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Maximizing Impact: A Grounded Theory Study of Primary Nursing Relationships in the Neonatal Intensive Care Unit

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Maximizing Impact: A Grounded Theory Study of Primary Nursing Relationships in the Neonatal Intensive Care Unit

by

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Dedication

To Patrick, who always believed I could do, well, anything, and stubbornly refused to listen to my fear about not being good enough.

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Primary care nursing (PCN) is a common nursing care delivery system within the neonatal intensive care unit (NICU). Some studies of the effects of this form of care delivery have demonstrated positive effects for patients, families, nurses, and healthcare facilities but some reported concerning negative effects for nurses. There has been little study of the underlying relationships that develop between the primary nurse and the family which can be complex because of involvement of the parents in the NICU environment. The few extant studies of PCN relationships in the NICU are either dated or conducted in regions outside the United States. Classical Grounded Theory (CGT) was used to study relationships between NICU primary nurses and families as CGT can elucidate theories that underlie sociological processes while staying firmly grounded in the data. Eleven participants were recruited purposively and through snowball sampling methods from geographic areas spanning the US South, Southwest, and West. The researcher collected data using recorded semi-structured interviews. Transcripts were analyzed using constant comparative method, substantive and selective coding, memoing, and sorting. The

participants' main concern was revealed to be *Maximizing Impact* and they resolved their concern through relationships they built with NICU families through a four-phase process named *Safeguarding this Family.* At present, primary care nursing relies on motivated individual nurses and most patients are not matched with a primary nurse. Better understanding of primary NICU nursing could increase the implementation of PCN improving care and nurses' experiences.

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List of Abbreviations

AES	Advanced Encryption Standard
CCM	Constant Comparative Method
CGT	Classical Grounded Theory
FCC	Family Centered Care
HIPAA	Health Insurance Portability and Accountability Act of 1996
IOM	Institute of Medicine
IRB	Institutional Review Board
NICU	Neonatal Intensive Care Unit
PCN	Primary Care Nursing
PDF	Portable Digital File
PICU	Pediatric Intensive Care Unit
Primaried	The act of being a primary nurse for a specific patient (infant)
Primary Family	The family of the primary infant. Most often mother and/or father though may include other relatives especially in single parent households.
Primary Infant	The infant patient in the PCN relationship.
Primary Nurse	The nurse who is involved in a PCN relationship.
NANN	National Association of Neonatal Nurses
NICU	Neonatal Intensive Care Unit
RN	Registered Nurse
SMYS	Show Me Your Stethoscope

US	United States (of America)
UTMB	University of Texas Medical Branch at Galveston

CHAPTER ONE: INTRODUCTION

INTRODUCTION

This dissertation presents findings from the Classical Grounded Theory (CGT) study that explored how neonatal intensive care nurses form relationships with infants and parents when engaged in primary care nursing (PCN). Chapter One presents the background of the study, the study problem, introduces the research question, discusses the aim of the study, and describes the significance of the study. Chapter One then reviews the methodology used to explore the study question and concludes with study delimitations.

STUDY BACKGROUND

Nursing professionals have always striven to provide the highest quality of care, although the exact model for care delivery has shifted over the years; nursing care delivery systems have not always been nurse-driven and have often been directed by the needs of facilities and payors rather than professional practice or patient-centeredness (Nelson, 2000). Patient-centered care delivery systems in the early 20th century had succumbed to more task-oriented models of care delivery as hospital growth boomed and nursing shortages grew (Nelson, 2000; Person, 2004). Primary Care Nursing (PCN) rose to prominence during the 1970s; a time when there was increasing nursing dissatisfaction with existing models of care as well as a surge in interest in establishing nursing as a profession with its own distinct theories and science (Tobbell, 2018).

The PCN model of care delivery was proposed as a way to increase nursing satisfaction by increasing autonomy and increasing patient satisfaction through more

individualized care (Manthey, Ciske, Robertson, & Harris, 1970; Manthey, 2002). Primary Care Nursing also supported professional nursing practice and although it was not explicitly linked to any specific nursing theory, it was compatible with theory-driven nursing practice (Felgen, 2004; Manthey, 2002).

The publication of the Institutes of Medicine's groundbreaking works at the turn of the 21st century outlined the deficiencies of healthcare in the United States and attributed much of the ineffectiveness and the failure to put patient's concerns at the forefront of care (Committee on Quality Health Care in America, Institute of Medicine, 2000; Kohn, Corrigan, & Donaldson, 1999). Proponents of PCN advocate for its increased implementation as a care delivery system because it focuses on the patient and has been shown to improve patient and nursing outcomes (Manthey, 2002; Butler, Collins, Drennan, Halligan, O'Manthúna, Shultz, Sheridan, & Vilis, 2011; Mattila, Pitkänen, Alanen, Leino, Loujus, Rantanen, & Aalto, 2014).

Infants hospitalized in a Neonatal Intensive Care Unit (NICU) are a unique population within the acute care setting. Infants in the NICU often require weeks if not months, of hospitalization due to the immaturity of their body systems (Kenner & Lott, 2014). The NICU infant is almost never alone as a patient as their caring and concerned parents are usually at the infant's side during the often long, tumultuous, and emotionally harrowing hospitalization. The NICU infant's parents must simultaneously cope with the distress of their child's tenuous condition as well as learning to care for the infant who will likely be fragile for some period of time if not for his/her entire life.

Study Problem

There is strong evidence that Primary Care Nursing improves patient and caregiver outcomes including fewer patient fall and medication errors, and increased patient, nurse, and physician satisfaction (Blair, Sparger, Walts, & Thompson, 1982; Hegedus, 1979; Kusk & Groenkjaer, 2016; Rigby, Leach, & Greasley, 2001; Sellick, Russell, & Beckmann, 2003; Shields, Turnbull, Reid, Holmes, McGinley, & Smith 1998; Shultz & Bender, 1986; Spurgeon, Hicks, & Barwell, 2001; Suhonen, Välimäki, Katajisto, & Leino-Kilpi, 2007; Wan, Hu, Thobaben, Hou, & Yin, 2011).

Utilization of primary care nursing in the NICU has received scanty research attention. One study established that while PCN is commonly presented as a neonatal unit's care delivery model, only about half of the NICU patients were actually assigned a primary nurse (van den Berg & Lindh, 2013). While there has been some study of PCN relationships between NICU nurses and families, the work is mostly dated or done in other countries with substantially different healthcare environments.

Study Aim and Research Question

The aim of this study was to better understand how NICU primary nurses develop relationships with their primary infants and families. Since there is evidence that far too few NICU infants are assigned to primary nurses, and there is overall a dearth of research examining primary nursing in the NICU. This study sought to fill some of the gaps in knowledge surrounding primary care nursing relationships and the nurses who engage in this form of care delivery by seeking to answer the research question: "How do neonatal intensive care unit (NICU) primary nurses develop their relationships with their primary

families?" The study sought to understand what was really going on (Glaser, 2013) as primary nurses developed relationships with the infants and families they selected for PCN.

SIGNIFICANCE

There are several gaps in the literature regarding PCN in general and specifically literature addressing this care delivery method within the NICU. The majority of the literature on PCN was published in the 1970s to 1990s and most was focused on the transition from other care delivery methods such as team nursing to PCN. Very little literature addresses the relationships at the core of PCN. Primary care nursing relationships are even more relevant when patients' lengths of stay are prolonged, such as in the NICU, and the relationships are more complex when the family is essential to the care of the patient as is common in the NICU.

Primary care nursing has been shown to deliver quality, safe, individualized, and relationship-based care. The findings of this study revealed a theory that can increase understanding of both the nurses who implement PCN and how they enter into and navigate PCN relationships with NICU infants and families.

OVERVIEW OF METHODOLOGY

This study used Classical Grounded Theory (Glaser, 1978; 1998; 2013) to explore the experiences of nurses who regularly practice PCN in the NICU environment. Classical Grounded Theory relies on participants to describe their reality surrounding a specific social phenomenon. Using the participants' data and implementing prescribed analytic

methods, the CGT researcher allows the participants' main concern to emerge from the data, and eventually, how the participants resolved their main concern (Glaser, 1998).

One of the biggest assets of CGT is allowing the researcher to discover "what is really going on" (Glaser, 1998, p.12) in social interactions. Allowing the participants to describe their experiences and keeping the analysis close to the data keeps the study firmly grounded. All concepts arise from the data as the researcher seeks to link concepts and discover a theory describing how the participants resolve their main concern (Glaser, 1978; 1998).

All of this study's procedures received prior approval by the University of Texas Medical Branch (UTMB) Institutional Review Board (IRB). Eleven registered nurses who engaged in PCN participated in data collection interviews conducted face-to-face, either in-person or by internet-enabled video chat. Data was collected in recorded semi-structured interviews.

Data analysis utilized the procedures prescribed by Glaser (1978; 1998) including substantive and selective coding using constant comparative method (CCM), memoing, and sorting. Memos were recorded all throughout the research process until finalization of the final written report.

STUDY DELIMITATIONS

The study's participants were limited to those who practiced in NICUs and participated in PCN for at least one year with at least three separate families in order to assure participation of primary nurses with sufficient experiences to add significant data.

The study sample was limited to participants from the American South, Southwest, and West with the majority practicing in Texas. Only one participant was male.

SUMMARY OF CHAPTER ONE

Chapter One has introduced the research study and has provided an overview of the background, research problem, aim of the study, and the research question. Chapter One included a review of the study's methodology (CGT) along with a brief account of the actual procedures implemented and concluded with a review of the study delimitations.

PLAN FOR REMAINING CHAPTERS

Chapter Two will review the extant literature on primary care nursing including literature specific to PCN in the neonatal intensive care unit. Chapter Three will offer a review of Classical Grounded Theory (Glaser, 1978; 1998; 2013) as well as how CGT was used to answer the research question: "How do neonatal intensive care unit (NICU) primary nurses develop their relationships with their primary families?" Chapter Four will discuss the research findings including the participants' main concern, various supporting categories, and the substantive theory: *"Maximizing Impact."* Chapter Five will provide a discussion of the study findings, implications, significance, limitations, and conclusions.

CHAPTER TWO: REVIEW OF LITERATURE

Chapter Two will provide a review of the literature relevant to primary care nursing (PCN) as a care delivery system in general and specifically to the Neonatal Intensive Care Unit (NICU). It is important however to start with a discussion how literature reviews are discouraged within Classical Grounded Theory (CGT) methodology and the researcher addressed this principle which is in contrast to most research methods.

A review of the literature is not recommended prior to conducting Classical Grounded Theory studies in order to avoid accumulating preconceived biases and remain open to emergence of novel theories (Glaser, 1978; 1998; 2013). The traditional dissertation process does not however, provide exceptions to reviewing the literature based on one's choice of methodology. In order to both meet the expectations of appropriate dissertation procedure as well as respect Glaser's exhortation to avoid biases, this researcher conducted an initial review of the literature months prior to the initial defense of the research proposal. Further exploration of the literature was avoided until after the majority of data analysis had been completed and well after identification of the core category and substantive theory.

The review of the literature will address the definition of PCN, how it emerged and rose to prominence as a care delivery system, variations in the practice, and its use in today's healthcare environment. This chapter will also address outcomes related to the practice of PCN including effects on patients, families, healthcare facilities, and the primary nurses themselves.

DEFINITION OF PRIMARY CARE NURSING

Primary care nursing (PCN) is a system of care delivery rooted in the individual nurse-patient relationship (Manthey, Ciske, Robertson & Harris, 1970). Primary care nursing rose to prominence in the 1970s both in response to the fragmentation of care under previous models of care delivery such as functional and team nursing as well as the desire to institute theoretically supported professional nursing practice (Manthey, 2002, Person, 2004, Ritter-Teitel, 2002). While PCN can be applied in a variety of settings, its origins were in acute care hospital settings as an attempt to re-capture individualized nurse-patient relationships. Primary care nursing means a nurse assumes care for an individual patient at or near admission becoming responsible for care planning, recruiting, and coordinating resources, and then following the patient until discharge (Manthey et al., 1970). Since the primary nurse does not work every day of the week, he or she may recruit associate nurses to follow the plan of care or facilitate communication to enable continuity of care in his or her absence. In many environments, including the neonatal intensive care unit, PCN extends to the entire family (Bethea, 1985). Primary care nursing can enhance delivery of care for patients and has many advantages for the nursing staff (Mattila, Pitkänen, Alanen, Leino, Loujus, Rantanen, & Aalto, 2014).

THEORETICAL SUPPORT FOR PRIMARY CARE NURSING

Marie Manthey, who is largely credited with articulating and popularizing PCN, rarely articulated any specific theoretical basis for PCN; instead she described PCN as a care delivery system that supports theoretically-driven professional nursing practice unlike the prevalent hospital care delivery systems up until the 1970s (2002). Primary care nursing

shifted hospital nursing practice away from a bureaucratically determined list of tasks and towards a professional practice model that enabled nurses to develop caring relationships with patients and to treat individual patient needs (Manthey, 2002; Pontin, 1999). While PCN did not spring out of a specific nursing theory, it found congruency with many nursing theories because it focuses on individualized nurse-patient relationships including Watson's Theory of Human Caring (Moore, 2002). The Theory of Health Promotion for the preterm infant, based on Levine's conservation Model of Nursing and Pender's Health Promotion Model has been used as the theoretical framework for studies of PCN with the NICU (McCarley, Dowling, Dolansky, & Bieda, 2018).

DIFFERENCES IN CONCEPTUALIZATIONS OF PRIMARY CARE NURSING

There have been many conceptualizations of PCN demonstrable through the literature. It is first important to understand the history of nursing care delivery which figures decidedly into the development of PCN. Implementation of PCN has varied widely depending on many factors from nursing and administrative buy-in to finances. The following section will review the literature leading up to the introduction of PCN, conceptualizations and variations in implementation of PCN, and how nursing culture has accepted the practice of primary nursing care.

Primary Care Nursing Over Time

Primary care nursing first appears in the literature in the early 1970s as an exhortation to return nursing to a personalized model of care delivery (Manthey et al., 1970; Person, 2004). In the early years of modern nursing (19th century through 1930s),

professional nurses practiced in individual homes, taking cases one at a time, and managing all aspects of care often while living in the home until the patient recovered (Manthey, 2002). The model of care delivery in hospitals was fragmented into tasks and most care was administered by student nurses still in training (Manthey, 2002). Cultural and economic pressures from the 1930s through the 1960s moved nurses into hospitals, and transformed care delivery systems (Manthey, 2002; Nelson, 2000). Increased investment in hospital infrastructure following World War II along with persistent nursing shortages brought about highly hierarchical care delivery, further fragmented care, and decreased nursing and patient satisfaction (Manthey 2002).

Primary care nursing was proffered as a solution to address the depersonalization of nursing, simplify communication channels, increase individual accountability, and promote professional practice. Primary nursing proposed that one nurse would coordinate all care for a particular patient from admission through discharge reducing the number of caregivers involved in any given patient's care.

Primary nursing became the dominant care delivery system in American hospitals from the 1970s through the 1990s (Manthey, 2003). Primary care nursing also spread across the globe and has been implemented in countries spanning five continents (Archibong, 1999; Boumans & Landeweerd, 1999; Dal Molin, Gatta, Gilot, Ferrua, Cena, Manthey, & Croso, 2018; Degerhammar & Wade, 1991; Drach-Zahavy, 2004; Gagnon, Waghorn & Covell, 1997; Jonsdottir, 1999; Korhonen & Kangasniemi, 2014; Nadeau, Murphy, & Belderson, 2017; Naef, Ernst, & Petry, 2019; Rigby, Leach & Greasley, 2001; Sharafi, Chamanzari, Pouresmail, Rajabpour, & Bazzi, 2018; Wan, Hu, Thobaben, Hou & Yin, 2011).

Economic pressures during the 1990s resulted in hospital restructuring (Ringl, 1994). Restructuring efforts brought about reduced numbers of licensed nursing positions with the remaining nurses being asked to delegate tasks to non-licensed assistants (Manthey & Lewis-Hunstiger, 2006; McGillis-Hall, Doran, Baker, Pink, Sidani, O'Brien-Pallas, & Donner, 2003; Ritter-Teitel, 2002). Another cost-saving measure of the 1990s was to shift nurses into 12-hour schedules and increase part-time and casual nursing positions (Grinspun, 2002).

In 2000, the Institutes of Medicine (IOM) raised an alert about the poor healthcare outcomes in the United States and proposed patient-centered care as a method for improvement by shifting the focus towards patient-centered outcomes (Committee on Quality Health Care in America, Institute of Medicine, 2000). Nursing researchers added evidence linking lowered nurse staffing levels to poor patient outcomes following the hospital restructuring measures of the 1990s (Aiken, Clarke, Sloane, Sochalski, & Silber, 2002).

Concerns about patient outcomes and the push to increase patient-centered care brought Primary Care Nursing back into focus. Nevertheless, many nurses had shifted into 12-hour and part-time positions that limited their days worked per week (Hedges, Nichols, & Filoteo, 2012; Jost, Bonnell, Chacko, & Parkinson, 2010; Grinspun, 2002; Manthey, 2001; Shirey, 2008; Stifter, Yao, Lopez, Khokhar, Wilkie, & Keenan, 2015). With bedside nurses only working two to three days per week, it was difficult to maintain the continuous responsibility for patients' progress throughout their hospitalization so some hospital units introduced case management models (Shirey, 2008). With case management models, a nurse case manager was present at least five days a week to monitor discharge progress

and provide continuous responsibility though with the caveat that they were not bedside providers or present 24 hours a day.

Primary care nursing has been one of the few modern models of care delivery introduced by nurses in an attempt to assert autonomy, institute professionalism, and organize care delivery in ways that supported theoretically based nursing practice (Fairbrother, Jones, & Rivas, 2010). Other care delivery systems have almost always arisen from market forces, propelled by nursing supply or financial constraints. Since the jarring reports on quality of healthcare from the early 2000s, emphasis on the exact model of care delivery has appropriately given way to emphasis on patient-centered care with an over-arching goal of achieving improved patient outcomes. Primary care nursing remains one of the few care delivery systems that is both consistent with patient-centered care, and with theoretically-driven provision of nursing care.

Variation in Implementation of Primary Care Nursing

While PCN gained tremendous popularity in the 1980s through 1990s (Mattila et al., 2014), there was a great deal of variation in how PCN was implemented to meet individual hospital and unit-level needs. Ideally, a primary nurse is assigned to a patient at or near admission and that nurse cares for the primary patient throughout the patient's hospital stay serving as the main coordinator of care and discharge planner (Manthey, 2002). Several associate nurses might be co-assigned to the patient and follow the primary nurse's lead. There are however, many variations in assigning primary nurses, some of which do not ensure that all patients have primary nurses rather relying instead on motivated nurses to choose particular patients; this usually which results in half or fewer

of the patients ever being assigned a primary nurse (Manthey, 2002; van den Berg & Lindh, 2013; Zander, 1992). There also are several variables that work against a primary nurse caring consistently for a primary patient. Such variables include shorter inpatient stays, the prevalence of longer shifts with fewer working days per week, increased numbers of part-time nurses, and difficulties imposed by very large units (McGillis-Hall & Doran, 2004; Settle, 2016). Some facilities allow several primary nurses to care for the same patient in an effort to cover different shifts and also in consideration of the substantial gaps created by twelve hour shifts. One study demonstrated that 50% of shifts in a unit using PCN were covered by nurses from outside the unit to provide for staffing to cover sick leave, holidays, and educational leave (Procter, 1995). This lack of primary nurse coverage for half of a patient's care shifts may help explain why case management has risen to prominence as a way to assure continuity of care and coordination of the care team (Ritter-Teitel, 2002).

Primary care nursing can be implemented in any nursing care environment but was developed specifically for nursing delivered in an inpatient setting at a time when lengths of stay were longer, and nursing staff schedules included more days per week (Jost et al., 2010; Manthey, 2002; Pontin, 1999). The care delivery system for specialties such as home health care, in-home hospice, and community nursing have been in alignment with the principles of PCN care delivery, that is, patient-centered and with a designated nurse assuming primary responsibility for care planning and provision of care (Pontin).

Some environments with short stays, such as emergency departments or day surgeries can benefit from a nurse who assumes responsibility for coordinating care and resources even when patients are only under care for a few hours. (Carabetta, Lombardo, & Kline, 2013; Jost et al., 2010). Primary care nursing's continuity of care can be helpful

in effective discharge planning. Having a primary nurse during the entire hospital stay or during repeated outpatient visits can be especially beneficial to patients with chronic long term illness or patients who may experience longer inpatient stays such as the NICU, oncology, or rehabilitation (Korhonen & Kangasniemi, 2013; Johansson, Lundström, & Heiwe, 2015; Manthey, 2002; Nadeau et al., 2017; Olstrom & Albanese, 2006).

Nursing Culture Acceptance of Primary Care Nursing

In the 1970s to 1980s, a tremendous cultural change accompanied the shift to PCN as nursing roles were being redefined. Prior to the introduction of PCN, most hospital units utilized team nursing in which all substantial care decisions were handed down from the team leader to the charge nurse to the bedside carers in a hierarchical manner (Norrish & Rundall, 2001). In PCN, care decisions were decentralized and were acted on by the primary nurse unless the decision required consultation with other departments (Manthey, 2002; Norrish & Rundall, 2001). As PCN took over, nurses eventually became accustomed to the new delivery system reporting feelings of increased autonomy and appreciation for the continuity of care though they did express worry about increased workloads and stress over prolonged nurse-patient relationships (Goode & Rowe, 2001; Jellinek, Herzog, & Stoddard, 1994; Jonsdottir, 1999; Laasko & Routasalo, 2001).

FACTORS FACILITATING OR INHIBITING IMPLEMENTATION OF PCN

Some of the factors inhibiting PCN include patient length of stay, patient location change, and nurse scheduling. Popular twelve hour shifts and increasingly popular part-time employment limit the number of days a week a nurse works and this can in turn affect

continuity of care especially as hospital lengths of stay shortened (Grinspun, 2002; Manthey & Lewis-Hunstiger, 2006; McCarley et al., 2018; Norrish & Rundall, 1994; Procter, 1995). Patients are often geographically moved from unit to unit during a hospitalization yet nurses are usually assigned to only one specific unit meaning a primary nurse will only care for the patient while the patient is in his or her unit (Goldschmidt & Gordin, 2006; Wiggins, 2008). The advent of case managers that became popular in the Care and Service Team model helped bridge this gap. Case managers however are rarely involved in true nurse-patient relationships and there is a concern about this segmentation in patient care that can staunch the PCN nurse's autonomy (Ritter-Teitel, 2002).

Factors that can facilitate primary nursing can be a unit culture or more specifically managerial support for the practice of PCN with Drach-Zahavy suggesting that there might not be any improvement in care provided by PCN if there is a lack of supervisor support (2004). One of the advantages of PCN over team nursing is autonomy but the primary nurse still needs to feel free to seek needed support from leadership in order to delivery high quality care (Drach-Zahavy, 2004). The presence of a supportive management team has also been reported to facilitate implementation of PCN (Kangas, Kee, & McKee-Waddle, 1999).

Advantages and Disadvantages of Primary Care Nursing

There is a significant body of literature describing the effects of PCN which will be described in the following section. This literature does come with significant limitations including the age of much of the literature and the variation in implementation of PCN as described earlier.

Effects of Primary Care Nursing on Patients and Families

Primary nursing as a care delivery method was proposed as a means to improve both patient and nurse dissatisfaction that had grown from the highly fragmented care under team nursing (Manthey et al., 1970). In the years following the introduction of PCN, several studies sought to compare several nurse-sensitive indicators and other patient factors, generally by comparing team nursing to PCN (Blair, Sparger, Walts, & Thompson, 1982; Boumans & Landeweerd, 1999; Chavigney & Lewis, 1984; Dal Molin et al., 2017; Goode & Rowe, 2001; Hegedus, 1979; Jonsdottir, 1999; Kangas et al., 1999; Laasko & Routasalo, 2001; Olstrom & Albanese, 2006; Reed, 1988; Rigby et al., 2001; Sellick, Russell & Beckmann, 2003; Shields et al., 1998; Shultz & Bender, 1986; Spurgeon et al., 2001; Suhonen et al., 2007; Wan et al., 2011).

Patient outcomes related to primary nursing have included decreased stress and anxiety (Blair et la., 1982; Hegedus, 1979). Shultz & Bender (1986) also noted fewer patient falls and reductions in medication errors when comparing PCN to team nursing. Several studies have focused on the effect of PCN on peripartum patient outcomes. Gagnon, Waghorn, & Covell (1997) reported less use of oxytocin in mothers with primary nurse midwives, but none of the other measured outcomes such as rate of Caesarean section, duration of labor, or pain scores were significant when compared to standard care. Wan et al.'s study (2011) examining the effect of primary nurses that follow mothers home after delivery reported increased knowledge and rates of breastfeeding as well as less breast discomfort and urinary retention. Some studies have demonstrated improved patient satisfaction scores or perception of individualized care (Dal Molin et al., 2017; Sellick et

al., 2003; Shields et al., 1998; Spurgeon, et al., 2001; Suhonen, et al., 2007; Wan et al., 2011).

Other studies, however, found no significant differences in patient satisfaction ((Blair et al., 1982; Chavigney & Lewis, 1984, Shukla & Turner, 1984) and no differences in patient stress when comparing PCN to team nursing (Gardner, 1991). Notably, the discussed patient outcome studies did not address nurse to patient ratios, a factor that has since shown a strong correlation to patient outcomes (Aiken, Clarke, Sloane, Sochalski, Busse, Clarke, Giovannetti, Hunt, Rafferty, & Shamian, 2001; Aiken, Cimiotti, Sloane, Smith, Flynn, & Neff., 2011).

There are few studies examining patient outcomes associated with PCN in the NICU. Mefford and Alligood (2011) did not examine PCN specifically but rather consistency of caregivers. Increased consistency of caregivers was a powerful mediator of need for mechanical ventilation and oxygen therapy, parenteral nutrition, and it shortened length of stay for NICU infants. Gonya, Feldman, Brown, Stein, Keim, Boone, Rumpf, Ray, Chawla, &Butter (2018) examined several forms of positive human interaction received by extremely preterm infants (24-25 weeks gestation at birth) including whether the infants had primary care nurses. Their study showed that formerly extremely preterm infants that had NICU primary care nurses showed significantly less dysregulation as toddlers (Gonya et al., 2018).

Effects of PCN on Nursing Staff

The effects of PCN on the nurse are generally positive with a few exceptions. Nurses consistently report increased feelings of autonomy, which is one of the defining

characteristics of PCN (Allen & Vitale-Nolen, 2005; Gardner, 1991; MacGuire & Botting, 1990; Manley, Hamill, & Hanlon, 1997; Melchior, Halfens, Abu-Saad, Philipsen, van den Berg, & Gassman, 1999; Thomas, 1992). Studies also link PCN to increased nurse satisfaction, inter-disciplinary collaboration, and support for professional growth of nurses, as well as reduced work stress (Adams, Bond, & Hale, 1998; Allen & Vitale-Nolen, 2005; Gardner, 1991; Mäkinen, Kivimäki, Elovainio, & Virtanen, 2003; Sellick et al., 2003; Thomas, 1992). Some nurses can feel increased stress when practicing PCN, even when other measures such as autonomy and overall job satisfaction are improved (Webb & Pontin, 1996). Research findings comparing nursing turnover in PCN versus team nursing environments vary with some studies reporting no statistically significant differences between units using different models (Boumans & Landeweerd, 1999; Fairbrother et al., 2010) and other studies reporting decreases in staff turnover for units using PCN (Gardner, 1991; Melchior et al., 1999). A few studies have examined nursing absenteeism between units using PCN versus team nursing with inconsistent results. The Boumans & Landeweerd (1999) study showed slightly lower (but statistically insignificant) absenteeism in units using PCN but they also discussed methodological concerns with contamination and Hawthorne effects. McPhail, Pikula, Roberts, Browne, and Harper (1990) found no significant difference in absenteeism between PCN and team nursing units but it was a pilot study and power may have been too low to detect differences. In another study by Alexander, Weisman and Chase (1981), PCN was implemented in two different hospitals with only one showing a decrease in absenteeism. The incongruity of the effects of PCN on nurses could be from several factors including inconsistent implementation of

PCN (Zander, 1992) and varying responses that could be linked to nurses' educational backgrounds and experience (Gardner, 1991; Fairbrother et al., 2010; Zander, 1992).

Virtually all research comparing PCN to other forms of care delivery happened in the years when PCN was new and was replacing the current care delivery method. Team nursing is being re-introduced in Canada due to concerns about costs and shortages of licensed nurses (MacKinnon, Butcher, & Bruce, 2018). Using Institutional Ethnography, the authors concluded that the new system of team nursing (termed Care Delivery Model Redesign) was orienting nursing to fragmented and task-focused care delivery, some of the strongest motivations for abandoning team nursing (MacKinnon et al., 2018).

Effects of PCN on Healthcare Facilities

Hospitals have had concerns about PCN as there was a widespread belief that this form of care delivery required an all-Registered Nurse (RN) staff that would increase costs, a belief refuted by those responsible for originally popularizing PCN (Manthey, 2002). Study findings are inconsistent regarding the costs of implementing PCN over team nursing. Some studies find costs are lower with PCN, often attributed to a decrease in administrative staff (Betz, Dickerson, & Wyatt, 1980; Gardner & Tilbury, 1991; Wolf, Lesic, & Leak, 1986). Other studies comparing costs found that the costs were higher; however, in most of these studies, the units changed their staffing mix to all or mostly RNs (Shukla, 1983; Shultz & Bender, 1986). One study from an NICU studied the relationship between consistency of caregivers (largely related to PCN) and infant length of stay finding that consistency of caregivers was a powerful mediator of length of stay which would tend to decrease costs (Mefford & Alligood, 2011). The vast majority of the literature addressing

organizational effects of PCN is from prior to the year 2000 and would, like other outcomes discussed so far, be constrained by inconsistent implementation of PCN, and individual unit and nurse characteristics (Zander, 1992).

PRIMARY CARE NURSING IN THE NEONATAL INTENSIVE CARE UNIT

Primary care nursing in the NICU serves to establish mutual trust between parents and the primary nurse and, which in turn, facilitates the teaching and preparation needed for parents to care for infants who may still require some support in the home (Korhonen & Kangasniemi, 2014). Primary care nursing is also useful in the NICU as it enhances and complements two existing philosophies of care already prevalent in the NICU: developmental care and family-centered care (Altimier & Phillips, 2013). There is substantial theoretical and empirical support that these two philosophies of care are beneficial to preterm infants and their families (Als & Gilkerson, 1997; Gibbins, Hoath, Coughlin, Gibbins & Franck, 2008; Örtenstrand. Westrup, Broström, Sarman, Åkerstrom, Brune, Lindberg, & Waldenström, 2010; Montirosso, Del Prete, Bellù, Tronick, Borgatti, & NEO-ACQUA Study Group, 2102). Primary care nursing, through many mechanisms including continuity of care, supports both family-centered and developmental care (Fegran & Helseth, 2009; Manthey et al., 1970; Settle, 2016).

Developmental Care and Primary Care Nursing

Developmental care is based on synactive theory of development (Als & Gilkerson,1997). Briefly, the synactive theory is based on knowledge that the human fetus is actively forming synaptic neuronal connections for which the intra-uterine environment

is ideal. Even relatively healthy preterm infants who escape the myriad of prematurity-related complications still face struggles related to the harsh, extra-uterine environment of the NICU. Preterm infants are still attempting to complete the tasks normally accomplished in the protective uterine environment. If born preterm, it is essential to protect the immature brain from stimuli as it is not sufficiently developed to handle. Frequent observations of the infant's behavior can assist the provider to identify which stimuli the infant can handle (Als & Gilkerson, 1997). Functionally, developmental care urges controlled light, noise, and other noxious stimuli using the infant's physical cues as guides. Developmental interventions include providing physical boundaries (to simulate limited intra-uterine space), opportunities for suckling, kangaroo care, and clustering interventions to limited time periods. PCN's consistent caregivers support developmental care because the PCN nurse can be more attuned to the subtle preterm infant cues (Settle, 2016).

Developmental care has been shown to improve short and long-term outcomes of preterm infants, specifically length of stay, chronic lung disease, and mental disability (Peters, Rosychuk, Hendson, Coté, McPherson & Tyebkhan, 2009). Even though some studies show positive outcomes, two Cochrane Reviews, one in 2003 and one in 2006, revealed few differences in long-term outcomes of NICU infants though the studies had methodological limitations including small sample sizes and lack of randomized controlled trials (Symington & Pinelli, 2003; Symington & Pinelli, 2006).

Family-Centered Care and Primary Care Nursing

Family-centered care (FCC) is a philosophy of care that encourages parental involvement in the care of their child, emphasizes respect, supports the family unit, and

urges collaboration between the care team and parents (Malusky, 2005). Family-centered care represents a holistic view of the child/infant within its family and is accepted as a standard of care by both pediatric and neonatal physicians and nurses (American Academy of Pediatrics, 2012; American Nurses Association and Society of Pediatric Nurses, 2003; National Association of Neonatal Nurses, 2011). The emotionally vulnerable parents of infants and children in the NICU and pediatric intensive care unit (PICU) value individualized care and therapeutic relationships with healthcare staff (Cleveland, 2008). FCC has been associated with many positive outcomes for infants and pediatric patients including shorter lengths of stay, improved mental health for parents, improved family and staff satisfaction, and even decreased medical errors (American Academy of Pediatrics, 2012). Elements of FCC are considered so complementary and essential to developmental care that authors refer to the two simply as Family-Centered Developmental Care (Craig, Glick, Phillips, Hall, Smith, & Brown, 2015).

In spite of strong support for implementation of family-centered practices in the healthcare of children, efforts often fall short of the true objective. At times healthcare providers simply shift care responsibility to the parents and fail to develop true collaborative relationships (MacKean, Thurston, & Scott, 2005). Primary care nursing has been seen as a strategy to facilitate patient and family-centered care and actualize all the elements of FCC (Korhonen & Kangasniemi, 2014).

Primary care nursing remains a favored care delivery system in NICU (Goldschmidt & Gordin, 2006; Settle, 2016) although, as in other specialties, there are often modifications to the originally proposed ideal model (Manthey et al., 1970; Goldschmidt & Gordin, 2006; Settle, 2016). The modifications are largely in an attempt to

closely match a given infant's specialized nursing needs with the pool of available staff for any given shift while still also attempting to maintain some level of continuity of care (Goldschmidt & Gordin, 2006; Settle, 2016).

The Dynamics of Implementation of Primary Care Nursing

There is great heterogeneity in how PCN is implemented in most of the studies examined. PCN as originally outlined by Manthey et al. (1970), described a care delivery method of matching a nurse with a patient at or near admission and having the nurse care for the patient consistently until discharge. The actual implementation in the ensuing years has varied among hospitals, nursing specialties, and patient populations (Giovannetti, 1986; Mattila et al., 2014; Zander, 1992). Due to the significant variation of PCN practice even just within the inpatient hospital setting, the focus of this review in regards to dynamics and implementation of PCN will remain limited to literature describing PCN in the NICU.

Development of PCN pairs in the NICU

The development of PCN relationships within the NICU environment is addressed in the literature only sparingly. While some NICUs assign specific nurses to infants at or near birth, others allow the nurses to select which infants they will follow as primary patients, sometimes even allowing the match to occur prior to the infant's birth when the mother tours the NICU in anticipation of a high-risk delivery (Bethea, 1985; Lind & Sterk, 1992; van den Berg & Lindh, 2013). Lind & Sterk alone described nurses' rationales for selecting specific infants as their primary patients with some of the top reasons being the infant's particular physical condition and a desire to provide continuity of care (1992). van

den Berg & Lindh's study provided no rationales for nurse selection of a primary infant, although it was noted that the infants with lower gestational ages were more likely to be matched with a primary nurse (2013).

Primary Nurses' Relationships with Infants and Families

There are several studies, mostly qualitative, examining the relationship between primary nurses and families. Little emphasis is placed on the nurse's relationship with the infant likely due to the inability to assess reciprocity secondary to the infant's limited developmental capabilities. A long term primary nursing relationship can reassure a parent and increase their confidence in the care the infant is receiving (Smith, 1987). Scharer & Brooks (1994) articulated the grounded theory: "Transfer of care" describing how NICU primary nurses and the infant's mothers developed relationships emphasizing the importance of forging mutual trust. Development of trust between the parents and primary nurse is a recurring theme in literature addressing PCN in the NICU (Bethea, 1985; Fegran, Fagermoen, & Helseth, 2008; Fegran & Helseth, 2009; Scharer & Brooks, 1994; Korhonen & Kangasniemi, 2014).

Phases of the PCN Relationships from Beginning to End

The first phase of the NICU primary nurse's relationship to the infant and family is the point at which the nurse and family enter the relationship. As discussed previously, many NICU nurses usually are empowered to choose their primary infants and families. Only one study has been identified that investigated the motives of primary NICU nurses for selecting specific infants and families (Lind & Sterk, 1992). The most highly ranked motives were the infant's particular medical issues, maintaining continuity of care, nurses'

personal impressions of the infant and family, altruism, and nurses' self-esteem (Lind & Sterk, 1992). The next phase of the relationship is when trust and closeness develop between the primary nurse and the family (Fegran et al., 2008; Fegran & Helseth, 2009; Scharer & Brooks, 1994). Trust helps parents and caregivers respect each other's input as they work as a team to help the infant grow and develop sufficiently for discharge (Scharer & Brooks, 1994). The nurse-parent relationship can develop into a kind of friendship requiring the nurse to balance emotional closeness and distance (Fegran & Helseth, 2009; Scharer & Brooks, 1994). The primary relationship enters a new phase as the infant's condition improves and time for discharge approaches. Some nurses reduce contact with the parents in order to allow them more independence in caring for their infant (Scharer & Brooks, 1994). The last phase of the relationship occurs after the infant is discharged home with a great deal of variation in how this phase proceeds. Some primary nurses form relationships that last months or longer after the infant's discharge while others cease contact at discharge (Fegran et al., 2008; Fegran & Helseth, 2009; Korhonen & Kangasniemi, 2014). For those who continue in contact, the relationship between primary nurses and the families after discharge may entail minimal contact such as the family sending pictures and updates on the infant's condition, to nurse-parent discussions on how to care for the infant, to meeting in person and interacting as friends (Korhonen & Kangasniemi, 2014; Scharer & Brooks, 1994).

CURRENT STATE OF KNOWLEDGE ON PCN, ADEQUACY, & GAPS IN THE LITERATURE

The state of knowledge of knowledge about PCN is unclear, likely due to confusion surrounding shifting definitions and implementation of PCN. Primary care nursing in its

original meaning defined a care delivery system that applied to all patients admitted to an inpatient facility (Manthey et al., 1970). What is found in many hospitals may look similar to PCN, but specific elements such as 24-hr responsibility have been shifted to case management nurses who coordinate a multi-disciplinary team in providing patient-centered care (Shirey, 2008). Patient-centered care, also described as a case management model, allows for primary nurses and thus the terminology remains though with a modified role (Manthey & Lewis-Hunstiger, 2006). Changing roles such as moving the 24-hour responsibility to a case manager and away from the bedside provider while keeping the term PCN clouds the current state of knowledge on the practice of primary nursing.

Literature on PCN is abundant in the 1970s, 1980s, and even the 1990s although the focus is largely quantitative in nature and generally concerned with comparing PCN to team nursing care delivery. The literature examining PCN more qualitatively as it affects primary nurses, patients, and their families remains scant. Literature focused on PCN in the NICU is even more limited and have tended to focus more on continuity of caregivers (an element of PCN) rather than PCN itself.

There are many gaps in the nursing literature addressing PCN as it is practiced in the 21st century. More significantly, there is even less literature exploring PCN in the NICU environment and specifically related to American experience. Even including literature from decades past, there are very few descriptions of theories addressing PCN relationships in the NICU.

SUMMARY OF CHAPTER TWO

Chapter Two has provided a review of the literature on Primary Care Nursing both generally and particularly to the neonatal intensive care environment. The Chapter began with introduction to and description of PCN including the great variation in practice. The Chapter also reviewed outcomes of PCN on patients, families, nurses, and healthcare facilities. The Chapter also described the scant available literature on primary care nursing the NICU including several qualitative studies. The Chapter concluded with an analysis of the extant literature and identification of gaps in the literature which justified the need for the present study.

PLAN FOR THE REMAINING CHAPTERS

Chapter Three will discuss the current study's methodology, CGT (Glaser, 1978; 1998; 2013) and how CGT was selected and utilized for the present study. Chapter Four will discuss findings from this CGT study exploring how NICU primary nurses develop relationships with their primary families including a detailed discussion of the main study finding: *Maximizing Impact*. Chapter Five will provide a discussion of the substantive theory as it relates to the extant literature, study implications, study strengths, and study weaknesses.

CHAPTER THREE: METHODS

Chapter Three provides a description of Classical Grounded Theory (CGT) and its implementation in this study. The Chapter details how the study implemented CGT techniques in exploring how nurses who practice primary care nursing (PCN) in the neonatal intensive care unit (NICU) enter into and develop relationships with their primary families and the infants' families. The Chapter begins with a description of CGT and the appropriateness of selecting this methodology for the study. The Chapter provides a description of the study sample, recruitment, criteria for inclusion, the setting for data collection, procedures for data collection and management, and data analysis. The chapter then presents a discussion of how the study met Glaser's (1998) criteria for trustworthiness in a CGT study and how those criteria were applied to this study. The chapter concludes with a discussion of the techniques applied for protection for participating human subjects.

RESEARCH DESIGN

Grounded Theory methodology was first described by Glaser and Strauss in 1967. Glaser and Strauss were led to develop the method by their dismay at logically deduced sociological theories that had been developed based on ungrounded assumptions and their desire to formulate more accurate, inductively-derived, theories that were grounded in data rather than starting with pre-existing theories and forcing new data to fit into previously defined frameworks (Glaser, 1998; Stern & Porr, 2011). Glaser and Strauss proposed that research data itself could reveal theoretical concepts by use of a rigorous process, allowing the researcher to discover the underlying theory that drives the social interactions of the participants (1967). Later refinements in Grounded Theory methods by Dr. Glaser gave

rise to Classical Grounded Theory (Glaser, 1978; Glaser 1998; Glaser 2014). The CGT researcher relies on the participants to describe their reality surrounding the phenomenon of interest. The researcher analyzes these data seeking to identify the participants' biggest challenges and their main concern, then understand how participants worked through or resolved their main concern (Artinian, Giske & Cone, 2009; Streubert & Carpenter, 2011).

Classical Grounded Theory methodology relies on identifying appropriate study participants, gathering participant data, and use of prescribed analytic procedures (Glaser, 1998). Classical Grounded Theory procedures are designed to help the researcher avoid preconceived bias and remain sensitive to the emerging patterns of an underlying explanatory theory (Glaser, 1998). The theory is discovered by allowing categories and concepts to arise from the data and allowing the patterns of their relationships to be revealed through analytic procedures (Glaser, 1998, Richards & Morse, 2013). Use of prescribed CGT procedures allow the researcher to identify the participants' most pressing challenges, their main concern, and how the participants resolve this main concern (Artinian et al., 2009; Streubert & Carpenter, 2011).

Classical Grounded Theory was selected for this study due to its rigor and flexibility in allowing the emergence of theory through systematic data collection and analysis procedures (Glaser 1998). The use of CGT in this study was intended to allow the researcher to explore how NICU nurses form PCN relationships with their primary infants and their families balancing intimacy with professional distance, all during a time when the family structure is stressed and adjusting to its fragile new member. The main goal of this CGT study was to identify the main concern of the Neonatal Intensive Care Unit (NICU) nurses who were or had been involved in Primary Care nursing (PCN)

relationships with NICU infants and their families in regards to the phenomenon of interest, the Primary Care Nurse's relationship with the infant and family. The goal of data analysis in the study was to identify the underlying theory that explained how the NICU nurse participants resolved their main concern. Analysis of the study data revealed that participants' main concern was *Maximizing Impact,* which they resolved using a process that was labeled *Safeguarding This Family,* consisting of four phases. The substantive theory that emerged, labeled *Maximizing Impact,* explained how the participants resolved their main concern through the development of primary care nursing (PCN) relationships which enabled them to *Maximize (their) Impact* on the infants and their families.

RECRUITMENT, SAMPLE, AND SETTING

The study proposal was approved after submission to the University of Texas Medical Branch (UTMB) Institutional Review Board (IRB) (See Appendix A & B). Participant recruitment began after IRB approval was in place. The following sections will review recruitment methods, general characteristics of the sample of the participants, and the settings for data collection.

Recruitment

Recruitment utilized purposive and snowball sampling. Potential participants were recruited using a recruitment flyer (see Appendix C) that was disseminated electronically and by information shared within the researcher's professional network and by study participants with their colleagues. The recruitment flyer included information on the

general topic of the research and contact information (email and phone number) for the researcher.

A recruiting message that included the flyer was posted to the National Association of Neonatal Nurses (NANN) community website on May 22, 2018 (see Appendix E). On May 23, 2018, the same recruitment flyer with a targeted slightly modified message was posted on the informal Facebook page: NICU Harris Staff Alumni and Current, (see Appendix D) for current and former NICU nurses who had worked at the researcher's current place of employment. On the NICU Harris Facebook page, the accompanying posting stated interested parties could also contact the researcher through Facebook's messaging service.

The posting in the NANN community website yielded four potential participants who met inclusion criteria; three initially agreed to participate. One of the four from the NANN community website ceased communication early in the recruitment process and another ceased communication after expressing concerns regarding the technical aspects of conducting the interview by video chat. Two successful data collection interviews resulted from recruitment on the NANN community website. There were multiple responses from the NICU Harris Facebook page. All participants were encouraged to share the study information with other nurses fitting the study criteria and one participant entered the study through snowball recruitment. Eight successful data collection interviews arose from recruitment on the Harris Facebook page and one successful data collection interview arose from a snowball referral from a Harris Facebook page participant.

Upon initially being contacted by a potential participant, the researcher responded using the same format (email or Facebook Messenger). (Since all but one of the participants

were female, female pronouns will be used in the following discussions for simplicity and to protect the privacy of the one male participant.) If the potential participant contacted the researcher through Facebook Messenger, the researcher would request the potential participant's phone number then call her to discuss the study and determine whether she met the study inclusion criteria and was willing to participate in the study. Inclusion criteria were reviewed with the potential participant prior to scheduling the data collection interview. All participants were currently working in the NICU, had cared for at least three primary infants in their career and at least one primary infant in the last year. All participants additionally confirmed their written and spoken fluency in English and were willing to participate in an interview lasting up to 90 minutes with a possible follow up interview not to exceed 30 minutes. If the nurse wanted to participate in the study, the researcher set up a mutually agreeable date, time, and setting for the data collection. A copy of UTMB's Fast Facts Sheet (see Appendix F) was either texted to these participants or emailed to them depending on their preference.

The potential participants who received the study information through the myNANN community website contacted the researcher using email so the researcher's initial response was an email message that included a copy of UTMB's Fast Facts Sheet (see Appendix F), a request for the potential participant's phone number and a good time for the researcher to contact her by phone. During the ensuing phone conversation, the researcher discussed the study, reviewed the criteria for participation in the study and set up a date, time, and setting for the data collection. Two participants were successfully recruited and interviewed through the myNANN community website.

Two participants were referred by snowball recruitment though only one of those was interviewed. The snowball-recruited participant who was interviewed was informed of the study by another participant then she made face-to-face contact with the researcher who verbally reviewed the criteria for the study and set up a data collection session. The Fast Facts sheet was emailed to this participant per her preference. Theoretical saturation was achieved and data collection had ceased prior to any contact between the researcher and the second snowball-referred potential participant therefore she was not interviewed.

After verifying eligibility to participate and prior to setting up a data collection appointment with each potential participant, the researcher explained the purpose of the research, data collection methods including use of voice recording only, and methods used to protect participants' identity. Potential participants were given an opportunity to ask any questions regarding the research and their participation. Most of the questions from participants had to do with what kind of artifacts the researcher was interested in, or what kind of data collection session might be best suited to the participant (in-person versus video chat).

Sample

The study sample included eleven participants who self-identified as registered nurses currently working in the NICU and engaged in PCN. The participants' demographic information is discussed in more detail in Chapter Four including a summary of demographic data presented in Table 4.1.

Setting

Face-to-face interviews were conducted at a mutually agreed upon time and in a mutually agreed upon venue. The researcher offered to conduct interviews either in person in her home office or using a live video chat (either Skype or Facetime). Seven participants opted for the live video chat option while four participants opted to have their interviews in person at the researcher's personal office. Regardless of the venue, the researcher was always located in her home office which offered a quiet and private environment. When setting up the appointment for the interview, all participants were encouraged to find a quiet and private area where there would be minimal distractions on their side prior to starting the interview.

DATA COLLECTION PROCESS

A few days prior to the agreed-upon data of the data collection session, the researcher confirmed the upcoming appointment and venue (in person versus video chat) using the contact method the participant had previously selected when arranging the interview, usually text message or Facebook Messenger. If the participant had opted to be interviewed in the researcher's office, the researcher assured the environment was quiet and free of distractions, received the participant to her office, and made sure the participant was comfortable. If the participant preferred to participate in the study using the video chat option, the researcher connected with her on the video chat platform (either Facetime or Skype), introduced herself, and engaged in light conversation for a couple of minutes to put the potential participant at ease. The researcher reviewed the data collection procedures, clarifying that the interview would be audio only, and would be transcribed at

a later date. The researcher explained that any identifying information would be removed prior to analysis including the participant's name and any names mentioned in the course of the interview including individuals, facilities, or specific locations. The researcher then used the narrative in Appendix G to obtain verbal consent. The narrative contained a description of the purpose of the study, potential risks of participation, what efforts were being employed to protect the privacy of information, and that the participant was free to choose to not answer any question or to discontinue their participation at any time. The consent narrative also included a question to the participant regarding any questions she might have about the study. Once all questions had been answered to the potential participant's satisfaction, the researcher continued the narrative asking the participant for verbal consent to proceed with the recording. The verbal consent allowed the researcher to begin recording the interaction and the researcher once more reviewed the last paragraph of the consent narrative recording the nurse's verbal consent to participate in the study.

Data collection began with collection of demographic information such as the participant's age, gender, and nursing experience including how many years of practicing PCN, either in the NICU or in other specialties. The demographic data is presented in Table 4.1 in Chapter 4 and the demographic questions are listed at the beginning of the interview guide (Appendix H). Data collection used the interview guide developed specifically for the study (see Appendix H). The interview began with a grand tour question. Glaser recommends the use of an open-ended grand tour question rather than fixed formal interview guides but allows an initial interview guide that can be altered, amended, or discarded completely as guided by ongoing analysis (Artinian et al.., 2009; Glaser, 1998; Stern & Porr, 2011). Glaser (1998) believes that overly structured interview guides with

inflexible questions may focus the participant responses too much on the researcher's interests and constrain what the participants share therefore preventing data from emerging organically (Glaser, 1998). The interview began with the grand tour question: "We've discussed how my interest is in how primary care nurses develop relationships with the infants and families. I'd really like to hear your thoughts on that." The researcher encouraged the participants' discussions using prompts such as "Can you tell me more about that?" or "I'd like to hear more about the time that. . ." The researcher added additional questions as additional participants were interviewed; these included questions about the nurses' experiences when their primary infants died, an issue that had emerged as a significant event primary nurses face. Another added question asked the participants about the significance to them of items such as cards or small gifts they may have received from their primary families. The initial interview guide simply asked the participant to discuss those items, which mostly resulted in descriptive responses; asking about the significance of the item elicited more in depth responses.

One of the last questions on the interview guide was if there was anything the participant wanted to add about PCN that had not already been discussed. This question allowed the participants to add many thoughts about PCN that had not been addressed by the interview guide and added substantial data to the study. The last question inquired whether the participant was willing to be re-contacted regarding the study for any follow up questions and that the participant could re-contact the researcher in any of the same ways they had initially or since then (email, text message, Facebook Messenger, or in-person).

Additional data collection included field notes the researcher recorded immediately following the data collection sessions. The field notes documented details observed during the data collection sessions including exact setting (in-person versus video chat) and any observations of the participant's manner or mood during the data collection (Holton & Walsh, 2017). The researcher also recorded memos following the interviews in order to document more abstract ideas or questions that emerged during the data collection. Glaser (1978) encourages the use of memos throughout the entire CGT process but since they are a critical element of data analysis, a more extensive discussion of memos will be presented in the "data analysis" section below.

DATA MANAGEMENT

In-person interviews required less data management than video-chat enabled data collection sessions. The researcher used her password-protected Apple MacBook Air computer with a secure internet connection for all the video-enabled interviews. Participants were encouraged to use secure devices on their end for the interview. Both Facetime and Skype applications use end-to-end encryption with Advanced Encryption Standard (AES) assuring privacy as long as both users are using the application (as happened in all participant interviews).

All participant interviews were digitally recorded using two devices, the researcher's IPhone 8 as a primary device and a Sony voice recorder (ICD-PX333) as a backup device. The researcher's IPhone 8 was password protected and the voice recorder was kept locked in the researcher's file cabinet with the key under her control. The dual recording process was used for both in-person interviews and video-chat interviews. Once

the interviews were completed, the audio file from the primary device was transmitted securely to the Trint transcription service. Trint is an internet service that uses artificial intelligence to transcribe audio files. Files were uploaded securely using Transport Layer Security then stored temporarily (and securely) on the Trint server until the researcher reviewed the transcript and made needed modifications. The Trint transcription service generally took no more than about 15 minutes to prepare an initial transcript draft for the researcher to review. The quality of the transcripts was variable. Every transcript required the researcher to carefully review it for accuracy with some transcript corrections taking several hours. Each transcript was compared to the audio file as the researcher followed along making corrections for complete accuracy. Once all corrections had been completed, the corrected transcript copy was transferred as a portable digital file (PDF) to the researcher's password-protected computer then permanently deleted from the Trint server.

An original copy of the transcript was saved to the researcher's computer with a backup on a thumb drive which was kept locked in the researcher's filing cabinet. A copy of the original transcript was then de-identified removing features such as names, places of employment, geographic locations, or any other highly identifiable features. All participant names were replaced with a participant code with the first assigned the code p1, the second was p2, and so forth. The researcher also maintained an Excel spreadsheet with the participants' names and their codes (p1, p2, etc. . .). The de-identified transcripts were used for data analysis.

DATA ANALYSIS

Data collection and analysis in CGT are ongoing and occur simultaneously with other processes (Glaser, 1998; Holton & Walsh, 2017). As prescribed by Glaser (1998), data analysis began with the first participant interview, informed subsequent data collection, and continued even during the writing process. Glaser prescribes several CGT data analysis procedures that should be utilized in order to identify patterns in the data; these procedures include coding, memoing, and the constant comparative method (Glaser, 1978; Holton & Walsh, 2017).

Coding

Classical Grounded Theory coding proceeds in two phases, initial open or substantive coding, followed by selective coding. Open coding involved a line-by-line analysis, beginning with the first transcript as the researcher identified sections of data that might indicate concepts emerging from the data (Holton & Walsh, 2017). This initial substantive coding was accomplished by following Glaser's rules for open coding which charge the researcher to identify: "What is this data a study of?" and "What is actually happening in the data?" (Glaser, 1978, p. 57). Open coding leads to clusters of coded data grouped into categories. Open coding continued as the primary method of data analysis until a core category emerged which described the participants' main concern. The core category, or main concern that emerged in this study was *Maximizing Impact.* After the main concern was identified, selective coding began. Selective coding allowed the researcher to focus on coding categories most related to the main concern or the core category (Glaser, 2005). As selective coding proceeded, the researcher was able to identify

patterns among the categories and discover that the participants resolved their concern of *Maximizing Impact* through a four-phase process named *Safeguarding this Family.*

Constant Comparative Method

The Constant Comparative Method (CCM) served as the central process throughout data analysis occurring concurrently with data collection, coding, and theorizing (Holton & Walsh, 2017). Constant Comparative Method enabled the researcher to generate codes and later, to identify theoretical codes that explained the relationships in the data (Glaser & Holton, 2004). As theoretical patterns or relationships emerged, they were recorded as memos, which in turn served as additional data.

Memos

Memos document underlying concepts, ideas, and questions the researcher noted during the data analysis process, assisting the researcher to move the data into abstraction. Memos recorded the researcher's ideas and theorizing throughout the data collection, analysis, and even writing up process. Memos guided the development and evolution of categories as well as the identification of the participants' main concern and how they resolved their main concern. Memos documented how the theory developed over time as the researcher discovered how the participants resolved their main concern.

Sorting

Sorting occurred near the end of the data analysis process. It served as a means to fully integrate the research findings and produce a rich and relevant theory. Sorting of the

theoretical categories was especially useful in identifying the four phases of *Safeguarding This Family*. Sorting allowed the researcher to organize findings by similarities and connections until relationships between the categories were clear and supported the emerging theory.

Summary of Data Analysis

All the previously discussed data analysis methods; substantive and selective coding, CCM, memoing, and sorting were employed to allow a substantive theory to emerge from the participants' data. The first objective was to find a core category or main concern. The first few months of data analysis employed substantive coding, CCM, memoing, and sorting until the core category *Maximizing Impact* emerged. After discovery of the core category, selective coding using CCM took the place of substantive coding while still continuing memoing and sorting. As data analysis continued, a four-phase process; *Safeguarding this Family,* emerged as the mechanism participants were using to resolve their main concern. Continued coding revealed no new categories and data collection was discontinued.

TRUSTWORTHINESS

Glaser states the trustworthiness, or rigor, of a Classical Grounded Theory should be judged using four criteria: Fit, Relevance, Work, and Modifiability (1978; 1998). The following sections describe each criterion and how the researcher met each criterion.

A Classical Grounded Theory study and its resulting theory *Fit* when the "concept(s) adequately express the pattern in the data which it purports to conceptualize"

(Glaser, 1998, p. 18). The data analysis process in this study allowed concepts to emerge from the data rather than constructing concepts and fitting the data into them, and allowing concepts to emerge from the data assuring fit and allowing the data to point towards their organizing theory (Glaser, 1998). The methods prescribed by CGT allowed emergence of concepts and the relationships binding them together (Glaser, 1978).

The theory *Maximizing Impact* has *Relevance* to the field of NICU primary nursing, an expected consequence of allowing the theory to emerge from the data. When a theory deals with participants' main concern, it should naturally "evoke instant grab" (Glaser, 1998, p. 18) because the theory has practical utility, or relevance, to those experiencing the same social phenomenon (Holton & Walsh, 2017). When theory precedes data, that theory may or may not be relevant to those involved in the phenomenon of interest. In CGT, the participants describe their main concern and how they resolve it assuring relevance of the theory and allows a theory to emerge from the data; thus, the theory is grounded in the data.

Work describes the ability of the theory to interpret and explain what is really going on and therefore to predict how this process works to explain the study and how the theory should work in the future for others experiencing the same, or similar, phenomenon (Glaser, 1978). The workability of the theory, *Maximizing Impact,* emerges naturally since the theory fits and is relevant; it interprets what the participants in the study did in order to *Maximize (their) Impact.*

Modifiability is a potential strength of the theory *Maximizing Impact.* Modifiability describes how theories generated through CGT are never sacred and fixed but rather subject to modification given new data (Glaser, 1978). The present theory is presented as the best fit for the current data however, it is *modifiable* given any new data were subjected to the

same CGT procedures. Modifiability assures theories remain relevant by allowing continued fit and workability in the face of evolving environments.

PROTECTION OF HUMAN SUBJECTS

The study posed minimal risk to the participants. Although there were no identified physical risks, there was a potential study-associated risk of loss of confidentiality of shared information and potential psychological distress associated with some of the more emotional topics shared by the participants.

Initial recruitment of participants was purposive and non-coercive and participants self-selected. The researcher contacted potential participants with relevant experience within her personal and professional networks informing them of the study and inviting participation. With initial contact, the potential participant was verbally given a brief description of the research. If the individual was still interested, the researcher reviewed potential risks of participation including loss of confidentiality or psychological distress and what measures were in place to secure data and ameliorate psychological distress. When an interview was scheduled the researcher provided the participant with a "Fast Facts" document that included the IRB approval number, study name, principle investigator and phone number, faculty chair and phone number, study purpose, study summary, study risks and benefits, and how to address questions (see Appendix F). An electronic or hard copy of the "Fast Facts" document was made available to all participants with all choosing to receive the document electronically.

Each nurse who participated in the study provided verbal consent prior to data collection (see Appendix G for the consent narrative that was read to the participant who

then verbally affirmed their willingness to participate). The consent narrative reviewed the participant's ability to refuse to answer any individual question and also to stop the interview or fully withdraw from the research at any time. The participant was also informed that a list of counseling resources was available at her request. The consent narrative also included an opportunity for the participant to ask any questions about participation or the study in general. At the conclusion of the consent narrative, the researcher finally asked if the participant was still willing to participate and upon an affirmative response, the recording devices were activated and consent was confirmed once more during the recording.

Several measures were in place to protect the participants from psychological harm. All participants were informed of the purpose and topic of the study upon initial contact and if still interested, the risks of participation were briefly reviewed at that time. As described above, all participants received a copy of the "Fast Facts" sheet, were informed of the potential risks and benefits, and had the opportunity to refuse to answer any question or stop the interview at any time. The participants also were informed that they could ask for a list of psychological resources. No participants verbalized the need for a list of psychological resources.

In order to protect the participants from risks associated with loss of confidentiality, the researcher assured that all data were secured. Interviews were conducted in private quiet locations where others could not overhear the interviews. Interviews conducted via video chats took place using encrypted servers and secure video chat applications. Recordings of the interviews were maintained on either the researcher's password protected IPhone under direct control of the researcher at all times or on a digital recorder

stored in the researcher's locked file cabinet when not directly in use by the researcher. Audio files were transmitted securely to and from the transcription service then deleted off the transcription server immediately on completion. All transcripts were kept on the researcher's password protected computer or on a thumb drive that was stored in a locked file cabinet. Transcripts were de-identified immediately upon completion of the transcription process and only the de-identified copies were used for data analysis.

SUMMARY OF CHAPTER THREE

Chapter Three has reviewed how Classical Grounded Theory was utilized to explore the question: "How do neonatal intensive care (NICU) primary nurses develop their relationship with their primary families?" The Chapter has described CGT research design, sampling methods, recruitment procedures, data collection, data management, data analysis, and how study rigor was assured using Glaser's criteria (1978). The final section of the Chapter reviewed how the human subjects were protected including assuring informed consent, confidentiality, and protection against psychological harm.

PLAN FOR REMAINING CHAPTERS

Chapter Four will discuss findings from this CGT study exploring how NICU primary nurses develop relationships with their primary families. Chapter Four includes a detailed discussion of the substantive theory *Maximizing Impact* that emerged from the data. Chapter Five will provide a discussion of the substantive theory as it relates to the extant literature, study implications, study strengths, and study weaknesses.

CHAPTER FOUR: FINDINGS

INTRODUCTION

Chapter Four provides a discussion of the findings of this Classical Grounded Theory study that explored the research question: "How do neonatal intensive care unit (NICU) primary nurses develop their relationship with their primary families?" The Chapter begins by describing the study sample demographics. The Chapter then turns to a discussion of the substantive theory that emerged from the data, *Maximizing Impact*, beginning with a discussion of the participant's main concern and how they resolved their main concern, which comprises the substantive theory.

DEMOGRAPHICS

The study included eleven participants, all with at least two years of experience with primary care nursing (PCN) in the neonatal intensive care unit. Table 4.1 summarizes the demographic data. Only one of the participants was male, therefore female pronouns will be used in this document for the sake of uniformity and to protect the identity of that participant. Ages of the participants ranged from 27 to 71 (M=45.5 years); they had been bedside nurses from three to forty-three years (M=17.7) and had practiced PCN from between two and seventeen years (M=7.9). Nine of the participants were employed in the North Texas area; and one participant specified that all her PCN experiences took place in California and Colorado, so those states are listed in Table 4.1 as the states of her PCN practice. Additionally, there was one participant from Florida, and one from North Carolina. Participants had had experiences as primary nurses in NICUs in three different hospitals in the North Texas region, one hospital in the Southeast Texas region, and four

other hospitals across the nation, ranging from the American Southeast to the Southwest and Western regions.

Table 4.1

Demographic data

Age	Gender	# of years as Bedside RN	# of years as Primary RN	State of Primary Practice
27	F	3	2	FL
43	F	11	10	CO/CA
66	F	43	8	TX
36	F	14	3	TX
71	F	29	10	TX
54	F	13.5	12	TX
34	F	12	6	TX
35	F	11	9	TX
29	F	7	2	TX
53	F	24	17	NC
53	M	28	8	TX
M=45.5		M=17.7	M=7.9	

Direct quotations are distributed all throughout this discussion to illustrate the study findings. Each participant will be cited parenthetically as p (for participant) followed by a number indicating where the participant fell sequentially in the order of interviews conducted (1-11). Following a colon will be numbers indicating the actual line location of the quotation on the transcript. For example, the following quote: "Not everyone should be a primary care nurse" (p7: 587) comes from Participant 7, which was the seventh interview, and is located on line 587 of the transcription.

All of the participants in the study described PCN in their NICU practice as being almost exclusively voluntary. Individual nurses made the decision to "follow" (provide PCN to) an infant and the infant's family: "I've always been able to pick my primaries [infant], I've never been forced. . . because I feel it's a personal choice" (p2: 81-83). A few of the participants assessed whether the family would be open to their infants' receiving PCN: "We are allowed to select our primary [infant]. But it's also like a mutual agreement between the parents and the nurses" (p4: 123-124).

While the decision to take on a primary infant was voluntary, most of the participants believed that once the primary nurse decided to take on an infant, the primary nurse should commit to caring for that infant consistently for the remainder of that infant's hospitalization. One participant stated, "For the most part, the consensus, or at least the modus operandi right now . . . is that if you're a primary care [nurse] . . . you are not to disengage until they [the primary infant] are discharged. . . If you're going to make a commitment you make it all the way through [the hospital stay]" (p11: 913-915). Another participant, who also preferred long-term commitment, described her beliefs about short

versus long-term commitment: "I really think that it's a disservice to the infants, to the families, when people don't want to finish it [follow infant until discharge]" (p4: 337-339). Only one participant reported not following an infant until discharge, mostly because of issues that arose with the mother: "I turned her [primary infant] over, [but] it was time for her to go to progressive area [less acute section of the NICU], so it was okay" (p5: 108-109). While most of the participants believed that PCN should be a commitment that lasts until the infant is discharged, this variation in practice emphasizes the high degree of autonomy of the nurses not only as to whether to engage in PCN, but also in how each nurse actually performs PCN.

MAXIMIZING IMPACT

Maximizing Impact is the main concern for NICU nurses engaged in primary care nursing. Although maximizing one's impact is a priority for any NICU nurse providing patient care, the NICU nurses who participated in the study believed that primary care nursing gave them an additional advantage in accomplishing that goal. In typical NICU admissions, parents are highly involved with and concerned about the welfare of their infants. As such, parents of infants in the NICU are a frequent and active presence in the day-to-day care for their infant; moreover, they will be required to take on the role of full-time caregivers for their infants when the infant is discharged. Understanding the importance of the parents for the infant's long-term outcomes, the NICU primary nurse's concern goes beyond merely providing adequate physical care to the infant during any given shift. The NICU primary nurse also strives to involve the parents in the infant's care

as well as assuring parents' mental well-being in order to support them as they develop into a family unit.

Primary NICU nurses seek to resolve their main concern of *Maximizing (their) Impact* through PCN. Primary care nursing allows the nurses to utilize their individual strengths and skills as NICU nurses; in addition, the close nurse-family relationships that usually develop in PCN allow the primary nurse to extend her effect far after the infant's discharge as well as to have a positive impact on parents' ability to cope and care for their infant while in the NICU and long-term. Primary nurses tend to choose infants and parents who are well matched to the individual nurse's skills and interests, thus serving to support the nurse's efforts to *Maximize (her) Impact*.

SAFEGUARDING THIS FAMILY

Primary NICU nurses resolve their main concern of *Maximizing (their) Impact* by developing relationships with their primary families through a four-phase process labeled *Safeguarding this Family.* The relationship that develops usually is between the nurse and the parents, but may involve other close family members especially when there are non-traditional families or social turmoil within the family. *Safeguarding this Family* consists of the phases of *Seeking and Identifying, Enacting, Transforming,* and *Evaluating*. The four-phase process *Safeguarding this Family* will be discussed in more detail below, but it is necessary first to describe the personal characteristics and beliefs the study participants believed are necessary for a nurse to succeed, and therefore *Maximize (her) Impact* by *Safeguarding this Family.*

INNATE FACTORS

The study participants described innate factors including certain commonly held beliefs and personal characteristics, they believed were necessary for nurses to choose to engage in PCN and for nurses to be successful as primary care nurses.

Commonly held beliefs

The participants thought that they held certain overarching beliefs about primary nursing and how it helped them achieve their goal of *Maximizing (their) Impact*. They believed PCN allowed them to provide superior quality of care and that it benefitted the infants, the families, and the NICU primary nurses themselves. They all believed that primary care nursing results in better outcomes for the infants: "I think it's just a real benefit to the babies in the NICU" (p4: 350). "In my opinion with primary care nurses, I feel like they [infants] get discharged sooner" (p8: 373). One participant felt that an advantage of PCN was that it allows primary nurses to "catch things quicker [signs of illness in infant]" (p9: 332). Another participant believed that overall, PCN gave NICU infants a survival advantage: "The primary nurse makes such a difference, . . . we do save a lot of babies that maybe wouldn't be here" (p5: 149-150).

The participants also believed that PCN benefitted the parents because it offered "comfort for the family" (p2: 304) and the parents "felt safe with us taking care of their babies" (p2: 291). One nurse reported that an infant's mother told her: "We felt at peace when you're there and we would sleep good" (p11: 723). Another participant summed up how the short term benefit of PCN to parents becomes a long term benefit for the infant: "You're really developing relationships with the parents, who in a way are our patients at

times, psycho-socially I believe. I think a huge *huge* factor in how some of these babies do is the emotional health and capability to cope on behalf of the parents [that is gained by their participating in PCN]" (p1: 63-67).

The participants also believed that consistency of care benefits all involved: the infants, the parents, and the nurses. As one participant declared: "Primary nursing *is* consistency of care" (p8-313). One of the distinguishing features of PCN is that the primary nurse cares for the primary infant for most, if not all, shifts the nurse works. The nurses themselves benefitted from consistency; it enabled them to be better clinicians because they are able to build up in-depth knowledge about the infant including the infant's physical status and neuro-behavioral states: "Knowing the baby so well, that's the main thing I like about it" (p5: 76). This detailed knowledge allows the primary nurse to detect subtle changes in the infant's condition and identify even slight deteriorations, a vital ability since NICU infants can decompensate quickly: "You [primary nurse] know even a minute change that isn't normal for that baby, . . . you just know every little fine thing" (p5: 64-68). When a nurse has been caring for an infant consistently through the infant's entire NICU stay, the nurse has seen "the whole rollercoaster" (p4: 343). Primary care nurses "know where the family started [infant's physical status, parent's psycho-social status], . . . [or] if they've had issues going on [e.g. infant's physical complications, parents' psycho-social issues]." (p4: 345). While infants and families benefit most from the consistency of care allowed by PCN, the nurse also benefits because PCN empowers her to *Maximize (her) Impact* through the breadth and depth of knowledge of the infant, the infant's particular issues, and infant's family.

The participants also believed the importance of developing a close relationship with the infant's family. The participants believed primary care nursing provides a framework for building a fuller relationship that helps them *Maximize (their) Impact*: "Primary nursing for, for me, gives me a chance to build relationships with the families. . . I develop just a positive relationship with them" (p2: 27-30). They also thought that effectively practicing PCN requires that the nurse enjoy or appreciate the value of such relationships: "I just love that, having that connection with the families" (p1: 61). One participant commented on how she "like[d] building relationships" (p11: 74), while another nurse stated that to be an effective primary nurse, one needed "to be a people person" (p10: 76). Another participant said that primary nursing, by its nature, attracts nurses who enjoyed having more emotionally close relationships; she compared herself to nurses who don't practice PCN: "I like relationship in general. . . Some nurses are skills-based and they're not into relationship and you can see their relationship is with their skills and their knowledge" (p11: 52-55). Another participant noted: "I can't think of anyone [her primary families] that we didn't get close" (p6: 187).

The participants believed that developing a relationship with the parents helped them be more effective in teaching the family, enabling them to help the parents to be more knowledgeable about their infant, involved in the care, and "more prepared when they're being discharged" (p8: 374). The participants believed the time spent developing the PCN relationship helped that nurse be a more effective educator: "[The primary nurse] takes a lot of time to educate the families and talk to the families about what's going on with their baby," (p7: 607) and when a primary nurse has: "developed that relationship. . . they [parents] really take it to heart and accept that education" (p5: 224-246).

Overwhelmingly, the participating nurses believed that not only is PCN a benefit to the infant but they also saw few drawbacks: "There is really not a huge downside I think" (p5: 94). "I've always felt like it's a positive experience for everyone involved" (p8: 84). There is always some kind of relationship between any NICU nurse and the infant's family even outside the bounds of PCN, but the PCN relationship between the nurse and the infant and family is even closer. Participants believed the closeness of this relationship helped the parents be more open to the primary nurse's interventions and education, which combined with the primary nurse's more precise knowledge of the infant allowed the primary nurse to *Maximize (her) Impact*.

Nurses Characteristics

Participants described several personal characteristics they believed were essential to the skilled primary nurse. Commitment is vital because the nurse may be with this infant and family for months. "It takes a lot of . . . dedication" (p1: 105) because "with primary care nursing, it's a long marathon so you have to keep coming back to it [same infant]" (p11: 165). Compared to some NICU nurses who prefer high-energy and ever-changing assignments to care for acutely ill infants, "They're into the adrenaline" (p158); primary nurses need "patience, the desire to take the boring sometimes" (p2: 65). The participants agreed that primary nurses possess "a different mentality" (p2: 202).

The participants believed a primary nurse must be "open, *non-judgmental*" (p10: 75). The primary nurse needs to "take someone [parents] for what they are, not what I think they should be. . . in other words, not be judgmental" (p11: 147-150). This characteristic is especially important for nurses who are dealing with families with complex medical-social

issues: “I’d say the ones that are really hard are the [opioid] withdrawal babies because people don’t understand the parents. . . But trying to understand them and not judge them [is important] so you can help them be a little bit better of a parent because they have enough struggles in their life you know” (p10: 407-412).

The participants believed the ability to emotionally self-regulate was important to the NICU primary nurse as they are often called upon to navigate relationships with emotionally fragile families as well as medically complex infants who may ultimately experience poor outcomes. The participants often discussed this emotional self-regulation as understanding how to keep appropriate emotional-social distance which they often termed “professionalism”. The primary nurse may encounter: “difficult families and personalities. Or you get the chronic kid that cries all the time and you’re at your wit’s end sometimes” (p7: 175-177). It is important for the primary nurse to remain patient and tolerant when dealing with families who: “ask a million questions. . . or are rude; or are, you know, not the easiest parents to deal with” (p2: 137-139). Parents of NICU infants are often in the midst of the biggest crisis of their lives and the primary nurse needs to convey: “professionalism and compassion without letting whatever’s running in our head necessarily come out. . . We can be exasperated or annoyed or upset, but we can’t let that part be displayed” (p2: 140-145). The need to emotionally self-regulate applied not only to times the nurse felt frustrated but also to the sadness the primary nurse might encounter: “Sometimes we have our emotions and we want to cry with the families or we want to be upset but sometimes you can’t do that at that time because you still have to be professional” (p7: 554-556). Another participant discussed the challenges of emotional self-regulation when caring for infants and families when the infant may face negative outcomes: “Even

though some situations could end up being negative [poor infant outcomes], you still as a primary nurse have to remain strong . . . as far as . . . emotions and everything" (p8: 191-195). The participants believed emotional self-regulation was essential to being an effective primary nurse because it is important that nurses appear calm and in control even when they are experiencing strong emotions; this control and calm demeanor helped primary nurses safeguard the families' emotional state by reinforcing their confidence and trust in the care team.

On the other hand, when it came to expressing or developing positive emotional ties to the infant and family, the participants thought primary nurses needed less restraint: "You develop an attachment, you know, and you get to love on these little, these little babies" (p2: 59). The primary nurse should "[be] able to be invested emotionally" (p4: 92), and "you've got to love the people [parents] (p11-168). One participant went as far as to say that primary nurses need to have a "desire to love" (p2: 75). Some participants thought that primary nurses develop relationships that resembled those of a family member and should be willing: "to really give yourself to a stranger and their family, to really almost kind of become part of their own family, . . . [to] express all your emotions" (p9: 79-82). Another participant reinforced the near-familial language: "I feel like I kind of am like a second parent, . . . a surrogate parent when their [the infant's] family's not there (p4: 59-61)".

The participants also believed the ability to advocate for the infant and family was an important characteristic for primary nurses. One stated that the nurse is, "number one, the patient advocate first" (p5: 44). Another participant added that primary nurses must: "have a relationship with the entire care team" (p1: 108), and need to understand: "that you

are that patient's voice" (p1: 109). The primary nurse also speaks up for the parents who don't always know how to approach the provider staff: "She [infant's mother] would let me know things [medical concerns], I would go to the doctors and explain things [parent's concerns]" (p5: 178). The primary nurse must also work with other members of the care team, maintaining a "good rapport with interdisciplinary staff" (p7: 216). One participant discussed how: "A primary nurse needs to be someone that is willing to always advocate even though you might be getting pushback [from other providers]" (p8: 174-176).

In summary, the participants described how successful primary nurses must possess innate factors including beliefs about PCN and specific personal characteristics. The primary nurse must believe in the positive effects of PCN for the infant, its family, and the nurse herself. Personal characteristics that allowed NICU nurses to be effective primary nurses included a willingness to engage in close personal relationships, being able to emotionally self-regulate, and the willingness to advocate for the infant and family.

In addition to describing innate factors needed to successfully engage in PCN relationships, the participants also described their experiences with PCN which revealed their main concern of *Maximizing (their) Impact*. The substantive theory, *Maximizing Impact,* emerged from the participants' in-depth descriptions of their primary care nursing experiences. The NICU primary nurse develops relationships with the families in the four-phase process *Safeguarding this Family* in order to *Maximize (her) Impact.*

Safeguarding this Family began with the *Seeking and Identifying* phase, continued with the *Enacting* phase, then the *Transforming* phase, and ended with the *Evaluating* phase. As each phase is described the discussion will examine the evolution of the

relationship between the primary nurse and family as the primary nurse *Safeguards this Family* in order to *Maximizer (her) Impact*.

SAFEGUARDING THIS FAMILY-PROCESS

The data revealed a four-phase process the participants used to develop relationships with their primary infants and families. This process; *Safeguarding this Family,* is how primary nurses resolve their main concern of *Maximizing (their) Impact.* Primary care nursing in the NICU revolves around a relationship that develops amongst three main parties: the primary care nurse, the infant, and the infant's family. The study participants tended to describe themselves as the main actors driving the primary care nursing relationship which is consistent with their statements that PCN is almost exclusively voluntary on the part of the nurse. The participants believed the primary nurse's individual characteristics and beliefs, described above, were crucial to each of the four phases of *Safeguarding This Family*. The following sections will describe each of the four phases in detail.

Seeking and Identifying

Safeguarding this Family begins with *Seeking and Identifying*, in which the potential primary nurse and infant/family find each other and commit to the primary nursing relationship. The primary nurse usually takes the lead in *Seeking and Identifying* families she is interested in taking on in a primary nursing relationship. One way a nurse may proceed with *Seeking and Identifying* is to become familiar with a potential primary family sometimes by "getting assigned to the same baby" (p1: 135) a few times. Other

participants became aware of a potential primary infant if the nurse had "admitted the baby [to the NICU], [and] had taken care of baby a couple times" (p10: 103). Once the nurse became aware of the infant, she may have asked to be assigned to the infant in order to further evaluate: "if you feel this might be a chance for a primary [relationship]" (p5: 25-28). The main goal of *Seeking and Identifying* is to find an infant and family where the individual nurse believes she will have the highest potential to *Maximize (her) Impact*. Nurses who take on primary infants and families usually choose to do so based on one or both of two factors, either skill-need matching or compatibility.

SKILL-NEED MATCHING

The NICU primary nurse's driving principle when *Seeking and Identifying* a primary infant is a belief that the infant or family might benefit from the care of that individual nurse, her unique skills, and her personality. Although some participants were not always specific about what needs they saw, they were clear that they saw a need they felt uniquely qualified to fulfill: "There's something I can see. . . I feel like there's a need I can fulfill" (p11: 30-32). "The reason why I pick that primary family is because I've met the family and they're lovely people and I feel like they need me" (p6: 190-192). "I've got to have a sense of there's potential for change and if I can make a difference in their life" (p11: 188-190). Most importantly, "I tend to pick patients where I'll make the most impact" (p8: 172).

The participants occasionally described having more specific skills and strengths they sought to match those strengths and skills to the needs of the infant and family in order to *Maximize (their) Impact*. For example, some PCN nurses have skills that make them more comfortable dealing with specific NICU populations: "I like them [infants] when

they're small like 24, 25, 26 weekers" (p5: 167-169). Other nurses have other special skills such as: "I tend to flock to primary patients that do not speak the language. . . I feel like you know, with you not knowing the language, not knowing the environment, not knowing how things are in our NICU makes it even harder for them" (p8:166-172). Some nurses hold certifications such as lactation consultants, and they want to be able to use those skills helping NICU moms: "Being a primary nurse, I know how I can be more effective in supporting and teaching on how to make breastfeeding a success" (p3:165). A participant described how she was motivated to primary an infant when: "you know someone [infant] that's going to need a trach[eostomy] and ostomy [colostomy]; [the parents are] going to need a lot of education,. . . .a lot of support" (p8: 108). A primary nurse may be drawn to an infant because of the infant's complex health status: "It's high acuity that draws me to those families because I like all the stuff that's going on, knowing that they're going to, hopefully, lose some of that equipment as their progression through the NICU goes, and they're going to get to go home without any of those things" (p7: 266-271). One participant felt drawn to infants and families who, they believe, may not be getting the best management and coordination of care: "If I see an infant who's not receiving good continuity of care and they need certain things put into place. . . that's when I really want to jump in and kind of be that sense of stability for them" (p1:147-150). The participants understood that they would be better able to *Maximize (their) Impact* if the infant and family's needs were well-matched with their individual strengths, skills, and interests.

Other nurses possessed skills especially suited to defending difficult infants and families, or at least those who are perceived as such by other staff. Some described such families as ones who might be struggling with issues such as unstable homes and/or

substance abuse. One participant took on such a family as primary because "We [staff] didn't know if the baby was going to go home with her [the mother] and those are situations that sometimes nurses don't want to necessarily take on" (p2:114). A participant noticed a mother, who had substance abuse problems, rarely visited: "I took that baby because I felt that baby needed me" (p5: 188). Another nurse described taking on a family other nurses had disparaged due to their immigration status: "There were people who wouldn't take care of them. People who would talk nasty about them and their situation" (p9: 175). A participant described how she would take families who had developed a negative reputation within the NICU: "They're [infant's family] just difficult to deal with so nobody wants to be at that bedside, and that's not the baby's fault. . . A lot of times the family is just misunderstood" (p10: 129-130). While most participants choose their primary families, one nurse believed her skill in dealing with difficult families had led her to be: "placed with a couple of families just due to my strong personality and I'm not a pushover" (p7:276). Sometimes the participant believed a family needed a primary nurse to stand up for them: "You know, gossip goes around the NICU about who is being difficult and what's going on. . . I had not had any experience with this family of them being difficult" (p1: 159-165). Another participant willingly took on an infant whose mother had been: "so difficult that when she did call nobody wanted to even talk to her. And I took that baby" (p5: 187). One nurse described how she took a family as primary even though: "some of the nurses thought they were scary because they had lots of tattoos but sitting there talking to them and, and just learning about their history, their life, like it really opens up. . . doors and just makes that connection better" (p4: 154-157).

In the *Seeking and Identifying* phase, the participants were drawn to an infant or family based on some perceived need the nurse believed she could meet through PCN. Identifying infants and families that needed the skills the particular nurse possessed allowed that nurse to *Maximize (her) Impact*. While skill-need matching is essential to *Seeking and Identifying* primary infants and family, sensing compatibility is also important.

COMPATIBILITY

One of the most important factors the participants considered when taking on a primary infant and family was inter-personal compatibility: "You have to have some kind of positive connection" (p5: 36). A participant expressed why this connection was important: "I believe a lot in making sure you have a good connection with the family because I will not primary an infant if the parents are not going to be a good partner with me" (p1: 139-141). Another participant described this connection as: "just sort of a gut feeling" (p2: 85). "Sometimes it's just trying to match the personality of the family. . . to the nurse" (p7:235). "Most of the time I signed up as primary must because I felt a connection with the family. You can kind of tell whether you guys are going to get along" (p10: 31-33).

The nurses believed compatibility was enhanced when the family could develop a trusting relationship with the nurse: "It's just a feeling that I get that the parents trust me, and like when I care for their infant, and that is usually when I would make that decision" (p6: 32-34). One participant felt that without trust, she couldn't be as effective as a primary nurse: "If I don't have a connection with them. . . then I'm not going to be able to help that family cause they probably don't have tons of trust in me" (p10: 110-113). Because trust is

so important to the PCN relationship, some nurses would seek assignment to a certain infant and family if they thought they might be well suited in a PCN relationship to "see if you can develop that relationship of trust between you and the parents and if it does develop and they're interested in you being [their] primary [nurse] and would like for you to; that's how you get them" (p5: 170-173).

While most of the primary relationships were initiated by nurses, some participants included family input in the decision to engage in PCN: "It's. . . like a mutual agreement between the parents and the nurses" (p4: 124). One nurse usually waited for the parents to ask her to be their primary nurse "But usually by the time they ask in the back of my head I've already got a stirring [of wanting to be the primary nurse]" (p11: 35-37). "I choose to . . . have a family pick me and make a good fit. I think you should be willing to hear their [parent's] opinions on that" (p9: 85-87). "I always wanted it to be the parents' choice if they wanted me to primary" (p2: 97).

The participants recognized that inter-personal compatibility and a sensing trust were essential to establishing a primary nursing relationship and that sometimes primary nurses included family input. Without these elements of compatibility, it was unlikely that the relationship needed to *Maximize Impact* would ever be initiated.

Seeking and Identifying, the first phase in *Safeguarding this Family*, is when a potential primary nurse who possesses most or all of the innate qualities discussed earlier would be on the alert, or seeking infants and families who are well-suited to the nurse's individual skills and qualities. The potential primary nurse identifies an infant and family who might be a good fit for her skills and then further assesses whether she and the family can be compatible. If the potential primary nurse identifies a family as a good fit, the

primary nurse and family agree she will become the infant's primary nurse. A relationship between the nurse and primary family that is a good fit increases the potential for the nurse to *Maximize (her) Impact*.

Enacting

Once the primary nurses had sought and identified an infant and family who are a good fit for a primary care nursing relationship, they began the next phase of *Safeguarding this Family* which is *Enacting.* The *Enacting* phase is when the main work of PCN occurs and when most of the relationship is developed. The primary nurse engages in several interventions intended to *Safeguard this Family* so she can *Maximize (her) Impact.* The following paragraphs will discuss the various ways that primary care nurses work to *Safeguard (these) Families* so they can *Maximize (their) Impact*. During the *Enacting* phase, some of the nurse's actions directly safeguard the infant's health while other actions develop the relationship with the parents and *Safeguard (the) Family* as a unit. Many families have already expressed some trust in the nurse, as discussed above, but as the relationship develops, seeing the primary nurse more frequently tends to deepen trust between parents and primary nurses. This developing trust increases the nurse's ability in several realms including teaching and preparing parents for independent infant care and supports the efficacy of PCN.

One of the aspects of PCN the participants discussed specific to the *Enacting* phase was how PCN enabled continuity of care*:* "I know that baby. . . I can recognize if they're getting sick or if you know, any differences" (p6: 40-43). "I'm going to probably know more because I've been with that baby" (p2: 56). Continuity of care enables the nurse to

perceive subtle clues of illness: "I know if they're acting different than they normally would. I can recognize if they're getting sick or . . . any little differences. . . because I have them every time I work" (p6: 41-43). One participant added that the in-depth knowledge of a particular infant distinguishes PCN from standard NICU nursing: "You know the baby so well, that makes the primary nurse role so different than just real[ly] good bedside nursing" (p5: 135-137). While the nurse is developing in-depth knowledge of the infant, continuity of care also allows the primary nurse to build in-depth knowledge of the family. One of the ways primary nurses do this is simply to "spend time with them, talk to them" (p10: 39) or by "being a good listener for that family" (p9: 94-95). Continuity of care facilitates in-depth knowledge that enables the primary nurse to *Safeguard this Family.*

As the primary nurse develops in-depth knowledge of the infant and family, she can start to build the relationship with the family: "I know the babies better than others because I have a chance to take care of them more often than other nurses and therefore I know the parents as well" (p3: 42-44). Spending time together at the infant's bedside helps build the bond between the parents and nurse: "Making that relationship where you discuss similar interests and dislikes" (p9: 126). Some primary nurses also build the relationship in creative ways: "It was Mother's Day and I had put a crib note down [next to the infant] because we have cameras in our beds. . . [The note] said: 'I love my mom.' So it's like as if it's a note from the baby. . . They [parents] loved it so much" (p11: 581-585). Another participant liked to make cards celebrating milestones for the infants: "I make, for all my babies I make footprint cards. . . like a big. . . scrapbook page" (p4: 316-320). Primary nurses spend time building these parental relationships which in turn, builds trust: "I am someone that they [parents] can come to rely on. . . maybe ask a question that they may not

ask another nurse or maybe talk to me about a difficult situation (p8: 219-222). Establishing a trusting relationship with the family *Safeguards this Family* by ensuring better informed parents who are more competent and are comforted by having a trusted caregiver.

The participants also described how they used the relationship to help build parent skills in caring for their infant: "You have to be one that allows the family to do more. . . really allowing the parents to be more involved, . . . because that really helps build their confidence" (p8: 206-211). During *Enacting,* participants would involve parents in care and educate them in order to help *Safeguard this Family* by preparing the family for discharge: "Her [infant's mother's] anxiety was significant. . . I got her slowly to really begin doing skills" (p11: 800-802). One participant sees one of the goals of being a primary nurse was that during *Enacting*, the primary nurse would: "push the parents even further to get more involved" (p1: 144). Another participant had seen some nurses who do not engage in primary nursing as less trusting of parents providing infant care: "Some nurses are like, 'This is my territory, please hands off!'. . . But I try to integrate the families as much as possible" (p7: 45-49). The participants understood that building parents' skills during *Enacting* helped *Safeguard this Family* even after discharge by educating the parents and trusting them to perform the hands-on skills all during the hospital stay. Prepared parents helped extend the reach of the nurse's care and *Maximized (her) Impact.*

One of the most common ways participants described their efforts to *Safeguard this Family* had to do with advocacy. Championing the infant's needs is augmented by knowing the infant well through consistency of care. One participant said knowing: "something's really not right with this kid and you get somebody [provider] to listen to you because you're like, 'Hey, I've take[n] care of this baby for a month. This is different for him. This

is not his normal'" (p7: 75-78). Another participant further described caring for a primary infant and alerting the providers: "There's something wrong with him. . . he never acts this way. He ended up having. . . a lot of his bowel removed and the only clear sign was irritability. Had [he had] a nurse that never had taken care of him. . . he could have ended up dying" (p8: 127-134). When the primary nurse is more familiar with the infant and family by caring for them frequently, she is able to *Safeguard this Family* since she is better able to know what they need and champion those needs with the provider staff.

As the *Enacting* phase progresses, the participants described becoming a team with the family and that this relationship "helps get families through the NICU stay" (p8: 36) because "you're teaming up with the parents and you have a really good idea what the care plan is" (p1: 59). One participant described collaborating with a mother: "We agreed on a lot of things. . . You know we kind of were on the same page with plan of care. She felt I fought for her daughter" (p4: 177-180). Some of the participating nurses helped build the sense of being on the same team by sharing personal experiences: "We were going to withdraw support. . . I sat down with them and I explained how I had gone through this with my son in the NICU. . . I wanted them to know they weren't alone" (p6: 202-209). Becoming a team helps the nurse *Safeguard this Family* by involving the parents in working toward a mutual goal of caring for the infant.

The participants in this study described the primary nurse relationship as one that can become quite close requiring great thought in managing boundaries professionally. There was a great deal of variation in how each participant worked out how to handle personal and professional boundaries: "when to initiate, when to stop, when to pull back, how to guard yourself, your own emotions" (p11: 154-156). A participant said one reason

managing boundaries is difficult is that: "For a short time there we're an extended family for them" (p10: 427). A common issue the participants encountered was managing social media contact, both during and after the infant's hospitalization. The participants often dealt with primary families who wanted to have personal or social media contact while the infant was still in the NICU, a practice discouraged by most facilities. A primary nurse told a family: "Let's not do this [have contact outside of the NICU] until after discharge and the baby's out of the hospital. . . [because] as of right now, I'm your caregiver" (p9: 263, 279). Participants generally agreed it was best to avoid sharing personal phone numbers: "I've always said. . . 'I can't give you my phone number because that's not something we normally do'" (p8: 225-227). A participant described a situation when she had cared for an older sibling of an infant who had been admitted to the NICU: "So with that [family] I really tried. . . to make boundaries since we had already had [each other's] phone numbers, just like: 'Try not to contact me. . . outside of work since now you're in there [in the NICU]'" (p4: 184-187).

Most of the participants avoided engaging in social media contact with the families at least until the infant was discharged home: "I typically don't become Facebook friends with anybody until they leave the unit" (p10: 239). One participant's unit had a strict social media policy so she had to inform primary families: "I'm not able to accept your friend request on social media due to the facility that I work at which does not allow that. But thank you for reaching out to me" (p7: 468-470). The participants gave careful thought to managing appropriate personal boundaries with their primary families during the infant's hospitalization, an issue that has become more even more complicated by the ubiquity of social media. Nurses understood that crossing boundaries could lead to professional

consequences and while not stated, they understood that this would endanger their future ability to be a nurse much less a primary nurse.

During *Enacting*, the NICU primary nurse having selected an infant and family for PCN now proceeds to do the main work of primary care nursing while she develops the *Safeguarding* relationship. The NICU primary nurse relies on continuity of care as a major facilitator to learn the specifics of the infant and family and using that in-depth knowledge, she is able to provide more patient- and family-centered care to the primary family. The *Safeguarding* relationship continues to develop as the NICU primary nurse further develops mutual trust with the family while carefully navigating professional boundaries.

Transforming

As infants approach the end of their stay in the NICU, the participants described how the primary relationship must undergo a *Transformation* process in preparation for the infant's discharge. A clean and stark solution could be to cease all contact after the infant is discharged but this is not the approach most of the participants described. Since a caregiving relationship does not continue after the infant's discharge, the family and nurse must address how the relationship will change in the future with personal boundaries continuing to be an area requiring great thought.

Primary nurses often continue the relationship after the infant is discharged home. One participant voiced a common sentiment: "I feel like once you build a relationship [with a primary infant and family] . . . it's very important that you don't just break it [relationship] just because they're being discharged" (p8: 331-333). Although some participants initially indicated that PCN relationships should not continue after discharge, they later described

events that clearly meant they had continued their relationship with the family after the infant's discharge. One said, "I try to cut the cord when they [primary infant and family] leave the hospital [are discharged]" (p3: 327), but later in the interview she reported: "I was chosen to be one of the godmothers [for her former primary infant] . . . I was there for her [infant's] christening and I see them every Christmas" (p3: 300-305). Another participant also believed primary nurses should "learn to let go when it's time to say goodbye" (p2: 75) but then later said, "I got to be good friends with his [primary infant's] mom. . . I did get to see him as he got older" (p2: 245-249). The participants' willingness and ability to continue relationships with their primary families could be influenced by policies of the facilities where they worked, some facilities already had, or were soon to implement policies forbidding nurses from having any personal or social media contact with former patients or families. "[The] facility [where] I work at, we're not allowed to do that [continue contact with family after discharge]" (p7: 465). One participant said the no-contact policy was due to concerns related to "This whole HIPAA, privacy, how much with social media" (p10: 238). The prohibition weighed heavily on a participant after her primary infant passed away: "I didn't lose a baby, she [the mother] did; and it makes me really sad to not be able to communicate with them. You know, it's kind of like, 'Oh, your baby died. Goodbye.' And that's it." (p10: 314-317). While participants expressed conflicting narratives about whether they should continue to have relationships with families after the infant's discharge from the NICU, they generally preferred to maintain some sort of a relationship with the infants and families as long as it was not prohibited by existing facility policies. The continuation of the relationship was not essential, but the continued relationship gave

nurses important information as they moved into the next phase when they *Evaluated* whether they had *Safeguarded this Family* and *Maximized (their) Impact.*

Participants who worked in NICUs where there were no explicit constraints on contact between nurses and the families after the infant was discharged from the hospital were willing to remain in contact but they respected the parents' wishes regarding contact: "I give them the option: 'Find me, here's my e-mail, you can e-mail me, I love updates. Or find me on Facebook. I would love to follow you and see how they're doing'" (p9: 238-240). Some participants explained their motivation for allowing parents to take the lead on whether to remain in contact with the nurse: "I don't want there to be any sort of conflict of interest or them feeling obligated to keep in touch with me" (p2: 265-267). "I let them kind of control, control the contact" (p1: 328). "I believe my limitations are a professional one and that's my comfort zone" (p11: 497). The participants reported that families often initiated the topic of continuing contact after discharge: "I think it's always been the family . . . [and that if the family does bring it up] . . . there hasn't been a time I feel uncomfortable to say yes" (p4: 297-300). Another participant was more vehement in her insistence that the family have control over initiating contact after the infant's discharge: "It's 100 percent up to the family. I don't believe it's up to me to, to seek that out. I think that would be unprofessional and inappropriate. . . I run the danger of meddling in somebody's life" (p11: 557-563). As a consensus, the participants respected the parents' wishes about continuing to have a personal relationship as long as it was not forbidden by their employers.

Several participants addressed the importance of clarifying the parameters of the post-discharge relationship with the parents: "It's important for me to redefine the [post-discharge] relationship" (p1: 334). Parents often will continue to look to the nurse for

medical advice, which they have done since the infant was born so participants emphasized the importance of maintaining appropriate boundaries: "I didn't advise them, on care [once the infant was discharged]. I didn't want to get into that" (p5: 242). "I'm no longer their nurse and I cannot give medical advice or anything like that" (p10: 207). One participant described a tricky situation that occurred when a few weeks after discharge, one of her primary infants was re-admitted to the Pediatric Intensive Care Unit (PICU) in her hospital:

> "I went up to visit her after work. . . That brought up a lot of issues for me as a nurse and I was very honest with the family about this. I said, 'I'm not here to know about your baby's condition in the PICU, I'm not involved in her medical care'" (p1: 310-316).

Primary nurses have to clarify how the primary relationship will change after the infant is discharged when the relationship *Transforms* from a caregiving relationship to a non-clinical relationship once the infant has been discharged from the NICU.

The Transformed Post-Discharge Relationship

While the participants were clear on the need to stop the caregiving relationship upon discharge, the participants described quite a bit of variation in the post-discharge relationship. As noted above, post-discharge contact between nurses and former patients and their families was forbidden by some facilities. When such relationships were not forbidden, the nurses and parents worked out parameters for how they would stay in contact after the infant's discharge from the NICU. Some participants kept contact limited to: "text messages you know, and updates. . . [contact has] primarily been online" (p2: 252-254). "I just appreciate the communication through Facebook" (p3: 331). "I've received videos, I received pictures" (p9: 292). One participant created a private Facebook group: "I have

[nurse's name] preemie list, it's a closed group. . . They'll send me pictures and as they grow on that page, and then [it] is just for me and I don't share that with anybody else. . . It's pretty nice" (p5: 423-434). Another participant described staying in contact through email: "So I get a little updates and sometimes if I haven't heard from [the family] . . . in a few months. . . I wrote him [dad] a little email: 'Hi, how are you doing. . . What is she [former primary infant] getting into these days?' And I promptly got a video" (p9: 263-267).

Other participants described meeting the families in person*:* "Some of my primaries, they come for their [medical] appointments in [the city] and they make sure they come and visit me and that's exciting" (p3: 295-297). The participants mostly worked in larger cities where many of the specialty services needed by former NICU infants are located, so the families often let their primary nurses know "'We're coming into town'. . . and I'll meet up with them" (p4: 241-243). One participant was delighted to describe a meeting with a former PCN family: "She [former primary infant] came right to me and we snuggled and we chatted and talked. . . When it was time to go [her dad] went to grab [the infant] and she turned her back to him because she didn't want me to let go of her. . . And we were, like, 'Oh my gosh, she must remember you!'" (p6: 233-239). Another participant described encountering former primary families who are part of the same immigrant community: "Of course the [shared nationality] friends [former primary families] that I've had, I follow up with them but mostly they are the ones who I see at the events that we [shared nationality] do" (p3: 332-334). A few participants attended parties: "I go to birthday parties; I get invited to their graduation. . . They always invite me to things and sometimes I go" (p5: 314-316). One participant had attended multiple life celebrations for a former

primary family who was adopting triplets who had been in the NICU, one of whom later passed away: "I was invited to his funeral. . . I was invited to when they adopted the babies. . . I went to their first birthday party. I've been to their second birthday party" (p7: 412-415). The mother of one participant's former primary infant visited the nurse after hearing the nurse had been seriously ill in the hospital: "She brings out this box to the house. . . packed with food and all sorts of things and stuff to do. . . There was a picture in there [of the infant]. . . I have it sitting at my desk now, it was very touching to me" (p11: 309-330). Another participant enjoyed seeing former primary families at the facility-sponsored yearly reunions: "Especially on micro babies [former extremely preterm infants] which I get involved. . . We hug each other and we exchange words and it's very comforting to see them" (p3: 292-294).

Some participants described continuing the relationship with the family even in the case of the infant's demise: "I feel like I have developed relationships with the families already and I continue to have a relationship with some of those families; well, probably all of those families" (p6: 52-55). Another participant described how she doesn't attend many funerals of former NICU infants, but did attend the funeral of a former primary infant with whose family she had "developed [a] personal relationship. . . I mean, they think to me almost like a family member [so when the infant passed away and the funeral was scheduled] . . . I haven't been to very many of them, it's hard for me to do that. . . but I did go to his, and that was good" (p5: 262-264).

Participants described engaging with the families in other rites or practices surrounding the loss of their primary infants. A participant recounted how, following the loss of her infant, a mom: "had forgotten plaster footprints and wanted them. . . she didn't

want them mailed. . . and I drove like an hour and 15 minutes to take her plaster footprints of her son" (p7: 421-424). Another participant described reading the Facebook post of one of her primary families whose child did not survive his NICU experience "asking if somebody could make her a quilt out of [her infant's] blankets so she could wrap herself in it and I thought, 'Well, my mom could probably do that.' I called my mom and asked her. . . and she agreed" (p6: 286-290). This participant also had been invited to meet with a bereaved family:

> ". . . for his 1-year birthday. We were going to do a balloon release. . . for [the infant's] birthday. [His family] invited his primary nurses: [three different coworkers] and me, and invited all of our families. So all of our husbands went and our kids so they could have it be a whole big family affair" (p6: 308-312).

Resolution of the *Transformation* phase allows the relationship between former primary nurses and the families to evolve into something between a friendship and at times almost family: "I guess, I mean, I feel like I can call them my friends. . . definitely not a medical or nursing relationship anymore, it's more of a personal friendship" (p4: 268-285). One participant described the time when she helped a primary family through the loss of one of their twins: "Of course that's very emotional and they went through a lot. . . I still stay in touch with them, and actually we found very similar bonding so we're actually good friends now outside the unit" (p10-147-153). Another participant reported how a parent asked her: "'Can you move in with us?' And I say: 'Do you have room for my husband and my dog? [laughing]' So that's how much the attachment goes as far that you're part of the family. I like that feeling" (p3: 382-386). Another participant described how: "I have a very

close relationship [with former primary families] . . . I'm Nanna [nurse's name], that's my name. To all of them [former primary families] I'm Nanna [nurse's name]" (p5: 155-158).

The *Transformed* relationship is dramatically different from the relationship seen between the nurse and family that existed earlier while the infant was hospitalized. As the primary nurse and family approach the anticipated discharge of the infant, they negotiate new boundaries for the post-discharge relationship, a relationship that no longer will be characterized by caregiving but one that is more like the relationship between friends or family members.

Evaluating

All the participants described *Evaluating* the primary relationship, both during the hospitalization as well as long after the infant's discharge. The participants *Evaluated* the impact of PCN on the infant, the impact on the families, and the impact on themselves. This phase consisted of evaluations that occurred while the infant was still hospitalized, as well as evaluations that occurred over time, long after the infant had been discharged home. Long term reflection on the relationship was particularly valuable in the *Evaluating* phase. Although some relationships are terminated for a variety of reasons (facility policy, parental or nurse choice), but this does not preclude some level of *Evaluating*. When a primary nurse is able to continue the relationship with the infant and family after the infant's discharge, the nurse has access to richer and more in-depth information that facilitates her *Evaluation* of her impact.

POSITIVE EVALUATIONS

Most of the participants' *Evaluations of* their impact were positive. Some of the positive effects of *Maximizing Impact* were short term, but most of the effects become apparent over time as the nurses observe the families or as they reflect on the primary care relationships they had experienced.

Effects on family

The participants discussed the impact they had had while the infant was in the NICU. Participants believed the relationships they build with families allowed them to have a positive impact on the infants and families with the effect on the parents being as significant as the effect on the infants. Participants frequently discussed how parents trusted their primary nurses. Trust between parents and primary nurses often presents itself to some degree before the *Safeguarding* relationship is even formally initiated as discussed under the *Seeking and Identifying* phase. This trust generally continues to develop and deepen throughout each of the phases of the relationship during the infant's hospitalization and afterward: "They get to trust you so much; they know you're doing the best thing for the baby. . . It is an extreme case of trust" (p5: 53-58). One participant described how this trusting relationships had been especially important for parents whose infant had experienced a serious crisis such as emergency surgery: "Having someone [there]. . . She [infant's mother said] knew when she went home, her son was being taken care of" (p2: 157-158). Another participant recounted a discussion she had years afterward with a parent regarding their time in the NICU: "She said: 'We trusted you and we always slept well when you were there.' And I never knew the impact it had on them. . . She said: 'We felt at peace when you were there'" (p11: 716-723). A participant emphasized the importance of

a familiar face for parents in frightening situations: “Being able to rely on the same nurse to be able to say: ‘Hey, I don’t feel comfortable with the situation’, and kind of look for you” (p8: 88-89). She further elaborated that parents: “knew that if they needed something, that they had an issue or anything that I could help them with, find the resource, find the answer, they could come to me” (p8: 308-310).

Some of the participants discussed how the relationship developed during *Safeguarding this Family* engendered such strong trust from the parents that the family contacted the primary nurse if the infant had a crisis even when that nurse was not working. One primary family had a participant’s phone number from the hospitalization of an older sibling so the nurse had asked them not to contact her during the current infant’s hospitalization to maintain appropriate boundaries. Nevertheless, the parents still contacted her because “[The infant] was really sick and she [the mom] was letting me know” (p4: 191-192). Another participant’s primary infant had been transferred to more specialized facility where he: “had an incident, ended up in PICU. . . so they had to let him go [allow natural death]. So they called me to come and I was there with the family, held the baby, stayed with the family while the mother and father let him go” (p5: 218-222).

Effects on the family from engaging in relationships developed through *Safeguarding this Family* can also be long-term, although this generally means that the primary nurse was able to maintain contact with the family. When such contact occurred, the families often expressed appreciation for that nurse’s care which in turn, factored into the primary nurses’ evaluation of how she had *Maximized (her) Impact* through *Safeguarding this Family*. One participant recounted how former primary parents had verbalized appreciation: “I’ve . . . been told that if it hadn’t been for me, they [parents] don’t

know where they would have been in their NICU experience" (p8: 338-340). Another reported that a parent told her: "We told [a friend] about you and you're just so wonderful and how well you took care of our baby and loved our baby like your own" (p9: 304-306). A participant described why she valued getting updates and pictures from families: "It's knowing that I made . . . a small impact, a big impact. . . these parents still tell me, 'Thank you. . . look at her now, this is her fourth birthday and I just want you to know because of how you took care of her. Look where she is now'" (p8: 348-355).

Unfortunately, mothers who have had one high risk pregnancy often face the risk of a future high risk pregnancy and a subsequent admission of the infant to the NICU. The study participants described how the trusting relationship the family had developed with the nurse led them to reach out to their primary nurse again when facing another high risk pregnancy: "She [former primary mother] got pregnant again. . . and asked me if I was going to be there in the NICU whenever that baby girl delivered just in case" (p7: 424-427). Another participant described a similar experience: "They've had two babies in our NICU and I primaried both of them" (p4-170). One participant had cared for a couple's first infant who had passed away. When the second infant was born, she reported, "I walked in that [NICU] room and there's the dad sitting there. 'Hi', I say. . . 'Do you want me to take him?' 'Yes!' [father replied] So I went back in there [to the charge nurse] and changed my assignment. He's [the infant] home, healthy, doing great. . . That trust is really there and really awesome" (p5-224-230).

Participants described observing short and long-term effects on former primary families of the relationships developed through *Safeguarding this Family*. In the shorter-term, primary nurses saw parents who more at ease and trusted their primary nurses which

in turn helped the parents become more at ease and more capable of caring for their infants. The participants also described longer-term effects they saw in former primary families when families maintained their relationships with their primary nurses. Maintaining longer-term relationships with the nurses allowed the family to express appreciation as they shared the joy of watching their child grow and achieve milestones with their PCN nurses.

Effects on infants

Although the participants' descriptions of the effects of *Safeguarding this Family* on their primary infants mostly focused on the infant's progress following discharge from the NICU, they did report some short-term effects. For example, a participant said primary nurses are better at understanding an infant's behavioral cures, such as knowing a particular infant tends to get fussy at a certain time every night: "because he needs a diaper change and he'll go right back to sleep instead of [the nurse] going in there and having to trouble shoot 500 things" (p7: 117-119). Another participant said her in-depth knowledge of her primary infant's behaviors allowed her to realize the infant was showing subtle signs of illness, she pushed for action from the physicians ,which in turn, lead to diagnosis of an early-stage intestinal perforation: "Even though it [the perforation] was negative, I felt like it was a positive thing because. . . my gut, knowing him, knowing his [infant's] demeanor that was totally off. . . helped the situation" (p8: 137-140).

The participants also *Evaluated* the effects of the *Safeguarding this Family* relationship on the infants even when there were less desirable outcomes. For example, when one participant was describing the death of one of her primary infants, she found she was comforted by the realization that: "You are one of the few people that get to know this baby along with the parents" (p10: 359-361). Another participant remembered an infant

who had been discharged home into a worrisome social situation: "You worry about those kind of babies when they go home. . . I know I gave him a good, a good start of lovin' and care" (p5: 206-208). Another participant described a tragic situation where the mother: "had the baby and basically left the hospital" (p7: 573). This nurse felt the care she imparted on this infant, shared through the relationship she had built, comforted that infant in their short life: "I'm the one that held that baby when that baby passed away, . . . knowing that baby was loved at least while that baby was here on Earth" (p7: 576-582). When *Evaluating,* the primary NICU nurse has to come to terms with grievous outcomes at times, and has to reconcile how or if she was able, in some substantial way, to *Maximize (her) Impact.*

Observing the infant after their discharge allowed the primary nurse to *Evaluate* whether she had *Safeguarded this Family* by seeing the infant's long-term development over time. Staying in touch with families enabled participants to better evaluate this impact:

> "I like to see their growth. You look at their pictures you don't just see a pretty child or whatever, you look to see how are they walking. Are they standing? You know, is their head flat, is it rounded? . . . You do an assessment on their pictures, see if they're normal. As a nurse we can't help ourselves [laughs]" (p5: 403-408).

Another participant described meeting a former primary family:

> "He [former primary infant] is a spitfire and his developmental status is way ahead. . . He [former primary infant] says something about, well you know, 'A stop sign is. . .', and he says how many sides and he gives the proper name for it. . . And I'm thinking: 'this is a 3-year-old child!" (p11: 518-527).

A participant described how she enjoyed: "the yearly updates especially like kiddos that you thought would never have any quality of life, and each update you get on their

milestones . . . is awesome 'cause it sometimes will help you through a really rough day to remember what you're doing, what you do" (p10: 181-186).

The infant's well-being is at the heart of the participants' drive to *Safeguard this Family*. Participants recognized some positive effects of PCN in the short term such as being able to respond more precisely to the infant's physiological or behavioral cues averting, or at least ameliorating, distress and possibly having long-term ramifications. Most of the effects of PCN that the participants saw in the infants were related to the infant's long-term development. The on-going relationship with the family allowed participants to see the outcomes of care they had provided to their primary infants and its family. Even in cases when their primary infant did not survive, the participants believed the primary nurse relationship allowed them to *Maximize (their) Impact* and *Safeguard the family* even in the face of the infant's short life.

Effects on primary nurses

Part of the participants' *Evaluating* of whether they had *Maximized (their) Impact* was how the *Safeguarding this Family* relationships affected the nurses themselves, personally and professionally. As with the infants and families, the effects on the primary nurses were both short and long-term. Additionally, the participants discussed negative effects on themselves resulting from the relationships. The participants did not discuss any negative effects for infants and families; they only discussed negative effects on the primary nurses themselves.

Consistency of care, which the study participants mentioned frequently as a benefit of PCN for the infants and families, also was seen as having positive effects for the primary nurse: "I like consistency with the patients. . . It just, it makes me enjoy my job more" (p2:

53-58). Another participant said that having a primary infant: "kind of gives me a purpose to go to work because I have this continuity of care." (p1: 49-51). The in-depth knowledge a primary nurse acquires regarding the infant: "makes patient care not necessarily more so simple but consistent" (p7: 127-128). Consistency of care introduced a degree of predictability in an often unpredictable environment and allowed the nurses to *Safeguard this Family.*

Participants found relationships with their primary infants' families were deeply rewarding. "I just love that, having that connection with the families" (p1: 61). Another participant added, "Primary nursing. . . gives me a chance to build relationships with the families, and. . . I get a sense of satisfaction" (p2: 27-30). One participant also enjoyed developing relationships with the infants as well: "I love that I get to form a relationship with the parents but most likely the baby" (p9: 38-39). The personal experiences not only are personally rewarding for the nurse, but at least one participant was able to write about a particularly poignant relationship with the family of one of her primary infants as part of her application for career advancement: "That's one of the things that impressed them [clinical ladder committee]" and as a result she was able to "get the benefit [of clinical ladder advancement]" (p3: 370-372).

Another positive effect participants described was that the primary nurse's intense knowledge about the infant led to their opinions being sought by other providers; thus their voices were heard. "I feel like. . . we [primary nurses] were relied on heavily for any decision [about the primary infant] . . . They [physicians] would always, *always,* ask for our opinion. . . because they just felt like we were more of a . . . reliable resource because we took care of the patient more frequently" (p8: 67-74). When the primary nurse develops

the closeness and in-depth knowledge of the infant, she: "really gain[s] trust with the physicians that I work with" (p1: 31). "The doctors value the [primary] nurse's input" (p1: 111). The participants described increased clout with the provider staff when they raised concerns about their primary infant: "The doctor relationship with us as a primary [nurse] is a little bit different. . . If we ask for something we want, they know that it's something we really needs" (p5: 78-81). The participants attributed this increased trust to the consistency of care inherent in PCN: "If anyone needed to ask you a question, like a provider, they can rely on you as a reliable source,. . . because you have taken care of this patient more frequently than any other nurse" (p8: 47-50).

Some of the participants believed the relationships affected their sense of worth and value beyond the standard nursing role: "I feel like I'm a critical part of their care team versus when I don't have a primary [when it] is just going to work" (p1-54-55). One participant reported that in addition to the physicians, other nurses respected the relationship she had with her primary family. The other nurses sought her input on care of the primary infant by contacting her about nursing interventions when she wasn't working: "Some of the nurses have text[ed] me at home to ask me. . . what is your feeling on this?" (p4: 94-95). The benefits of the relationship is apparent to other professionals; one participant said that on occasion a physician will request that a specific nurse provide PCN to a certain infant and family: "I think it's great that doctors ask nurses to be [primary]. It's very, it obviously helps your ego" (p1: 398-399). The participants appreciated having their voices heard not only because it benefitted the infants and increased their clinical prestige, but also because having their voices heard helped them feel they really had managed to *Safeguard these Families* by *Maximizing (their) Impact* as members of the healthcare team.

Many of the effects on the nurse were long-term. Unlike the short term effects, the long-term effects for the nurse were less about the day-to-day nursing tasks and more about the nurse's general way of practicing nursing or her perceptions of her own nursing practice. Maintaining relationships with the infants and families allowed the nurses to fully evaluate and enjoy their impact on the infant and family.

Pictures and videos of their primary infants they had care for allowed the participants to reflect on how PCN allowed them to *Maximize (their) Impact* by *Safeguarding this Family*: "You [realize you] made such an impact on this family's life and this baby's life that it just, it really takes you back" (p9: 301-303). Another participant described the meaning she derived from pictures of her former primary infant that the family had shared with her: "I think everybody struggles with . . .whether we're really making a difference, or if we're valued, and what it [pictures] tells me is 'I am valued'" (p11: 641-651). One participant was asked to describe how she felt about the pictures posted in the Facebook page she had created for her former primary families. Her eyes filled with tears and initially she was unable to speak; she patted over her heart: "Yeah, that's my, that's my heart. That's why I love primary nursing so much" (p5: 436-439).

Some participants received cards or modest gifts in a show of appreciation from their primary families: "I get, you know, cards, I get pictures" (p8: 337). "I've gotten things like . . . a thank you card at discharge" (p1: 371). "Some nurses get gift cards" (p9: 380). "The grandma likes to knit so she made me . . . these socks" (p3: 347). The participants often reflected on the impact they had had on families when looking at the mementos they had brought to the interviews: "It's just like a special little memento to me to remember that I was involved in his care. . . it's an emotion that's attached to it. . . It's just the memento of

remembrance of that particular infant" (p7: 523-538). Another nurse shared: "She [mother] gave me this [figurine]. This is so, so, important to me and I always have it [on] my mantle in my family room so I get to see it a lot" (p3: 344-346). One participant explained the significance of something as simple as a greeting card: "I feel like they're never going to forget who we are. There's always going to be a special place in their hearts for us because we helped take care of their baby" (p2: 288-290). A participant described a parent presenting her with "A picture of me holding her son, and she'd framed it, she'd done a lot of nice things and that meant the world to me" (p11: 87-88). One participant said that pictures and thank you cards from families "remind me of what I'm doing. Just to kind of keep me grounded" (p10: 226). Another described how a parent gathered all the footprint cards the nurse had made for the infant throughout their NICU stay: "'Look [what] we did!' So they had, they used that [footprint cards] as part of their decoration for her first birthday. . . [the display made the nurse feel] really special. That one, that they kept it, and that they thought it was important enough to display [to] everybody and celebrate her life . . . very heartwarming" (p4: 322-329). While one participant was reflecting on the significance of cards and pictures, she said she believed they served as: "little signs that give me encouragement to say, 'Don't stop doing what you're doing even if you can't perceive a difference,' that you never [know] the impact that people will feel a difference there'. . . If I hadn't had those things revealed to me over time, I would probably think of myself as a total, you know, piece of junk" (p11: 761-768).

The participants all enjoyed receiving pictures, videos or small gifts of appreciation. These mementos validated the primary nurses' beliefs that they had *Maximized (their) Impact* by *Safeguarding this Family*.

NEGATIVE EVALUATIONS

At times, the participants had negative experiences. Some nurses felt overwhelmed by the intensity of the emotions associated with the relationship or from caring for infants who had poor or terminal prognoses. Other nurses experienced potential relationships that for a variety of reasons, failed to develop fully. There were times when that the nurse's *Evaluation* led to the conclusion that the relationship had had a negative effect on the individuals involved, specifically, the primary nurse herself.

Emotional toll for primary nurse

One of the negative outcomes reported by the study participants is that the relationship with the infant and family can exact a negative emotional toll. One stated: "It's emotionally draining, just that connection" (p4: 81). Another participant shared: "I find it necessary to take breaks [from PCN] and I kind of have a kind of guard on myself that I'm not going to do primary back to back. . . It's a very emotional process and depending on the infant it can be a rollercoaster" (p1: 36-40). Another said the emotional toll is a reason other nurses are hesitant to engage in PCN: "I know some people's caveats are: 'Well, it's too emotional, you get too tied to them, or it's too difficult'" (p9: 340-341). The infants' frailty is not always the cause: "My last primary, mom had really, *really,* high anxiety. . . so [she needed] constant reassurance. . . and that in itself. . . can be very draining to us to have to be at that level all the time" (p2: 119-124). Another participant voiced similar experiences: "It takes a lot of energy. . . Sometimes the family can be a very needy family. That means a lot of attention" (p10: 80-83). After the death of her first primary infant, one of the nurses said she had to take time away from PCN to *Evaluate* whether she would engage in PCN in the future: "I didn't know if I could care for, do, put myself through all

that heartache again. . . I realized the benefits outweighed the cons and the negative things that might happen" (p9: 66-71) and she ultimately decided to return to PCN.

Anticipating a poor outcome for the infant increases the emotional toll for the nurse in a PCN relationship. The nurse must continue caring for the infant and family despite her sadness at knowing "what the long term outlook is for a child with a devastating diagnosis. So you're loving that child. . . despite the fact that you know they're not going to have a very promising future" (p1: 80-82). One nurse stated that when it came to the nurse's own emotions, "you have to kind of glaze them over because you are the rock that the parents need in . . . difficult situations" (p8: 195-197). Another painful experience faced by PCN nurses was: "when we have to withdraw care, which has unfortunately happened for me several times" (p6: 50-51). She later said that at times she: "didn't know if I could do it [care for infants facing withdrawal of medical interventions]" (p6: 203). Another participant admitted that she didn't always know how to deal with her feelings grief while helping a family through a loss:

> "We want to cry with the families. . . but you can't do that at that time [when withdrawing care]. . . you're doing everything that needs to be done for that family at that time and let them grieve. But then you as. . . the care provider never grieves for that loss, and for me, I don't" (p7: 554-560).

This nurse further elaborated that "I just put it [her grief] in [a] box. . . I'm not going to deal with that box because maybe I don't know how to deal with that box or I don't need to deal with that [grief]" (p7: 560-563).

Safeguarding this Family by providing PCN requires far more emotional engagement than routine NICU nursing even in the best of circumstances. If the infant

faces a devastating outcome or death, the primary nurse must deal with more painful emotions than the average bedside nurse because of her personal, prolonged, investment in the relationship with the infant and family. Nevertheless, the nurses who participated in the study continued to believe they had *Safeguarded the Family* even in situations that resulted in loss and grief, because those experiences came along with the highly invested nature of the relationships.

FAILED RELATIONSHIPS

Several of the participants had experienced relationships with families that they felt had been unsuccessful. Relationships can fail when trust never develops or breaks down between the family and primary nurse; lack of trust stunts the development of the relationship during every phase of *Safeguarding this Family.*. Although most of the problems with trust become an issue during the *Enacting* phase after the family and nurse had agreed to a primary nursing relationship, trust problems that arose during the *Seeking and Identifying* phase meant the relationship was unlikely to be fully *Enacted.* If a relationship is never fully *Enacted*, it is unlikely to go to the *Transforming* phase or to continue after the family is discharged home. Participants did, however, reflect on failed relationships in an attempt to learn how they might have been able to salvage the relationship or how they could act differently with future PCN relationships.

Some of the participants described times when trust had never developed or never fully developed, between the primary nurse and the family during the *Enacting* stage: "They [primary family] tended to have more rapport with the day shift nurses. . . They didn't stay at night so I didn't have much of that relationship" (p7: 435-438). The nurse

believed that lack of interaction between herself and the primary family was the factor that impeded development of her *Safeguarding this Family* relationship with them. Another participant also brought up the lack of nurse-parent contact as problematic: "They [parents] are not engaged. Now they are friendly when they're there but they just don't call, they don't visit" (p11: 362-364). One nurse had put a great deal of real effort into engaging with the family but the family remained untrusting:

> "It frustrated me because you would spend so much time and effort with these families to educate them. . . and they would look at you like you're an idiot. . . They're screaming bloody murder at you and it's not necessarily directed at you but . . . you're the one right there at the bedside. . . They're looking at you like: 'Do I trust her? Do I not trust her?'" (p7: 147-158).

Trust can also be lost between the primary nurse and the family during the *Enacting* phase. A participant described parents who had been watching their child on a unit-provided web-cam: "They perceived that I was rough handling their baby. So you know the cameras, it's a little distorted view. . . They didn't come to tell me that they had feelings about that, they just went to the charge nurse" (p5: 278-282). Another participant who experienced a failed primary relationship, said:

> "They actually ended up, I would say, firing me [as a primary nurse] because they demanded that I do something that I was. . . not going to do. . .and they didn't like the fact that I told them that. . . It was really hard; I didn't feel really close to the babies. I didn't feel close to the family. . . It just wasn't an enjoyable situation for me" (p2: 172-184).

The lack of trust can come from the nurse as well as from the family: "They'll [parents] say they're coming in at a certain time and they just don't show up and they don't call. . . When they establish [such] a pattern, I just think, well, that put you in the unreliable pattern which creates a frustration for me" (p11: 105-109). This same participant lost trust in another family whose members persisted in attempting to give her excessively personal and expensive gifts: "There was a violation that occurred because she [grandmother] was not respecting my boundaries . . . So I went and . . . took my name off the primary list [for that infant]" (p11: 863-872).

Developing trust is the cornerstone of the *Safeguarding this Family* relationship. When trust fails to develop or is lost, the relationship suffers and may even be terminated prematurely as the NICU primary nurse has lost a crucial element necessary for them to have a relationship with the family that would allow her to *Maximize (her) Impact*.

BARRIERS TO EVALUATION

The participants described circumstances that impaired their ability to *Evaluate* their impact. These circumstances affected nurse-family contact after the infant died or was discharged. While cessation of contact did not bar the nurse from *Evaluating* her impact, it did hinder the nurses' reflections on the relationship during the *Evaluating* phase.

Experiencing a devastating medical complication or death can cause parents to withdraw or terminate the relationship with the primary nurse prior to discharge or to terminate the relationship if the infant dies. Although some relationships may persist after a devastating medical complication or the death of the infant, several of the participants described how some families pulled back from the relationship at those times:

> "I feel like they [primary family] appreciated me . . . but there wasn't that quite, I don't know if the word is closeness, as I had with my other ones. . . It may have been their, their, baby . . . had a bad head [severe intraventricular bleeding], and I think they were very angry about it" (p4: 214-219).

Another participant described sharing her contact information with the family after their infant passed away because: "it might be beneficial for the family to have someone who was very close to their child and close with them. . . but they haven't ever contacted, and that's rightfully ok" (p9: 283-286). The participants who experienced parents' withdrawing from the relationship after a devastating complication or demise understood through the *Evaluation* phase that there was little to nothing they could have done to change the circumstances; the nurses respected the parents' need for space to deal with the loss.

The failure of the nurse's efforts to *Maximize (her) Impact* by *Safeguarding this Family* can often be tracked back to either a lack of trust between the parents and nurse, or subsequent to a devastating infant outcome. Regardless of the cause of the disengagement, the nurse's ability to *Evaluate* her impact is seriously hampered when there is no long-term contact that enables the nurse to observe how the infant and family continue to develop over time.

On occasion, the nurses were prohibited from using personal contact in *Evaluating* whether they had *Safeguarded this Family* due to facility-imposed barriers. Some facilities choose to restrict direct contact between nurses and families after discharge. One participant's facility only permitted the families to remain in contact with their former primary nurses by going through the leadership team, so the nurse had to tell parents: "You [parents] have to send pictures to the unit or to the main management, then they share

pictures with us [primary nurses] and any updates (p7: 484-486). Another participant was distressed over her unit's recent implementation of a no-contact policy: "I can't put this caring into this family and then the minute they leave say, 'I don't care about you anymore'" (p10: 328-329). As a result, she decided to stop engaging in PCN. She commented, "People [other primary nurses] aren't going to want to put that emotional energy into it [PCN] and then never know that the minute they walk away whether they [infants] did well or not. . . So that's why. . . I've pulled away" (p10: 399-404).

When *Evaluating* the impact of their care, primary nurses largely relied on observing how their former infants and families faired over time, both developmentally, and as a family unit. Sometimes this *Evaluation* was inhibited or forbidden for reasons including a no-contact policy from the facility or if the family or nurse decided to cease contact. Although the primary nurses can still reflect on and evaluate the relationship they had with the family during the infant's hospitalization, contact after the infant's discharge enables a fuller *Evaluation.*

Overall, primary nurses used the *Evaluating* phase to inform whether they would engage in PCN in the future. Positive experiences served to inspire them to engage in PCN in the future, even in the presence of some negative outcomes. When nurses were not allowed to maintain contact with the family following the infant's discharge from the hospital, constraining their ability to *Evaluate* their efforts, they may be less interested in continuing to provide PCN in the future, since after all, such close relationships can potentially be detrimental to the nurse.

SUMMARY OF THE THEORY

Primary Care Nursing allows Primary NICU nurses to *Maximize (their) Impact* by developing relationships that *Safeguard this Family*. Primary NICU nurses tend to be those with certain innate characteristics and beliefs who then develop relationships with their primary infants and families through the four-phase process, *Safeguarding this Family.*

The first phase of *Safeguarding this Family, Seeking and Identifying* occurs when the primary nurse becomes aware of an infant and family who will benefit from her skills and interests. Nurses are drawn to a particular infant or family for a number of reasons, but also are concerned about whether they and the family will be able to work together for the welfare of the infant. The nurses include the parents in the decision as to whether the nurse should become their infant's primary nurse.

The second phase, *Enacting,* encompasses the bulk of the infant's in-hospital stay. During this phase, the primary nurse engages in interventions focused on *Safeguarding this Family* which in turn serve to *Maximize (the nurses') Impact*. The main mechanisms utilized by the nurses during the *Enacting* phase include enabling continuity of care, developing a relationship with the family, building the parent's infant care skills, championing the infant's needs within the NICU healthcare environment, and becoming a team with the parents, all while managing boundaries professionally.

As the infant approaches discharge, the nurse's relationship with the family enters the *Transforming* phase. During this phase, and barring any constraints by the facility, the primary nurse and family negotiate how the relationship will proceed after the infant is discharged home. Primary nurses respect the family's wishes regarding whether to continue a post-discharge relationship, but they also make it clear the caregiving element

of the relationship will not continue. The *Transformation* phase encompasses the redefinition of roles for nurses and families and includes the type and frequency of contact that will take place when the infant is discharged home. There is variation in the *Transformed* relationships; some primary nurses only maintain contact through text messages and emails while others visit in person and participate in events such as birthday parties. As the PCN relationship *Transforms*, the relationship between the nurse and family goes from one that had been focused on caregiving in the hospital to a relationship more analogous to a friendship or even a kinship.

The *Evaluating* phase occurs all throughout phases of *Safeguarding this Family,* but especially after the infant has been discharged. Primary nurses in this study tend to have mostly positive evaluations of their PCN relationships, with a few negative evaluations. *Evaluating* during the infant's hospitalization allows the nurse to recognize aspects of the relationship, such as the benefit of consistency of care for the infants, their parents, and the primary nurses themselves. Primary nurses also recognize how engaging in PCN tends to increase the respect afforded to them from the rest of the healthcare team, which increases their personal sense of worth and value. For the most part, primary nurses found the relationships personally rewarding and enjoy engaging in PCN.

In the longer term, receiving pictures and videos of the former primary patients allows the nurse to reflect on the effect of her care and more closely observe her impact on the infant and the family's development. Small gifts and mementos serve as tangible reminders to primary nurses of the care they gave and how they are appreciated.

Primary nurses sometimes feel that providing PCN had had negative personal effects because of the intense emotional toll of the relationship. Trust is the key to the

success or failure of the primary nurse's relationship with the family. If trust never develops or is lost, either on the part of the nurse or the family, then the opportunity for the primary nurse to *Maximize (her) Impact* by *Safeguarding this Family* is severely impaired.

Summary of Chapter Four

Chapter Four has provided a detailed review of this CGT study that explored how NICU primary nurses develop relationships with their primary infants and families.

Plan for Remaining Chapter

Chapter Five will provide a discussion of the study. The Chapter will compare the study findings to the extant literature. It also will include a discussion of the study's strengths and limitations of the study, the study's implications, and the significance of the study.

CHAPTER FIVE: DISCUSSION

INTRODUCTION

This Classical Grounded Theory (CGT) study explored the relationships between primary neonatal intensive care unit (NICU) nurses and their primary infants and families in order to better understand how those relationships develop over time. The study employed Classical Grounded Theory (CGT) to identify a substantive theory in order to more fully understand the relationship development between primary nurses and families in the NICU. This Chapter will provide a review of the study, including the methodology; the study findings; and the substantive theory that emerged from the data. The Chapter will compare the study findings to the extant literature, as well as any contributions the study makes to the extant literature. The Chapter will continue with a discussion of the indications for future research that arose from the findings of this study, then will consider the implications of the study for NICU nurses who currently practice or might practice PCN as well as implications for the individual NICUs where PCN is in practice as well as those who either do or are interested in practicing PCN. Finally, this Chapter will discuss overall significance of the study findings, the strengths and limitations of the study, and any conclusions can be drawn from the study.

STATEMENT OF THE PROBLEM

Primary care nursing (PCN) is a widely practiced model of care delivery in many inpatient nursing units including the NICU (Fairbrother et al., 2010; van den Berg & Lindh, 2013). In spite of its apparent prevalence, primary care nursing (PCN), especially within the NICU environment, is inconsistently implemented, poorly understood, and lightly

studied. Primary care nursing is congruent with the Institute for Medicine's (IOM) call to reform healthcare in part by basing delivery of patient care on "continuous healing relationships" (Committee on Quality Health Care in America, Institute of Medicine, 2001, p. 8). Healing relationships are at the heart of PCN making it an ideal model of care delivery to meet the IOM's recommendations because it provides a framework where those healing relationships can form (Moore, 2002). Primary care nursing also is consistent with family-centered care and developmental care, two philosophies of care accepted as the standard of care for neonates and their families (Als & Gilkerson, 1997; Committee on Hospital Care and Institute for Patient- and Family-Centered Care, 2012; Committee on Quality Health Care in America: Institute of Medicine, 2001).

Prior to the current study, there was limited study of PCN in the NICU setting. There was only one grounded theory study of the relationships of PCN nurses and NICU mothers (Scharer & Brooks, 1994), and none utilizing Classical Grounded Theory. The extant literature on PCN in the NICU is largely from the 1990s or earlier, and the more recent research has been conducted in European nations with potentially different social and healthcare environments. This study offers a unique and current perspective of bedside NICU nurses who practice in the United States, and the relationships they form with their primary infants and families, both during the infant's hospitalization and following discharge.

REVIEW OF THE METHODOLOGY

Classical Grounded Theory (CGT) was selected for its rigor in exploring subjective phenomena when the current knowledge is nonexistent, limited, or poorly applicable (Glaser, 1978; 1998). Classical Grounded Theory seeks to explain, not just describe what

is happening in social environments (Holton & Walsh, 2017). The focus of CGT is to generate theory from the data while staying firmly grounded in the systematically obtained data which serves to validate the emerging theory (Glaser, 1978). The goal of CGT is to understand "what is really going on" (Glaser, 1998, p. 12) with a group of individuals who have experienced the same phenomenon; in this case, nurses who experience primary care nursing in the NICU setting. Classical Grounded Theory guided the researcher to identify the participants' main concern, then, using CGT analytic techniques, allowed the emergence of a substantive theory from the study, a theory that can explain how the participants resolved their main concern.

The main concern of the nurses who participated in this study was *Maximizing Impact* which was the nurses' intense concern that they be able to do all they could to help their primary infants and the infants' families to thrive during the hospitalization and as they continued to develop over time. The participants resolved their concern by *Safeguarding this Family* by developing PCN relationships with the infants and families. The care delivery system of PCN, as it is commonly practiced in which nurses select their primary infants and families allowed the participants to choose infants and families well suited to their particular skills and strengths. Being the infant's primary nurse allowed continuity of care which in turn enabled *Safeguarding this Family* through development of the nurse-family relationship; this relationship developed in four phases described as *Seeking and Identifying, Enacting, Transforming,* and *Evaluating*. The nurse-parent relationships supported PCN and the primary nurse's ability to *Maximize (her) Impact* both during the infant's hospitalization and after the infant was discharged.

The eleven study participants were registered nurses currently working in a NICU, and who had cared for a minimum of three primary infants ever and at least one primary infant in the previous year. Participants were recruited using purposive and snowball sampling. Recruitment efforts were terminated once theoretical saturation was achieved (Glaser 2001). Data collection was conducted using face-to-face interviews either in person or with the video chat applications Facetime or Skype.

Data analysis began with the first interview and proceeded iteratively as described by Glaser (1978; 1998; 2014) with the purpose of identifying patterns in the data and to answer the question of "what is going on here" in the data (Glaser, 1998, p.12). Data analysis was conducted in the iterative manner prescribed by CGT until patterns emerged from the data (Glaser, 1978; 1998; 2014). Data analysis began with line-by-line coding and memoing while employing the constant comparative method (Holton & Walsh, 2017). Coding, memoing, and constant comparative method (CCM) led to the identification of the core category, or the participants' main concern which was *Maximizing Impact.* Continuing analysis led this researcher to identify patterns and theoretical relationships among the categories ultimately leading to recognize that *Safeguarding this Family* described how study participants resolved their main concern.

STUDY FINDINGS: THE SUBSTANTIVE THEORY: *MAXIMIZING IMPACT*

Maximizing Impact emerged as a substantive theory that could explain how NICU primary nurses resolved their main concern through a process of *Safeguarding this Family. Safeguarding this Family* is the process that primary NICU nurses initiate when they become aware of an infant and family whom they feel especially well-suited to help. Primary NICU nurses develop relationships with NICU families through primary nursing.

Primary care nursing relationships support the practice of PCN, and the relationships formed while practicing PCN help the NICU primary nurse *Maximize (her) Impact.* The nurse-parent relationships occur in four phases during *Safeguarding this Family*: *Seeking and Identifying, Enacting, Transforming,* and *Identifying.*

Not all NICU nurses engage in PCN even if this is a model of care delivery encouraged in their units. The nurses who participated in the study described qualities they believed were necessary for nurses who participate in PCN, these included commonly held beliefs about PCN and personal characteristics such as skill with relationship-building.

The NICU nurses who seek to *Maximize (their) Impact* by *Safeguarding Families* begin in the *Seeking & Identifying* phase when the nurse becomes aware of an infant and families who might be a good fit with her skills. The bulk of the work involved in *Safeguarding this Family* occurs during the *Enacting* phase when the primary nurse employs continuity of care, champions the infant's needs, builds the parent's skills, becomes a team with the family all while managing boundaries professionally. As the infant approaches time for discharge, the primary nurse anticipates the change in the relationship and begins to move into the *Transforming* phase when the time when the primary nurse assesses whether the primary family wishes to continue in contact after the discharge and if so, how the PCN relationship will transform following the infant's discharge from the hospital assuming there are no facility-imposed barriers. It is important for the primary nurse to clarify that the relationship will cease to be caregiving or clinical. The final phase of *Safeguarding this Family*, *Evaluating* tends to occur after the infant's discharge from the hospital; it also can occur throughout the PCN relationship. The primary nurse evaluates the impact she is having, or has had on the infant, the family, and on herself

as a result of the PCN relationship. The nurse observes the progress of the infant and family during the hospital stay, the infant's development over time, and how the family adapts as a unit. Most primary nurses have positive evaluations of their experiences with PCN. In the short term, they note the benefits of continuity of care for all involved, the respect the nurse receives, and the progress made by the infant and family during the hospitalization. Primary nurses largely rely on the relationships they maintain with former primary families in order to more fully evaluate their impact.

Neonatal Intensive care unit primary nurses have mostly positive evaluations of how and whether they *Maximized (their) Impact* by *Safeguarding this Family*. Other nurses may have provided PCN to NICU infants who experienced devastating complications and prognoses, who died, or infants whose parents might have withdrawn from the relationship. Primary nurses can experience emotional distress in such situations and not all primary nurses know how to deal with the emotional toll.

COMPARISON TO EXTANT LITERATURE

The comparison of the study findings and extant literature will address the contributions of the study findings to the literature addressing the practice of primary nursing and nursing practice in general.

Primary care nursing (PCN) is a form of care delivery designed specifically for the acute care hospital setting (Manthey et al., 1970). There is a dearth of literature addressing the use of PCN in the NICU.

There are a number of advantages of PCN in any nursing specialty. These advantages include decreased stress and anxiety for patients (Blair et al., 1982; Hegedus,

1979); improved patient satisfaction scores (Dal Molin et al., 2017; Sellick et al., 2003; Shields et al., 1998; Spurgeon et al., 2001; Suhonen et al. 2007); fewer patient falls, medication errors, infections (Dal Molin et al., 2017; Shultz & Bender, 1986); and decreased breast discomfort, urinary retention, and increased rates of breastfeeding in postpartum women (Gagnon et al., 1997; Wan et al., 2011). Other studies have failed to demonstrate any advantage to PCN over other forms of care delivery such as team nursing (Blair et al., 1982; Chavigney & Lewis, 1984, Gardner, 1991; Kangas et al., 1999; Laasko & Routasalo, 2001; Olstrom & Albanese, 2006; Shukla & Turner, 1984). None of these studies addressed NICU primary nursing and few of these measures would translate directly to the NICU environment. While the current study did not measure patient's stress, anxiety or satisfaction, the study did reveal that primary nurses believed that because PCN often engendered tremendous trust from the parents, it provided comfort, a feeling of safety, and peace for those parents. The NICU primary nurses also believed they could provide superior care compared to standard NICU nursing. The superior care arose from continuity of care enabling the primary nurse to become intimately familiar with the particular infant's physiological states as well as the parent's and the infant's behavioral states and needs. The positive effects of primary NICU nursing fit with what would be expected if the primary nurse had achieved her goal of *Maximizing (her) Impact* by *Safeguarding this Family*.

The literature reports vary on the effects of PCN on the nurses. One of the most significant reported effects of PCN is related to nursing autonomy, a key component of PCN, in which the primary nurse is able to take responsibility for directing and coordinating care of their patients in contrast to other care delivery systems that tend to

fragment responsibility across multiple caregivers. Nurses practicing PCN consistently report increased feelings of autonomy (Allen & Vitale-Nolen, 2005; Dal Molin et al., 2017; Gardner, 1991; MacGuire & Botting, 1990; Manley et al., 1997; Melchior et al., 1999; Thomas, 1992). Participants in the present study talked about nursing autonomy more in regards to the individual nurse's ability to choose to take on a primary infant and family, being in a pivotal position in the infant's care during hospitalization, and in some cases in the decision to continue in contact with the family after discharge. The theory *Maximizing Impact* illuminates the importance of autonomy to the primary NICU nurse. Nurses who have the ability to select their own primary families understand which families fit best with that nurse's skills and abilities. Continuing the relationship after the infant's discharge allows the primary nurse to more effectively evaluate whether she had *Maximized (her) Impact* while disallowing post-discharge relationships suppresses *Evaluating* and potentially stifles the NICU nurse's incentive to engage in future PCN relationships.

Previous literature also revealed other positive effects related to the PCN care delivery method including increased nurse satisfaction (Adams et al., 1998; Allen & Vitale-Nolan, 2005; Sellick et al., 2003). The nurses in the present study believed they made a greater difference to individual infants and families, had greater input into inter-disciplinary decision making, and their input was valued (Allen & Vitale-Nolan, 2005; Sellick et al., 2003) The nurses consistently reported that engaging in PCN was deeply rewarding; some of the most rewarding aspects of PCN included the relationships with primary families, increased collaboration with the healthcare team, feeling heard, valued, and receiving respect from other members of the healthcare team. An important element of

Maximizing Effectiveness is that a NICU primary nurse has the ability to induce changes for any given infant and family through PCN.

Previous literature varies regarding the effect of PCN on nurses' work-related stress. Some studies have found that PCN tends to reduce nurses' work stress (Thomas, 1992) while other studies showed that PCN has no effect on nurses' stress (Mäkinen et al., 2003). Webb and Pontin (1996) reported increased stress experienced by primary care nurses, although the authors believed the stress was offset by increases in overall job satisfaction and role development. The present study tended to affirm this finding: while participants generally reported enjoying their autonomy as primary nurses they also reported struggling with the stress and emotional toll that often accompanied close relationships with infants and families, particularly in cases when the infants might suffer devastating outcomes. Nevertheless, several of the participants in the present study continued to practice and enjoy PCN even after experiencing poor family and infant outcomes.

One of the primary motivations for this study was the paucity of current literature on PCN in spite of it being a commonly practiced mode of care delivery (Goldschmidt & Gordin, 2006; Settle, 2016). Given the dearth of NICU-specific PCN literature, this study sought to begin by exploring one of the most essential underlying elements in PCN within the NICU; the relationship between the nurse and family. One study that did explore nurses' motivations for selecting primary infants examined nurses' reasons for selecting certain primary infants with the most common motivations being specific medical issues, attempts to maintain continuity of care, impressions of the infant or their parents, altruism, or to increase their own status within the unit (Lind & Sterk 1992). Lind and Sterk's

findings are congruent with many of the findings in the current study though the current study explores not only motivations for selecting primary infants but also offers a more complete picture of PCN in the NICU by going beyond just the reasons for choosing primary infants and further exploring how and why primary NICU nurses engage in PCN.

A study in a Swedish NICU by van den Berg and Lindh (2013) helps bolster the significance of the current study by finding that far too few NICU infants are matched with a primary nurse. Only 50% of the infants admitted to the Swedish NICU were matched with a primary care nurse; moreover, being matched to a primary nurse predicted other processes supportive of family-centered care such as nursing admission interviews and discharge notes. The current study did not offer any specific analysis of the uptake of PCN within any unit although it did elucidate the distinct characteristics of practicing primary nurses in the NICU and it offered insights to what factors motivate a NICU nurse to engage in PCN.

Goldschmidt and Gordin (2006), in recognition of the value of partnerships with parents explored a process that aimed to increase continuity of care associated with PCN in the NICU. The study unit already practiced PCN but was concerned that continuity of caregivers was suboptimal due to the large size of the unit and the need to accommodate day-by-day staffing and infant acuity (Goldschmidt & Gordin, 2006). The researchers manipulated staffing patterns were manipulated to increase continuity of care and decrease the number of caregivers resulting in increased parental satisfaction as well as nurses' reports of better continuity of care and happier families (Goldschmidt & Gordin, 2006). There were few similarities between the Goldschmidt and Gordin's study and the present study other than a focus on PCN and the prominence of continuity of care. Goldschmidt

and Gordin's study confirmed perceptions of the current study's participants that increased continuity of care improves care, or at least perceptions of quality of care.

McCarley et al. (2018) described a quality improvement project that sought to fully integrate family-centered and developmentally supportive care in a large NICU by increasing consistency of caregivers through PCN. Study results were mixed with researchers reporting an increase in consistency of care for infants with longer lengths of stay but less consistency of care for infants with shorter lengths of stay. One of the most significant barriers identified in the study was lack of buy-in from nursing staff who were not volunteering in sufficient numbers to sustain PCN for the infants in the study. The current study and the McCarley et al. study were not similar in aims or design, but McCarley et al. did include some qualitative data on primary nurses' perceptions of PCN that revealed that primary NICU nurses thought PCN helped them provide better care for infants and families and they enjoyed knowing their patients better, a finding similar to the current study. The current study and McCarley et al.'s study both addressed the potential for an emotional toll on the primary nurse especially if the infant has a poor outcome.

In spite of the limited literature on PCN within the NICU, a few studies have examined the relationship between the primary nurse and the infant's parents. Scharer and Brooks (1994) examined the relationships between mothers and NICU primary nurses using grounded theory though not CGT (Chenitz & Swanson, 1986; Strauss & Corbin, 1990). Scharer and Brooks described the evolution of the relationship between the mother and primary nurse in the theory: *Transfer of Care* which occurs in four phases from the infant's admission until their discharge (1994). While there are similarities between *Transfer of Care* and *Maximizing Impact,* there are several notable differences. Scharer

and Brooks included mothers in the study along with their infant's primary nurses giving a different perspective from the current study that concentrated on only the primary nurses. *Transfer of Care* described far more conflict between mothers and nurses though this may have been reflective of the inclusion of maternal data or may have been reflective of the culture of the time which had not fully embraced family-centered care. The participants in the current study were much more likely to include the parents in the decision to be in a PCN relationship whereas few of the participants in the Scharer and Brooks study involved parental input. This may be reflective of the era since family-centered care which encourages parental participation is emphasized more now than in the time of the Scharer and Brooks study. The Scharer and Brooks study described conflict and even competition between mothers and primary nurses. The current study revealed much less conflict between primary nurses and NICU infants' parents.

Two Norwegian studies, published in 2008 and 2009, describe the relationship that develops between primary nurses and NICU parents (Fegran et al., 2008; Fegran & Helseth, 2009). One study (Fegran & Helseth, 2009) concentrated on the relationship as a whole and its significance to parents and primary nurses as it develops in the NICU environment. It found that the physical proximity of the NICU environment often obliges both parents and the nurses to develop closer emotional ties and that this closeness engenders and supports trust-building. Primary nurses as professionals recognize the need to maintain some distance with the more experienced nurses understanding that maintaining distance helps them manage the inevitable emotional labor that can develop from these close relationships (Fegran & Helseth, 2009). The other study (Fegran et al. 2008) described the relationship that develops between primary nurses and families as

having three phases which tended to mirror the infant's progression: Acute critical, Stabilizing, and Discharge phase. The study also described how most primary NICU nurses slowly detached from the family as the infant became more stable and prepared for discharge under the parents' care. Both of these studies (Fegran et al., 2008; Fegran & Helseth, 2009) focused on a topic similar to the focus of the current study; that is, the development of the relationship between primary nurses and NICU parents. Fegran et al.'s study described the nurse-parent relationship in phases which roughly mirror the infant's progression through the hospitalization. The major differences between these two studies and the current study were that the Fegran studies were conducted in Norway, which differs significantly in society, economy, and health organization from those that exist in the Southern and Southwestern United States, where most of the participants in the current study resided and practiced. The Fegran studies also integrated the views of the NICU parents, which was not done in the current study. The current study also sought to identify an underlying theory while the Fegran studies did not articulate an independent theory or even theoretical basis for their study although they did overlay some of their findings onto Family-Centered Care (FCC), which is better described as a philosophy of care rather than theory. The current study also explored the relationship between parents and nurses after the infant is discharged home in greater depth.

Korhonen and Kangasniemi (2014) also described the termination of the relationship between NICU parents and primary nurses through in-depth interviews exploring NICU primary nurse's narratives. The study exposed three common narratives among the NICU primary nurses where the main plot was regulating the caring relationship along a closeness-distance axis. The Korhonen and Kangasniemi study had some

similarities to the current study in that it recognized the closeness that develops in PCN relationships and explored the continuation of the relationship between primary nurses and NICU families after the infant is discharged. Some of the differences were that the Korhonen & Kangasniemi study focused on NICU primary nurses in Finland where the social and healthcare environment is quite different from the current study's US-based participant population. The Korhonen & Kangasniemi study used Narrative methodology (Polkinghorne, 1995; Riessman, 2003) and did not seek or relate its findings to any underlying theory.

The current study adds better understanding of how relationships form between NICU primary nurses and their primary infants and families. The study added a deeper understanding of the motivations NICU nurses have for participating in PCN which is important since participating in PCN often relies on individual nurses to initiate the process. This enhanced understanding of nurses' experiences and motivations could help address the low rate of NICU infants assigned to primary nurses.

IMPLICATIONS

The substantive theory *Maximizing Impact* addresses the motivations of NICU nurses to engage in Primary Care Nursing (PCN). It explains how the relationship develops between the primary nurse, the NICU infant, and the infant's family during and after the infant's hospitalization. The theory has implications for nursing professional practice, bedside nurses, nursing leadership, healthcare organizations, education, and policy.

Nursing Professional Practice

This study's findings reveal that PCN can allow NICU nurses to practice in such a way as to make their efforts have the greatest effect on the infants in their care, the infants' families, and on the nurses themselves. PCN allows for development of long-term, in-depth relationships between the nurse and the infants and their families in the nurse's care and results in the nurse experiencing a more rewarding professional nursing practice. The nurse-patient relationship lies at the center of the nursing profession. Over the history of modern nursing history however, changes in care delivery driven by concerns of efficiency and finances rather than professional practice often de-prioritized the individual nurse-patient relationship. Primary care nursing has been described as a way to facilitate nursing professional practice as it encourages individual responsibility and autonomy of individual nurses (Manthey, 2002). The substantive theory *Maximizing Impact,* affirms these principles in that it allows the individual NICU primary nurse to feel that she as a professional has the capability, the agency, and the autonomy to *Safeguard Families.* The majority of the primary nurse's impact is implemented in the *Enacting* phase of *Safeguarding this Family.* The *Evaluating* phase of the relationship allows the primary nurse to assess the *Impact* of her practice. Even the *Seeking and Identifying* phase affirms the primary nurse's professional autonomy where she is empowered to choose which infants and families with which to initiate PCN.

This study reveals that not all nurses, even skilled and effective nurses, are suited to engage in PCN. There are certain innate characteristics of the successful primary nurse in the NICU including sincere belief in the effectiveness of PCN, willingness to engage in close relationships, emotional self-regulation, and a willingness to advocate for the family.

There is a fine balance to being close to the infant and family and maintaining professional boundaries. When relationships, such as those engendered by PCN, are very close and the infant experiences a devastating outcome, the primary nurse must learn and understand how to manage her own emotions and decide when or if to return to another PCN relationship.

Whereas poor outcomes are infrequent, primary nurses frequently contend with maintaining professional boundaries between themselves and the family. The study revealed that boundaries are a common struggle as the primary family often desires a deeper relationship with the nurse although professional standards and unit management often dictate stringent standards on certain kinds of contact between nurses and patients or parents. Most primary nurses restrict certain kinds of contact such as phone calls away from work and social media contact until the infant has been discharged home; then they often allow more contact as the nurse's caregiving relationship with the family has ended. The study reveals that primary nurses do not always know exactly how to manage and negotiate those boundaries and many need some sort of mentoring and compassionate guidance on this matter. This study illuminated the importance of the post-discharge relationship between the nurse and the nurse's primary infant and family in inspiring nurses to participate in future PCN relationships. This was illustrated dramatically by one participant who attributed her unit's recent prohibition of contact between nurses and parents after discharge to her decision to discontinue participating in PCN leading to the suggestion that prohibition of contact between the nurse and her primary infant and the family after discharge might tend to stifle PCN.

Another implication of this study is that PCN serves as its own motivator, an important factor given the known benefits of PCN. The final phase: *Evaluating,* serves as a driver for nurses to engage in future PCN allowing the primary nurse the opportunity to evaluate the infant and family in the long term. The post-discharge relationship lets the nurse witness the effects of her care; whether she was able to *Safeguard this Family* through observation of the infant and family long-term. Primary care nursing is largely described as voluntary, and it can be emotionally taxing; therefore, observing the infant's progress over time can be validating and inspire the primary nurse to engage in future PCN relationships. When a facility forbids or seriously restricts contact between former primary nurses and the families, it can inhibit the *Evaluating* phase and may inhibit a NICU nurse's desire to engage in PCN, and, potentially, the desire of other NICU nurses to engage in PCN.

The focus of this study has been the nurses who provide PCN in the NICU; nevertheless, the study could have implications to other areas of nursing practice that serve populations that have long hospitalizations, particularly those in which there is intense family involvement such as pediatric units caring for children with chronic conditions, oncology, and long-term care. Although the substantive theory *Maximizing Impact* addresses primary nursing care relationships; the theory could inform any healthcare setting that involves long-term relationships especially those where the families are highly involved in care such as primary care settings, and settings that provide physical, occupational, and speech therapy especially those in pediatrics or geriatrics.

Healthcare Organizations

The implications of this research for healthcare organizations include reaping the benefits of improving outcomes for infants, families, and nurses. Enhanced understanding of the process of relationship formation between NICU primary nurses and families has the potential to increase the utilization of PCN within the NICU environment. The Institutes of Medicine have long recommended healthcare redesign where delivery is evidence-based, patient-centered, and relationship-based (Kohn et al., 1999). Organizational changes over the last few years have brought about an environment that includes many challenges to maintaining continuity of care, even in the presence of PCN; such changes as the increased numbers of part-time care providers and those working fewer days per week due to twelve-hour shifts (Grinspun, 2002). In the present environment where outcomes can dictate compensation, healthcare organizational concerns extend beyond staff turnover and absenteeism and now include patient outcomes such as length of stay, patient (parent) satisfaction scores, and infection rates; PCN has been shown to affect or mediate all of these outcomes (Alexander et al., 1981; Dal Molin et al., 2017; Gardner, 1991; Mefford & Alligood, 2011; Melchior et al., 1999).

Understanding that PCN is beneficial to the infants, families, nurses, and consequently, to healthcare organizations, the organizations could benefit from efforts to support nurses who engage in PCN. While it is understandable that some healthcare organizations might have concerns about overly familiar relationships between nurses and families post-discharge, the benefits in encouraging future PCN relationships might suggest more forbearance. Neonatal units could encourage PCN practice by supporting the nurses who choose to practice PCN through recognition and reward, by allowing PCN

experience to count towards advancement in a clinical ladder, or on the nurse's clinical evaluation for merit raises. Primary care nursing should be one of several items that could assist a nurse's career advancement, thereby recognizing that not all nurses are suited to PCN, and that nurses who are not suited to PCN can offer value in different ways.

The NICU could also support PCN relationships by having charge nurses ensure that primary nurses are given priority assignment to their primary patients. Recognizing that coping with the emotional toll of PCN can be taxing, NICUs could encourage participation in support groups for PCN nurses where nurse participants could voice their concerns, express their emotional needs, and share coping techniques with peers also engaged in PCN. This kind of support group could be especially beneficial to nurses interested in engaging in PCN as well as newer nurses as they navigate the complexity often involved in PCN relationships. Support groups could also be helpful as peer-to-peer support when the nurse's primary infants suffer devastating events; an experience poorly understood except by those who themselves have gone through such events.

Education

The study has implications for nursing education, both initial nursing education and professional education for practicing nurses. None of the participants discussed learning about PCN while they were receiving their initial education. Nursing students could benefit from learning about different care delivery methods, their advantages and disadvantages, and common concerns with each care delivery method. Practicing PCN while students or early in their career may not be appropriate, and several of the study participants reported that their units required a minimum of two years' experience before engaging in PCN. Experienced primary nurses can model PCN for newly practicing nurses in the NICU in

order to demonstrate techniques for building relationships. Support groups (discussed in healthcare organization section above) could be open to newly practicing nurses with an interest in PCN in order to disseminate knowledge and stimulate interest in PCN.

Professional education also could be offered for nurses either interested in or currently practicing PCN. Such education could focus on a formal review of PCN, practical tips for implementation, and guidance on the trickier aspects of PCN, including professional boundary issues. Education could be integrated into support group sessions to offer a framework for discussions for the group members as well as increasing knowledge. Current primary nurses also should be offered education on the importance of self-care, especially following devastating outcomes for their primary infants.

SIGNIFICANCE

The current study offers several significant contributions to the current knowledge on PCN, especially within the NICU environment. Classical Grounded Theory has never been used to explore the formation of PCN relationships. The current study offers a substantive theory, *Maximizing Impact,* that explains why and how NICU nurses engage in PCN. The study further reveals an underlying process, *Safeguarding this Family,* that explains how NICU primary nurses resolve their need to *Maximize (their) Impact* by forming PCN relationships with their primary infants and families. The current study also highlighted how having close and long-lasting relationships between NICU nurses and families is actually part of the process *Safeguarding this Family* and in turn contributes to the primary NICU nurses' motivations to engage in future PCN. Observing long-term effects on the family including not only the infant's physical outcomes but also the family's

psychological and emotional outcomes helps the NICU primary nurse understand if she has truly *Maximized (her) Impact.*

Understanding the implications of *Maximizing Impact* can offer guidance for institutions and their leadership on how to support and encourage their staff to engage in PCN. Additionally, the current study offers insights regarding PCN that can be integrated into initial and continuing professional nursing education to enhance knowledge of care delivery systems in general, and PCN more specifically

STUDY STRENGTHS

This is the first study that utilized Classical Grounded Theory to explore primary NICU nurses' descriptions of how they develop relationships with their primary infants and families. Use of CGT allowed the emergence of a substantive theory, *Maximizing Impact,* that explains how NICU primary nurses go about developing and sustaining the relationship with parents of at-risk infants, a relationship that gives the nurse, and thereby the entire healthcare team greater depth of understanding of what parents need in order to take on the care of the infant, and thereby enhances the development of the family's long-term relationship. The study participants were primary NICU nurses from several geographic locations and a number of different hospitals allowing diversity of the study participants and richness of the study data.

Another study strength was that it used real data from current NICU nurses actively practicing PCN. Due to the procedures assuring that all study findings remained grounded in actual data, the theory that emerged works to understand and explain what is actually going on with how and why PCN relationships form in the NICU between nurses and families. Finally, the study's theory and findings are modifiable, and through modifiability can maintain and expand their usefulness to healthcare settings beyond the NICU.

STUDY LIMITATIONS

A modest study sample (n=11) could be considered one of the study's limitations. Although there was some diversity among the study participants, many of the participants were from the same general geographic area and most were females (females = 10, males = 1). The study only examined the perspectives of NICU bedside nurses and not parents, who are essential elements of the PCN relationship; nevertheless, the focus of the study was the perspective of the nurses themselves. Study participants were self-selected, and were currently practicing PCN; nurses who no longer chose to participate in PCN were excluded from the sample with the potential result that the study did not include the perspectives of such nurses. This may have limited data especially regarding primary nurses who had negative experiences that had driven them away from PCN.

SUGGESTIONS FOR FUTURE RESEARCH

Future research could seek to develop the substantive theory *Maximizing Impact* into a formal theory by testing the applicability of the theory in other arenas of nursing practice. Alternatively, research using a similar approach could be conducted in other nursing fields such as pediatrics, oncology, long term care, and rehabilitation where there may be intense family involvement over a long period of time allowing close provider-family relationships to develop. Since many of the findings in this study did not relate directly to nursing-exclusive functions, findings of this study could also guide future study of long-term provider-family relationships in other fields such as primary care medicine or speech, occupational, and physical therapy.

Future study could focus more on the patients (when appropriate) and families involved in PCN relationships. This could involve study of their experiences alone, or

alongside some of their PCN providers in order to explore specific relationships as a whole. Future study also could involve the experiences of former primary nurses in order to understand their motivations for no longer participating in PCN practice. This would be especially enlightening if the primary nurse had practiced for some significant period of time before choosing to cease participation in PCN. Future study also could assess the effects of PCN on outcomes including those affecting parents such as confidence in caring for their infant, or satisfaction with care.

While the current study included participants from several States, expanding into different geographic areas could help either confirm current findings or if there are significant differences, could aid in modifying the original theory. Since PCN is practiced internationally, studies could be conducted in different countries in order to assess the effect of differing social environments on the practice of PCN and the development of PCN relationships.

CONCLUSION

Although primary care nursing (PCN) has consistently shown benefits for patients throughout decades of study, implementation is often low and benefits to nurses are less clear. Prior to the current study there has been little understanding of the experiences of primary nurses and little recent effort to articulate theories to explain the formation of the primary care nursing relationship in the NICU setting. This study explored how PCN relationships develop between primary nurses and NICU families using Classical Grounded Theory. The substantive theory *Maximizing Impact* emerged from analysis of data collected from experienced NICU primary nurses. *Maximizing Impact* offers insight on innate characteristics of primary NICU nurses, how relationships are initiated,

developed, and transformed over time through the four-phase process *Safeguarding this Family*. The study also clarifies the importance of the long-term transformed relationships in spurring these nurses to take on subsequent primary patients and families. The substantive theory has implications for all who engage or have interest in PCN including bedside nurses, healthcare organizations and their leadership, and nursing educators. The study also has implications for future research on nurse-patient relationships, especially those relationships developed in patient-centered care delivery systems such as primary care nursing.

APPENDIX A: INSTITUTIONAL REVIEW BOARD APPROVAL

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Institutional Review Board
301 University Blvd.
Galveston, TX 77555-0158
Submission Page

16-May-2018

MEMORANDUM

TO: Stephanie Bailey
Grad School Biomedical Science GSBS9999

FROM: Dwight Wolf, MD
Chairman, IRB #2

RE: Initial Study Approval

IRB #: IRB # 18-0090

TITLE: A Grounded Theory of Primary Nursing Relationships in the Neonatal Intensive Care Unit

DOCUMENTS: Research Protocol version 16-1-2018
Fast Fact sheet
Verbal Consent Script

The UTMB Institutional Review Board (IRB) reviewed the above referenced research protocol via an expedited review procedure on **11-May-2018** in accordance with 45 CFR 46.110(a)-b(1). Having met all applicable requirements, the research protocol is approved for a period of 12 months. The approval period for this research protocol begins on **16-May-2018** and lasts until **11-May-2019**.

The requirement to obtain informed consent is waived in accordance with 45 CFR 46.116(d).

The research protocol cannot continue beyond the approval period without continuing review and approval by the IRB. In order to avoid a lapse in IRB approval, the Principal Investigator must apply for continuing review of the protocol and related documents before the expiration date. A reminder will be sent to you approximately 90 days prior to the expiration date.

The approved number of subjects/medical records/specimens to be enrolled/utilized is **25.00**. If, the approved number needs to be increased, you first must obtain permission from the IRB to increase the

APPENDIX B: IRB TRANSITION TO FLEXIBLE REVIEW

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Institutional Review Board
301 University Blvd.
Galveston, TX 77555-0158
Submission Page

30-Dec-2018

MEMORANDUM

TO: Stephanie Bailey
Grad School Biomedical Science GSBS9999

FROM: Dwight Wolf, MD
Chairman, IRB #2

RE: Transition to Flexible IRB Review

IRB #: IRB # 18-0090

TITLE: A Grounded Theory of Primary Nursing Relationships in the Neonatal Intensive Care Unit

DOCUMENTS: Protocol Dated March 15 2018, Fast Fact Sheet and Verbal Consent Script

The UTMB Institutional Review Board Chairman or designee has reviewed the above-reference research protocol due to recent revisions in the IRB policies. Having met all the applicable requirements, the research protocol is approved for continuation on **30-Dec-2018**.

Please Note: Continuing Review for this research protocol is no longer required under UTMB IRB Policy 24.1 - Flexible IRB Review. However, a Status Report is required to be submitted to the IRB every three (3) years. A reminder will be sent approximately 90 days prior to its due date.

It is your responsibility to:

1. Obtain prior IRB approval for any modifications including addition of new recruiting materials, changes in research personnel or site location, funding source, sponsor amendments or other changes to the protocol or associated study documents.
2. Report all Unanticipated Problems, protocol violations and unresolved subject complaints as outlined in the IRB Policies and Procedures Section 8.
3. Submit a Notice of Study Closure once project is complete, or when personal identifiers are removed

APPENDIX C: STUDY RECRUITMENT FLYER

Are you a Primary Care Nurse?

Do you regularly "primary" babies and their families in the NICU?

Are you willing to take part in a research study regarding your experiences with the primary care nurse's relationship with the infant and family?

If interested, please contact:

Stephanie Bailey RN-C, BSN

sjbailey@utmb.edu

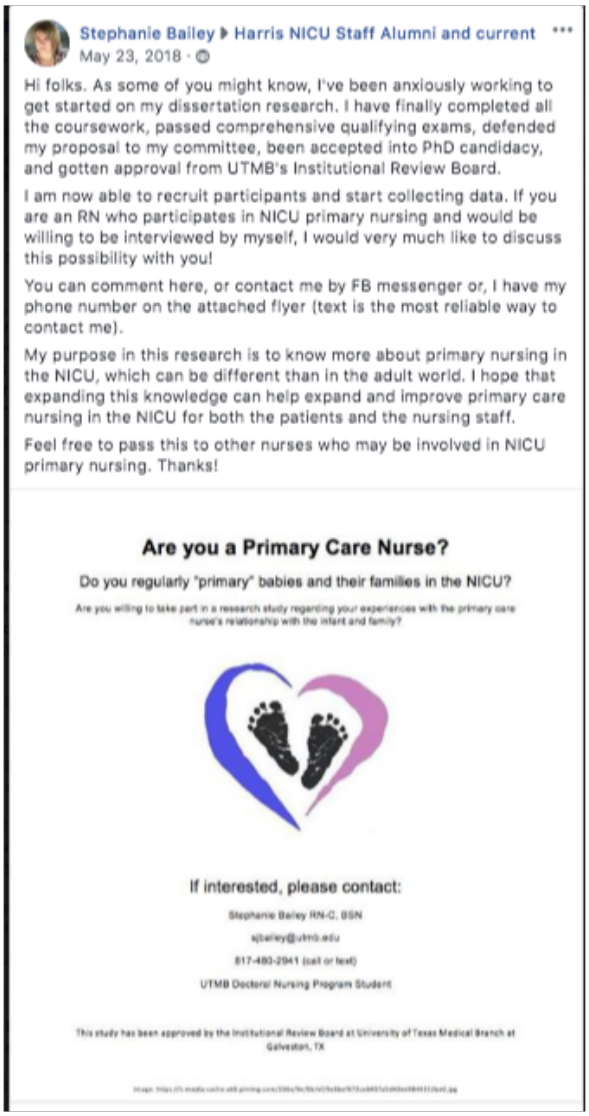
817-480-2941 (call or text)

UTMB Doctoral Nursing Program Student

This study has been approved by the Institutional Review Board at University of Texas Medical Branch at Galveston, TX

Image: https://s-media-cache-ak0.pinimg.com/236x/9e/0b/ef/9e0bef672ce6437a5d40ee9849352be0.jpg

APPENDIX D: RECRUITMENT FACEBOOK POST FOR HARRIS NICU GROUP



Stephanie Bailey ▸ Harris NICU Staff Alumni and current
May 23, 2018 ·

Hi folks. As some of you might know, I've been anxiously working to get started on my dissertation research. I have finally completed all the coursework, passed comprehensive qualifying exams, defended my proposal to my committee, been accepted into PhD candidacy, and gotten approval from UTMB's Institutional Review Board.

I am now able to recruit participants and start collecting data. If you are an RN who participates in NICU primary nursing and would be willing to be interviewed by myself, I would very much like to discuss this possibility with you!

You can comment here, or contact me by FB messenger or, I have my phone number on the attached flyer (text is the most reliable way to contact me).

My purpose in this research is to know more about primary nursing in the NICU, which can be different than in the adult world. I hope that expanding this knowledge can help expand and improve primary care nursing in the NICU for both the patients and the nursing staff.

Feel free to pass this to other nurses who may be involved in NICU primary nursing. Thanks!

Are you a Primary Care Nurse?

Do you regularly "primary" babies and their families in the NICU?

Are you willing to take part in a research study regarding your experiences with the primary care nurse's relationship with the infant and family?

If interested, please contact:

Stephanie Bailey RN-C, BSN

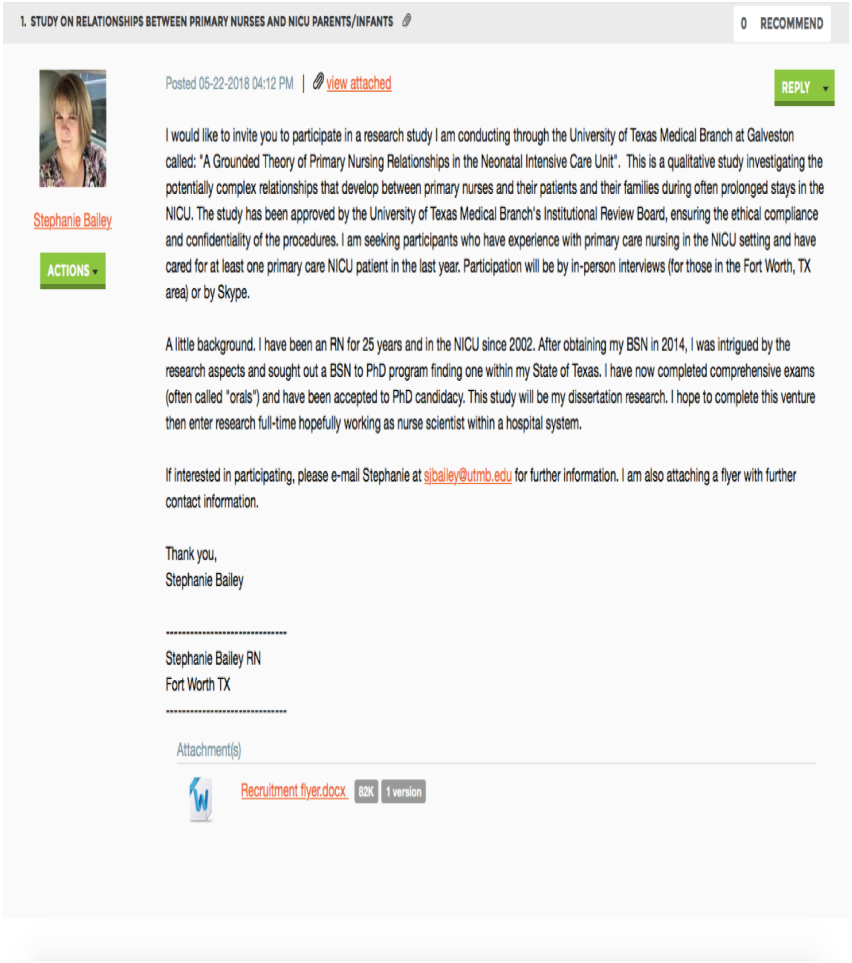
sjbailey@utmb.edu

817-480-2941 (call or text)

UTMB Doctoral Nursing Program Student

This study has been approved by the Institutional Review Board at University of Texas Medical Branch at Galveston, TX

APPENDIX E: NANN COMMUNITY RECRUITMENT POST



1. STUDY ON RELATIONSHIPS BETWEEN PRIMARY NURSES AND NICU PARENTS/INFANTS

0 RECOMMEND

Posted 05-22-2018 04:12 PM | view attached

REPLY

Stephanie Bailey

ACTIONS

I would like to invite you to participate in a research study I am conducting through the University of Texas Medical Branch at Galveston called: "A Grounded Theory of Primary Nursing Relationships in the Neonatal Intensive Care Unit". This is a qualitative study investigating the potentially complex relationships that develop between primary nurses and their patients and their families during often prolonged stays in the NICU. The study has been approved by the University of Texas Medical Branch's Institutional Review Board, ensuring the ethical compliance and confidentiality of the procedures. I am seeking participants who have experience with primary care nursing in the NICU setting and have cared for at least one primary care NICU patient in the last year. Participation will be by in-person interviews (for those in the Fort Worth, TX area) or by Skype.

A little background. I have been an RN for 25 years and in the NICU since 2002. After obtaining my BSN in 2014, I was intrigued by the research aspects and sought out a BSN to PhD program finding one within my State of Texas. I have now completed comprehensive exams (often called "orals") and have been accepted to PhD candidacy. This study will be my dissertation research. I hope to complete this venture then enter research full-time hopefully working as nurse scientist within a hospital system.

If interested in participating, please e-mail Stephanie at sjbailey@utmb.edu for further information. I am also attaching a flyer with further contact information.

Thank you,
Stephanie Bailey

Stephanie Bailey RN
Fort Worth TX

Attachment(s)

Recruitment flyer.docx 82K 1 version

APPENDIX F: FAST FACTS SHEET

FAST FACT SHEET **IRB# 18-0090**

Study Name: A grounded theory of primary nursing relationships in the neonatal intensive care unit.

Contact Information:

Principal Investigator:	Stephanie Bailey	Office/Cell: 817-480-2941
Faculty Chair:	Carolyn Phillips	Office 409-772-8234

Purpose:

This study is to better understand how relationships between NICU primary nurses and the families of NICU infants develop during and after hospitalization of the infant. Better understanding of these relationships and possibly developing an underlying theory could help increase the quality and frequency of NICU primary nursing and better support staff who engage in these relationships.

Concise Summary:

Participants will provide verbal consent after an explanation of the expected interview procedures. Interviews will be recorded and may last up to 90 minutes initially. Participants may be asked to participate in a follow up interview which would last no more than 30 minutes.

The interview will occur in a mutually agreed upon venue which will be one of the following: 1. A quiet private location where the researcher will meet in person with the participant. 2. Video chat between the participant and researcher over a secure internet connection. The researcher will be in her private office and will encourage the participant to be in similarly quiet private location.

Risks/Benefits:

Some of the questions we may make the participant feel uncomfortable. They may refuse to answer any of the questions, take a break or stop their participation at any time. In order to keep the participant's identity and information confidential all identifying names and locations will be replaced with generic codes before analysis.

We hope the information learned from this study will benefit primary nurses and their patients in the future through better understanding of the way primary nursing relationships develop.

Questions:
For questions about the study, contact Stephanie Bailey or Dr. C. Phillips at the numbers listed above.

APPENDIX G: NARRATIVE TO OBTAIN ORAL CONSENT

Narrative for Obtaining Verbal Consent

We've talked about your willingness to participate in my research study regarding your experiences of developing a relationship with your primary care infants and their families. This is part of my course of study at the University of Texas Medical Branch at Galveston, Texas.

My research interest is focused on the experiences and thoughts of primary care nurses with their primary infants and those infant's families. You've identified that you are a bedside nurse that has experience with primary care nursing in neonatal ICU. There are some risks in participating but they are minor. There could be a loss of confidentiality about the information you provide and you might become emotionally distressed thinking about the questions. In an effort to protect the privacy of your information, I will assign you a participant ID that will be used instead of your name. All information that could personally identify you will be removed or masked. If you become emotionally distressed during the interview, I will pause and ask you if you wish to continue. You are free to stop participating at any point and for any reason.

The information I'm going to ask you will be regarding your demographics and also the questions about my research interest: relationships between primary nurses and their infants and families. I don't anticipate this interview will go over 90 minutes but I might ask you for one follow-up interview. The follow-up interview should be shorter.

There are some potential benefits that could arise from this research. These may include enhanced knowledge about how primary care nursing works for yourself in your practice. The study may also potentially help identify needs for education of nurses about primary care nursing and identify ways to grow the numbers of NICU nurses who participate in primary care nursing. Additionally, if the number of NICU nurses participating in primary nursing increases, then more NICU families could benefit from the relationships with primary nurses and the enhanced care these nurses provide.

You may stop the interview and completely withdraw from the study at any time. You may also refuse to answer any question posed in this study. I can provide a list of counseling resources you can pursue if you indicate you feel the need.

Are there any questions for me regarding your participation or about the study in general? (Researcher will pause and answer any questions that are posed. Once the questions are answered, the researcher can proceed to the next question).

Can you confirm that you are still willing to participate in this study? If you confirm this, you agree that I can now turn on the recording device to begin the data collection—the questions.

APPENDIX H: INTERVIEW GUIDE

Interview Guide

Demographic Information:

Age:

Gender:

Years in Nursing:

Number of years you have been involved in Primary Care Nursing (PCN):

Years in NICU nursing:

Years you have been involved in PCN in the NICU:

General Questions:

Tour question:

> We've discussed how my interest is in how primary care nurses develop relationships with the infants and families. I'd really like to hear your thoughts on about that.

Probe:

> What do you like about primary nursing care? (What things about PCN make you wish you *always* had a primary?

Probe:

> What are some of the difficulties you face as a primary nurse? (What things make you think you will *never* primary another infant again?)

Tour question:

> What do you think it takes to be a good primary nurse?

Tour question:

> Are you allowed to select your primaries? If so, how do you decide on a primary?

Probe:

> Tell me about taking on families that others have termed difficult?
> Have you watched other nurses deal with "difficult families"?

What did you think of how they handled things?

Probe:

Tell me about a primary patient and family you were especially close with and some that you weren't.

How do you deal with families that won't engage or have disengaged?

Tour question:

Can you tell me about experiences with following families past discharge?

Probe:

Who is "in charge" of the decision to follow the infants and families to discharge or after?

Probe:

Tell me about following up with infants and their families after discharge.

Tour question:

Have you brought any items (pictures, crafts, cards, letters) you would like to show me and tell me about?

Tour question:

Is there anything else about PCN you would like to add that we haven't discussed so far?

Tour question:

May I contact you again for more questions or for a follow-up interview?

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