 2004). During my analysis, I remained open “to all theoretical directions” (Charmaz, 2014). Concepts and categories derived from initial open coding then guided the following interviews.

Microanalysis is a form of open coding and is often used in the early stages of analysis when the researcher “is trying to get some sense of the meaning of data and to find concepts that reflect that meaning” (Corbin & Strauss, 2015, p. 70). It is both exploratory and detailed. The purpose of microanalysis is to help the researcher dive deep into the data and generate ideas. During microanalysis, I initially analyzed transcribed

interviews and observations line-by-line to generate concept possibilities and compare ideas against the data. During both open coding and microanalysis, I discarded irrelevant interpretations and revised remaining interpretations as needed (Corbin & Strauss, 2015).

Axial Coding

Axial coding is usually used in the middle and later stages of analysis, although the lines between coding strategies are not definitive (Böhm, 2004; Strauss & Corbin, 1990). As opposed to open coding, where data are broken down into concepts and categories, “axial coding is the process of relating subcategories to a category” (Strauss & Corbin, 1990, p. 114). During this coding process, I made connections between the categories by determining the category’s antecedents, context, and its action-interactional strategies.

Selective Coding

Selective coding is “the process of selecting the core category, systematically relating it to other categories, validating those relationships, and filling in categories that need further refinement and development” (Strauss & Corbin, 1990, p. 116). The core category represents the main theme of the research. It is abstract enough to be representative of the study’s participants (Corbin & Strauss, 2015). I based the central category on five suggested criteria by Corbin & Strauss (2015, p. 189): (1) It must be sufficiently abstract so that it can be used as the overarching explanatory concept tying all the other categories together. (2) It must appear frequently in the data. This means that within all, or almost all, cases there are indicators that point to that concept. (3) It must be logical and consistent with the data. There should be no forcing. (4) It should be sufficiently abstract so that it can be used to do further research leading to the

development of general theory. (5) It should grow in depth and explanatory power as each of the other categories is related to it through statements of relationships.

Coding for Process

Coding for process is the “linking of sequences of action/interaction as they pertain to the management of, control over, or response to, a phenomenon” (Strauss & Corbin, 1990, p. 143). To analyze process is to show the continual change in action/interaction sequences. In coding for process, I noted changes in the conditions that affect action and interaction over time and the response to that change. I also documented any consequences that occurred from the action/interaction response and how those consequences impacted future actions/interactions (Strauss & Corbin, 1990).

Memos and Diagrams

Memos are written records of analysis. Depending on the research phase and area of coding, memos can vary in length and content (Strauss & Corbin, 1990). Memos help “enable the analyst to keep an ongoing record of the analytic process” (Strauss & Corbin, 1990, p. 223). Memos not only contained interpretations and summarization of the coding steps, but also provided direction for further data collection. Diagrams are “visual devices that depict relationships between analytic concepts” (Strauss & Corbin, 1990). Because diagrams are visual conceptualizations of the data, it can help the researcher move past description and explain findings in a clear and organized way (Corbin & Strauss, 2015). To demonstrate my process throughout data collection and analysis, memos and diagrams were dated and included a reference to the original document. Each memo also contained a heading that denoted the concept or category it belongs to.

Criteria for Evaluating a Grounded Theory Study

Little consensus exists as to how a qualitative study should be evaluated. Unlike quantitative studies, which use reliability and validity to assess the quality of a study, qualitative researchers are more likely to evaluate a study's trustworthiness through dependability, transferability, confirmability, and credibility (Corbin & Strauss, 2015; Polit & Beck, 2021). Dependability requires the evidence to be consistent and stable (Polit & Beck, 2021). Transferability is "the extent to which qualitative findings can be transferred to other settings" (Polit & Beck, 2021, p. 157). To promote transferability, it is important to provide thick descriptions of the research setting, context, and processes. Confirmability tells the reader that the study's results are representative of the participants and context, and not the researcher's biases (Polit & Beck, 2021). Credibility is an important aspect of trustworthiness, and a focus of Corbin & Strauss' (2015) evaluation of grounded theories. Credibility is confidence in the truth of both the data and the researcher's interpretations of that data (Corbin & Strauss, 2015; Polit & Beck, 2021). Corbin and Strauss (2015) provided checklists evaluating methodological consistency (Appendix D) and the quality and applicability of a grounded theory study (Appendix E). I used both checklists throughout data collection and analysis to improve the trustworthiness of my study.

Applying the Final Theory

Corbin and Strauss (2015) referenced the criteria used in a substantive grounded theory should meet those originally found in *The Discovery of Grounded Theory* (Glaser & Strauss, 1967). These criteria include: 1) The theory must closely fit the substantive area in which it will be used, 2) It must be readily understandable by laymen concerned

with this area, 3) It must be sufficiently general to be applicable to a multitude of diverse daily situations within the substantive area – not to just a specific type of situation, and 4) It must allow the user partial control over the structure and process of daily situations as they change over time (Glaser & Strauss, 1967, p. 359).

I ensured fit through adhering to the constant comparative method, theoretical sampling, and keeping separate research and reflexive journals. Concepts in a grounded theory study should be derived from data and participant's own words, hopefully making the resulting theory understandable to individuals in the NICU. I worked to make the resulting theory both sensitizing to the substantive area yet abstract enough that it can be adapted to changing contexts. By adhering to grounded theory methods, understandable language, and allowing for adaptability, this should give practitioners control over its use in everyday situations.

CHAPTER 4

RESULTS

This current study aimed to explore the relationships between nurses' attitudes, beliefs, and biases toward families and the decision-making process related to delivering FCC. The proposed research question was: How do nurses' attitudes, beliefs, and biases toward families influence the implementation of FCC principles by nurses in the NICU? The specific aims of this study were to:

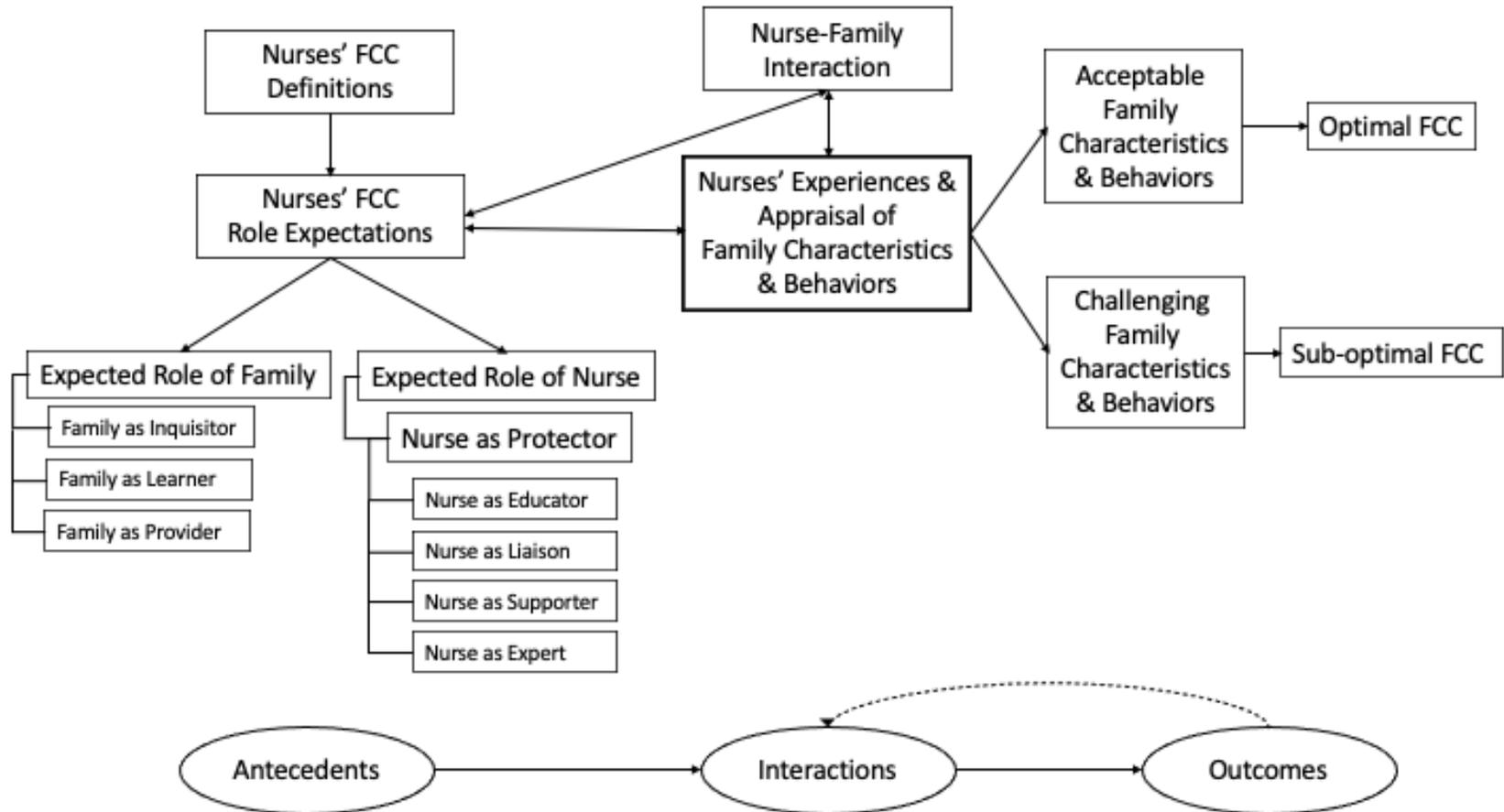
1. Identify nurses' knowledge and existing practice of family-centered care principles.
2. Identify nurses' attitudes, beliefs, and biases toward different family types.
3. Explore relationships between nurses' attitudes, beliefs, and biases toward individual families and nurses' decision-making processes when implementing FCC principles.
4. Construct a substantive grounded theory of NICU nurses' decision-making processes during FCC implementation.

Findings from this study that answer the research question and satisfy the specific aims will be presented in this chapter. Identification of nurses' knowledge and existing practice of FCC principles is explored through the nurses' identified definitions of FCC and subsequent category of *FCC Role Expectations*. Nurses' attitudes, beliefs, and biases that emerged from the study data are identified within the core category of *Nurses' Experiences and Appraisal of Family Characteristics and Behaviors* and subsequent categories of *Acceptable* and *Challenging Family Characteristics and Behaviors*. The relationships between nurses' attitudes, beliefs, and biases toward individuals and nurses' decision-making process are evident in the outcomes of *Optimal and Sub-Optimal Family-Centered Care*. The resulting substantive theoretical model is presented in Figure 1.

Figure 1

Nurse Appraisal of Families and Resulting Family-Centered Care Practice

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Specific Aim 1: Identify nurses' knowledge and existing practice of family-centered care principles

To address specific aim 1 and identify nurses' knowledge and existing practice of FCC principles, participants were asked about their personal definitions of FCC and how education on FCC was translated to practice. The following questions from the Interview Guide (Appendix A) served as the basis for discussion in initial interviews and were adapted as concepts emerged:

1. What comes to mind when I say family-centered care?
2. How would you define FCC?
3. How does your unit define it?
4. How were you taught or trained on FCC principles?
5. How do you incorporate that training in your daily practice?
6. What do you think are the various responsibilities involved in FCC? Prompts:
What are the nurse's roles and responsibilities? Families?

What emerged from the data were nurses' self-described definitions of FCC and the subsequent categories within *FCC Role Expectations* as detailed in the following sections.

Nurses' Family-Centered Care Definitions

At the initiation of each interview, participants were asked how they defined FCC, how their unit defined FCC, and how they were educated on FCC principles (see Interview Guide, Appendix A). It was important to gather a baseline of how nurses defined ideal FCC in order to understand how their practice changed throughout the process of family interactions. Additionally, asking participants to share their knowledge

and perceived definitions of FCC provided simple initial questions to help ease both myself and the participant into the interview and build rapport.

The FCC definitions provided by the participants highly correlated with the concepts and definitions found in the literature reviewed in Chapter 2 and in Tables 1 and 2. The participants' definitions included concepts of sharing information with families and including families in infant care and health care decisions. Per Nurse J:

Yeah, when I think of family-centered care, I definitely think of involving the family in care as much as possible. Most importantly to me would be keeping them updated and informed, not just telling them what's going to happen, but elaborating on what that means, making sure they truly understand the care that we're providing, and allowing them ample time to process things, and ask questions when possible. I also think if the family can come to the bedside frequently, encouraging them to truly be involved in their baby's care, as involved as they want, maybe not pressuring them, but offering holding a finger, or just jumping in there and getting involved in g-tube care, and starting teaching on trach care as soon as they're ready, and changing diapers, things like that.

Recognizing cultural differences and individualizing care was also discussed by participants. Understanding family needs and listening to the wishes of the families was described by Nurse B:

For me, family-centered care is just ensuring that we're understanding what the families desire and what kind of like culturally and kind of what they're going through as they're coming into the hospital, whether it be a premature birth, whether it be a cultural difference or things like that, and sharing that as the

nursing and medical team, we're collaborating to ensure that we can provide the best care possible...I would say it would be individualizing care, ensuring that we are catering to individual families desires and help within the health care framework as much as possible and utilizing all of our resources, ensuring that we're doing the best we can to ensure that family feels that their voice is being heard for their individual patient that's being taken care of in the hospital.

When participants were asked if they knew how their hospital unit defined FCC, the majority (n=8) of nurses assumed that their unit defined FCC in the same way as their own definitions, though they could not articulate exactly what that definition might be. When asked how they were educated about FCC, most participants stated they had received education during their hospital orientation upon hire, however they were unable to remember specifics related to when and how FCC was incorporated into their orientation. A few participants (n=4) could remember specific FCC content during orientation, including PowerPoint presentations, seminars on FCC, discussions with NICU families, and talks on cultural diversity of families and FCC delivery. All of the nurses identified their preceptors as having a key role in their learning about FCC. While preceptors did not necessarily mention FCC specifically, participants were able to identify how preceptors demonstrated FCC in their work with families. Participants then used this modeling by the preceptor to adjust their own practice with families.

So, I think they were really knowledgeable when, say, a social situation came about or a different cultural background came about and kind of showing me, OK.... Here's an example of a social work note, how we can utilize what they find out from their information and what families tell us about how we can

collaborate with each other in order to provide the best family-centered care...And I thought my preceptors were great. If they didn't know the answer, they would ask a charge nurse, something like that. So, we could, I could, learn the best way possible of how to do this in the future by myself. And I thought that was extremely beneficial in order, just like providing basic family-centered care. It was really incredible to see how some of the preceptors build that bond with family and just trying to get that personable trust between the nurse and the family and how their requests could be better met by us and how we can go about things in different ways to make their experience as positive as possible and how we can include them better with care if they want to do something different. So, I thought they did an incredible job with, depending on each family situation and how each individual can be catered to differently. (Nurse B)

When asked how they implemented the FCC principles they discussed with and observed from preceptors, participants primarily identified asking the family questions to gather information, explaining what they were doing during cares and procedures, and encouraging families to participate in their infant's physical care.

If I have parents there visiting, I try to make them as involved as possible in what I'm doing when I'm in the room. So, I'll always let them know what I'm doing before I do it. And I'll always encourage parents "Oh, do you want to change the diaper? Do you want to hold them? Do you want to feed them? Have you done this before?" And I've had multiple instances where I was really surprised where the mom said, "Oh, I never changed his diaper before. I didn't know I could, or I haven't been taught how to feed yet." The baby's a couple of days old and so I'll

take the time to make sure, even if it's a first-time parent, "I'll stand here with you. We'll change the diaper together, so you're not freaked out. I know it's your first baby." So, I try to take a little bit of extra time with parents to make sure they're given the opportunity to do things. (Nurse D)

Nurses' Family-Centered Care Role Expectations

After exploring the nurses' knowledge and education on FCC principles, the next step in addressing the first specific aim was to identify existing practice of FCC principles. Participants were asked about their perceptions of nurses' and families' roles and responsibilities in FCC delivery and how those responsibilities were carried out in practice. The definitions of FCC provided by the participants in the previous section were closely intertwined with the roles and responsibilities participants identified for themselves and families. The ensuing section begins with descriptions of the main categories and subcategories that emerged from the data regarding nurses' expected roles of themselves, followed by the nurses' expected roles of families.

Expected Role of the Nurse

Early in the interview process, participants were asked what they believed their roles and responsibilities were in providing FCC. Overwhelmingly, nurses believed that being a protector was a large part of their care provider role, primarily protecting the infant they were caring for. To a lesser degree the protector role also applied to the family as a unit. The nurse protected the infant and family through providing education, serving as liaison between the health care team members, providing support and resources, and being the expert in infant care. These various roles were synthesized and labeled as the

main category of *Nurse as Protector*, with the subcategories of *Nurse as Educator*, *Nurse as Liaison*, *Nurse as Supporter*, and *Nurse as Expert*.

Nurse as Protector

Across all interviews, participants identified safety of the infant in their charge as a key concern and goal when delivering FCC. Participants felt that it was their responsibility to protect the infant from parents who were perceived as lacking in engagement, while simultaneously attempting to provide FCC.

So that's kind of difficult with like trying to provide that best family-centered care as possible, all members of the team working together, wanting to empower the mom while she was there and allowing her to do things. But because of other factors in her life, that she kind of wasn't able to participate as much as she wanted. And it was kind of causing safety concerns with the patient. (Nurse B)

Participants identified scenarios where lack of engagement by parents was perceived as parents not wanting to care for their own children. Nurse C framed these situations as nurses being reluctant to provide FCC for disengaged parents but including families in infant care anyway solely for the benefit of the infant and for the infant's safety.

And then with like care, I feel like most nurses want to involve the parents just for like the baby's safety, I feel like is the main thing, because sometimes depending on the parents, taking them home seems a little unsafe whenever they don't want to care for their own kids. So, I feel like the nursing staff really kind of pushes towards it [FCC].

Questioning the capability of the parents to provide adequate care for their infant, particularly when discussing discharge, was apparent throughout the interviews. Nurses

felt it was important to make sure parents were deemed competent in providing care for their infant to make sure it was “safe” for the infant to go home. This was often true in cases where infants were in the NICU for extended periods of time, as termed “chronic kids” by Nurse H:

I've seen people get attached to our chronic kids that they get assigned to a lot with the families that aren't there. When they do show up, they have a negative vibe towards that family because they're not there and they've been taking care of this kid this whole time. Or those kids that end up getting fostered, it takes them [the nurse] a second to trust the foster family. “How much do you know?” “Did you really even want this kid?” “Did you end up with this kid?” There's a little bit of distrust there, I think, especially with those kids. The chronic kids, I've seen it with a couple of our chronics, where the families were never there until they were starting to go home. Then we're like, "Do we really think this family's capable of doing this when they go home?"

Perceptions of parent capability were directly related to whether or not the parents had demonstrated skills in front of the nurse. Nurse H described circumstances in which she was questioning the health care team’s plans for discharge, because she was concerned the family was not capable at that point to take over full-time care:

But realistically, if they go home tomorrow with this baby, do you feel like this baby will be safe? Because I don't feel like this baby will be safe." There's some people [parents] that get that way, and don't pick them up, come call me when you're ready because they're [infant] trached and they've got all this extra stuff. They have to learn; they have to do it. Maybe they've done it the past 22 times

they've been there, but they haven't done it with you. Every time you're there, they're not there so you don't think they're capable of anything, and you want to be there for everything.

Nurses sometimes felt the need to justify their actions to parents with rationales when there were safety concerns, so they wouldn't be perceived as "being mean." As Nurse F described when talking with a mother about delayed holding, "I'm not being mean. I'm really not being like, 'You can't hold your baby.' I'm like, 'Let me just explain why we do the things we do. It's all for safety.'"

Nurse as Educator. All participants acknowledged that education was a primary role of the nurse during the delivery of FCC. This role included the FCC principles of information sharing, supporting the family in learning about care, and collaborating with family about what they needed and wanted to learn. When asked how much of the nurse's role was focused on education, Nurse F stated:

A lot. Usually if I have a brand-new mom...Sometimes this is their fourth pre-term baby and they already know the drill for the NICU, but especially if they're a first time in the NICU, the first time that I ever walk in to do an assessment, I sit there and explain the whole head-to-toe as I go with them and take a long time to do it, because I ask them a few questions. "Do you want to feel for yourself to understand what we're feeling?" Getting that parent involved in just as much education as possible as to why we do the things we do.

Educating families was also a means of providing for infant safety. When caring for a mother with a history of substance abuse, Nurse B described:

So, educating [mom] if you are holding your baby while you're here, you cannot fall asleep while doing this. Like we have safety concerns. We educate her on different things like that. And there was a different layer of substance abuse coming in during that time as well. So, it was providing programs for that and different things like that. And on the nursing and medical side, we really wanted to ensure as much as possible that we were providing all the education by way, like we need to ensure, and we document when these things occur as best as possible so that we are ensuring the patient safety and kind of educating the mom. We're, all of us, are focused on her [infant] safety and we want you [mom] to feel as comfortable as possible in cares.

Participants often interpreted their educator role in relation to clarifying information from the health care team, particularly since nurses have more contact with the family throughout their shifts.

I feel like the team medical team sees them like once a day in the morning and then they're not there, so if they [parents] have a question about a diagnosis, a lot of times they'll get like head ultrasounds and the parents are like, "oh, what is, like what are the results of that." Just making sure that we're contacting the providers when needed, explain certain things, so I feel like we're kind of like the main educators for like day-to-day care. (Nurse C)

Nurses would tailor their education to fit individual family needs, as Nurse H stated:

"...well, everybody's different, everybody's background knowledge and baseline knowledge is different. So, tailoring the way you communicate and what you teach and what you emphasize based on each individual person." When expanding on

responsibilities of the nurse, Nurse H recognized the different needs of families and approaches to information sharing:

I think getting an idea of a family's background like if there's a parent that has had four pregnancies, but this is their first child, and they're early. Or there's a family who is pulling all their financial resources to be there because they live four and a half hours away and have two other kids. Or someone who has five other kids, and none of them have ever been this little before. They all have different mindsets of everything, and they all have to have everything explained in different viewpoints or stressed in different ways.

Educating families was a way to provide for inclusion in infant care. Education often took the form of “show one, do one” as Nurse I explained:

As far as, "Oh, and I also can't get here because I have this or whatever." And then, definitely when it comes to even just actual bedside care, "Let me show you how to give her a bath. Let me show you how to take her temperature. Let me show you how to feed her," once it's time for them just start PO feeding. Showing them stuff to empower them so that they can actually participate in the care of their baby, so they're comfortable.

The concept of empowering parents through education was apparent across several (n=3) of the interviews.

Especially in the NICU, and I don't mean to make a generalization at all, because we get people from all walks of life, all socioeconomic backgrounds. But a lot of times we do have people from a little bit lower socioeconomic background, just because of a lack of education, even for their own health, so then they have worse

pregnancies. And then that obviously leads them into a NICU stay. And so, sometimes it's just literally, they had no idea about this or had no idea about that. They need all that education so that they can have that empowerment of knowledge. (Nurse I)

In addition to empowerment, Nurse B described scenarios in which an infant was only expected to stay in the NICU short-term but ended up as a long-term case with medical complications. This situation shifted the focus of FCC and education:

And that wasn't even the initial thought process of the family when they first came to the NICU and how we can empower that family to start if they're only able to be here for a couple hours, how we can work together as an interdisciplinary team and give them as much information as possible during that time, obviously within scope of not being overwhelmed, but again, empowering them to be like, OK. So, this is different. What can we do together? How can, would you like for me to show you this now, when you try with the next set of cares or how we can go about this and kind of understanding that the family-centered care can evolve over time of maybe a family at the beginning needing a lot of different things that we need to provide that are different than, say, a different family next door. But how that can change for each family throughout a hospital stay. (Nurse B)

Nurse as Liaison. Participants saw themselves as central to the FCC process and often described themselves as the mediator and collaborator between the family and physicians, nurse practitioners, social workers, and other members of the health care team. As Nurse F stated, "I think we're the keeper of helping folks, helping the families

cope, getting information. We're that central hub for them” and “We wear a lot of hats.” Participants felt nurses had closer, more hands-on relationships with families that allowed them to build rapport and be able to connect the members of the health care team together.

I think helping them [families] gather information and making decisions is a huge part the nurse plays. Because they're kind of like the liaison between the medical teams and help coordinate with other services that could help benefit them...I feel like they are with the patient most of the time. I feel like you kind of build a rapport with the family, so they feel more comfortable talking to you and then it kind of better helps like combine the teams. (Nurse E)

Nurse B described the nurse as the central facilitator of FCC:

I think the nurse is like the ideal like person and that's like the center facilitating family-centered care. I think the nursing role is incredible, being able to work so closely with so many teams. Be at bedside, hear what mom and dad are saying when you're doing your cares, doing different things, advocating for them with the medical team and different things like that. So, I think the nurse plays like the most vital role in the whole interdisciplinary team and providing that family-centered care because if we're seeing something that's going on, how we can reach out to social work and say, like, mom mentioned this to me. Is there anything they can do about this? Or if it's going a certain situation and they're wanting, say mentioned something about a spiritual service or wanting the baby baptized or some like that, how we can reach out to spiritual services and get them involved to make that the best way possible. I feel like nursing has a really incredible role

of being able to hear what the family saying, having those great conversations...So, I think the nurses, the person to make sure that we're advocating appropriately and utilizing your interdisciplinary team the most and going about how we can provide the best family-centered care.

Nurse as Supporter. The supportive role was often viewed as providing emotional support for parents, although it could include finding financial support and other resources for the family. By providing support, nurses felt this allowed for increased parental engagement with their infant. Nurse A included concepts of support when defining FCC when stating:

It is multifaceted in the sense that even though we're providing medical care for the infant, we're also providing emotional support and financial or other sort of support to the family in which allows them to be there for their baby.

Nurse B also included concepts of support when describing personal and unit definitions of FCC. This was described as advocating for families and providing resources so that families desires could be heard, and care individualized:

In my opinion, the NICU defines it as ensuring that we're hearing and understanding the patient's family. So, what the mother has gone through that has led that individual baby to come through the NICU, how we can advocate for that baby, whether it be through pain management after a traumatic birth, whether it be how we can best provide the environment for a premature infant and how we can go about providing those resources for families that are, especially the NICU environment.

Concepts of safety were again evident in the supporter role.

So, with breastfeeding and being able to ensure we're providing that positive environment for the mom, she's wanting to do that otherwise and ensuring positive cultural environment, if there's certain things that her family desires to have within the patient environment, seeing if that's possible as much as possible in a hospital environment and just ensuring that this is a new baby, it should be the most positive time in the family's life. And no one obviously wants to ever be in the NICU situation. So how we can make that situation as best as possible and collaborating with the family in order to make the hospital situation go as positive as possible and working with them to ensure the baby is on the road to going home in the safest environment as possible. (Nurse B)

Providing support for families meant bringing in other members of the health care team, overlapping with the liaison role. Social workers were critical in getting resources for the families and were mentioned by almost all participants in the study.

Making that experience as positive as we can and utilizing our interdisciplinary team with social work and other people to make sure that other aspects can be taken care of, whether it be transportation, meal vouchers, if they qualify, other things like that in order, So, these families can focus on their child and how we can ensure that we are providing that best experience with educating, using translators and just going about that the best way possible... This is a social situation because of X, Y and Z, and these are the resources you utilize in order to provide the best family care. This family requested that we do this and how can we honor this request within the hospital system? So, I think education has been

great and starting as a nurse and ensuring I'm utilizing all my resources in order to provide the best care. (Nurse B)

In addition to social workers, managers and lactation consultants were also called in by the nurse for parental support.

Managers are great at that because they come by and they do family rounding and they check in with the parents and make sure that there is nothing else we can be doing to make their stay a little bit easier. But people I directly call the most definitely social workers. They are my lifesaving heroes. I will say lactation consultants help, too, because they make sure that the moms, if they wish to provide milk, that they're supported in that sense as well, because for that for a lot of moms, it is something they feel like they can do for their babies. So just the teamwork, just everybody on the care team might end up calling usually one at one point or not during the day. (Nurse A)

Several participants identified the supporter role when asked about nurses' responsibilities and how FCC practices are incorporated into daily care. Nurse A described the nurses' role as "partially a service industry":

So, I want to make the room, feel like a temporary home. I'm careful saying that because I don't want them to feel like that's a home in a sense, that I don't want them to feel like they're staying there forever. I want them to be comfortable. So, I try to get them lots of blankets. I try to get them water. I mean, nursing is just partially a service industry. So, I try to make sure that when they're in the hospital that they feel like we are supporting them and supporting their baby as well. So, I call social work if I hear any financial or emotional concerns that I can't assist

with. There's been a couple of times where I have moms who I felt like we're going through postpartum depression, so I involve social work as well.

Nurse G described her responsibilities as being “a little bit of everything”:

Just me saying, for example, if I have a baby that's breastfeeding, it's very important that the mom is nourished and hydrated, and emotionally well enough that she will be able to produce milk. Or if parents have all their kids and needs not to be there. And so, we need to be, I don't know, a little bit of everything. Little bit of emotional, little bit of physical, a little bit of cultural care, and connect the dots. And maybe call in a social worker, or call in a physician to explain better, I don't know. That in general, aware of every single little detail that's surrounding them.

Nurse as Expert. Nurses considered themselves the expert when it came to knowledge of how to care for the infant. This knowledge included expertise in diagnoses, prognosis, and simple and complex technical skills. The expert role was often expressed positively within the educator role, particularly around demonstrating care and parent inclusion. However, the nurse as the expert could be expressed ineffectually when nurses adopted a mentality that the baby was “theirs” and it was hard to keep themselves from stepping in and just taking over for a parent who was struggling or not following directions. Nurse J described the struggle when she stated, “I think NICU nurses especially kind of adapt that mama bear mentality.” She went on to state:

I mean, I feel like it's a very unique field, because you talk to someone who comes from the PICU, or maybe someone who's been a NICU nurse for years and years, and has kind of let that mentality go, but I feel like we're very much the

family that still texts families when the baby's celebrating their two-year birthday, and still wants to know how things are going. And we'll take care of a baby for two days and still check up on them when they're three months into their NICU stay. And a lot of other floors are kind of taught they're going to be in and out of the hospital potentially, like you'll see them when you see them. Whereas we really do feel like, I don't know if we take it on as our responsibility to protect this child, or it's an innate, maybe it's that innate kind of, well, the parents don't know what's going on...And so in the NICU, we're kind of like, well you don't know, so until you know, I'm here. I'm here for this child.

Nurse H described a scenario in which she was trying to explain to a family about how to hold the infant correctly:

Or you can't think of a way to explain, how to explain, side-lying to a family, but you can show them because you do it all the time. But they look really awkward trying to do it and you're like, "I wish I could just pick up the kid for two seconds and do it and you can see me do it." But I can't because that's not moving forward. But that's my struggle is side-lying, I think is explaining that to a parent; and not wanting to pick them up for burping. And not wanting to pick them up and just do it myself.

There was an internal struggle for nurses who rationally recognized that the parents probably knew more about their own child than they did, but still felt that they knew more intellectually. As Nurse J explained her struggle with this knowledge conflict, "But even then, when the parents do know, we will always know more. Just because we

went to school. Those parents probably do know more about their child than we do, but it's a hard balance.”

Nurses often viewed the infant as their primary patient, the family as secondary. This was coupled with the notion of ownership, by incorporating in discussions that the infant was “my baby.” Nurse H described another scenario in which she had cared for a critically ill infant numerous times, and questioned the parent’s abilities since they had rarely visited:

We've seen her on her really bad days where she poops and dies. We've seen the worst of it, and we've had days where we're like, "Please don't go to lunch because I don't want to have to listen for her. Is she good today? Is she having a good day because I don't want to be the person that listens to her. Or you're the only person in [the unit] that's working in [your area] that day and you don't have her, and that person goes to lunch and now she starts to die, and four other people go in there and they don't know what to do for her. But you do and you've got two other sick kids. Those days it's like that was my baby. I've saved her so many times, and you're taking her home and I've seen you here like four times and she's three times smaller than you. You're [the infant] such a tiny little person. How are you [parent] going to take care of her? (Nurse H)

Expected Role of Family

Following identification of the roles nurses were perceived to fulfill when providing FCC, participants were asked if families had a role in FCC. All participants agreed that families, in fact, had responsibilities in FCC. Participants felt that parents needed to ask questions, be open to learning from the nurse, and provide care for their

infant. The main categories that emerged in this area include *Family as Inquisitor*, *Family as Learner*, and *Family as Provider*.

Family as Inquisitor

Participants identified families as having a responsibility to ask questions about their infant and their care in order for FCC to be facilitated by the nurse. Asking questions was a way for families to demonstrate engagement. When asked specifically what parent engagement looked like, Nurse G stated, “Participating in the cares, asking questions, being attentive to the patient's needs.” Nurse H had a similar response with, “They are present when they can be. They ask for updates beyond just weight gain, they want to know how did they sleep throughout the night? Were they crabby?” Nurse E added asking for resources:

It can range from questions or just asking for more resources or education to kind of better understand their child and what's going on with them or as much as helping give their child a bath or provide skin to skin.

Nurses would open up opportunities for families to feel comfortable asking questions, as noted by Nurse C:

I usually, if it's like care time, really, ok, do you want to change the diaper or do you want to feed, like if both mom and dad are there like, who wants to do what?
Do you have any questions while you're doing it...?

When parents were unable to be present at the bedside, they were expected to call and ask questions. As Nurse A stated, “I like when my parents call me, though, I want them to call so that they can ask me questions.”

While it was expected that parents ask questions during their infant's NICU stay, participants recognized that parents may be too intimidated to ask questions, or simply not know what questions to ask. Nurse J explained, "I think I've worked with so many parents that, I ask them if they have questions, and they say, 'I honestly don't even know what to ask right now'." Nurse A described a scenario in which rounds with the medical team can be overwhelming for parents to ask questions:

So sometimes after rounds, I'll sit down with them and say, you know, what things did you understand? What things didn't you understand? Because rounds as a group of upwards of like nine people and it can be very intimidating to ask questions. So, I just want them, to make sure that they're, they know they're welcome here and that they know that there is a team here who can answer their questions and that they are involved in the care of their baby.

Nurse I felt families did have a responsibility to seek out information, but also described scenarios where parents may feel intimidated by the NICU environment:

I feel like they have a role. I don't know if ... I mean, I feel like we all have a responsibility to try and educate ourselves, but I think also unless they are empowered to know that they can have all that, that they're not going to seek that out. And I think that any kind of hospital environment can be intimidating, especially a NICU. Not only is it an ICU, but it's also full of teeny-tiny babies and now your baby is in there and teeny-tiny and sick.

Family as Learner

In addition to asking questions, families were expected to be receptive to what the nurse had to say and teach.

I feel like when the family is receptive... You can just kind of go in there and you have plenty of time and they're like wanting to learn and wanting to do things and they're curious and they're interested in what you have to say. (Nurse C)

Following up on the responsibility of the family asking questions, Nurse I expressed, "I mean, I do think a responsibility, because they need to try to seek out information, but more than anything, I mean, I think their role is to try to kind of be the learner in a way." Engaging a family was easier when the family was perceived as willing to learn and be receptive.

I feel like when the family is welcoming and they're willing to communicate with you more, I find that easier to help, involve them, and go throughout the day.

Because you feel like that communication line is open and that they're receptive to things that you and the medical team are saying and actively involved or at least are willing to be actively involved. (Nurse E)

Family as Provider

Ultimately, families were expected to be present and actively engaged with their infant and participating in hands-on care. This engagement could include simple tasks such as holding, bottle or breastfeeding, changing diapers, and taking temperatures to more complex technical tasks like gastrostomy tube feedings and tracheostomy care.

They are present when they can be... Families that come in and even if their kid has so many things going on, all they can do is a tenth of that and they're so excited to do the tenth of that. They will put the pants back on or something super simple. Or the families that will do all of it and let you just do your assessment, and they'll move out of the way, let you do what you need to do. Then at the end

of the day, like everything else, they are actively involved in like it's their home and we're just the extra help medically that's present. (Nurse H)

For Nurse F, parent engagement progressed throughout the NICU stay:

Sometimes something as simple as just changing a diaper. Usually in the beginning, that's where they start because, especially with the really tiny guys who can't be picked up for 72 hours, we start with just the diaper care. But usually by the end, they're moving the pulse Ox probes, they're taking the baby's temperature, they're doing the diaper change. We just walk in there and they just give us the report.

Participants in the study were quick to rationalize parent behavior if the family could not be physically present and actively engaged with the care of their infant. These rationalizations often included justification for parent absence due to lack of transportation or having multiple children to care for at home. However, if families could not be actively engaged and present at the bedside, they were expected at minimum to call frequently for information and updates on their infant's status.

Nurses' beliefs about concepts of FCC delivery emerged from the data and served as the basis for the participants' definitions of FCC and the various role expectations. As defined in Chapter 1, beliefs are "something that is accepted, considered to be true, or held as an opinion" (Belief, 2018) and reflect a person's understanding of themselves in relation to their environment (Fishbein & Ajzen, 1975). Beliefs create the basis for attitude formation (Fishbein & Ajzen, 1975), which will be explored further in the following sections.

Specific Aims 2 and 3: Identify nurses’ attitudes, beliefs, and biases toward different family types; explore relationships between nurses’ attitudes, beliefs, and biases toward individual families and nurses’ decision-making processes when implementing FCC principles

To address specific aims 2 and 3, participants were asked about situations in which FCC was easy or difficult to provide. This was followed with prompts about the families’ role in facilitating FCC or how the family might become a barrier to FCC delivery. The following questions guided initial discussions and were adapted during theoretical sampling:

1. I have had nurses say that how they provide FCC “depends on the situation.”
What are your thoughts on that statement? How do families fit into that “situation”?
2. What types of situations do you think might change the way nurses practice FCC?
3. Can you think of examples in which you or other nurses were involved?
4. What helps you facilitate FCC?
5. Can you tell me about a time when FCC was easy to provide?
Probe: What was the role of the family in that situation?
6. Can you tell me about a time that you perhaps felt reluctant to provide FCC?
Probe: What was the role of the family in that situation?
7. What do you believe are the barriers for you or your coworkers to provide FCC?

In the initial planning and writing of this study, it was anticipated that participants would identify and describe families in terms of “types” (e.g., nuclear, extended, single-parent, LGBTQ+, race/ethnicity). However it became clear by asking open-ended questions about how families were perceived in general, participants were more likely to describe families in terms of their characteristics and behaviors, such as “open”, “receptive”, “hostile”, or “quiet.” The resulting categories were labeled as *Family Characteristics and Behaviors* rather than “types” to be reflective of the data nurses provided.

During the nurses’ appraisal of families and subsequent categorization of families having acceptable or challenging characteristics, evidence of attitudes and biases emerged. Attitudes were defined in Chapter 1 as “a psychological tendency that is expressed by evaluating a particular entity with some degree of favor or disfavor” (Eagly & Chaiken, 2007, p. 598). Biases are prejudices “in favor of or against one thing, person, or group compared with another, usually in a way considered to be unfair” (Bias, 2018) and can be implicit or explicit. Biases influence an individual’s behavior toward others (Staats et al., 2015, p. 14). Participants’ attitudes and biases of families are threaded throughout the resulting substantive theory and are explored in the following categories that emerged from participants’ interview data, including *Nurse-Family Interactions*, the core category *Nurses’ Experiences and Appraisal of Family Characteristics and Behaviors*, and *Acceptable and Challenging Family Characteristics and Behaviors*. Resulting behaviors by the participants based on attitudes and biases is revealed in the categories of *Optimal* and *Sub-Optimal Family-Centered Care*.

Nurse-Family Interaction

Prior education and knowledge of FCC principles and role expectations were brought by the participants into every *Nurse-Family Interaction*. For the participants in this study, these preconceived notions were both the antecedent and the context for their expected interactions with families. It is important to note that the relationship between the participants' role expectations and their interactions with families was bidirectional. Not only was there an impact on interactions from those preconceived ideas of how roles were fulfilled, but once interactions with families began, nurses could alter their role expectations. This could take the form of emphasizing the *Nurse as Educator* and *Nurse as Expert* roles if the family had less NICU experience and educational background. Less expectation of a family to be a *Provider* was demonstrated for families earlier in the NICU stay versus long-term admissions. In cases of first-time interactions without prior knowledge or background of the family, *Nurse-Family Interactions* were the antecedent to the *Nurses' Appraisal* of the family and their behaviors.

Nurses' Experiences and Appraisal of Family Characteristics and Behaviors

During and following *Nurse-Family Interactions*, participants would evaluate their experiences with families and the characteristics and behaviors those families exhibited. This continual evaluation was essential in linking nurses' knowledge of FCC and their actual practice. The ongoing cycle of *Nurses' Experiences and Appraisal of Family Characteristics and Behaviors* developed as the core category in the substantive theory.

According to Corbin and Strauss (2015), the core category:

...represents what researchers determine is the main theme of the research. A core category is a concept that is abstract and broad enough to be representative of all participants in the study. In addition, it is the category among others that seems to have the greatest explanatory power and the ability to link the other categories to it and to each other. (p. 188)

The core category is one that is threaded throughout all of the data. In the current study, the participants' constant assessment and reassessment of perceived roles, how and if they are fulfilled by the nurse and family, interactions between nurse and family, and the resulting nurses' FCC practices are continually linked to the *Nurses' Appraisal*. The outcome of that appraisal is critical to answering the research question and specific aim 3. Out of this central category the categories of *Acceptable Family Characteristics and Behaviors* and *Challenging Family Characteristics and Behaviors* developed.

Acceptable Family Characteristics and Behaviors

Participants were asked what helped facilitate FCC and what an "ideal" family did that made providing FCC easier for the nurse. The resulting discussions led to the development of the category of *Acceptable Family Characteristics*. Many of the characteristics identified as facilitating FCC were highly intertwined with the roles and responsibilities participants expected families to play (*Family as Inquisitor, Learner, and Provider*). Participants again identified that families who asked questions were interested in learning about their infant and who were receptive to the nurse's education were easier to communicate with and to provide care for.

I feel like when they're really engaged and not just hands on, but with any type of engagement, it makes it easier. Because if you are teaching them something, you

know that they'll be receptive because you can show them and kind of have them perform the skill as well. Or, even if that's not something hands on, you feel like they kind of understand when you're explaining something to them. (Nurse E)

Nurse G described an ideal family as, "Being flexible, and learning and accepting, and asking questions" and "Families that want, if they're not they're too scared, but they're willing to learn." Nurse C stated it was easier to provide FCC when, "You can just kind of go in there and you have plenty of time and they're like wanting to learn and wanting to do things and they're curious and they're interested in what you have to say."

Additionally, families who were excited to engage in care and actively communicated with the nurse were seen as easier to care for. Already having background knowledge was also a benefit.

Usually when I have a very receptive family who is open and you walk in and you say good morning or good night to them and they're just really open and easy to talk to, they have some education as far as being able to explain things and they understand what you're trying to say...Mostly it's having that very receptive family who really welcomes anything you can tell them or are really so excited to do something as simple as put a Tempa-DOT under the baby's arm. (Nurse F)

Actively being present at the bedside was also important. However, the level of importance was contingent on the family having resources.

...a family where they have the ability to be at the bedside, maybe mom and dad can split shifts. There aren't transportation issues, so you can rely on them to come. Maybe they work so they have a set schedule, but you can rely on them to be here at the times in which they say they'll be here. On the days that they're not

here, they call at least once a shift for updates. They're probably a notebook family, they are recording different events, they write down their questions as they happen. (Nurse J)

Not all acceptable characteristics were directly related to expected roles. As with the previous example, families having their own outside support and resources were easier to care for. Nurse J even included self-care as an ideal characteristic:

They probably have an excellent ... they've found either a Facebook community, or pre-COVID, a face-to-face support group. They have resources to kind of help them go through this, that's not just us. And they're really good at self-care, you know? They're able to kind of step away from the bedside to take care of themselves, and they understand that you can't pour from an empty cup, because that leads to more anxiety in the patient's room, which I think affects the baby.

Through continued interactions with families and positive appraisals, participants found themselves naturally providing *Optimal Family-Centered Care*.

Optimal Family-Centered Care

When families were perceived as having acceptable characteristics and behaviors, *Optimal Family-Centered Care* was predictably provided. Optimal FCC was implemented as described in the participants definitions of FCC, discussed earlier in this chapter. This included increased information sharing, collaboration, and giving more opportunities for family engagement with their infant. Across many of the interviews, participants described wanting to make the NICU experience “positive” for the family. Nurse B nicely summarized her daily practice when “ideal” FCC could be facilitated:

But on a day-to-day when families are present again, I just try to go in and try to individualize my plan of care as much as I can with the family when they're there and kind of again, kind of assessing the situation and making a plan for the day. Their level of understanding what their level of involvement is and how we can encourage them more if they're wanting to or going about things in a different way that makes them more comfortable empowering them to pick up their baby and how we can move our leads around so they can put them, hold them how they want to. Different things like that's always going about different things and understanding kind of where they are at. Throughout the day. So, walking in, introducing yourself and kind of saying the plan for the day or during care. How are things going? Asking them what do you like to do? Different things like that...assessing the situation constantly with the family within my daily practice. And again, how can we better make that experience positive for them.

Challenging Family Characteristics and Behaviors

Following questions about facilitating FCC, participants were asked about barriers to FCC, and family behaviors that might make FCC more difficult to implement. Much like the family characteristics and behaviors identified by participants as acceptable, characteristics and behaviors of families that were deemed as more challenging to work with were often related to, yet in opposition of, the expected roles that nurses placed on families. Not meeting those expectations often led to participants identifying the family as more difficult to work with. Additionally, families who were perceived as challenging the nurse's role were identified as difficult.

Overwhelming, participants cited a perceived lack of parental engagement, both with the nurse and with the infant, as a one of the most challenging characteristics. Participants also found themselves competing with cell phones and other distractions when trying to provide care. Nurse G described difficult encounters as, "... parents that just sit in the corner, says no words and just look at you and trying to, like, and stares at their phone all day...." Nurse A also found disengagement due to distractions difficult to deal with, particularly in cases of education, coupled with safety concerns:

I know it sounds crazy, but a lot of times when I'm trying to show them things, I find that they're like taking a video or taking pictures or talking to someone. And so, I'm having trouble kind of teaching them in that situation. Of course, if they are touching their phones, I want them to clean their hands before they come into the isolette or before they handle their babies. So, it's just kind of a little bit difficult in that sense. I find the phones are in my way a lot, but I think it's just this generation. (Nurse A)

Concepts of parents proving they could care for their child prior to discharge was again evident in the interviews. A lack of engagement went against the *Family as Provider* role.

You know, we, we offered the parents the diaper change. We offer them. We try to find barriers, but they're not they're just not participating in cares. And we're not having any luck. Like we're sitting there feeding them [infant] and they're [parents] sitting there watching us feed their baby. It's just not appropriate... But if it's an issue of, you know, the parents are more interested in playing on their phones or whatever else then it needs to be a conversation with the entire team,

because the parents need to know that they have to show full participation in the patient, in the patient's cares before they can take them home. (Nurse A)

While nurses expected families to ask questions, per the *Family as Inquisitor* role, asking too many questions was identified by several participants as challenging to deal with.

Another situation just briefly would be when the family is so overly nervous that they analyze everything that you do to the point where they're asking you questions constantly. You're trying to assess the baby and you're just you put the stethoscope in and they're still asking questions and you can't even hear them.

You're like, hold on one second. That kind of situation makes a little bit harder. I had one of those recently as well, but still important, still need to do it [FCC].

(Nurse A)

Many participants felt that families who asked too many questions during cares were questioning the nurses' abilities and expertise, thereby challenging the *Nurse as Expert*.

We have some parents who want to control every single aspect of every single thing that's going on with their child and that's often just not possible. So, anything you do you're told you're doing wrong type of thing. Like "why would you move with whole flex like that? Why are you doing that? Why are you touching them like that? What are you doing right now?" And I can't work where every single thing I'm doing is being scrutinized or criticized. Those types of environments specifically are very challenging for me because I don't want to spend whole time defending myself to you [parents], but I promise I know what I'm doing. (Nurse D)

Nurse F also felt as if the constant presence by parents was a reflection on the nurse's abilities to provide competent care.

But it's almost a little bit more hostile where they've seen all the fine tune minute details of continuous days they sleep there. They might sleep through one care, or they'll get mad if you don't wake them up for a diaper change. They leave between cares when the kid is sleeping to shower and do what they need to do. But they're always back before somebody has to touch them. Sometimes it's an encouraging feeling because the family is willing to do all those things and sometimes it comes off a bit more hostile because it's more judgmental on the nurses. (Nurse H)

Parents who were constantly at the bedside often led them to compare one nurse's actions to another nurse and question why things were done differently. This led to participants labeling these types of families as "opinionated" or "judgmental."

I think some are the first-time parents that don't leave the room at all. They see everybody's everything and they have opinions about everyone and everything and they've seen everybody do an assessment their own way. They've seen every provider come in and round their own way. They're very opinionated, they feel like they're very knowledgeable, because they've been around, and it makes it very difficult to do your job when everybody's different. But they've also seen everybody, so they feel more... it's not entitled but, I don't know, they feel more powerful, I guess. I don't really know how to word it because it's not a negative thing but it's so much. (Nurse H)

Nurse H continued, explaining that families who ignored the nurse's advice were believed to be hard to work with and therefore were challenging:

Everybody has a different viewpoint on how things are done, and it doesn't matter how long the parents have been there, doesn't matter how old they are. It's personalities, I think, are a big part of it. But the biggest burdens are the ones that are there watching your every move and the parents that will take two seconds to listen to you, roll their eyes and do it their way anyway. Those are the two hardest families to work with.

Not all challenging family characteristics were related to role expectations. A majority of participants described situations in which families were upset, angry, or even hostile towards them. These actions made study participants nervous when interacting with families who displayed these and other uncivil behaviors.

So, whenever the family that's verbally aggressive or clearly unhappy with their care through the things that they've said or, you know, said directly about me, to me, or whatever else, it makes me very uncomfortable to walk into the room. And it definitely makes me want to get out of the room as soon as possible. So that's a situation where family centered care comes to the backburner, because I'm more worried about the interaction I'm going to have with the family at the bedside.

(Nurse A)

Nurse G described a scenario in which she was subject to verbal abuse and physically aggressive behaviors that came from a mother.

The worst for me is the physical abuse, or physical, physical. I mean, verbal or physical abuse...And so, when I was scrubbing the hub to give the medications,

she literally slap my arm, like she went and slapped me. And I was like, "Whoa, you know what? That's not acceptable." Call the charge nurse, call security...I was like, "Ah." I will not forget, I was like, "I don't feel like caring for this child anymore." And I loved the baby, the baby was the sweetest thing, but it was hard for me to finish the shift.

Working with families with a history of substance abuse was also challenging for participants. Safety of the infant, especially after discharge from the hospital to home, was an ultimate concern of the nurse and increased the nurse's anxiety and underscoring the *Nurse as Protector* role. This concern for the infant's safety led to increased education by nurses and nurses requesting involvement of a social worker. Nurse C detailed:

...I think we get a lot of like withdrawing kiddos. And I feel like with those families, it's just kind of a lot to have social work involved. And sometimes they have a foster family and sometimes they have like, they go home with their family that's still on drugs. I feel like that's always just kind of a common thing that can make me feel anxious. So, whenever I kind of have a feeling like that, I'm kind of like, oh, well, they're going home, with this family that's still obviously on drugs. But when I have one of those, I try to do more education and then definitely like write more social notes in the chart and just kind of like get the team involved about my concerns, like safety-wise and what we're seeing and what the parents are saying at the bedside.

Families with a history of substance abuse were also unable to perform their roles in FCC, which concerned Nurse F as she stated,

I believe the families have to be receptive to it [FCC] and want to be involved in it, which doesn't always happen. But that's usually because of other circumstances...we have unfortunately a lot of drug addict babies and unfortunately sometimes their families aren't stable enough to take on their part of that family-centered care.

Several participants found opposing personalities with families a characteristic that was perceived as problematic when implementing FCC. When probed about how FCC might “depend on the situation”, Nurse H explained:

I don't think it necessarily depends on the situation; I think it depends on personalities. I think a lot of it is do they make eye contact with you when you talk to them? Because if they don't, I'm not going to put in 100% effort to give you information when you're not even looking at me when I'm talking to you. Is it someone who's on their phone the whole entire time you're in the room, and doesn't even engage the fact that you're present? Just lets you do what you do with the baby and leave. Those people don't like you say, "Hi, I'm your nurse," and they're on their phone the whole time, or they're not around when you're around. It just gives you this feeling so it's like the vibe they put off and the personality they present, or the personality you present.

Maybe you're really bubbly, upbeat person, and they're a really quiet, reserved like take it as it goes, ask a couple questions, terrified to touch the diaper and you're like, "Let's just try it." They're like, "I'm going to pee my pants right now." They don't end up receiving you very well and then you just feel like that family hates you. Then when you go in next time, you're just going to do the bare

minimum and it's all of our perceptions. But I don't really think it's anything situational, I think it's 100% personality, or the vibe that you get, or the vibe that you feel. I think a lot of it is subconscious but some of it is very conscious.

What was considered opposing personalities could also include those families whose behavior reflected that they were upset and perceived as confrontational.

Oh yeah. I've worked with a couple of difficult families where in report you're told "Oh, the mom is so mean she'll eat you apart." I'm like, Oh God. Because I'm a very nonassertive, non-confrontational person. So, when I have a very strong personality in a parent, sometimes I have to pump myself up mentally before I even enter the room. So, I'm like if she yells at me, I cannot. (Nurse D)

When asked if there was a pattern in the type of nurses who found families more challenging, Nurse D explained it was a mix, and not necessarily dependent on age or years of experience. Regarding personalities, she stated:

With some families, Type A nurses, not going well, but like the more laid back, they'll get along with them. So sometimes it is, you can tell if the personality of the mom, the personality of the nurse, if they are opposites, they have a little bit more of an issue.

Additional challenging family characteristics cited by the participants were racial, cultural, and language differences. While these characteristics were not perceived as negative traits, they proved to be harder for the study participants to manage in order to fully implement FCC. Nurse J described scenarios in which religious and cultural differences were at odds with what nurses perceived as being what was best for the infant

and, in this case, the medical determination of withdrawing life support during end-of-life care.

I think with culture, especially when it comes to end-of-life care. I've worked with a lot of the Hasidic Jewish families and Muslim families. And they are not allowed to withdraw without permission from their church, and I've never seen the church grant that power. And family, I think...the nurses a lot of times really struggle with how are you doing this to your child? And the families, I've talked to some of them, and they don't view it as doing to their child, and I think because of that, it leads to a lot of ... and maybe also the nurses feel like the families don't truly understand what's happening, and so they feel the need to educate the family, that this is painful, and this is not helping their baby anymore, and so I feel like a lot of nurses, I don't want to say overeducate, but they educate the family with ... if you overhear that conversation, they have a very clear, I perceive a very clear goal of the end of that education. And it's kind of to say, well, this isn't saving your baby, is the premise of that whole conversation. And they go over very specific details as to how things work, and it's good, it's education, but I think also sometimes you'll come out of those educations and that's when families come forward, and they have this list, and they're like, "These are the things you're not allowed to say to me anymore."

And so, I would assume that the family is intelligent, and they've kind of picked up on nursing's goal, from that conversation. Yeah. And say, "We don't want anything to do with this." So definitely those kind of cultural, and then diocese, and I don't think it's ... like I don't want to say, hey, it doesn't have to do

with the different religions opposing, I think that's just another point where we get very uncomfortable, because we don't identify with that, and a lot of the conversation that usually comes up is like, "Well, I would never do that to my child." And I feel like culture, race, anytime you kind of get into that "I wouldn't do that" perspective, that's when things get dicey in the patient family interactions.

Several participants mentioned language barriers as preventing full family engagement in FCC, as seen in Nurse J's statement, "Sometimes with language there's also barriers. Recently, I've had some patients that their family only speaks one language, and they don't understand English. Sometimes resources mixed with language barriers makes it harder to make them involved." Nurse I mentioned similar difficulties, particularly around providing education:

...we had one who this poor mom, they were like...the dad spoke Spanish and some English, very little. And then the mom only spoke some sort of Mayan dialect. She was from some small town in, I guess, the mountains or some small, very remote village and she only spoke this Mayan dialect that is very rare. I mean, so how do you even speak to her? I mean, you can't even use Spanish translation. You know what I mean?

I mean, we have a lot of stuff at our disposal. I mean, I think our little interpreter iPads actually did have the language. But trying to explain ... And her kid had some congenital anomalies, so some chromosomal abnormalities. And it's like, "This is extensive. And you have to try to do teaching and send this kid home with this mom." I mean, it was just a whole thing.

And then recently, we had a really sick little, tiny guy and his poor mom is only 16. She only speaks Spanish. Had to have bedside surgery, all this different stuff. It's like, how do you explain that? Number one, she's a teenager and she doesn't speak English. And her baby was really sick. I mean, it's a barrier, even if we try to use interpreters...you know what I mean?

Two participants mentioned potential racial biases, particularly between White nurses and Black parents. When asked how situations with families who are perceived as not being engaged are resolved, Nurse F briefly described a scenario in which a mother believed her infant was not being properly cared for due to her race. The participant herself did not perceive race to be an underlying cause of differences in FCC delivery in this particular instance but recognized that the mother had the right to hold those perceptions. Following a family conference between the mother and health care team where the mother was given the opportunity to “air out those grievances” and “be heard,” more positive communication and engagement between the nurses and the mother occurred.

Nurse I highlighted racial differences when asked about the roles and responsibilities families might play in FCC delivery, particularly around the subject of expecting families to ask questions. This discussion prompted Nurse I to describe how differences in communication between White nurses and Black families may lead to conflict. The participant identified a situation in which a Black mother became upset when a White nurse suggested contacting social work to help explain an aspect of the infant's care. Nurse I explained to the nurse a Black mother may interpret calling the

social worker as “to them, social worker means, DFS [Department of Family Services], you’re trying to take my baby.”

...[Mom] knew that if she [infant] couldn't get down off of her oxygen, off of her high flow, she wasn't going to be able to try to PO and she wanted her to go home. She wanted her to get off her oxygen, start eating and go home. This nurse went in. She's like, "Well, she's just desatting a little bit. I'm just going to turn her oxygen up a bit and then I'll turn it right back down." And the mom kind of gave the nurse a hard time. And she's [nurse] like, "I'm sorry. Do you want me to have the medical team or social work come and explain to you why we're doing these things or whatever"? She's like, "I just don't feel like you're liking my answers." And I'm like, "You can't say, 'Do you want me to call the social worker?' That's like you're saying, 'Do you want me to call the social worker on you? You want me to call DFS on you?' You can't say that to a Black mom. That's exactly what they think immediately when you say, 'Social worker.' To them, social worker means, 'DFS, you're trying to take my baby.'"

[The nurse] was like, "Of course I didn't mean it that way. I felt like she was upset with me, so she'd rather talk to [name deleted], who's our social worker." And I was like, "I know, but you can't say stuff like that. You have to understand how that comes across." She's like, "Well, I know now. But I mean, I didn't mean it that way."

Nurse I believed it was a lack of racial and cultural understanding and miscommunication on the part of the White nurse that may have led to disparities in care and not intentional behavior. In both cases, the participants believed the nurses had good intentions during

their care but were uneducated about racial differences that could lead to misunderstandings.

All participants identified challenging family characteristics and behaviors that impacted FCC implementation. The impact of these characteristics and behaviors became evident when *Sub-Optimal Family-Centered Care* was provided.

Sub-Optimal Family-Centered Care

When families were perceived to have challenging behaviors, participants were more apt to provide *Sub-Optimal Family Centered-Care*. This type of care included less information sharing, providing less opportunities for families to engage in infant care, and family avoidance by the nurse. Getting into the room and performing tasks before the family arrived was a strategy often used by participants to evade family confrontations.

And [another nurse] had told me that this mom, she was in the hospital and then she was going to go home and shower and change and then room in with the baby overnight, and I was taking care of the baby. We do delay bathing, but it was getting close to the time where the baby was going to need a bath and get the linens changed and all that, and they had said she [mom] can be really difficult because she had been over multiple times and she already wasn't following the rules. I was like, okay, before she comes, let me go ahead and change the linens and do the bath and get that done, because while I wanted her to be a part of the care, at the same time I didn't want to have to do... Like, this is going to take forever just because explaining everything to her takes a really long time because she's not educated to fully grasp this concept. (Nurse F)

This was coupled with the notion that it would be easier on the nurse to just do everything herself.

With situations like that, I think a lot of us try to get some of the stuff that we would normally involve families with done, that way it's not as hard on us on our shift. Whether that's correct or not, I don't know, I just know we try to make it as easy as possible on ourselves. (Nurse F)

Working with angry and hostile parents increased the participants' feelings of wanting to leave the room and spend less time with the family.

And so sometimes if I'm getting a lot of personal pushback, it's a big struggle for me to spend the adequate amount of time in that room and really try to make a relationship with the parents and educate them and facilitate what I need to because I just want to leave, I just want to get the heck out of the room. And I've been in a couple of those situations and it's something that with every shift I work, I get a little bit better at. But it's my human nature, if you yell at me, I just want to leave. I do not want to be there facilitating any anything. And I've had a couple of shifts where it's been really rough with that type of situation. (Nurse D)

Avoidance was a strategy largely used by nurses when confronted with families who appeared nonreceptive or judgmental.

But I don't feel like it's fair of me to continue putting forth 110% of my energy on a family that's not receiving it. It just it wears you out, anyway. But to do it to a positive family is a lot of work, but to do it to a family who doesn't seem to give a crap or thinks less of you as a person or is judging you like they know better, that is frustrating. You just don't want to be in there, you don't want to talk to them

any more than you have to. Some people look busy, some people don't even chart in eyesight of the room, if there's a person that's like that. (Nurse H)

Nurse C felt that continuing to engage with families that were perceived as nonreceptive was a waste of time that could be spent elsewhere.

I feel like sometimes like I was saying, depending on the family themselves. Like how active they want to be? It can kind of be discouraging for the nurse to want to sit there and waste thirty minutes of your time trying to teach them how to safely feed their kid when they're either not interested or not caring about the information. And they just go back and do it the way that they want to do it. I feel like sometimes it can be frustrating when the family is frustrating, and kind of making the nursing team, not want to be as involved as they probably should be or would be with other families that are less stressful.

The sentiment of wasted time was echoed by Nurse H when dealing with judgmental parents. She also spoke to the common strategy of providing less “personable” treatment that was described by several participants.

The parents that come off really judgy. If I get a really negative judgmental vibe from them, I'm less engaged with them. I'll talk to the child like they're a little grown up, I've done that my whole time. But I will engage with the kid, I will talk to the child, but I won't put any extra effort to talk to the parent while they're there. If they ask me things, I will politely answer them. If they want to do things, I will let them be involved but I won't go out of my way to be personable with them. Because I don't feel like it's being well received anyway, so why am I going

to waste my extra energy and effort that day on somebody who's not going to give a rats about two out of the 27 words I said to them in that little setting.

I don't do anything different with the patient. I don't tell them they can't do anything. I want parents to be as involved as they want to be, but I feel like my involvement with the parent, my communication towards them and my communication with them is either very short or curt when I have gotten a negative vibe from them, or they have put forth a negative energy or negative responses towards me. Then I'm like, "Okay," and we won't be friends. I'm here to do a job, I'll keep your baby alive for 12 hours, and you'll get another nurse...(Nurse H)

Limited communication was evident across interviews when participants spoke of encountering challenging families. This could take the form of decreased information sharing along with less rapport building strategies. Nurse F described how this change in communication was most evident in nurses who were typically very friendly with families.

I've witnessed, not so much avoidance, but we have some awesome nurses, and all the parents love them. They just have these bright, bubbly personalities. I'm not that way, but they are, and I can tell that bubbly personality goes away and they become very much a one-word answer kind of situation where they're still engaging in the families but not like they normally do...I think instead of going in and talking about how cute and wonderful, they're just like, "Oh, we're going to do an assessment." Not really having the full background conversation, or "Hey, how are you doing? What's going on today? Did you happen to catch this on

television?" It's mostly like, "We're starting at the head and checking the central lines." It's very, just the facts. Which isn't...when you see them engage with other families you can tell there's a difference.

Nurse F went on to explain how less opportunities for family engagement were provided by nurses:

They'll just go in, get their assessment done, they'll still do the education and talk but there is less of a "Do you want to hold the baby? Do you want to help me give a bath later on?" It's just get in, get out. Give the information you need to give, but there's no elaboration. There's no fluffiness. I don't know if that makes sense, that there's no fluffiness added to it.

Less opportunities were afforded to families with substance abuse histories. Several participants mentioned they just wanted parents to go home so they could just care for the infant.

I did have a patient, the mom and dad would always come in reeking of marijuana. There's a very prominent smell, and then you could tell that they weren't sober when they would come in. And that's really hard, because then they would ask to hold the babies and help care and trying to figure out... I didn't want to have to work with them. I just wanted to take care of the little ones and go because they weren't sober enough to really be participating in care, but you still have to try to work with them even though you know that it's probably not best for the [infant]... And I wouldn't, when mom would ask, "Can I hold him?" Not a good time. I had to have the very difficult conversation of, "I believe you're not

sober. And if you're not sober, I can't let you hold this little one."...I just wanted them to go home. (Nurse F)

Summary

This study aimed to answer the question, “How do nurses’ attitudes, beliefs, and biases toward families influence the implementation of FCC principles by nurses in the NICU?” and construct a substantive theory. The findings of this study were grounded in the data collected through interviews with NICU nurses and categories emerged through grounded theory analytic methods.

Specific aim 1 of the study was to identify nurses’ knowledge and practice of FCC principles, which was discussed in the *Nurses’ Family-Centered Care Definitions* and their resulting practice based on those definitions. By asking what roles nurses and families played in FCC implementation, the main category of *Nurses’ Family-Centered Care Role Expectations* emerged, along with the subcategories of *Expected Roles of the Family* and *Expected Roles of the Nurse*. Families were expected to function as *Inquisitor* by asking questions, *Learner* by being receptive to education, and *Provider* by performing the required tasks to care for their infant. The participants saw the nurse’s role as one of *Protector*, whereby they provided for infant safety. This role was supported by the *Nurse as Educator*, *Nurse as Liaison*, *Nurse as Supporter*, and *Nurse as Expert* roles. Through these supporting roles, nurses taught parents how to care for their infant, acted as a mediator between the family and health care team, supported families emotionally, and demonstrated her knowledge and expertise in infant care. Nurses’ definitions of FCC and role expectations were carried into each nurse-family interaction, providing the antecedent and context for the interactions and following FCC delivery.

Specific aims 2 and 3 were to identify nurses' attitudes, beliefs, and biases towards family types and to explore the relationships those attitudes, beliefs, and biases had on nurses' decision-making processes when implementing FCC principles. Resulting categories included *Nurse-Family Interactions* and the core category of *Nurses' Experiences and Appraisal of Family Characteristics and Behaviors*. Before and during interactions with families, nurses would continually evaluate a family's behaviors and identify families as having *Acceptable* or *Challenging Characteristics and Behaviors*. Bidirectional relationships were noted between *Nurses' Family-Centered Care Role Expectations*, *Nurse-Family Interactions*, and *Nurses' Experiences and Appraisal of Family Characteristics and Behaviors*, each having an impact on one another. Having acceptable characteristics and behaviors led the nurses in many instances to the outcome of providing *Optimal Family-Centered Care*, while challenging characteristics and behaviors could lead to *Sub-Optimal Family-Centered Care*. Optimal care matched participants' FCC definitions, while sub-optimal care by the nurse could include limited family interactions, avoidance behaviors, reduced communication, and offering less opportunities for families to participate in infant care.

Finally, specific aim 4 was to construct a grounded theory of NICU nurses' decision-making processes during FCC implementation. This was accomplished through constant comparison of the collected data, synthesis of the findings, and creation of a core category, main categories, and subcategories as presented here. The theoretical model is shown in Figure 1.

CHAPTER 5

DISCUSSION

The purpose of this study was to examine nurses' attitudes, beliefs, and biases toward families and the influence these views have on the implementation of FCC in the NICU and to uncover social processes underlying practice. The research question was, "How do nurses' attitudes, beliefs, and biases toward families influence the implementation of FCC principles by nurses in the NICU?" A grounded theory approach was used to answer the research question and develop a substantive theory. Ten registered nurses working at least one shift per week in the NICU were interviewed by phone or Zoom web conference. The resulting data were analyzed through constant comparison, leading to the construction of the theory and model *Nurse Appraisal of Families and Resulting Family-Centered Care Practice* presented in Chapter 4. In this chapter, findings from the study will be discussed within the context of the current literature, strengths, significance, and limitations of the study will be presented, along with implications for future research and practice.

Findings of the Study in Context of the Current Literature

Concepts of family-centered care began to emerge in the 1950s but research into nurses' and families' experiences with FCC did not gain interest until the past two decades. Even then, research has focused on defining FCC principles, FCC interventions and their impact on infants and families, perceived barriers in delivering FCC, and more recently, racial disparities during FCC implementation. FCC research in the NICU has been fairly limited, and prior research has often been done in countries outside of the U.S. This current study builds on this past research and is one of the first to specifically

examine how NICU nurses' appraisal of families directly impacts FCC delivery. This section will focus on how this study's findings are situated within, and expand upon, the current literature.

Nurses' Beliefs in FCC Principles and Actual Practice

It was evident in every interview that participants were able to define FCC concepts that were in alignment with definitions provided by major health care organizations. All participants recognized the value of FCC and believed in its principles. This was consistent throughout the previous literature, with participants identifying the importance of collaboration with families and individualizing FCC (Alabdulaziz et al., 2017), including families in infant care (Boztepe & Kerimoğlu Yildiz, 2017), sharing information (Jones et al., 2015), and supporting families (Bruce et al., 2002). Participants often spoke about making the parents feel welcome in the NICU and creating a positive environment for families. This was also reflected in Jones et al. (2015) study in the special care nursery:

Nurses also verbalized the importance of making parents feel positive about their ability to provide direct care to their infant. There was a genuine desire to assist parents to '*parent*' and to make sure they were left feeling positive about doing the activity again or 'trying' again.

However, findings from the current study clearly indicated that knowledge of FCC does not always translate to practice. When participants appraised families as having acceptable characteristics and behaviors, FCC was implemented by the nurses in a way that was closely aligned to their personal definitions. Coyne et al. (2011) found that "some nurses mentioned spending more time with 'nice' families which implied that

parents who met the nurses' expectations and performed as team players could be rewarded with extra attention." In addition to "extra attention", participants in this study felt more comfortable spending time in the room with families and providing additional opportunities for families to engage in infant care.

Participants in the current study used several strategies to deal with families seen as having challenging characteristics and behaviors. These strategies included avoidance, limiting communication, limiting opportunities for involvement. Coyne (2008) also found nurses used exclusionary tactics to deal with families who were deemed as difficult to work with, typically after other efforts to engage the family had failed.

When inclusionary tactics failed with problem parents, nurses used avoidance tactics by minimizing the direct contact between themselves and parents. Nurses reported avoiding interactions with parents who asked many questions, created emotional scenes or refused to co-operate with hospital routines. They reported staying in parts of the ward viewed as out of bounds to parents, such as treatment rooms or the ward office. When nurses could not avoid such parents, they removed them from the ward by persuading them to take breaks from the child's bedside.

Participants in the current study expected parents to show up and be present when expected in order to provide care for their infant. Parents who were continually absent were perceived as difficult to work with. This is consistent with Coyne et al. (2011) findings of similar attitudes:

Nurses tended to measure family life in terms of visiting patterns and were likely to have negative attitudes towards mothers who did not adhere to a regular time schedule or who could not spend as much time at the hospital as others. More often than not, participants associated acceptable and challenging family characteristics with meeting their role expectations.

Disparities in care were also noted in participants' discussions of providing care for parents of different cultures, religions, or a history of substance abuse. Part of the disparity in care was linked to a lack of knowledge around how to communicate with challenging families. This was also seen in Jones et al., (2015), who found that nurses perceived communicating with mothers from different cultures or those with substance use as particularly challenging. Participants in the current study also discussed that providing care for families whose primary language was not English was difficult and time consuming. Keeping information sharing to a minimum was a coping strategy employed by the participants.

Previous research has noted a disparity in care of families across racial, ethnic, and socioeconomic class, with minorities and less educated parents receiving lower quality FCC (Azuine et al., 2015; Bleser et al., 2017; Coker et al., 2010; Guerrero et al., 2010). Participants in the current study identified situations in which families had a lack of resources or less education. However, this was seen as less of a challenge in most cases and primarily part of the *Nurse as Supporter* and *Nurse as Liaison* roles in order to provide resources and optimal FCC for families. Two participants who self-identified as non-White, discussed two specific situations in which they believed that racial differences led to conflicts between the nurse and family. In both situations, the

participants believed the root cause of conflict was the nurse's lack of knowledge about race and cultural practices rather than an intention to provide sub-optimal FCC.

Discussions about differences in FCC delivery based on race, ethnicity, or culture were not initiated by participants that self-identified as White.

Nurses' Role Expectations

When investigating nurses' and parents' perspectives of parent participation in pediatric wards, Coyne (2008) identified role expectations that nurses had both of themselves and of parents:

Nurses expected parents to stay and provide emotional care, childcare and some nursing care for their children. Nurses viewed their role as facilitators rather than doers. Parents were expected to be co-operative, helpful and undemanding, follow all instructions and get involved in doing care.

In this current study, these parental roles were also identified and further classified into formal roles of *Family as Provider* and *Family as Learner*. Accordingly, Coyne et al. (2011) further described nurses' roles as "including teaching, education, supervision, support, advice, reassurance, information giving and relationship building." These were formally operationalized in this study's findings of *Nurse as Protector*, *Nurse as Educator*, and *Nurse as Supporter*. The *Nurse as Liaison* role was also evident in Coyne et al. (2011) study:

A multidisciplinary collaborative approach was considered vital in promoting FCC. There needs to be guidance, support and open communication between all members of the multidisciplinary team. Nurses advocated the need for all health professional to work together to meet needs of child and family not just nurses.

When roles were not respected or fulfilled, participants labeled parents as more difficult. Parents who never left the bedside, continually asked questions, and were perceived as judging the nurse's knowledge and practices were challenging to work with. Aein et al. (2010) found that the constant presence of mothers at the bedside and their comments about the nurses' care were "...considered as 'interference' and challenged nurse's authority leading to nurses clashing with mothers to defend the boundaries of their work." Coyne et al. (2011) had similar results, including the disruption from hostile families, also seen in this current study:

Parents behaving aggressively towards nurses and other health professionals constituted a major disruption, resulting in them being labelled 'nightmare' families. Parents who asked many questions or questioned treatment decisions could be seen as being over-educated, possessing too much information and trying to pre-empt the professional's role. This behavior was viewed as seriously disruptive because it challenged nurses' authority and was time consuming.

Additional Barriers

Although not mentioned in the final theory, some additional barriers outside of family characteristics and behaviors were described by nurses. These included physical space, difficulty accessing tools and resources, and lack of adequate time to spend with families. These barriers have often been a focus of previous research findings, particularly in studies on nurses' experiences of FCC (Aein et al., 2011; Benzies et al., 2019; Coyne et al., 2011; Turner et al., 2014). However, this was not as much of the focus of the nurses' perceived barriers as it has been in previous research, perhaps reflecting a change in environmental structure and staffing in more recent years.

Strengths & Significance

There is limited literature on FCC nursing practice in NICUs in the U.S., and no research to date specifically examining nurses' views of families and how these views impact their FCC delivery. Previous research has focused on this historical context of FCC, definitions of FCC, the direct impact of FCC delivery, and nurses' and families' experiences with FCC principles. Much of the literature on FCC has been completed outside of the U.S. This study was unique in its grounded theory approach and expands the current literature on FCC in the NICU by exploring the why and where FCC knowledge is at odds with nursing practice. The findings of this study help to bridge the gap between FCC philosophy and practice by understanding nurses' thought processes and decision-making when applying FCC principles. The resulting substantive theory and model are grounded in the views of NICU nurses themselves and can provide a framework for future FCC research and practice.

Limitations

Major limitations of this study should be discussed. The first limitation is the relative homogeneity of the participants that completed interviews. The majority of participants self-identified as White, with all participants identifying as female. Most participants had a year or less experience in the NICU. While data saturation was achieved with this sample of participants, and this sample is representative of the demographics of nurses employed at the study setting, future research would benefit from the inclusion and perspectives of racially and ethnically diverse participants and older nurses with more NICU experience.

The second limitation was the lack of in-person interviews and field observations of nurses' practice within the NICU setting. During initial development of this study, in-person interviews and observations of nurses' FCC practice and interactions with families was planned. However, due to the Covid-19 outbreak beginning in March 2020, hospitals were closed to visitors, and the study was reorganized to include phone or Zoom interviews and in-person observations were eliminated. Eight participants chose to complete phone interviews, with two completing interviews by Zoom. Phone interviews proved challenging for several reasons. Without face-to-face interactions, it was difficult to gauge physical or emotional cues that may have led to further questions and prompts. Participants were often distracted and interrupted during phone interviews, typically due to other persons, making it difficult for participants to follow questions and stay on track with the interview. While interviews on their own can be sufficient in providing data in a grounded theory studies, in-person observations of the participants during their daily interactions with families would have provided rich data to support the resulting theory. The study relied on participants' self-reported practices, which may not have accurately reflected actual behavior.

Finally, this study took place in a single NICU. As discussed in Chapter 2, definitions of FCC and how it is practiced can vary between health care organizations. This study aimed to bridge the gap between nurses' attitudes, beliefs, and biases of families and the delivery of FCC. In order to understand how nurses' FCC practices changed over the course of nurse-family interactions, it was important to understand how nurses defined FCC. Using a single NICU served as a starting point for developing the theoretical model based on nurses' knowledge and personal definitions. It was beyond the

scope of this current study to examine cultures and varying definitions and conceptualizations of FCC across multiple NICU sites.

The inability to access the facility for recruitment also proved challenging, with reliance on emails, phone calls, and flyers placed in the unit being completed with the help of the NICU's administrative assistant.

Future Implications

This study culminated in a substantive theory grounded in nurses' knowledge of FCC, appraisal of families, and resulting practice. The findings of this study and theoretical model can help to inform the FCC practices of nurses at the study setting and is abstract enough to be applied and refined in additional NICUs. To practice optimal FCC, nurses must begin to recognize how their appraisal and classifications of family characteristics and behaviors, particularly around perceived role expectations, impact their FCC implementation. Opportunities for future research and changes to nursing practice are provided here.

Research

Future research is needed to refine the model. This study was completed in a single, urban NICU. More research is needed across multiple sites and populations to increase the adaptability of the theory. Additional studies in which nurses are observed during their daily practice and FCC delivery would provide much needed data to support or refine categories that have been based on self-reported behaviors. As mentioned in the limitations of the study, future researchers should seek out diverse participants, including racial and ethnic minorities and older, more experienced nurses. Two participants perceived there were racial biases that existed between White nurses and Black families.

Follow-up studies should specifically examine potential racial and ethnic biases that may lead to disparities in FCC care practices and refine the current theory to include these categories.

The focus of this study was nurses' perceptions of families and how their FCC delivery was impacted. Role expectations and how they were met was a key finding in this study. Families were expected to fulfill roles that may or may not have been made clear to them. What was not expressed by participants in the current study was how families may perceive their own roles and the roles of the nurse. Future research should specifically address families' perspectives and experiences of what roles they believe they should play during a NICU admission and their expectations of the nurse.

Practice

Participants identified many of the commonly held principles of FCC in their personal definitions. However, participants were unclear how their hospital unit may specifically define FCC and vaguely remembered the concepts being covered in hospital and unit orientation. Continued education on FCC principles and expected FCC practices and delivery in the unit is warranted. Hospitals that do not place an emphasis on FCC during NICU nurses' orientation would benefit from specifying which definition and principles have been adopted and provide specific examples of how the principles are operationalized in day-to-day nursing practice. Education on FCC principles should not only be included in orientation, it should also be reinforced during annual FCC review and through visual cues posted throughout the NICU listing the unit's definition of FCC and how the principles should be incorporated into practice.

Participants highly valued FCC principles and entered interactions with families with full intentions of providing optimal FCC. However, several participants identified a deficit in their own communication skills as a barrier when working with families with challenging characteristics and behaviors. Particular areas of concern for participants were speaking with families who were perceived as disengaged, upset or hostile, not receptive to education, or under the influence of alcohol or drugs. To increase nurses' perceived self-efficacy during communication with these families, it is recommended that NICU unit educators include communication-specific education for nurses both during initial unit orientation and on a continued basis. Recommendations for communication education include: (1) therapeutic communication-specific modules during orientation and continued education that include role play and real-world simulations, and (2) unit debriefings with nurses about situations that have been identified by nurses as challenging to help highlight and allow a safe environment to practice strategies that can be used in future nurse-family interactions.

This study has highlighted the importance the nurses' role expectations of families and its impact on FCC. Much of the *Nurses' Appraisal* of families and subsequent determination of *Acceptable* or *Challenging Family Characteristics and Behaviors* was related to whether roles were being met and respected. Participants expected families to ask question, be receptive to education, and actively provide care for their infant. In discussions of safety and preparing the infant and family for discharge, participants described education and checklists that must be completed prior to discharge, typically including tasks related to physical care of the infant. What was missing in the interviews was clear communication with families about the roles nurses expected

families to fill. It is recommended that during unit orientation, perceived role expectations of nurses and families be acknowledged and discussed. Discussions should include the impact these role expectations have on the delivery of FCC. Strategies to communicate these expectations with families would lead to enhanced clarification for families and improve nurse-family relationships. Strategies include written role expectations of both nurse and family to be listed in the NICU welcome packet for parents. Signs placed in the infant's room encouraging families to "Ask Us Anything! Let's Learn Together! Join Us in Care!" would provide positive messaging for families and may decrease hesitancy to engage with both the healthcare team and their infant.

Additionally, the NICU included in this study may benefit from the introduction of the Creating Opportunities for Parent Empowerment (COPE) NICU Program to help increase parental engagement. This program is intended to provide education for parents on their preterm infant, the NICU environment, and how to engage with their infant and NICU staff. In addition to improved infant outcomes, the COPE program has shown to decrease parental stress, depression, and anxiety and improve interactions between parents and infant (Melnyk et al., 2008; Melnyk et al., 2006). The program includes COPE training for nursing staff and a four-phased program for parents from NICU admission through two weeks following discharge (Cope for Hope, Inc., 2015).

Finally, participants in this study provided possible rationales for family behaviors that were deemed challenging, particularly for parents who were perceived as disengaged. Examples of rationalizations included the families having other children to care for, limited access to resources, or being overwhelmed with the complex nature of their infant's care. Despite the understanding nature of these rationales, nurses still tended

toward providing sub-optimal FCC. It was not apparent in the interviews that nurses had extensive education or skills on how to provide support for families that may be disengaged due to stress. Trauma-informed nursing practice has recently become accepted in the NICU and recognizes the “impact of trauma and toxic stress on the hospitalized infant-family dyad” (Coughlin, 2017). To help support NICU nurses in their efforts to provide optimal FCC, it is recommended that the NICU incorporate trauma-informed care (TIC) education alongside other suggested education found in this section. In particular, the NICU would find Coughlin’s (2017; 2021) texts *Trauma-Informed Care in the NICU: Evidenced-Based Practice Guidelines for Neonatal Clinicians* and *Transformative Nursing in the NICU: Trauma Informed, Age-Appropriate Care* useful for Coughlin’s thorough descriptions of TIC, specific measures and practices, and roles of the NICU professional in providing FCC. Fleishman et al. (2019) also provides specific TIC nursing and organizational guidelines that would be useful for TIC implementation, including providing clear and consistent messaging about services and roles, using plain language and teach back when providing education, providing universal TIC to patients regardless of history, and evaluating policies and leadership practices that may conflict with TIC practices.

Conclusion

The purpose of this study was to examine nurses’ attitudes, beliefs, and biases related to families and the influence these views have on the implementation of FCC in the NICU and to uncover social processes underlying practice. A Straussian grounded theory approach to data collection and analysis was used to create the substantive theory of *Nurse Appraisal of Families and Resulting Family-Centered Care Practice*. This

theory was grounded in the views of NICU nurses actively working with infants and families.

This study is innovative in its grounded theory approach and is the first study to specifically address the impact of nurses' attitudes, beliefs, and biases toward families on FCC delivery in the NICU. This research expands current FCC knowledge by identifying nurses' definitions of FCC and expected roles of families and nurses in FCC delivery, nurses' appraisals of families, and subsequent changes in FCC delivery based on family characteristics and behaviors. Future research with multiple sites and diverse participants is needed to refine the theory and increase its adaptability across NICUs and other populations. Future studies should also include families' perspectives on FCC roles. Recommendations for NICU nursing practice include continuing education on FCC principles and enhanced communication strategies when working with families. The inclusion of the COPE NICU Program and trauma-informed care training for NICU nurses is recommended to support both families and nurses and increase parental engagement and optimal FCC delivery.

APPENDIX A
INTERVIEW GUIDE

Introduction

I will begin the interview by introducing myself and explaining the purpose of my study, which is to examine nurses' knowledge and practices of FCC. I will then receive verbal consent for the interview and audio recording. I will offer them the chance to provide a pseudonym of their choosing to protect their privacy.

Questions and Prompts

1. What comes to mind when I say family-centered care?
2. How would you define FCC?
3. How does your unit define it?
4. How were you taught or trained on FCC principles?

Prompts: School? On the job training or in-services? Continuing education?

5. How do you incorporate that training in your daily practice?
6. How do you feel that FCC fits into your unit?

Prompts: Is it well accepted? Is there any resistance to the concept?

7. What do you think are the various responsibilities involved in FCC?

Prompts: What are the nurse's roles and responsibilities? Families?

8. Are there times when someone doesn't carry out their role or responsibilities?

Prompts: Can you give me an example? How is that situation resolved?

9. Are there times when there are conflicting views of FCC roles and responsibilities?

Prompts: Can you give an example? How is that conflict resolved?

10. I have had nurses say that how they provide FCC “depends on the situation.”

What are your thoughts on that statement? How do families fit into that “situation”?

11. What types of situations do you think might change the way nurses practice FCC?

12. Can you think of examples in which you or other nurses were involved?

13. What helps you facilitate FCC?

14. Can you tell me about a time when FCC was easy to provide?

Prompt: What was the role of the family in that situation?

15. Can you tell me about a time that you perhaps felt reluctant to provide FCC?

Prompt: What was the role of the family in that situation?

16. What do you believe are the barriers for you or your coworkers to provide FCC?

17. Is there anything I haven’t asked that you would like to tell me or talk about?

APPENDIX B

RECRUITMENT FLYER

NURSES NEEDED!

If you are a registered nurse providing direct care for infants and families, you may be eligible to participate in a research study.

The Study

This study will explore nurses' attitudes, beliefs, and biases toward families and the impact on family-centered care interventions.

Who is eligible?

- Registered nurse
- 18 years or older
- Providing direct care for infants and families
- Working a minimum of one shift per week in the NICU

What is expected?

- Complete one interview over the phone or Zoom
- Interview may last up to 1 1/2 hours
- May receive follow-up call within 6 months after interview



Compensation

Participants will receive their choice of a \$25 gift card to either Walmart or Target.

Interested in Participating?

Contact Paula Prouhet, PhD(c), RN at prouhetp@umsl.edu or (618) 593-2428

IRB: 2020782 Approved: 5/7/2020



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APPENDIX C

RECRUITMENT EMAIL

Looking for Registered Nurses in the NICU to Participate in a Research Study on Family-Centered Care!

We are exploring the influence of nurses' attitudes, beliefs, and biases of families on family-centered care practices in the NICU. Your experiences will give us valuable insight into the challenges nurses may face when providing family-centered care interventions.

What is expected?

Participants will complete one interview over the phone or Zoom. The interview may last up to 1 ½ hours. You may receive a follow-up call within six months after the interview.

Who is eligible?

To be eligible for the study, you must be a registered nurse, over 18 years of age, providing direct care for infants and families, and working a minimum of one shift per week in the NICU.

Compensation?

Participants will receive their choice of a \$25 gift card to either Walmart or Target upon completion of the interview.

Interested?

If you are interested in participating, or would like more information, please contact Paula Prouhet, PhD(c), RN, at prouhetp@umsl.edu or 618-593-2428.

APPENDIX D

CHECKPOINTS TO EVALUATE THE METHODOLOGICAL CONSISTENCY OF A GROUNDED THEORY STUDY

1. What was the target sample population? How was the original sample selected?
2. How did sampling proceed? What kinds of data were collected? Were there multiple sources of data and multiple comparative groups?
3. Did data collection alternate with analysis?
4. Were ethical considerations taken into account in both data collection and analysis?
5. Were the concepts driving the data collection arrived at through analysis (based on theoretical sampling), or were concepts derived from the literature and established before the data were collected (not true theoretical sampling)?
6. Was theoretical sampling used, and was there a description of how it proceeded?
7. Did the researcher demonstrate sensitivity to the participants and to the data?
8. Is there evidence or examples of memos?
9. At what point did data collection end or a discussion of saturation end?
10. Is there a description of how coding proceeded along with examples of theoretical sampling, concepts, categories, and statements of relationship? What were some of the events, incidents, or actions (indicators) that pointed to some of these major categories?
11. Is there a core category, and is there a description of how that core category was arrived at?
12. Were there changes in design as the research went along based on findings?

13. Did the researcher encounter any problems while doing the research? Is there any mention of a negative case, and how was that data handled?
14. Are methodological decisions made clear so that the readers can judge their appropriateness for gathering data (theoretical sampling) and doing analysis?
15. Was there feedback on the findings from other professionals and from participants?
And were changes made in the theory based on this feedback?
16. Did the researcher keep a research journal or notebook? (Corbin & Strauss, 2015, pp. 350-351).

APPENDIX E

CHECKPOINTS TO EVALUATE THE QUALITY AND APPLICABILITY OF A GROUNDED THEORY STUDY

1. What is the core category, and how do the major categories relate to it? Is there a diagram depicting these relationships?
2. Is the core category sufficiently broad so that it can be used to study other populations and similar situations beyond this setting?
3. Are each of the categories developed in terms of their properties and dimensions so that they show depth, breadth, and variation?
4. Is there descriptive data given under each category that brings the theory to life so that it provides understanding and can be used in a variety of situations?
5. Has context been identified and integrated into the theory?
6. Has process been incorporated into the theory in the form of changes in action–interaction in relationship to changes in conditions? Is action – interaction matched to different situations, demonstrating how the theory might vary under different conditions and therefore be applied to different situations?
7. How is saturation explained, and when and how was it determined that categories were saturated?
8. Do the findings resonate or fit with the experience of both the professionals for whom the research ended and the participants who took part in the study? Can participants see themselves in the story even if not every detail applies to them? Does it ring true to them? Do professionals and participants react emotionally as well as professionally to the findings?

9. Are there gaps, or missing links, in the theory, leaving the reader confused and with a sense that something is missing?
 10. Is there an account of extremes or negative cases?
 11. Is variation built into the theory?
 12. Are the findings presented in a creative and innovative manner? Does the research say something new or put old ideas together in new ways?
 13. Do findings give insight into situations and provide knowledge that can be applied to develop policy, change practice, and add to the knowledge base of a profession?
 14. Do the theoretical findings seem significant, and to what extent?
 15. Do the findings have the potential to become part of the discussions and ideas exchanged among relevant social and professional groups?
 16. Are the limitations of the study clearly spelled out?
 17. Are there suggestions for practice, policy, teaching, and application of the research?
- (Corbin & Strauss, 2015, pp. 351-352).

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VITA

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