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Caring for a Preterm Infant during the First Six Months Post NICU Discharge:

A Mother's Perspective

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at
Virginia Commonwealth University

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Chapter One

Overview

There are numerous studies in the current literature focusing on the intense emotions experienced by parents, following the birth of a preterm infant, (i.e., born prior to 37 weeks gestational age [GA]). Research findings have helped us understand the fear and anxiety they feel while attempting to navigate the neonatal intensive care unit (NICU) environment. What happens in those early weeks and months at home after discharge, however, is surprisingly absent from the literature. It is well known that preterm infants are readmitted to the hospital during the first few months after discharge at a rate of 10% - 35%, for an average 4.7 - 11.7 day stay and a cost of approximately \$376 million (Underwood, 2007; Escobar, et al., 2005). The most common reasons for readmission are respiratory, feeding and jaundice problems (Spicer, et al., 2008; Underwood, 2007; Escobar, et al., 2005; Brissaud, et al., 2005). What we don't yet know is what transpired during those early days and weeks at home and how mothers established their day-to-day routines. This missing information could foster a better understanding of family needs and promote the development of strategies to share with mothers prior to discharge, with the result being healthier transitions for both mothers and infants and a possible reduction in the inflated readmission rates for this cohort.

The purpose of this research was to help bridge the gaps in the literature on the topic of transitioning a preterm infant to home following NICU discharge. Eight mothers who met the criteria of having a preterm infant born between 24 and 34 weeks GA, admitted to a NICU for a week or more, and who had been discharged to home for 6 months or less, were purposefully chosen from a convenience sample. Each mother was interviewed and asked to describe those first few months at home, e.g., how she met her infant's needs, what she learned, and how she learned it. Two follow up questions were included and asked the mother what she would like us (HCPs) to know about her experience, and what she would say to other mothers whose infants were still in the NICU.

Most mothers spoke at length of the fear they felt when bringing their infants home, and how inadequate they felt trying to provide care that had heretofore been provided by a team of specialists. They described the

difficulty and confusion associated with getting their infants to sleep in a quiet home environment until they thought to duplicate the noises of the NICU, and how the monitors, which all infants wore home from the NICU, were both friend and foe, alerting them to potential problems, but awakening the entire household in the process. Each mother also spoke of her determination to do whatever was necessary to ensure that her infant was not rehospitalized, and how thankful she was that her infant had made it to this point.

Although each mother described a different approach to meeting the challenges associated with her infant, there was a consistency in the overall challenges each mother experienced. Most mothers wanted HCPs to know they were thankful for the part each had played in saving their infant's life but they also wanted to impart their parental wisdom on the best ways to give information to a parent, the need for uniformity in what they called the "rules" of the NICU, and how a little encouragement from any HCP was sorely needed by most parents.

These mothers were excited to be taking part in this study. They wanted to feel that something they saw, felt or did would make a difference for another mother with an infant in the NICU. Each thanked me for allowing them to share their experiences with me.

The references for this document will appear at the end of each section.

Chapter Two

Caring for a Preterm Infant during the First Six Months Post NICU Discharge:

A Mother's Perspective

A Dissertation Proposal

Lois Phillips-Pula

Virginia Commonwealth University

Hypothesis

There are numerous studies in the current literature focusing on the intense emotions experienced by parents, following the birth of a preterm infant, (i.e., born prior to 37 weeks gestational age [GA]). Research findings have helped us understand the fear and anxiety they feel while attempting to navigate the neonatal intensive care unit (NICU) environment. What happens in those early weeks and months at home after discharge, however, is surprisingly absent from the literature. It is well known that preterm infants are readmitted to the hospital during the first few months after discharge at a rate of 10% - 35%, for an average 4.7 - 11.7 day stay and a cost of approximately \$376 million (Underwood, 2007; Escobar, et al., 2005). The most common reasons for readmission are respiratory, feeding and jaundice problems (Spicer, et al., 2008; Underwood, 2007; Escobar, et al., 2005; Brissaud, et al., 2005). What we don't yet know is what transpired during those early days and weeks at home and how mothers established their day-to-day routines. This missing information could foster a better understanding of family needs and promote the development of strategies to share with mothers prior to discharge, with the result being healthier transitions for both mothers and infants and a possible reduction in the inflated readmission rates for this cohort.

This proposed study will bridge the gap in the literature by speaking with mothers of preterm infants who have been discharged from a NICU and have been home from one to six months. This period is considered important because of the wide range of developmental processes that take place during this time in an infant's life and because there is currently little-to-no information in the literature speaking to parental needs during this early post-discharge period. Studies have demonstrated that mothers of preterm infants expressed high levels of angst and depression coupled with feelings of incompetence during those first few weeks and months at home; whereas around the one-year mark they rated their abilities to provide adequate care for their infants at the same levels as mothers of full term infants of the same age

(Feeley, Zelkowitz, Cormier, Charbonneau Lacroix & Papageorgiou, 2009; Olshtain-Mann & Auslander 2008; Gennaro & Hennessy, 2003; Ternstedt & Schoolin 2003; Pridham, Lin & Brown 2001).

Specific Aims

The aim of this study is to construct a basic understanding of a mother's experiences caring for her preterm infant during the first six months following NICU discharge. There is currently no cohesive body of knowledge on this topic and so standards of practice, which could guide health care providers in teaching mothers how best to care for their preterm infant, have not been well developed or truly evidence-based. These findings will serve to inform healthcare providers of the needs of parents and infants once NICU discharge has occurred, and can serve as an evidence base from which to design discharge education.

Background and Significance

The birth of a healthy newborn is usually a celebrated event, with parents expressing joy at their accomplishment and making plans for a bright future (Ruchala, 1999). Mothers of preterm infants, however, face a different reality. In addition to feelings of sorrow, distress and grief, their coping skills are immediately challenged as their newborn is whisked away to the NICU and they are faced with whether the infant will survive and if so, what the long term effects might be (Griffin, J., 2010; Poehlmann, Schwichtenberg, Bolt & Dilworth-Bart, 2009; Kowalski, Leef, Mackley, Spear, & Paul, 2006; Bakewell-Sachs & Gennaro, 2004). This separation of mother and infant robs both of early bonding opportunities and the necessary time for mothers to learn early infant cues. Based on national averages, the average NICU stay is approximately 13 days, and is inversely related to an infant's GA, with infants at lower GA spending more weeks and sometimes months in the NICU (Berns, Boyle, Popper & Gooding, 2007). This forced separation severely limits the mother's ability to function in a normal parenting role, and results in the continued erosion of the maternal-infant bonding processes (Berns, et al.; Griffin & Abraham, 2006; Broedsgaard & Wagner, 2005). This combined emotional toll can result in

mothers of preterm infants exhibiting high levels of posttraumatic stress and other adverse mental health outcomes both during the NICU hospitalization and in the weeks and months post discharge (Feeley, Zelkowitz, Cormier, Charbonneau Lacroix & Papageorgiou, 2009; Melnyk, Crean, Feinstein & Fairbanks, 2008; Gennaro & Hennessy, 2003; Ternestedt & Schoolin 2003).

Preterm birth is a serious healthcare challenge in the United States with approximately 12.5% (approximately 1,500) of the 12,000 babies born each day making their arrival prior to 37 (completed) weeks GA. Of those 1500 infants, approximately 1.3% or 200 are born very (less than 32 weeks GA) preterm; and 1.2% or 173 are born at very low (less than 1,500 grams) birthweight (March of Dimes, 2009). In 2005, it was estimated that the total bill for medical care (including NICU admission), special education services and missed work days by parents of preterm infants totaled \$26.2 billion, or \$51,600 per infant (Callaghan, 2010; Armstrong & Meis, 2007).

There are several myths, assumptions, biases and perceptions surrounding the impact of NICU discharge on family members including:

Family stress decreases once an infant is discharged: The birth of a preterm, very low birthweight (VLBW) infant, especially during the first years of life, can have a formidable impact on the health of families. (Saigal, Pinelli, Streiner, Boyle & Stoskopf, 2010). In families of lower socioeconomic status or where the infant experienced neurological sensory injury (NSI), maternal stress remained at high levels and families reported emotional and health problems continuing through adolescence (Saigal, et al.). Mothers reported being always tired and experiencing a hollowness that continuously undermined their ability to bond with their infant (Jackson, Ternestedt & Schollin, 2003).

Long-term economic impact on the family of preterm infants can be mitigated through public assistance programs which pay for follow-up medical care: A follow-up study of preterm infants who had reached young adulthood conducted by Saigal et al., (2010) found that mothers and fathers reported that job advancements such as promotions, chances for continuing education, etc., were negatively impacted

by the birth of their preterm infant. Families of young adults with continuing intellectual disabilities reported lower average incomes, lower family savings and mothers who were either unable to work fulltime or to keep employment for more than five consecutive years due to missed work (Balakrishnan, et al., 2010; Saigal, et al., 2010; Singer, et al., 2007; Pohlman, 2005).

NICU discharge is a day of great positive energy for the mother: The transition to home is a time of vulnerability and a dichotomy of emotions for parents, with excitement tempered by the stress and anxiety they feel as they question their ability to provide adequate care for their infant who they may consider fragile and vulnerable (Willis, 2008; Bakewell-Sachs & Gennaro, 2004). Additionally, preterm infants have a greater chance of central nervous system immaturity and physical and behavioral problems, which can add further challenges for new parents (Wade et al., 2008; Willis, 2008; Bakewell-Sachs & Gennaro, 2004). Infants may be discharged with treatment modalities such as supplemental oxygen, specialized medications, tube feedings, etc., being continued at home. These continuing needs can overwhelm even the most well-prepared mother, leaving her with feelings of sadness and guilt (Lasby, Newton, Platen, 2004).

Mothers are taught all they need to know about caring for their infant during the NICU stay: In a study conducted by Miquel-Verges, Donohue & Boss (2010) 36 Latino parents were interviewed regarding NICU instructions. Nearly half (47%) of mothers reported receiving less than 1 hour of discharge teaching from NICU staff; 47% reported feeling prepared to take their infant home; 49% felt “somewhat” prepared (pg. 42); 3% were not sure, and even though 69% were hospitalized for more than two weeks, 85% of the mothers were unable to name any specific problem for which their infant might be at risk after discharge. There also appears to be differences between what discussions the staff had with parents prior to discharge and what parents were able to recall being discussed, demonstrating the degree of stress these mothers are under (Sneath, 2009).

Research Method and Design

The methodology proposed for this study is phenomenology. Immanuel Kant in 1764 defined

phenomenology as the study of phenomena or things (Speziale & Carpenter, 2007). Phenomenology as a scientific method was greatly influenced by Edmund Husserl (1859-19380), who proposed that the best way to understand a phenomenon was to seek information from those who had experienced it. Phenomenology was described by Spiegelbert and Merleau-Ponty as a method and a philosophy, and as such was grounded in the philosophical traditions of Husserl who believed that the act of being *present* during interviewing could facilitate a researcher's ability to understand a study participant's point of view (Phillips, Strunk & Pickler, 2009). Husserl's heart was on the meaning, the essence or central theme of an experience (Phillips, Strunk & Pickler).

Phenomenology is recognized as a methodology which employs rigorous investigation of a phenomenon as it was consciously experienced by another. Its purpose is to identify the essence of the experience which accurately portrays the phenomenon of interest, as seen through the consciousness of those experiencing it. The focus of inquiry is on developing meaning and understanding by revisiting the experience and listening to the stories of study participants (Moustakas, 1994). In order for the researcher to approach the topic with naiveté, sans *a priori* notions, an epoche process is undertaken to identify and note all preexisting thoughts about the phenomenon. The epoche process prepares the researcher to accept and represent the study participants' experiences exactly as presented, devoid of personal judgments (Moustakas). There are several valid approaches to phenomenology, each with slightly different procedures for collecting and analyzing data. Transcendental phenomenology, as informed by Clark Moustakas, is the approach chosen for this study. The Moustakas phenomenological approach involves the following steps:

1. Discover a topic rooted in an experience or phenomenon which has not previously been studied. Employ the epoche process to ensure that preconceived biases are not allowed to overshadow essential descriptions;
2. Conduct a comprehensive review of the professional and research literature noting design, methods and findings of previous studies;

3. Develop criteria to locate and contact study participants;
4. Provide study participants with instructions on the nature and purpose of the investigation;
5. Develop a question or broad topic to begin the interview process;
6. Conduct a person-to-person interview focusing on a specific topic and/or question, and report data exactly as presented by participants.

Moustakas recommended that researchers conduct face-to-face interviews with study participants in order to better grasp the context in which the phenomenon was experienced. He taught that interviews should take place wherever study participants were most comfortable (Moustakas, 1994). The setting for this study will be the study participant's home or another location of her choice. The focus will be on providing a comfortable, private and safe environment for the interviews to take place.

Concepts and terms specific to the Moustakas method of transcendental phenomenology include:

- *A priori*: From before, e.g., thoughts that exist through insight or intuition about a topic and are generally accepted as true.
- Essence: The central theme as verbalized by study participants.
- Epoche: A process whereby the researcher seeks to identify and note all consciousness and unconscious *a priori* thoughts regarding the phenomenon of interest.
- Transcendentalism: The ability to move beyond normal bound to identify both conscious and unconscious beliefs and biases (Husserl, 1970).
- Imaginative variation: The researcher's acceptance of whatever study participants state about a phenomenon as being a truth (Phillips, Strunk & Pickler, 2009).
- Intentionality: The act of being consciously present with study participants as they relate their experiences (Moustakas, 1994).

Rigor in qualitative research is not designed to be added as an epilogue but should be built into the study design from inception (Cohen & Crabtree, 2008). Four areas which assist in supporting rigor

are: Credibility, transferability, dependability, and confirmability (Speziale & Carpenter 2007; Hanks, 2008; Tuckett, 2005). Keeping good field notes contributes to a study's credibility. In addition to providing an additional data source, they also call attention to the context in which something is stated, or the body language being exhibited by study participants as they discuss a topic. Within the Moustakas method of phenomenological research, tape recordings are transcribed verbatim, adding to the credibility of findings. Transferability is supported through purposeful sampling of study participants and speaks to the probability that study findings will have meaning and importance to others. It is established by clearly and accurately presenting findings. Dependability addresses the constancy of findings and is supported through the keeping of accurate field notes that will provide an easily-followed trail from data collection to results. Peer review is also an important element of dependability and will be employed for this study. Reviews will be completed by another doctoral candidate who has an understanding of and will be using the Moustakas methodology for her research. Peer review helps acknowledge and work towards eliminating researcher bias. Confirmability is an area that has been challenging to attain in qualitative research. When dealing with human subjects, change sometimes happen on a moment-to-moment basis making it nearly impossible to duplicate original research findings. By employing detailed field-notes taking and providing enough data for an audit to be completed if needed, this important condition can be met.

Data Analysis Plan

Data will be analyzed using the Moustakas method of phenomenological data analysis. These steps include:

- Organizing the data by studying the transcribed interviews and forming preliminary groupings of information.
- Looking for and highlighting each experience that is relevant to the phenomenon of interest.

This is referred to as “horizontalization” (Moustakas, 1994, pg. 120). Each statement is given

equal value during this step.

- Reducing the data by testing whether or not a statement effectively addresses the phenomenon of interest and whether or not it's possible to label it. If statements don't meet the two requirements, they are discarded along with statements that are redundant, overlapping or vague. The remaining statements provide a structural meaning of the phenomenon.
- Clustering the remaining accounts into broad themes that will be used to develop the "textural descriptions" of the experience (pg. 118).
- Integrating the individual textural descriptions of the phenomenon into an overarching meaning of the experience, reflective of the essences as expressed by participants.

Human Subjects

The study participants will be drawn from a purposive sample of mothers whose preterm infants were discharged from a NICU within the past six months. Because this is a phenomenological study, there is no set number of participants required. However, it is anticipated that there will be from 6 to 15 mothers who participate. Inclusion criteria are: Mothers of infants born at 27-34 weeks gestational age who were admitted to a NICU for at least one week, and who have been discharged from a NICU for one to six months.

Exclusion criteria are: Mothers who are not able to read and write English or who are not the primary caregiver for their infant;

- Mothers who are not able to read and write English will necessitate interviewing through an interpreter, which means that direct comments from mothers will need to be translated into an English word-equivalent. Phenomenology seeks to understand a phenomenon from another's perspective, using direct quotes and statements from participants during data analysis. The use of a translator may compromise this important step.

- The aim of this study is to understand the day-to-day care given by mothers of preterm infants following NICU discharge. Mothers who are not primary caregivers in the home will not be able to adequately verbalize and support this aim.
- Wards of the State (or other agencies, institutions or entities) will also be excluded since the focus of this study is on a mother's caregiving.

Mothers who have previously given birth to a preterm infant admitted to a NICU;

- Mothers who have experienced a previous birth of a preterm infant who was admitted to a NICU will have a different perspective of this second experience, than those mothers experiencing it for the first time.

Mothers of infants who are ventilator-dependent or who have experienced a Stage IV intraventricular hemorrhage (IVH).

- The experiences of mothers of preterm infants, discharged to home with serious comorbidities such as ventilator dependency or Stage IV IVH, although important, are not the primary focus for this initial study.

Mothers under 18 years of age

- Adolescent mothers are not the focus of this study. Including them could result in the addition of confounding information since it is anticipated that their experiences will differ significantly from their adult counterparts.

Research Material

There will not be any research materials solicited or used for the purposes of this study.

Recruitment Plan

Mothers will self-identify from advertisements and flyers placed in local clinics, health care settings, and private pediatrician's offices, and through the snowball effect of word of mouth. Referrals by

other health care professionals will be sought, with mothers who express an interest being asked to contact the researcher via e-mail or phone. During this initial phone conversation, the researcher will outline the goals, procedures for gathering data and expected outcomes of the study, including how the information will be analyzed and shared, and seek buy-in from the mother. Following this initial discussion, a time and place for the face-to-face interview will be established and an informed consent form mailed to the study participant.

Privacy of Participants

Privacy of study participants will be supported through the use of pseudonyms during interviews, transcription and reports. The issues surrounding privacy and confidentiality really speak to research ethics and include the principles of autonomy, beneficence and justice. Autonomy speaks to not only protecting a study participant's identity or ensuring that collected data is kept safe, but also respecting each study participant as an individual, with individual needs and rights. Participants of this study will be assured that they may withdraw from the study at any point and may choose to have their data removed from study findings, without prejudice, to support their autonomy. Beneficence seeks to ensure that no harm is done to others, especially those in your care. Justice requires the researcher to apply ethical principles equally among all study participants without regard to status (Orb, Eisenhauer & Wynaden, 2001). Justice also requires the researcher to be cognizant of the vulnerabilities of study participants and to work diligently to not exploit or allow others to exploit those (Orb, Eisenhauer & Wynaden).

Confidentiality of Data

All information will be deidentified and tapes, notes and other materials will be stored in a locked cabinet and accessible only by the researcher and Dr. Rita Pickler, PI. At the end of a seven year period (or whatever current protocol dictates at that time), all hard-copy information will be shredded and computer information will be electronically deleted and shredded.

Potential Risks

Potential risk to study participants will be minimal. It is recognized that giving birth to a preterm

infant can be a cause of much concern and sorrow to mothers. For that reason, interviews will be conducted at a pace set by the study participant and areas of discomfort to the mothers will be minimized or eliminated altogether. A list of community based counselors will be available to mothers who feel they might need professional help to address problems.

Risk Reduction

Questions will be open-ended, without a set number to be answered and the flow of the interaction will depend chiefly on the comfort of the study participant.

Risk/Benefit

Risks, as noted above, will be minimal to study participants whereas the information gained from this research will inform the literature on this very important topic.

Compensation Plan for Participants

Mothers who agree to participate in and remain with the study through completion will receive a \$20 Target card in appreciation for their willingness to participate.

Consent Process

Informed consent will be collected by the researcher, with each study participant being asked to sign a consent form. Initial contact with study participants will be via telephone with the researcher and cover the aim of the study, the study design and the various steps to be employed during the study. Participants will be encouraged to discuss anything that is unclear or that they don't understand. Following this short, initial interview, an unsigned consent form will be sent to participants along with a self-addressed-stamped-envelope for them to return the signed form to the researcher. Prior to beginning the face-to-face interview, the researcher will provide a copy of the signed consent form to study participants and discuss anything that the participant feels is unclear.

Chapter Three

Abstract

Caring for a Preterm Infant during the First Six Months Post NICU Discharge: A Mother's Perspective

By Lois Phillips-Pula, MSN, RN

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University

Virginia Commonwealth University, 2011

Major Director: Jacqueline M. McGrath, PhD, RN, FAAN

The purpose of this study was to describe the experiences of mothers caring for their preterm infants at home, during the first six months after NICU discharge. Individual interviews took place with a purposeful sample of eight mothers who consented to be part of this research project, and met study criteria for inclusion. The Clark Moustakas approach to phenomenological data analysis was used to analyze data. Each interview began with an open ended question asking the mother to describe, in her own words, her experiences of caring for her preterm infant at home, following discharge from the hospital (NICU). Each experience was recorded and transcribed exactly as stated by the mother.

Credibility was supported by using three traditional phenomenological concepts: Prolonged engagement with each study participant, peer review of findings, and follow-up contact with each study participant for clarification of any statements that were unclear during transcription. The essence of the mothers' experiences was represented in their acceptance of their infant's challenges and their determination to help their child achieve the highest possible developmental levels. It became apparent when speaking with these mothers that they would deny their own physical and psychosocial needs, in order to ensure the best outcomes for their infants.

The themes that were evident among the mothers were: fear, guilt, determination, and hope. Fear that they would not be able to supply all that their infant needed, especially during those first few months following NICU discharge; guilt that their infant was having to suffer from being born too soon when they [the infant] had done nothing to ‘deserve’ it; determination that their child would have all the opportunities and support needed to overcome whatever obstacles might arise; and hope, hinging on belief, that all would be well. It is anticipated that findings from this initial study will be used to help better define what mothers need to know to provide best care for their infants prior to NICU discharge.

A review of mothering the preterm infant after NICU discharge

Introduction

Preterm birth, i.e., birth occurring prior to 37 weeks gestational age (GA), is a serious health care challenge both nationally and internationally. In the United States, approximately 1500 preterm infants are born each day, of which 200 are born at less than 32 weeks GA, and 173 are born weighing less than 1,500 grams or 3.3 lbs.^{1,2} In 2005 it was estimated that the total bill for medical care, special education services, Federal and state programs, and missed work days by parents of preterm infants totaled \$26.2 billion, or \$51,600 per infant.³

Research focusing on the intense emotions experienced by parents of preterm infants in the neonatal intensive care unit (NICU) is well represented in the literature and has helped inform our understanding of the grief, fear and anxiety they feel while attempting to navigate the NICU environment. Research has also indicated that preterm infants are readmitted to the hospital during the first few months after discharge at a rate of 10% - 35%, for an average 4.7 - 11.7 day stay, resulting in a cost of approximately \$376 million.⁴⁻⁷ Data covering the transitional period beginning at NICU discharge and continuing through the first weeks and months at home, however, is very limited. We don't have a complete understanding of what happens on a day-to-day basis for this cohort once they leave our care. The purpose of this paper is to examine the literature for findings that address this early transition-to-home period and to highlight the importance of this topic.

Background

The birth of a healthy newborn is usually a celebrated event, with parents expressing joy at their accomplishment and making plans for a bright future.⁸ Mothers of preterm infants however, face a different reality. In addition to feelings of sorrow, distress and grief, their coping skills are immediately challenged as their high-risk newborn is whisked away to the NICU and they are faced with questions regarding their infant's survival and what the long term effects of this early birth might be.⁹⁻¹¹ This separation of mother and infant robs both of early bonding opportunities and severely limits the time a

mother has to learn her infant's early cues. Moreover, given that the average NICU stay is 13 days, the ability of mothers to function in a normal parenting role is either severely limited or lost altogether, resulting in both the continued erosion of the maternal-infant bonding processes and poorer maternal infant attachment.¹²⁻¹⁴ This combined emotional toll can result in mothers of preterm infants exhibiting high levels of posttraumatic stress and other adverse mental health outcomes both during the NICU hospitalization and in the weeks and months post discharge.¹⁵⁻¹⁸

Methodology

Databases searched included CINNAHL, PubMed, Academic Search Complete and Google Scholar. Dates originally selected were 2000 – 2010, however, due to the lack of articles on this topic the search was broadened to include articles from peer reviewed, scholarly journals or websites, posted within the past 15 years. Terms were entered into the databases using Boolean logic to demonstrate relationships and included the keywords: *preterm infant, prematurity, NICU discharge, neonatal intensive care unit discharge, mother of preterm, parents of preterm, post NICU discharge, and transition from NICU*. Keywords were requested in either the title or the abstract of the document.

To provide an understanding of the broad context of this topic, articles were chosen for inclusion if:

1. They were research reports (data-based), reviews of the literature, reports of current policy or guidelines, or concept analyses;
2. They focused on the impact NICU admission has on infants and families;
3. They discussed the days leading up to NICU discharge or the post-discharge period;
4. The infant was discharged to home, and cared for in the home by a family member who was the primary caregiver.

A total of 113 articles meeting these criteria were initially identified, the majority of which discussed topics concerning the impact of preterm birth both nationally and internationally, survival statistics, the possible long-term consequences to the infant of preterm birth, and the challenges researchers and others face as they try to find solutions to this problem. From the 113 articles, 45 articles

were selected and read. They included topics particular to the consequences of preterm birth and covered issues such as the effects of NICU admission on the infant and family, preparing for NICU discharge, the evaluation of interventions, rehospitalization statistics, maternal depressive symptoms, and parenting the preterm infant. From these 45, 28 research reports and articles that focused on the effects of preterm birth, especially as it related to the impact to mothers and other family members, were chosen for inclusion in this review.

The 28 articles chosen for this review included 15, dating from 1999 to 2009, that were research based and presented findings on topics associated with preterm birth such as its impact on parents and families, maternal stress and depressive symptoms, the challenge of learning to parent in the NICU, parents' perceived needs in the NICU, rehospitalization statistics, and the high number of office visits required during the first year following NICU discharge. The studies used a variety of design methodologies including retrospective (4), longitudinal (3), descriptive (3), prospective (2), mixed methods (1), secondary analysis (1), phenomenological (1). Five articles dating from 1999-2010 presented surveys or focus group findings (2), and policy statements or guidelines (3) were also included in the review. These articles included information on communication skills, recommended changes to NICU discharge criteria and a midcourse review of Healthy People 2010 goals concerning preterm birth. Eight articles published from 1997 to 2009, included literature reviews (6), a concept analysis (1), an integrative review, and an assessment of an intervention (1) and focused on the steps involved in learning to parent a preterm infant, interpreting a preterm infant's behaviors, the preparation involved in NICU discharge, and an intervention designed to make NICU discharge less stressful for parents.

Results

The 28 articles chosen were read and findings summarized and presented in both table and narrative format. Table 1 (Appendix II) lists the 15 research-based articles and their findings. Most of the studies were longitudinal, descriptive or prospective in design, with sample sizes ranging from 14 parents who participated in a phenomenological study¹⁸ to 264,000 data-based records of preterm births

in California used for a retrospective study.⁵ Research questions dealt with topics of parents' satisfaction with NICU care,¹² the levels of stress mothers reported during the NICU admission and following NICU discharge,^{9,15} the steps involved in learning to parent a preterm infant, including the instructions received in the NICU,¹⁸⁻¹⁹ and the rates and causes of rehospitalizations for preterm infants.⁵⁻⁷ Measurement strategies used included the Perinatal PTSD Questionnaire (PPQ), used to measure post traumatic stress symptomatology in mothers of preterm infants,¹⁵ semi-structured and structured questionnaires,^{4,10, 14, 20, 21} and focused database searches to isolate criteria for retrospective reviews.⁵⁻⁶ Findings revealed that parents were reasonably satisfied with the information and care they received while their infants were in the NICU,¹² rehospitalizations for preterm infants is significantly higher than for full term infants, with preterm infants born at lower birth weights having the greatest chance of being readmitted,⁵⁻⁷ and mothers may continue to exhibit depressive symptomatology, including PTSD, for months or years after NICU discharge resulting in a blunted response to infant cues.^{9, 15, 21}

Table 2 (Appendix III), provides an overview of the major themes found in 17 of the articles, of which 8 were research studies, 5 were literature reviews, 2 were policy statements, 1 was a concept analysis and 1 was an intervention assessment. Although each of the 28 articles included in this review presented an overall theme or concept, the 17 articles included in Table 2 all appeared to have one or more themes similar to those found in at least one other article. With some articles, the theme appeared as a major aspect of their presentation and with others, it was not. Once they were identified from among the 28 total articles, they were included in table 2.

Major themes apparent in the literature include the following:

1. *The NICU environment is highly stressful for families of preterm infants and that stress does not immediately abate once the infant is discharged to home.* The short-term and long-term effects of maternal stress, originating with the birth of a preterm infant and continuing throughout the NICU experience, were represented in 10 articles, 3 of which were research studies.

Although the transition to home is something parents look forward to, it is fraught with emotion

as parents question their ability to duplicate the current level of care their infant is receiving in the NICU.^{2, 11, 13, 22} This concern is well founded since preterm birth continues to be the leading cause of death among newborns. Additionally, infants are being discharged earlier and parents are expected to assume responsibility for administering supplemental oxygen, tube feedings, etc.^{1, 23} Providing this care at home can overwhelm a family and have a formidable impact on family dynamics through the first years of life.^{20, 24} Infants discharged with feeding or respiratory problems have a much greater chance of being rehospitalized, which can add to the continuing chaos and disruption to family organizational processes.⁴⁻⁷

A longitudinal (20-year) study was conducted to compare 130 mothers of extremely low birth weight infants (ELBW) with 126 mothers of normal birth weight (NBW) infants to measure items such as maternal mood, marital disharmony, anxiety, overall health/pathologic conditions of the family and the amount of social support the families felt they received.²⁰ Findings indicated that families of lower socioeconomic status or where the infant had suffered a neurological sensory injury (NSI) resulting in a lowered IQ or physical health challenges, continued to report high levels of maternal stress and accompanying emotional and health problems throughout the infant's childhood, into early young-adult years. By the time the child was approaching young adulthood, however, the differences in stress and health problems between the ELBW and NBW groups were no longer significant. Interestingly, families of children who had experienced NSI rated their ability to function at a normal level higher than either the ELBW without NSI or the NBW cohort. These mothers reported that coping with their child's healthcare needs required the family to work together for the benefit of the child. They reported experiencing an abundance of support from extended family and friends and they were proud of being able to successfully manage their child's overall health care needs. A retrospective record review of 892 preterm infants born at ≤ 32 weeks GA, in five northern California Kaiser Permanente medical centers, found that each infant had at least 20 office visits during the first year of life and a total of 5.5 prescriptions annually.²² Most of the visits were noted to be with pediatric primary care providers, for non well-baby visits. Infants with BPD averaged 28 visits per year and 9 prescriptions. Two important findings from this study concerned

parents of preterm infants who viewed their infant as vulnerable (vulnerable child syndrome [VCS]), whether or not there was medical evidence to support their beliefs. The results of these beliefs can be higher health-care usage, poorer developmental outcomes at one year of age, and a risk for increased behavior problems, related to a poor child-parent relationship, as the child grows. The second finding concerned a question of how families of lower SES or who lived away from city hubs managed to get the care their preterm infant needed, especially during the critical first year of life. This area was recognized as one in need of additional research.

A prospective study (n=867) was conducted to survey NICU nurses and the families of NICU infants on their feelings of readiness to be discharged to home.²⁵ Infants admitted to the Beth Israel Deaconess Medical Center NICU from November 2003 until April 2007 for at least two weeks were included. Families were asked to rate how prepared they felt for NICU discharge, and NICU nurses were asked to rate how prepared they felt a family was for discharge, using the same 9-point Likert scale for scoring. Families were considered to be prepared for discharge if they and their nurse rated their preparedness at \geq seven points. Findings indicated that most families rated their preparedness at a significantly higher rate than their respective NICU nurses.

2. *Clinically depressive symptoms and post-traumatic stress disorder (PTSD) in mothers of preterm infants are more common and last longer than originally thought.* The topic of maternal depression was underscored in six of the articles, five of which were research studies.

Mothers of preterm infants exhibit high levels of depression and PTSD both during their NICU stays and in the months and years post discharge.^{15, 17-18} A study of 181 mothers of preterm and VLBW infants found that 32% had clinically significant depressive symptoms just before their infant's NICU discharge, which decreased to approximately 12% by 24-months post term.⁹ These findings are consistent with a qualitative study of 320 mothers of preterm infants in which mothers expressed continued feelings of anxiety and incompetence in caring for their infant, two months after NICU discharge.²¹ In a pilot study of 21 mothers of VLBW infants found that the mothers' symptoms of PTSD

acquired during the NICU admission were still significant at the six months post-discharge mark, as measured by the PPQ.¹⁵ A phenomenological study of 7 sets of parents (n=14) who had given birth to a preterm infant born ≤ 34 weeks, GA.¹⁸ She interviewed the parents at 1-2 weeks after the birth and again at the 2, 6, and 18 months marks. She found that parents described the learning-to-parent process as an internal progression from step 1, where they reported feelings of alienation with their infants to step 4, where they reported feeling an easy familiarity. In step 1, mothers expressed feeling ambivalent about what was going on around them. They felt separated from what was happening, in shock, and fearful that their infant might die. Fathers reported feeling at odds with reality, that what they were seeing was not real. Within the NICU, fathers felt comfortable with delegating infant care to the staff, whereas mothers felt it important to be acknowledged as the infant's mother. Step two in the process dealt with responsibility, which became more real as discharge approached and parents began to realize all that was involved in assuming the care of their infant. Mothers reported feelings of insecurity and fathers reported feeling unprepared for this responsibility; wishing they had been allowed input into the timing of the discharge. Step three, confidence, arrived on average when the infant reached 6 months of age. This is also the time when mothers reported that their infant began to look like a full term infant and fathers reported being able to participate with their wives in the care giving. Stage four, the final stage, was described as familiarity, and occurred when parenting their infant had become an integral part of their family life. Parents reported having developed a relationship with their child. Mothers reported feeling secure in providing care for their infant but still having occasional feelings of loss and guilt about not having a normal pregnancy and delivery. In contrast, fathers reported living in the present-day without dwelling on what happened at the birth or in the time immediately following the birth of their child.

3. *The maternal-infant bond, postponed during NICU admission, can be more difficult to establish post discharge.* Ten articles addressed the topic of maternal-infant bonding, of which six were research studies.

Having an infant admitted to a NICU separates a mother from her infant and replaces her parental

role with that of an engaged observer, as others care for her child.¹³⁻¹⁴ A concept analysis on transitioning to motherhood in the NICU reported that this change in status has a direct impact on a mother's ability to develop early maternal-infant attachment and impedes her identification with the maternal role.²⁶ In a phenomenological study of parents of preterm infants, found that mothers reported feeling continually tired after discharge, resulting in an exhaustion of both mind and body that undermined their ability to develop an attachment to their infant.¹⁸ Premature infants also are more likely to have central nervous system immaturity and disorganized behavioral health problems, which is manifested by gaze avoidance, limited vocalization and responsiveness to parents' efforts, all of which can have a negative impact on a new parent's expectations of parenting.^{11, 14, 22, 27} Finally, these factors coupled with a mother's emotional lability during these first few weeks and months post discharge has been found to further retard the establishment of a solid parent-infant relationship.²⁸

Conclusion

Research has highlighted some of the challenges faced by families of preterm infants admitted to and discharged from a NICU – stress, depression, the need for additional medical care, challenges related to bonding and attachment. However, an important gap in the literature exists concerning how mothers are facing the day-to-day obligations associated with caring for a preterm infant at home, especially during the first weeks and months after hospital discharge. The results of a successful transition to home can be far reaching, supporting the development of enhanced parenting strategies which in turn can support the achievement of the important early developmental milestones for the infant, and have a positive impact on the readmission rates for this cohort.

Although we have begun to recognize how important this transition period is, we have not yet taken the necessary steps to fill this research void with studies focused specifically on this time period. What little information we have is not well developed and consequently we don't yet understand how parents fared during this early discharge period, or what we could do to better prepare or support them. The development of a cohesive body of knowledge, from which standards of practice could be drawn,

would support both parents and nurses and would enable us, as health care providers, to discharge parents who were not only prepared for the task of caring for their preterm infant, but who would also know how to find and access additional resources to support a successful transition to home

Implications for Practice

NICU nurses work in a demanding, high-stress environment where their personal values as well as their nursing knowledge are constantly being challenged. Their jobs entail giving excellent medical care to their tiny patients while keeping a continuous dialogue going with their patient's family. Most NICUs have a check-list of skills considered important for parents to know prior to discharge, and as that time approaches, the NICU nurse assumes responsibility for seeing that each item on that list has been covered with the infant's parent/family. Currently, there is no consistency among NICUs about what is included on that list and as research has demonstrated, a gap exists between what mothers say they want to know and what NICU nurses think they need to teach.¹⁹ This is due, at least in part, to the fact that there is not a large enough body of knowledge from which to draw information concerning what needs to be provided to families and how best to provide it.

Need for Further Research

Additional research highlighting the transition period following NICU discharge is needed. A logical first step could include a qualitative study, asking mothers to describe their experiences of those first few weeks and months following NICU discharge. Other research may use focus groups in the post discharge period, which would enable us to better understand what parents felt their needs were and whether or not those needs were met. Still other studies might use open-ended discharge surveys presented to parents twice; first in the days immediately prior to discharge and second, in the early weeks after NICU discharge. Research designs that allow us to hear what parents have to say about this period would be important and would add to the limited knowledge that currently exists.

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Chapter Four

Caring for a Preterm Infant at Home: A Mother's Perspective

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Abstract

The purpose of this phenomenological study was to examine the experiences of mothers of preterm infants during the first six months at home following discharge from a neonatal intensive care unit (NICU). A purposeful sample of eight mothers was gathered and interviews were conducted over a four-month period. Each interview was audio recorded and took place in the study participant's home or another place of her choosing. Interviews were transcribed verbatim and analyzed independently with themes being identified and organized for each participant. From these analyses, the themes of fear, exhaustion, fortitude and thankfulness, were identified as being common to all study participants, and became the basis for developing the essence of the phenomenon. The essence of this experience for these mothers was their determination to do whatever was necessary to ensure the best possible outcomes for their infants. The data gathered from these personal interviews will help to further inform our understanding of this important time from the perspective of those who have experienced it and will aid in the design of interventions tailored to address the specific needs of mothers of preterm infants.

Keywords: preterm, NICU discharge, neonatal intensive care unit, phenomenology

The birth of a preterm infant can be devastating for a mother and her family. The wishes and dreams associated with the perfect pregnancy culminating in the perfect birth of the perfect infant have been shattered. Simultaneously, mothers are struggling to find their footing in the intensive care environment where their infants will be cared for and where mothers will sometimes, not-so-willingly abdicate their primary role as caregiver to another, for the good of their infant. Hospitalizations in the neonatal intensive care unit (NICU) hospitalizations can last for several weeks to several months; depending on the medical diagnoses associated with a younger gestational age (GA) at birth, such as low birth weight and long term developmental delays. The experiences of mothers during the NICU hospitalization is well-documented in the literature and has enlightened our understanding of the shock and grief mothers face during this period.¹⁻⁴ While research findings have highlighted the higher-than-normal hospital readmission rates (10%-35%) for infants born preterm,⁵⁻⁸ few studies have provided a clear view of the period of time immediately following NICU discharge (during those first few weeks and months at home) from the perspective of the mother.³⁴ This lack of information has led to a knowledge deficit in understanding what happens on a day-to-day basis after an infant is discharged from the NICU. The aim of this study was to learn from mothers of preterm infants by interviewing them during the first six months at home after their infant's discharge from the NICU, and asking them to describe in their own words their experiences of caring for their infant.

Background

Preterm birth is a serious healthcare challenge in the United States with approximately 12.5% of the 12,000 babies born each day at less than 37 weeks GA.⁹ In 2005, it was estimated that the total bill for medical care, including NICU admission, special education services and missed work days by parents of preterm infants totaled \$26.2 billion annually, or \$51,600 per infant.^{10,11} Although this financial cost is significant, the personal toll a preterm birth can take on parents, both in the short and long term, can

be immeasurable.

Unlike the birth of a healthy newborn, which is an event usually celebrated by both immediate and extended family members, the birth of a preterm infant leaves parents with feelings of grief and fear. Instead of envisioning future plans and great expectations for their child, planning takes on a different concentration with questions covering areas such as infant survival or short and long-term developmental outcomes.^{4,12-13} Often times the preterm infant is removed from the delivery or operating room immediately after birth and taken to the NICU where the focus is on providing immediate care for the infant rather than on missed bonding opportunities. This loss can severely limit the mother's opportunity to learn her infant's early cues. As time away from her infant increases, these processes are further eroded and both maternal-infant bonding and attachment become more difficult to establish.^{3,14-15} The accumulation of these lost opportunities added to the sorrow and grief the mother already feels can take a serious emotional toll on mothers and can lead to adverse mental symptomatology being exhibited for weeks, months or years.¹⁶⁻¹⁹

It is well known that discharge from the NICU is stressful for parents who must now be ready to provide care for a convalescing high risk infant at home.²⁰ Research has indicated that for mothers of infants born at lower gestational ages the concern experienced while providing home care can be even higher, resulting in higher than normal mother-initiated healthcare visits beginning during the first weeks and months post discharge, and continuing through the six month mark.^{4-5, 21} Because these early post-discharge months present with such intense challenges for mothers who are primary caregivers of their preterm infants, and because there is currently little research highlighting this specific time period, the first six months at home following NICU discharge was selected as the focus of this research.

Mothers who were the primary caregivers for their infants were sought and asked to answers two

broad questions: 1.) How did they experience those early days and weeks at home following NICU discharge, i.e., what did they learn about caring for their infant, and how was it learned, and 2.) In what contexts or situations did these experiences occur.

Method

Research Design

The research questions lent themselves to a phenomenological approach where the focus was on understanding and describing the every-day experiences of mothers of preterm infants in the post-discharge period.²² Although several approaches to phenomenology were considered, transcendental phenomenology as espoused by Moustakas was chosen to guide this study. Through phenomenology, a researcher may gain entrée into the lives of others in order to view things from the others' vantage. Its successful implementation requires a commitment by study participants to return to a phenomenon and to provide comprehensive, first-person descriptions.²³ Phenomenology uses an inductive approach to data collection, with one-on-one interviews, discussions and observations to focus on the entirety of the experience exactly as described by study participants.²³ Data were gathered through in-depth interviews that were audio recorded. Each interview was transcribed verbatim by the researcher. Study participants were contacted by follow-up telephone calls to discuss areas where wording or intent was unclear.

Study Participants

Phenomenology does not specify a required number of study participants but rather the focus is on having enough participants to adequately explore the phenomenon under study, e.g., usually no more than 10-12 individuals.²⁵ For this study, mothers of preterm infants who met the criteria of having had a first-person experience of the phenomenon and who were willing to participate in the study, were asked to self-identify.²³ Study participants were recruited through the use of advertisements placed in seven local

newspapers in northern Virginia and through flyers placed in OB clinics and the NICU of a large health center. Mothers were asked to contact the researcher via e-mail if they had an interest in participating. A consent form, along with a short synopsis of the study was mailed to each mother prior to the first interview taking place. Following the initial contact, volunteers were screened by telephone to ensure they met inclusion criteria. Participants who were 18 years of age or older, who had given birth to a singleton infant born between 24-34 weeks gestation, without serious sequelae, i.e., ventilator dependence, and who had been discharged from a NICU to home for one to six months, were invited to participate. From a group of 19 mothers who initially expressed an interest, 9 met study criteria. Of the mothers not selected to participate in the study, 7 had given birth to multiples and 3 had had their infant discharged from the NICU for longer than six months. Eight of the nine mothers agreed to be interviewed; one mother could not be contacted despite numerous attempts to do so. Mothers were informed that they could withdraw from the study at any time and have their data removed from findings.

Data Collection

The study was approved by the institutional review board at the study setting. Interviews were scheduled according to a mother's availability and took place either at her home or another place of her choice. Interviews lasted from 60 to 90 minutes. The interview process was one of open dialogue between the study participants and the researcher. The natural rhythm of each interview was established by the study participant with the researcher following the mother's lead. Spontaneous questions were used as follow-up to the mothers' descriptions in order to elicit detailed descriptions (see Table 1).²³

Data Analysis

Data were analyzed using the Moustakas²³ method and included the following steps: 1) The Epoche process of setting aside *a priori* thoughts; 2) Phenomenological Reduction, which reduces the

data through Horizontalization by identifying significant statements or horizons, setting aside redundant or other statements not considered pertinent to the current study, identifying and organizing themes from the horizon statements; 3) Imaginative Variation where textural and structural descriptions of the experience were developed; and 4) The integration of the fundamental textural and structural descriptions into a unified essence statement reflective of the spirit or essence of the phenomenon as it was experienced by all participants.

The Epoche Process

Moustakas referred to the Epoche process as one through which a researcher sets aside personal beliefs or biases and relies only on present consciousness to inform.²³ It is facilitated through first identifying and then consciously bracketing, any idea or personal experience that might serve to prejudice or bias the researcher's ability to accept each participant's retelling of the phenomenon exactly as described. The Epoche process was used throughout this study prior to each interview and again as transcripts were prepared and analyzed to facilitate the researcher's acceptance of each participant's experiences exactly as given.

Transcendental-Phenomenological Reduction

Horizontalization

The first step in the Reduction phase is horizontalization. During this step, data recordings were transcribed verbatim and each transcription was reread while listening to the data recording to ensure accuracy. Field notes were reviewed to provide context. Each experience was valued and accepted equally and became a complete description of the phenomenon as experienced by a study participant. Each statement was tested to ensure that it related to the phenomenon of interest and was not redundant. Statements not meeting the two criteria were set aside. Themes were identified and organized in textural

descriptions of the phenomenon, i.e., the *What* of the experience (see Table 2). This process was completed individually for each of the eight study participants.

Imaginative Variation

The third step in the process is referred to as Imaginative Variation. It is here that a researcher seeks to view the phenomenon as participants have seen it. This understanding enables the development of structural descriptions reflective of *How* each participant met the responsibilities associated with providing care for their preterm infant at home, i.e., what were the conditions associated with providing the care; were there other factors that had bearing on their experiences.²³ Once these descriptions had been developed for each study participant, they were reviewed and reflected upon, individually, by the researcher to ensure that they adequately portrayed the feelings expressed by study participants. Using the individual descriptions, comprehensive overall descriptions were formed for both textural and structural statements.

The Essence Statement

In order to complete this final step, the researcher reflected on the integration of individual and collective descriptions of the phenomenon as portrayed by study participants. Several words were selected as possibly reflecting the essence and through continued synthesis and introspection the researcher identified the strength and resilience that were integral to each participant's statements. This recognition enabled the researcher to construct an essence statement reflective of both the individual descriptions related by study participants and the overall descriptions representative of the group as a whole. The essence of these mothers' experience was their determination to do whatever was necessary to ensure the best possible outcomes for their infant.

Rigor

Three ways to establish rigor in phenomenological studies are: procedural rigor; ethical rigor; and auditability.²⁸ Procedural rigor is met when the researcher acknowledges and lists the limitations of the study along with any personal biases that might have influenced the outcomes. Biases and preconceived notions for this study were addressed using the epoche process. Limitations are noted in a separate area of the manuscript. Ethical rigor was established through protecting both the rights of subjects and the confidentiality of the data. Auditability speaks to a clear progression of events beginning with data collection and ending with valid conclusions that are presented to readers clearly without ambiguous statements or assumptions. The researcher adopted a consistent method for handling data that would allow an audit trail to be constructed as needed, and worked with a peer reviewer, familiar with the phenomenological process, who read and commented on all data as it was provided by the researcher.

Findings

Eight participants, all mothers of preterm infants, were interviewed over a period of four months. Of the eight, five were married, one was single and two were in what they described as ‘committed’ relationships. Four had college degrees, three reported having ‘some college,’ and one was working on her General Education Diploma (GED). Four participants reported owning their home, three lived in apartments and one was living with her parents. Their infants’ gestation, birth weight and days in the NICU are highlighted in Table 3. Table 4 highlights each participant’s individual themes that collectively became the four themes representative of all participants’ input.

When interviewing study participants about the early weeks and months at home, it was apparent that what they had experienced could not be accurately represented using a linear approach. Feelings associated with learning that their infant would be born too soon were intermingled with their feelings of having an infant in the NICU and these remembrances led to discussions about those first weeks and

months at home and what impact they felt the NICU had on that time. The essence of the mothers' experience was their determination to do whatever was necessary to achieve the best possible outcomes for their infants; the essence was derived from the analysis of structural and textural statements. The essence is exemplified through the themes; a) fear of the unknown b) exhaustion, c) fortitude and d) thankfulness.

Determination to do whatever was necessary: Fear of the unknown

Mothers spoke at length about the fear they felt as they met in the NICU for that last time to finish paperwork and get whatever final instructions were deemed necessary in order to complete the discharge of their infant. (Pseudonyms are used to identify the infants and their mothers.)

- Tina's mother, *"It took like two or three people there [NICU] to take care of her and now we have to rely on our two eyes and ears to care for her?"*
- Orson's mother, *"... he'd almost always have an episode of bradycardia, [whenever he fell into a deep sleep] which of course would scare me to death because this was the stage where we still had to physically stimulate him, so it was a nightmare."*
- Serena's mother, *"She was doing fine but her eating was not at the point where I would have said 'yes, she can be discharged,' so that was really scary . . . even though they told us she took longer than they would have liked to feed, but they still let her go."*

Several mothers reported receiving little to no information on the apnea, bradycardia monitors they were taking home with their infants.

- *"They just said 'When it [the monitor] goes off, check him, and once he starts breathing again it will shut itself off.'"*

Mothers also reported inconsistencies in the functioning of the monitors heightening their fears, e.g., alarming when the infant was awake and alert and not sounding when the infant had stopped breathing and was in jeopardy.

- Francis's mother, *"I brought him home from the doctor's office, I had fed him and changed him and I noticed that he was just laying there so I started talking to him, calling his name and rubbing him but he was turning blue and purple in the face and finally I called the paramedics . . . then his face got pink again and all this time his monitor never went off."*

Most of the mothers related how they looked forward to that time when their infant would no longer need the monitor, however, once that day arrived, they began to realize how much they had come to depend on its assurance that their infant was breathing.

- Tina's mother, *"At first I was too scared to take a shower . . . if I didn't hear her, how would I know she was still breathing or that her heart hadn't stopped? It's still there [fear] even after four months."*
- Orson's mother, *"I remember just constantly reading the CPR cards to make sure I knew how to do it because I was terrified something would happen to him."*

Mothers described feelings of impending doom during those first weeks at home.

- Tina's mother, *"Every day it's just you feel like 'I'm waiting for disaster to happen,' every day."*

Mothers reported being too afraid to put their infant in their own room or even their own bed to sleep and so every mother in the study admitted that their infant slept in their [mother's] bed. They remarked that they would wake up at all hours of the night just to feel for the infant to ensure he or she was still breathing.

- Tanya’s mother said *“She sleeps with us . . . I always feel like I gotta wake up and feel her . . . I have to make sure, I have to wake up and look over, make sure she’s still breathing and then I can go back to sleep.”*

Mothers also discussed their fear of what the future might hold for their infants. Several mothers reported that their infants were still having frequent pediatrician visits and most were currently progressing appropriately for their corrected ages.

Determination to do whatever was necessary: Exhaustion

Mothers reported feeling exhausted during those first months at home, which they related to both the extra care their infant needed and their need to be “instantly awake” whenever a monitor sounded or the baby made an unusual noise.

- *“Even when sleeping becomes a little easier you still wake up in a panic and need to check on [her] because you’ve slept for awhile and you don’t know what’s happened.”*
- *“What if I’m sleeping so hard that I don’t hear the monitor alarm?”*
- *“Every time he moves I wake up to be sure he’s ok.”*

Several mothers stated that once awakened, it was usually easier to just stay awake until the next feeding so they didn’t worry about sleeping through it. This was especially true when an infant was being fed every two hours in order to make up for weight lost during the transition to home. They related the first weeks at home as being a “blur” of trying to do what needed doing, snatch sleep, and maybe get a shower. The exhaustion the mothers felt also extended to their families, especially where an infant was on a monitor.

- Orson’s mother, *“It wasn’t just one of us getting up with the baby, one of us had to go and get our toddler and settle him back down and tell him ‘everything’s ok, it’s just a noise so*

don't worry about it' while one of us would tend to the baby . . . so it was just a circus . . . but not in a good way."

They spoke of the toll this lack of sleep took on spousal relationships and admitted being short-tempered and "at each other's throats" due to the exhaustion they felt. Mothers also described the energy it took to make the rounds of different medical specialists, especially if they didn't have any help. They spoke of getting their infant, apnea monitor and oxygen loaded into the car to get to a physician's office, unloading and then reloading for the ride home. For many mothers, this process was multiplied due to the number of appointments scheduled not only with the pediatrician, but also with a pediatric cardiologist, neurologist and ophthalmologist. They described those visits as necessary for the health of their infant but nevertheless, "painful" to experience. They reported feeling that the time spent just doing what was necessary for the survival of their infant robbed them of other moments to just sit and hold their babies. Several mothers in the study who worked at fulltime jobs outside the home, reported staying up an extra hour during the mid-night feedings in order to have uninterrupted, one-on-one time with their infants. They reported that having this special time allowed them to get to know their infants better, which they felt more than compensated for their loss of sleep.

Several mothers reported feelings of isolation. They felt that no one, not even their spouse or partner, really 'got' how difficult it was to provide the necessary care for their infant. These feelings were compounded when the spouse, partner or other family member returned to fulltime work, leaving the mother at home alone to care for the infant. One mother stated that whenever her husband would offer to take a middle of the night feeding because he felt guilty leaving her alone all day, she would let him, even though he had to get up for work the next morning. She stated that "I felt horrible and so I cut him no slack and made sure he was as miserable as me."

- Orson's mom, *"I don't care how many friends you have and how many babies they've had, if you didn't have a baby in the NICU, you don't get it."*

Determination to do whatever was necessary: Fortitude

Each mother stated that her infant would not be ‘held back’ because of preterm birth. They decided while their infants were still in the NICU they would have the best possible care regardless of the time or energy expended to ensure it. One of the younger mothers, who was without personal transportation, reported riding 90-minutes one-way to get her son to the required medical visits. Mothers who worked fulltime prior to giving birth tried to rework their maternity leave so that they could use most of it when their infant was discharge.

- Tina’s mom, *“I only took two weeks off [after her cesarean birth] and then went back to full time work, covering weekend nights in the ICU . . . so I wouldn’t use all my leave and could be home with her for awhile when she came home.”*

Mothers discussed their plans for meeting future challenges which included ensuring that their infant not only prospered but achieved. They spoke about goals and the overall outcomes they wanted for their infants and concluded each statement with an expression of determination, that everything would be “fine,” that “everything is going to be OK,” or “She’ll be fine . . . he’ll be fine. . . we’ll just see to it.” Many mothers recognized that they were their infant’s ‘champion,’ and best advocate. Several stated that although they listened to what the physicians said and considered their advice, they never forgot that their job was to advocate for their child regardless of what the long-term outcomes were projected to be.

- Tanya’s mother, *“You know what? She [is] gonna do those things [be] cause I’m going to make sure she does them.*
- Elizabeth’s mother, *“We don’t exactly know what’s going to happen as she develops, but that’s ok, we’ll take care of it (smiling at her daughter).”*

The mothers in the study discussed their responses whenever they felt their infant needed protecting, even if that meant doing battle with their spouse or partner.

- Tanya’s mother, “. . . they’re [fathers] like ‘Oh I don’t want to do that [physical therapy exercises] because she doesn’t like them . . . I just want to hold her and I’m aggressive, I’m like ‘Look, you HAVE to do this because this is how it goes.’”

Seth’s mom described visiting her pediatrician when her son was chronologically several months old, but only six weeks old, corrected, and the comments another mother was making about how delayed he appeared when compared to her [other mother’s] son. When Seth’s mother replied that her son had been premature and was actually only six weeks old, corrected age, the other mother gave her a look and she knew immediately that she didn’t believe her. She said laughing,

- “I’m a really non-violent person but at that moment I wanted to grab her and make her listen to what I had just said.”

One of the single mothers talked about working to make ends meet on a single salary while still providing the best developmental environment for her daughter. One item her daughter was especially drawn to at the developmental pediatrician’s office was a toy that made a crackling noise when you grasped it. When she returned home, she noticed that her daughter’s attention was drawn to the sound of a potato chip bag being opened and realized that it made the same crackling noise. During the next shopping trip, she bought a box of lunch-box size bags of chips and instructed her little brother and her son to “hurry up and eat and don’t throw the chip bags away.” The empty bags became an inexpensive toy that her daughter enjoyed and that served to help her develop a better grasp with her non-dominant hand. Another mother related all the poor predictions she had been told about her daughter’s abilities and how she decided she would listen but that in her mind she kept thinking “I know she can do better and I can work with her more. . . [And] she’ll be fine.”

Determination to do whatever was necessary: Thankfulness

Most mothers in the study spoke about at least one person who had worked with them and had made a difference.

- Orson’s mother, *“That NP [at the apnea clinic] was amazing . . . the best . . . she understood everything.”*
- Elizabeth’s mother, *“The nurses and neonatologist always talk to us like humans.”*

Although each recognized that giving birth to and caring for a preterm infant was the most difficult thing they’d ever done, they all expressed a thankfulness to be where they were currently.

- Elizabeth’s mother, *“It’s been a roller coaster and that’s ok”*
- Tanya’s mother, *“If you had seen her from before to now, you’d be like ‘wow, she really has [come a long way].’”*
- Francis’s mother, *“You just forget about everything that’s happened . . . you just forget about it.”*
- Seth’s mother, *“It’s been a long bumpy road, but it will be ok. Of course we were lucky with him.”*

Many spoke of the “miracles” that had happened to enable their infant to be alive and well and their wonderment at the positive outcomes they had experienced, especially when the odds were against it.

- Serena’s mother, *“I consider myself very lucky that she’s here and alive . . . a lot of babies just die of it [Abruptio] and she didn’t . . . and neither did I . . . so 25 weeks is not that scary compared to what could [have] happened.”*
- Elizabeth’s mother, *“She’s such an easy girl . . . all in all; she is just an easy girl.”*

One mother who is HIV positive expressed her thankfulness that her infant, thus far, has not shown any signs of developing the disease.

- *“All [the] tests came back negative. We’re working through it. [the next test is] at 18 months and if that one is negative, then they’ll just say, ‘negative.’”*

Each mother reported some measure of outside support from families, friends or through a formalized group. They voiced their thankfulness for the positive influence this support has made in their emotional outlook.

- Keith’s mother, *“Whenever I get tired my mom will say ‘bring him to me and go take a nap or something’ [and that] helps.”*

Mothers who belonged to formal support groups felt strongly that any mother with an infant in a NICU would benefit from the support and information they found through their groups. Most reported having moved from being in need of support to being able to give support to new mothers of preterm infants.

- Orson’s mother, *“I wish I hadn’t blown this group off while he was still in the NICU. The [hospital] social worker suggested it to me but I thought ‘I’m well educated, I have insurance, I don’t need a support group’ but I was wrong. They could have saved us so many days of needless frustration with simple little suggestions [and] that’s what I tell all new moms of pretermers now.”*

Discussion

The essence of these mothers’ experiences was identified as the mothers’ determination to do whatever was necessary to ensure the best possible outcomes for their infants. Mothers described their experiences

of the phenomenon in their own words, and although their descriptions were individualized the feelings associated with the experiences were similar to those of other mothers in the study. Table 4 highlights each participant's individual themes that collectively became the four global themes representative of all participants' input, identified as a) fear of the unknown, b) exhaustion, c) fortitude and d) thankfulness.

Several studies have reported on the challenges parents of preterm infants face while trying to navigate the NICU environment and the long-term consequences of stress on maternal outcomes.^{5,12-16,17,19,21,31,34} Other studies have focused on the early weeks and months following NICU discharge.^{19,31,34,35} One recent study,³⁴ using descriptive phenomenology interviewed mothers in the early weeks after discharge and found that adjusting to the maternal role at home was anxiety provoking and that mothers continued to have many needs during this time. This current study sheds additional light on the fear and exhaustion that continue for months post discharge as well as on other non-emergent problems that contribute to the significant stress already being experienced. This is consistent with research that shows that the first six months after discharge, the time span for this study, can be the time of greatest anxiety for caregivers.¹⁹

Mothers in this study described the time following NICU discharge as being the most difficult of their lives, fraught with unexpected challenges as they struggled to reprioritize their daily activities in order to manage their new role as primary caregiver for their infant.³³ This is consistent with research that indicates that even mothers of full term infants work to rearrange their lives to meet the needs of their infants, themselves and their families.^{30,31} Mothers in this study expressed being surprised at the extra demands on their time and energy, especially during the first several weeks after discharge as they continued their infant's feedings every two to three hours and made the rounds of required medical visits. These findings are consistent with those of other researchers who found that these feelings of exhaustion often extended through the first year of life and became so serious they could conflict with a mothers

ability to bond.^{19,36} This concern was expressed by study mothers who reported staying up after the mid-night feedings in order to have some alone-time with just their infants.

The study participants were candid in their discussions of times when they felt comfortable providing the care their infant needed and other times when they were anxious and unsure of what to do. They felt that the latter outweighed the former, especially at first. Mothers reported an overriding fear that permeated every infant-focused task they completed for the first several months at home following discharge, which is consistent with previous findings where mothers of low-birth-weight preterm infants reported feeling insecure about their role as caregiver even at the six month mark.¹⁹ Mothers also reported feeling continually overwhelmed with just the day-to-day requirements of the care they were being asked to provide, the medications they were being asked to administer, and the numerous steps they were required to remember in order keep their infant safe. These findings are supported by the work of other researchers who have demonstrated that preterm infants are being discharged earlier, sometimes while still requiring complex treatment modalities such as tube feedings, administration of medications or oxygen, all of which can leave even the most well-prepared mother feeling anxious, overwhelmed, unprepared and afraid.^{4,32,34,37} Mothers spoke at length about the stress caused by monitor alarms that would sound in the middle of the night, sometime needlessly, awakening the whole household, and their dismay at not knowing who to turn to for help. Simple things, such as the need to recreate the NICU environment at home so their infant would sleep, were new to them and most times it was something they reported not receiving information about prior to discharge from the NICU or even after discharge from their primary health care provider.

Mothers reported continuing feelings of anxiety, even after successfully making it through the first several months at home. They worried about what consequences their infant might face as a result of being born preterm. This is consistent with other research findings where parents reported still being

afraid and feeling anxious about what obstacles might lay ahead for their infants, at six months post discharge.⁴ It has been noted in other research that mothers of preterm infants often have an unrealistic view of what NICU discharge really means.³⁸ Their joy overshadows the reality of what's involved in caring for their infants at home and they feel the need to be constantly on guard for any changes that might indicate a problem. Mothers in this study reported their happiness at finally being able to provide all the feedings for their infants, however after the first several days of awakening every two to three hours, they realized the amount of time and energy involved and began to wonder how long they would be required to keep this pace. In a study of 152 mothers of preterm infants, participants reported making 109 visits to physicians, 14 visits to emergency rooms, 19 visits to clinics, 42 visits to a nurse and 11 visits to other health care providers during the first three months after discharge.³⁷ The mothers in this study support these findings by describing the numerous medically-necessitated office visits required during those first few weeks at home and the high levels of energy they expended getting their infants to them. All mothers reported making regular trips to pediatricians and most had at least one to two other healthcare visits each week. Coordination among health care visits was not always possible since some infants required specialized health care visits every other day for the first week or so.

Study participants expressed thankfulness for their infants and the fact that they had survived and been discharged to home. Even mothers who described the NICU environment as being intolerable reported forgetting everything negative that had happened once discharge day came. These feelings of thankfulness are supported in current literature where mothers expressed thankfulness that their infant had survived until discharge, for the help both they and their infants had been given, and for the knowledge and skill the NICU nurses displayed while providing care for their infants.^{19, 39, 40} One study mother who is HIV positive discussed her thankfulness that her infant had survived, and the difference she felt having the infant had made in her life. This is consistent with previous research focused on new mothers who

were HIV positive that found that many felt the birth of their child had provided a positive change to their lives.²⁹

All study mothers received extra support following the birth of their infants. Two reported help from family, and six received support in the form of formalized support groups established to assist mothers of preterm infants. The mothers considered the support they received a mitigating factor in managing feelings of isolation they experienced as they moved through their day-to-day routines of providing care for their infant. The positive impact of support has been well documented in the literature with mothers who received support from other mothers of NICU graduates reporting better overall outcomes for both mother and infant, especially if the support began during the early weeks after NICU discharge.^{4,33,40} This is important to note since feelings of isolation have been found to persist up to the one-year mark, after NICU discharge.²⁰

Implications for Research

There are a number of research studies that have examined challenges faced by mothers of preterm infants, including the shock at the diagnosis of a problematic pregnancy, the early birth and subsequent time spent in a NICU.^{1-4,18,19} Few studies, however, have explored the early months after NICU discharge by asking mothers to share their experiences in their own words. This study, while it addresses the knowledge deficit in this area, still presents only a partial picture of this important time. Additional research employing longitudinal design will provide a better understanding of what mothers feel they need during these important early months at home and how these needs might change over a longer time period.

Implications for Practice

The findings of this study have important implications for nursing and should serve to aid the design of interventions that focus on parental as well as infant outcomes.

- One area of concern for this cohort is the practice of co-sleeping with their infants. Recommendations on sleeping arrangements, including a discussion of the infant's sleeping requirements, needs to be more clearly addressed in discharge instructions and included in written form. Mothers in this study seemed to grasp the 'back to sleep' concept, yet the risks of co-sleeping seemed to be outweighed by their need to be near their infant during sleep. Including the risks of co-sleeping as part of discharge teaching might help to decrease this behavior.
- Mothers expressed high anxiety over giving infant-prescribed medications. Opportunities to administer medications several times prior to discharge under the nurse's supervision might address this concern.
- Mothers also expressed anxiety surrounding the use of monitors. Monitor teaching needs to occur in several different modalities and be reinforced by parents spending at least one night with their infant in the NICU, assuming total care of the infant, including monitor care. Although many NICUs do regularly institute this practice, it might be important to make sure the monitor does sound at least once during the night so that parents have the chance to respond to it and learn to intervene appropriately. If this is not possible, an impromptu instruction by the NICU nurse whenever their infant's monitor alarms might serve to alleviate some of this anxiety.
- Each mother discussed the support they received and how it helped mitigate feelings of isolation and sadness. The establishment or utilization of support groups need to be encouraged while an infant is still hospitalized. Monthly get-togethers located in the NICU parents' area with representatives from local support groups could be planned more regularly. These meetings could be attended by NICU staff or completely independent, occurring during the day, in the evening or on weekends, depending on the needs of the families in the NICU.

The study findings provide a look at what transpires after NICU discharge, from the mother's point of view, and in her own words. It is hoped that these findings will serve to better inform healthcare providers of the needs of parents and infants once NICU discharge has occurred.

Study Limitations

Limitations for this study include a convenience sample (n=8), of mothers, the majority of whom were drawn from a small geographic area in the Washington, D.C., Northern Virginia area of the United States, representing infants discharged from five different NICUs. Approximately 75% of the mothers who met the criteria for inclusion came from upper middle class backgrounds and were well educated with at least some college. Approximately 90% had both private insurance and were married. The differences in education levels, especially as it relates to income, have been shown to help mediate some of the effects of preterm birth.⁴¹ Even with these positive education findings, however, the concerns of these mothers were high which begs the question of what levels of concern mothers who are not so well educated or who are dependent on public assistance for medical care might have.

Conclusion

The transition from the NICU to the home is a time of mixed emotions for most parents as the high levels of care their infant has received by teams of well-trained professionals is, by necessity, transferred to them despite concerns that they lack the training they need to do the job. Moreover, the consequences of preterm birth do not end at discharge from the NICU. This study has reported on mothers' experiences of caring for a preterm infant following NICU discharge. The findings confirmed that this is a time of anxiety as these mothers face the new reality of caring for their infants at home. The aim of this study was to further inform our understanding of how mothers survived those early days at home after NICU discharge by asking them to describe in their own words, their experiences. Findings support that while some concerns are transient, particular to the first few weeks at home, others that are

not so temporary could be addressed by providing additional information within discharge instructions. Previous research findings concerning the importance of support and the difference it can make in a mother's reported emotional health were corroborated. Each of the mothers participating in this study admitted that it was the most difficult time in their lives and nothing they would like to repeat, yet, each expressed that whatever they had gone through both in the NICU and since discharge, was worth it. The suggestions made by these study participants are relevant to and have applicability for many mothers of preterm infants. Their willingness to not only share the areas that were the most stress-provoking for them but also to suggest easy, inexpensive ways to address these areas added significance to the findings.

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Appendices

VCU RESEARCH PLAN TEMPLATE

Use of this template is required to provide your VCU Research Plan to the IRB. Your responses should be written in terms for the non-scientist to understand. If a detailed research protocol (e.g., sponsor's protocol) exists, you may reference that protocol. **NOTE:** **If that protocol does not address all of the issues outlined in each Section Heading, you must address the remaining issues in this Plan. It is NOT acceptable to reference a research funding proposal.**

ALL Sections of the Human Subjects Instructions must be completed with the exception of the Section entitled "Special Consent Provisions." Complete that Section if applicable. When other Sections are not applicable, list the Section Heading and indicate "N/A."

NOTE: The Research Plan is required with ALL Expedited and Full review submissions and MUST follow the template, and include version number or date, and page numbers.

DO NOT DELETE SECTION HEADINGS OR THE INSTRUCTIONS.

I. TITLE

CARING FOR THE PRETERM INFANT DURING THE FIRST SIX MONTHS AFTER NICU DISCHARGE: A MOTHER’S PERSPECTIVE

II. RESEARCH PERSONNEL

A. In the table below (add additional rows as needed), indicate: (1) all project personnel including the principal investigator and individuals from other institutions, (2) their qualifications, and (3) a brief description of their role or responsibilities on the study.**
**** Personnel list should include anyone engaged in the research (VCU & non-VCU personnel) including independent investigators. Engaged means interacting or intervening with research participants and/or having access to identifiable private information about participants. See OHRP’s guidance on “Engagement of Institutions in Research” at <http://www.hhs.gov/ohrp/humansubjects/guidance/engage08.html>.**

NAME OF INDIVIDUAL	INSTITUTION	QUALIFICATIONS	RESPONSIBILITIES
Jacqueline M. McGrath	VCU-SON	PhD, RN; Faculty advisor	Oversight of project
Lois Phillips-Pula	VCU-SON	MSN, RN; Doctoral candidate	Student investigator; Collecting/analyzing data

NOTE: If an independent investigator is “engaged,” and the research involves a DIRECT FEDERAL award made to VCU (or application for such), the independent investigator must sign a formal written agreement with VCU certifying terms for the protection of human subjects. For an agreement to be approved: (1) the PI must directly supervise all of the research activities, (2) agreement must follow the ORSP template, (3) IRB must agree to the involvement of the independent investigator, **AND** (4) agreement must be in effect prior to final IRB approval.

B. Describe the process that you will use to ensure that all persons assisting with the research are adequately informed about the protocol and their research-related duties and functions.

Study participants will be contacted by telephone by the student investigator and given an overview of the project. Their involvement will include one face-to-face interview lasting approximately 90 minutes, and possibly one follow-up phone call for clarification of input.

III. CONFLICT OF INTEREST

Describe how the principal investigator and sub/co-investigators might benefit from the subject's participation in this project or completion of the project in general. Do not describe (1) academic recognition such as publications or (2) grant or contract based support of VCU salary commensurate with the professional effort required for the conduct of the project

There is no benefit to principal investigator or the student investigator.

IV. RESOURCES

Briefly describe the resources committed to this project including: (1) time available to conduct and complete the research, (2) facilities where you will conduct the research, (3) availability of medical or psychological resources that participants might require as a consequence of the research (if applicable), and (4) financial support.

Time available is variable, depending on participant's availability. Research will be conducted in participants' homes or another location of their choice. No medical or psychological resources will be required. Study participants who agree to participate in the study will be given a thank-you gift of a \$20 Target card at the study's conclusion, provided from the PI's research support account.

V. HYPOTHESIS

Briefly state the problem, background, importance of the research, and goals of the proposed project.

There are numerous studies in the current literature focusing on the intense emotions experienced by parents, following the birth of a preterm infant, (i.e., born prior to 37 weeks gestational age [GA]). Research findings have helped us understand the fear and anxiety they feel while attempting to navigate the neonatal intensive care unit (NICU) environment. What happens in those early weeks and months at home, however, is surprisingly absent from the literature. It is well known that preterm infants are readmitted to the hospital during the first few months after discharge at a rate of 10% - 35%, for an average 4.7 - 11.7 day stay and a cost of approximately \$376 million (Underwood, 2007; Escobar, et al., 2005). The most common reasons for readmission are respiratory, feeding and jaundice problems (Spicer, et al., 2008; Underwood, 2007; Escobar, et al., 2005; Brissaud, et al., 2005). What we don't yet know is what transpired during those early days and weeks at home and how mothers established their day-to-day routines. This missing information could foster a better understanding of family needs and promote the development of strategies to share with mothers prior to discharge, and could result in not only healthier transitions for both mothers and infants but

also could address the inflated readmission rates for this cohort.

This proposed study will bridge the gap in the literature by speaking with mothers of preterm infants who have been discharged from a NICU and have been home from one to six months. This period is considered important because of the wide range of developmental processes that take place during this time in an infant's life and because there is currently little-to-no information in the literature speaking to parental needs during this early post-discharge period. Studies have demonstrated that mothers of preterm infants expressed high levels of angst and depression coupled with feelings of incompetence during those first few weeks and months at home; whereas around the one-year mark they rated their abilities to provide adequate care for their infants at the same levels as mothers of full term infants of the same age (Feeley, Zelkowitz, Cormier, Charbonneau Lacroix & Papageorgiou, 2009; Olshtain-Mann & Auslander 2008; Gennaro & Hennessy, 2003; Ternstedt & Schoolin 2003; Pridham, Lin & Brown 2001).

VI. SPECIFIC AIMS

The aim of this study is to construct a basic understanding of a mother's experiences caring for her preterm infant during the first six months following NICU discharge. There is currently no cohesive body of knowledge on this topic and so standards of practice, which could guide health care providers in teaching mothers how best to care for their preterm infant, have not been well developed or truly evidence-based. Without a means of checks and balances it is not possible to measure how well NICU discharge instructions are a) being understood by mothers; b) teaching them what they need to know; c) resulting in better outcomes for mother and infant. These findings will serve to inform healthcare providers of the needs of parents and infants once NICU discharge has occurred, and can serve as an evidence base from which to design discharge education.

VII. BACKGROUND AND SIGNIFICANCE

Include information regarding pre-clinical and early human studies. Attach appropriate citations.

The birth of a healthy newborn is usually a celebrated event, with parents expressing joy at their accomplishment and making plans for a bright future (Ruchala, 1999). Mothers of preterm infants, however, face a different reality. In addition to feelings of sorrow, distress and grief, their coping skills are immediately challenged as their newborn is whisked away to the NICU and they are faced with whether the infant will survive and if so, what the long

term effects might be (Griffin, J., 2010; Poehlmann, Schwichtenberg, Bolt & Dilworth-Bart, 2009; Kowalski, Leef, Mackley, Spear, & Paul, 2006; Bakewell-Sachs & Gennaro, 2004). This separation of mother and infant robs both of early bonding opportunities and the necessary time for mothers to learn early infant cues. The average NICU stay is approximately 13 days, based on national averages, and is inversely related to an infant's GA, with infants at lower GA spending more weeks and sometimes months in the NICU (Berns, Boyle, Popper & Gooding, 2007). This forced separation severely limits the mother's ability to function in a normal parenting role, and results in the continued erosion of the maternal-infant bonding processes (Berns, et al.; Griffin & Abraham, 2006; Broedsgaard & Wagner, 2005). This combined emotional toll can result in mothers of preterm infants exhibiting high levels of posttraumatic stress and other adverse mental health outcomes both during the NICU hospitalization and in the weeks and months post discharge (Feeley, Zelkowitz, Cormier, Charbonneau Lacroix & Papageorgiou, 2009; Melnyk, Crean, Feinstein & Fairbanks, 2008; Gennaro & Hennessy, 2003; Ternstedt & Schoolin 2003). Preterm birth is a serious healthcare challenge in the United States with approximately 12.5% (approximately 1,500) of the 12,000 babies born each day making their arrival prior to 37 (completed) weeks GA. Of those 1500 infants, approximately 1.3% or 200 are born very (less than 32 weeks GA) preterm; and 1.2% or 173 are born at very low (less than 1,500 grams) birthweight (March of Dimes, 2009). In 2005, it was estimated that the total bill for medical care (including NICU admission), special education services and missed work days by parents of preterm infants totaled \$26.2 billion, or \$51,600 per infant (Callaghan, 2010; Armstrong & Meis, 2007).

VIII. PRELIMINARY PROGRESS/DATA REPORT

If available.

Not applicable.

IX. RESEARCH METHOD AND DESIGN

Include a brief description of the project design including the setting in which the research will be conducted and procedures. If applicable, include a description of procedures being performed already for diagnostic or treatment purposes.

The methodology proposed for this study is phenomenology. Immanuel Kant in 1764

defined phenomenology as the study of phenomena or things (Speziale & Carpenter, 2007). Phenomenology as a scientific method was greatly influenced by Edmund Husserl (1859-19380), who proposed that the best way to understand a phenomenon was to seek information from those who had experienced it. Phenomenology was described by Spiegelbert and Merleau-Ponty as a method and a philosophy, and as such was grounded in the philosophical traditions of Husserl who believed that the act of being *present* during interviewing could facilitate a researcher's ability to understand a study participant's point of view (Phillips, Strunk & Pickler, 2010). Husserl's heart was on the meaning, the essence or central theme of an experience (Phillips, Strunk & Pickler).

Phenomenology is recognized as a methodology which employs rigorous investigation of a phenomenon as it was consciously experienced by another. Its purpose is to identify the essence of the experience which accurately portrays the phenomenon of interest, as seen through the consciousness of those experiencing it. The focus of inquiry is on developing meaning and understanding by revisiting the experience and listening to the stories of study participants (Moustakas, 1994). In order for the researcher to approach the topic with naiveté, sans *a priori* notions, an epoche process is undertaken to identify and note all preexisting thoughts about the phenomenon. The epoche process prepares the researcher to accept and represent the study participants' experiences exactly as presented, devoid of personal judgments (Moustakas). There are several valid approaches to phenomenology, each with slightly different procedures for collecting and analyzing data. Transcendental phenomenology, as informed by Clark Moustakas, is the approach chosen for this study.

The Moustakas phenomenological approach involves the following steps:

1. Discover a topic rooted in an experience or phenomenon which has not previously been studied.
2. Employ the epoche process to ensure that preconceived biases are not allowed to overshadow essential descriptions;
3. Conduct a comprehensive review of the professional and research literature noting design, methods and findings of previous studies;
4. Develop criteria to locate and contact study participants;
5. Provide study participants with instructions on the nature and purpose of the investigation;

6. Develop a question or broad topic to begin the interview process;
7. Conduct a person-to-person interview focusing on a specific topic and/or question, and report data exactly as presented by participants.

Moustakas recommended that researchers conduct face-to-face interviews with study participants in order to better grasp the context in which the phenomenon was experienced. He taught that interviews should take place wherever study participants were most comfortable (Moustakas, 1994). The setting for this study will be the study participant's home or another location of her choice. The focus will be on providing a comfortable, private and safe environment for the interviews to take place.

Potential questions or topic areas include: What have you learned about caring for your infant and how did you learn it? What would you like us (health care professionals) to know about this experience? What advice would you give to other mothers whose infants are still in the NICU?

X. PLAN FOR CONTROL OF INVESTIGATIONAL DRUGS, BIOLOGICS, AND DEVICES.

Investigational drugs and biologics: IF Investigational Drug Pharmacy Service (IDS) is not being used, attach the IDS confirmation of receipt of the management plan.

Investigational and humanitarian use devices (HUDs): Describe your plans for the control of investigational devices and HUDs including:

- (1) how you will maintain records of the product's delivery to the trial site, the inventory at the site, the use by each subject, and the return to the sponsor or alternative disposition of unused product(s);**
- (2) plan for storing the investigational product(s)/ HUD as specified by the sponsor (if any) and in accordance with applicable regulatory requirements;**
- (3) plan for ensuring that the investigational product(s)/HUDs are used only in accordance with the approved protocol; and**
- (4) how you will ensure that each subject understands the correct use of the investigational product(s)/HUDs (if applicable) and check that each subject is following the instructions properly (on an ongoing basis).**

Not applicable.

XI. DATA ANALYSIS PLAN

For investigator-initiated studies.

Data will be analyzed using the Moustakas method of phenomenological data analysis.

These steps include:

- Organizing the data by studying the transcribed interviews and forming preliminary groupings of information.
- Looking for and highlighting each experience that is relevant to the phenomenon of interest. This is referred to as “horizontalization” (Moustakas, 1994, pg. 120). Each statement is given equal value during this step.
- Reducing the data by testing whether or not a statement effectively addresses the phenomenon of interest and whether or not it’s possible to label it. If statements don’t meet the two requirements, they are discarded along with statements that are redundant, overlapping or vague. The remaining statements provide a structural meaning of the phenomenon.
- Clustering the remaining accounts into broad themes that will be used to develop the “textural descriptions” of the experience (pg. 118).
- Integrating the individual textural descriptions of the phenomenon into an overarching meaning of the experience, reflective of the essences as expressed by participants.

XII. DATA AND SAFETY MONITORING

- **If the research involves greater than minimal risk and there is no provision made for data and safety monitoring by any sponsor, include a data and safety-monitoring plan that is suitable for the level of risk to be faced by subjects and the nature of the research involved.**
- **If the research involves greater than minimal risk, and there is a provision made for data and safety monitoring by any sponsor, describe the sponsor’s plan.**
- **If you are serving as a Sponsor-Investigator, identify the Contract Research Organization (CRO) that you will be using and describe the provisions made for data and safety monitoring by the CRO. Guidance on additional requirements for Sponsor-Investigators is available at <http://www.research.vcu.edu/irb/wpp/flash/X-2.htm>**

The study is minimal risk.

XIV. INVOLVEMENT OF NON-VCU INSTITUTIONS/SITES (DOMESTIC AND FOREIGN) NOT

APPLICABLE

1. Provide the following information for each non-VCU institution/site (domestic and foreign) that has agreed to participate:
- Name of institution/site
 - Contact information for institution/site
 - Engaged in Research or not (if YES AND the research involves a DIRECT FEDERAL AWARD made to VCU, include FWA #). See OHRP’s guidance on “Engagement of Institutions in Research” at <http://www.hhs.gov/ohrp/humansubjects/guidance/engage08.html>. See VCU WPPs <http://www.research.vcu.edu/irb/wpp/flash/XVII-6.htm> and <http://www.research.vcu.edu/irb/wpp/flash/XVII-11.htm>.

Name of Institution	Contact Information for Site	Engaged (Y/N) and FWA # if applicable

2. Provide a description of each institution’s role (whether engaged or not) in the research, adequacy of the facility (in order to ensure participant safety in the case of an unanticipated emergency), responsibilities of its agents/employees, and oversight that you will be providing in order to ensure adequate and ongoing protection of the human subjects. You should only identify institutions that have agreed to participate. If additional institutions agree to participate at a later time, they must be added by amendment to the protocol.

Not applicable.

XVI. HUMAN SUBJECTS INSTRUCTIONS

ALL sections of the Human Subjects Instructions must be completed with the exception of the section entitled “Special Consent Provisions.” Complete that section if applicable.

A. DESCRIPTION

Provide a detailed description of the proposed involvement of human subjects or their private identifiable data.

The study participants are a purposive sample of mothers whose preterm infants were discharged from a NICU within the past six months. Because this is a phenomenological study, there is no set number of participants required. However, it is anticipated that there will be from 6 to 15 mothers who participate. Each mother will be asked to describe, in her own words, the experience of caring for her preterm infant in her home following NICU discharge. Interviews will be audio recorded and transcribed by the doctoral student. Each mother’s information will be deidentified through the use of pseudonyms assigned to each study

participant. The list of those pseudonyms, along with any other identifiable information will be kept in a locked filing cabinet accessible only by the PI or doctoral student.

B. SUBJECT POPULATION

Describe the subject population in terms of sex, race, ethnicity, age, etc., and your access to the population that will allow recruitment of the necessary number of participants.

Identify the criteria for inclusion or exclusion of all targeted populations and include a justification for any exclusions. Explain the rationale for the involvement of special cases of subjects, such as children, pregnant women, human fetuses, neonates, prisoners or others who are likely to be vulnerable. If you plan to allow for the enrollment of Wards of the State (or any other agency, institution, or entity), you must specifically request their inclusion and follow guidance in VCU IRB WPP XV-3: Wards and Emancipated Minors available at <http://www.research.vcu.edu/irb/wpp/flash/XV-3.htm>.

The study participants will be a purposive sample of mothers whose preterm infants were discharged from a NICU within the past six months. Because this is a phenomenological study, there is no set number of participants required. However, it is anticipated that there will be from 6 to 15 mothers who participate.

Inclusion criteria are:

1. Mothers of infants born at 24 – 34 weeks gestational age who were admitted to a NICU for at least one week.
2. Mothers whose infants have been discharged from a NICU for one to six months.

Exclusion criteria are:

1. Mothers who are not able to read and write English or who are not the primary caregiver for their infant;
 - Mothers who are not able to read and write English will necessitate interviewing through an interpreter, which means that direct comments from mothers will need to be translated into an English-word equivalent. Phenomenology seeks to understand a phenomenon from another's perspective, using direct quotes and statements from participants during data analysis. The use of a translator may compromise this important step.
 - The aim of this study is to understand the day-to-day care given by mothers of preterm infants following NICU discharge. Mothers who are not primary caregivers in the home will not be able to adequately verbalize and support this aim.

- Wards of the State (or other agencies, institutions or entities) will also be excluded since the focus of this study is on a mother's caregiving.
2. Mothers who have previously given birth to a preterm infant admitted to a NICU;
 - Mothers who have experienced a previous birth of a preterm infant who was admitted to a NICU will have a different perspective of this second experience, than those mothers experiencing it for the first time.
 3. Mothers of infants who are ventilator-dependent or who have experienced a Stage IV intraventricular hemorrhage (IVH).
 - The experiences of mothers of preterm infants, discharged to home with serious comorbidities such as ventilator dependency or Stage IV IVH, although important, are not the primary focus for this initial study.
 4. Mothers who are under 18 years of age
 - The focus of this study is not adolescent mothers, therefore any mother under the age of 18 will not be selected for this sample.
 5. Mothers of multiples
 - Mothers who have given birth to multiple preterm infants will have different day-to-day experiences (caring for two infants) than mothers providing care for only one preterm infant, which is the focus of this study.

C. RESEARCH MATERIAL

Identify the sources of research material obtained from individually identifiable living human subjects in the form of specimens, records, or data. Indicate whether the material or data will be obtained specifically for research purposes or whether use will be made of existing specimens, records, or data.

The research materials solicited or used for the purposes of this study will come from interviews; the materials will be collected only for this study and no existing records will be used.

D. RECRUITMENT PLAN

Describe **in detail** your plans for the recruitment of subjects including:

- (1) how potential subjects will be identified (e.g., school personnel, health care professionals, etc),
- (2) how you will get the names and contact information for potential subjects, and
- (3) who will make initial contact with these individuals (if relevant) and how that contact will be done.

If you plan to involve special cases of subjects, such as children, pregnant women, human fetuses, neonates, prisoners or others who are likely to be vulnerable, describe any special recruitment procedures for these populations.

Mothers will self-identify from advertisements and flyers placed in local clinics, health care settings, ads in local newspapers and on the VCU teleGRAM, and through the snowball effect of word of mouth. Referrals by other health care professionals will be sought, with mothers who express an interest being asked to contact the researcher via e-mail or phone. During this initial phone conversation, the researcher will outline the goals, procedures for gathering data and expected outcomes of the study, including how the information will be analyzed and shared, and seek buy-in from the mother. Each participant who is interested in participating in the study will be mailed an informed consent form for their review. This initial discussion will also establish a time and place for the face-to-face interview. Prior to the start of the interview, any further questions regarding the study will be addressed and participants will be asked to sign an informed consent form that will be collected by the researcher. Each participant will receive a copy of the signed form for their records

E. PRIVACY OF PARTICIPANTS

NOTE: Privacy refers to individuals and their interests in controlling access to their identities, their physical person, and how and what kind of information is obtained about them. Privacy also encompasses the interests of defined communities (e.g. those with a

certain diagnosis or social circumstance) in controlling access to the group identity and information about the group or individuals as part of the group.

Describe how the privacy interests of subjects (and communities, if appropriate) will be protected including:

(1) in the research setting (e.g., in the identification, recruitment, and intervention settings) and

(2) with the information being sought and the way it is sought. For example, providing drapes or barriers, interviewing in a private room, and collecting only the amount of sensitive information needed for identification, recruitment, or the conduct of the study.

Privacy of study participants will be supported through the use of pseudonyms during interviews, transcription and reports. The issues surrounding privacy and confidentiality really speak to research ethics and include the principles of autonomy, beneficence and justice. Autonomy speaks to not only protecting a study participant's identity or ensuring that collected data is kept safe, but also respecting each study participant as an individual, with individual needs and rights. Participants of this study will be assured that they may withdraw from the study at any point and may choose to have their data removed from study findings, without prejudice, to support their autonomy. Beneficence seeks to ensure that no harm is done to others, especially those in your care. Justice requires the researcher to apply ethical principles equally among all study participants without regard to status (Orb, Eisenhauer & Wynaden, 2001). Justice also requires the researcher to be cognizant of the vulnerabilities of study participants and to work diligently to not exploit or allow others to exploit those (Orb, Eisenhauer & Wynaden).

F. CONFIDENTIALITY OF DATA

NOTE: Confidentiality refers to the way private, identifiable information about a subject or defined community is maintained and shared.

Check all of the following precautions that will be used to maintain the confidentiality of identifiable information:

- Paper-based records will be kept in secure location and only accessed by authorized study personnel
- Electronic records will be made available only to those personnel in the study through the use of access controls and encryption
- Identifiers will be removed from study-related data (data is coded with a key stored in a separate secure location)
- For research involving web-based surveys, data is secured via passwords and encryption
- Audio or video recordings of subjects will be transcribed and then destroyed to prevent audio or visual identification. Note the date of destruction (e.g., 3 months from close of study; after transcription is determined to be error free).
- Obtaining a Certificate of Confidentiality
- Other precautions: Consents and data files are stored in different, locked locations.

G. POTENTIAL RISKS

Describe potential risks (physical, psychological, social, legal, or other) and assess their likelihood and seriousness. Where appropriate, describe alternative treatments and procedures that might be advantageous to the subjects.

Potential risk to study participants will be minimal. It is recognized that giving birth to a preterm infant can be a cause of much concern and sorrow to mothers. For that reason, interviews will be conducted at a pace set by the study participant and areas of discomfort to the mothers will be minimized or eliminated. Additionally, since talking about their experience may cause sadness or other distress, the student investigator will prepare a list of community resources available to new mothers. She will offer this list to mothers who state they are sad or who exhibit signs of distress.

H. RISK REDUCTION

Describe procedures for protecting against or minimizing potential risk. Where appropriate, discuss provisions for ensuring necessary medical or professional intervention in the event of adverse events to the subjects. Describe the provisions for monitoring the data collected to ensure the safety of subjects, if any.

Questions will be open-ended, without a set number to be answered and the flow of the interaction will depend chiefly on the comfort of the study participant.

I. ADDITIONAL SAFEGUARDS FOR VULNERABLE PARTICIPANTS

Describe any additional safeguards to protect the rights and welfare of participants if you plan to involve special cases of subjects such as children, pregnant women, human fetuses, neonates, prisoners or others who are likely to be vulnerable.

Safeguards to protect the rights and welfare of participants might relate to Inclusion/Exclusion Criteria: (“Adults with moderate to severe cognitive impairment will be excluded.” “Children must have diabetes. No normal controls who are children will be used.”) Consent: (“Participants must have an adult care giver who agrees to the participant taking part in the research and will make sure the participant complies with research procedures.” “Adults must be able to assent. Any dissent by the participant will end the research procedures.”) Benefit: (“Individuals who have not shown benefit to this type of drug in the past will be excluded.”).

Not applicable.

J. RISK/BENEFIT

Discuss why the risks to participants are reasonable in relation to the anticipated benefits to subjects and in relation to the importance of the knowledge that may reasonably be expected to result. If a test article (investigational new drug, device, or biologic) is involved, name the test article and supply the FDA approval letter.

Risks, as noted above, will be minimal to study participants whereas the information gained from this research will inform caregivers on this very important topic.

K. COMPENSATION PLAN

Compensation for participants (if applicable) should be described, including possible total compensation, pro-rating, any proposed bonus, and any proposed reductions or penalties for not completing the project.

Mothers who agree to participate in and remain with the study through completion will receive a \$20 Target card in appreciation for their willingness to participate.

L. CONSENT ISSUES

1. CONSENT PROCESS

Indicate who will be asked to provide consent/assent, who will obtain consent/assent, what language (e.g., English, Spanish) will be used by those obtaining consent/assent, where and when will consent/assent be obtained, what steps will be taken to minimize the possibility of coercion or undue influence, and how much time will subjects be afforded to make a decision to participate.

Initial contact with study participants will be via telephone with the student researcher and cover the aim of the study, the study design and the various steps to be employed during the study. Participants will be encouraged to discuss anything that is unclear or that they don't understand. Prior to beginning the face-to-face interview, any further questions regarding the study will be answered by the student researcher and a signed informed-consent form will be provided for each participant's signature, and collected by the student researcher. Each study participant will receive a copy of the signed form for their records

2. SPECIAL CONSENT PROVISIONS

If some or all subjects will be cognitively impaired, or have language/hearing difficulties, describe how capacity for consent will be determined. Consider using the VCU Informed Consent Evaluation Instrument available at <http://www.research.vcu.edu/irb/guidance.htm>. If you anticipate the need to obtain informed consent from legally authorized representatives (LARs), please describe how you will identify an appropriate representative and ensure that their consent is obtained. Guidance on LAR is available at <http://www.research.vcu.edu/irb/wpp/flash/XI-3.htm>.

Not applicable.

3. ASSENT PROCESS

If applicable, explain the Assent Process for children or decisionally impaired subjects. Describe the procedures, if any, for re-consenting children upon attainment of adulthood. Describe procedures, if any, for consenting subjects who are no longer decisionally impaired. Guidance is available at <http://www.research.vcu.edu/irb/wpp/flash/XV-2.htm> and <http://www.research.vcu.edu/irb/wpp/flash/XVII-7.htm>.

4. REQUESTS FOR WAIVERS OF CONSENT (COMPLETE IF REQUESTING ANY TYPE OF WAIVER OF CONSENT OR ASSENT)

NOT APPLICABLE

4-A. REQUEST TO WAIVE SOME OR ALL ELEMENTS OF INFORMED CONSENT FROM SUBJECTS OR PERMISSION FROM PARENTS: A waiver of informed consent means that the IRB is not requiring the investigator to obtain informed consent OR the IRB approves a consent form that does not include or alters some/all of the required elements of consent. **Guidance is available at <http://www.research.vcu.edu/irb/wpp/flash/XI-1.htm>. NOTE: Waiver is not allowed for FDA-regulated research unless it meets FDA requirements for Waiver of Consent for Emergency Research (see below).**

4-A.1. Explain why a waiver or alteration of informed consent is being requested.

4-A.2. Describe how this study meets ALL FOUR of the following conditions for a waiver or alteration:

- The research involves no more than minimal risk to the participants. → Explain how your study meets this criteria:

- The waiver or alteration will not adversely affect the rights and welfare of participants. → Explain how your study meets this criteria:

- The research could not practicably be carried out without the waiver or alteration. → Explain how your study meets this criteria:

- Will participants be provided with additional pertinent information after participation?
 Yes
 No → Explain why not:

4-B. REQUEST TO WAIVE DOCUMENTATION OF CONSENT: A waiver of documentation occurs when the consent process occurs but participants are not required to sign the consent form. **Guidance is available at http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XI-2.htm. One of the following two conditions must be met to allow for consenting without signed documentation. Choose which condition is applicable and explain why (explanation required):**

- The only record linking the participant and the research would be the informed consent

form. The principal risk to the participant is the potential harm resulting from a breach of confidentiality. Each participant will be asked whether he/she wants documentation linking the participant with the research and the participants wishes will govern. → Explain how your study fits into the category:

The research presents no more than minimal risk of harm to participants & involves no procedures for which signed consent is normally required outside of the research context. → Explain how your study fits into the category:

4-C. REQUEST TO WAIVE SOME OR ALL ELEMENTS OF ASSENT FROM CHILDREN ≥ AGE 7 OR FROM DECISIONALLY IMPAIRED INDIVIDUALS: A waiver of assent means that the IRB is not requiring the investigator to obtain assent OR the IRB approves an assent form that does not include some/all of the required elements. Guidance is available at <http://www.research.vcu.edu/irb/wpp/flash/XV-2.htm>.

4-C.1. Explain why a waiver or alteration of informed consent is being requested.

In order for the IRB to approve a request for waiver of assent, the conditions for 4-C.2, 4-C.3, OR 4-C.4 must be met. Check which ONE applies and explain all required justifications.

4-C.2. Some or all of the individuals age 7 or higher will not be capable of providing assent based on their developmental status or impact of illness. → Explain how your study meets this criteria:

4-C.3. The research holds out a prospect of direct benefit not available outside of the research. → Explain how your study meets this criteria:

4-C.4. Describe how this study meets ALL FOUR of the following conditions:

- The research involves no more than minimal risk to the participants. → Explain how your study meets this criteria:
- The waiver or alteration will not adversely affect the rights and welfare of

participants. → Explain how your study meets this criteria:

- The research could not practicably be carried out without the waiver or alteration. → Explain how your study meets this criteria:

- Will participants be provided with additional pertinent information after participation?

Yes

No → Explain why not:

4-D. REQUEST TO WAIVE CONSENT FOR EMERGENCY RESEARCH: Describe how the study meets the criteria for emergency research and the process for obtaining LAR consent is appropriate. See guidance at <http://www.research.vcu.edu/irb/wpp/flash/XVII-16.htm>.

Not applicable.

5. GENETIC TESTING

If applicable, address the following issues related to Genetic Testing.

5-A. FUTURE CONTACT CONCERNING FURTHER GENETIC TESTING RESEARCH

Describe the circumstances under which the subject might be contacted in the future concerning further participation in this or related genetic testing research.

Not applicable.

5-B. FUTURE CONTACT CONCERNING GENETIC TESTING RESULTS

If planned or possible future genetic testing results are unlikely to have clinical implications, then a statement that the results will not be made available to subjects may be appropriate. If results might be of clinical significance, then describe the circumstances and procedures by which subjects would receive results. Describe how subjects might access genetic counseling for assistance in understanding the implications of genetic testing results, and whether this might involve costs to subjects. Investigators should be aware that federal regulations, in general, require that testing results used in clinical management must have been obtained in a CLIA-certified laboratory.

Not applicable.

5-C. WITHDRAWAL OF GENETIC TESTING CONSENT

Describe whether and how subjects might, in the future, request to have test results and/or samples withdrawn in order to prevent further analysis, reporting, and/or testing.

Not applicable.

5-D. GENETIC TESTING INVOLVING CHILDREN OR DECISIONALLY IMPAIRED PARTICIPANTS

**Describe procedures, if any, for consenting children upon the attainment of adulthood.
Describe procedures, if any, for consenting participants who are no longer decisionally impaired.**

Not applicable.

5-E. CONFIDENTIALITY OF GENETIC INFORMATION

Describe the extent to which genetic testing results will remain confidential and special precautions, if any, to protect confidentiality.

Not applicable.



MOTHERS OF PRETERM INFANTS

- Was your infant admitted to a neonatal intensive care unit (NICU) for **at least 1 week**?
- Has your infant been discharged from the NICU **for 6 months or less**?

If so, we would like to speak with you about a research study!

What: A study of mothers of preterm (premature) infants

Where: In your home or another place of your choosing

How: One face-to-face interview and a possible follow-up phone call

Who: Lois Phillips-Pula, MSN, RN (Doctoral Candidate), [703/507-9540](tel:7035079540); phillipspull@vcu.edu OR Jacqueline McGrath, PhD, RN, Faculty Advisor jmmcgrath@vcu.edu

Virginia Commonwealth School of NURSING

Appendix I

RESEARCH SUBJECT INFORMATION AND CONSENT FORM

TITLE: Caring for the Preterm Infant during the First Six Months Post NICU Discharge: A Mother's perspective

VCU IRB NO.:

This consent form may contain words that you do not understand. Please ask for an explanation of any words that you do not clearly understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

PURPOSE OF THE STUDY: The purpose of this research study is to understand a mother's experience in caring for her preterm infant at home, after NICU discharge. You are being asked to participate in this study because you have given birth to a preterm infant who spent time in the hospital NICU and who is now at home with you as the primary caregiver.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT: If you decide to be in this research study, you will be asked to sign this consent form after you have had all your questions answered and feel you understand what your agreement to participate involves. In this study you will be asked to arrange a time for a face-to-face interview, either in your home or in another place of your choice. The interview will last no longer than 90 minutes (1-1/2 hours). During the interview, you will be asked about what it has been like caring for your infant following NICU discharge. The interview will be tape recorded to get your ideas, but no names will be recorded on the tape, and you will be given a pseudonym (a different name) which we will use in the study reports. If you like, you may request a second face-to-face or telephone interview. If there is something the researcher doesn't understand, she may call you to clarify a meaning. At the end of the study the researcher will write an article for publication in a health care journal, however again, only pseudonyms will be used and no identifying information will be shared.

RISKS AND DISCOMFORTS: Sometimes remembering and discussing a subject can be uncomfortable. You do not have to talk about any subjects you do not want to talk about, and you may ask for a time-out, when the tape recorder will be turned off, if you need to take time to rest. Your participation is strictly voluntary and you may leave the study if you think that might be best for you.

BENEFITS TO YOU AND OTHERS: The benefits derived from your participation in this study are not

known; however, you are providing needed information to an area where a mother's point of view has not previously been included. If you stay in the study until the end, you will receive a small thank-you gift of a \$20 Target card for use as you see fit.

COSTS: The only cost for participating in this study is the time you will spend in the interview.

ALTERNATIVES: The alternative is to not participate in this study.

CONFIDENTIALITY: Potentially identifiable information about you will consist of interview notes and recordings. Data are being collected only for research purposes. Your data will only be identified by pseudonyms and will not include your name, address or telephone number. All information gathered will be stored in a locked research area, with data files password protected and deleted within 7 years of study completion. Access to all data will be limited to study personnel. We will not tell anyone the answers you give us; however, information from the study and the consent form signed by you may be looked at or copied for research or legal purposes by Virginia Commonwealth University. What we find from this study may be presented at meetings or published in papers, but your name will never be used in these presentations or papers. The interview session will be audio taped, but no names will be recorded. The tapes and the notes will be stored in a locked cabinet. At the completion of the study, the tapes will be destroyed.

VOLUNTARY PARTICIPATION AND WITHDRAWAL: You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may also choose not to answer particular questions that are asked in the study. Your participation in this study may be stopped at any time by the study staff without your consent. The reasons might include:

- the study staff feels your participation might affect your health or safety;
- you have not been able to follow study instructions; or
- any administrative reasons that would require your withdrawal.

QUESTIONS: In the future, you may have questions about your participation in this study. If you have any questions, complaints, or concerns about the research, contact:

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If you have any questions about your **rights** as a participant in this study, you may contact:

Office for Research
Virginia Commonwealth University
800 East Leigh Street, Suite 113
P.O. Box 980568
Richmond, VA 23298
Telephone: 804-827-2157

You may also contact this number for general questions, concerns or complaints about the research. Please call this number if you cannot reach the research team or wish to talk to someone else. Additional information about participation in research studies can be found at <http://www.research.vcu.edu/irb/volunteers.htm>.

CONSENT

I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study. I will receive a copy of the consent form once I have agreed to participate.

Participant name printed

Participant signature

Date

Name of Person Conducting Informed Consent

Discussion / Witness ³

(Printed)

Signature of Person Conducting Informed Consent

Date

Discussion / Witness

Appendix II

Table 1. Samples of Follow-Up Questions

Follow up questions asked to clarify a statement:

- When you said _____, what did you mean by that?
- Can you describe what you were feeling while this was going on?
- What was going on around you as this was happening?
- Were you alone when this was happening or was someone else with you?
- When you heard that, what did you think?
- Did you notice any unstated messages while this was happening?
- What was of most concern to you and how did you address those concerns?

Table 2. Data Examples

Themes	Data Examples: Quotes from Study Participants
Fear of the unknown	<ul style="list-style-type: none"> • I thought he was doing good but he had so many follow up appointments that at one of his appointments they didn't think we was doing good at all. . . he had fluid on his lungs. • Even though I'm a nurse, it's still very scary. • When I'm in the shower and I can [sometimes] hear her crying, I mean that's too bad that she's crying and I feel bad for her, but it's comforting because she's crying and that means she's still breathing. • That was the first time it hit me that he really <i>needed</i> help breathing [when her infant pulled out his nasal canula and stopped breathing]
Exhaustion	<ul style="list-style-type: none"> • Every time he moved [at night] I woke up so I didn't sleep much. • At first we thought 'Oh, this is fun! And so we woke up a midnight, 3 o'clock in the morning and we were so happy . . . but then on the third or fourth day in we began to think 'Oh, this is hard!' • I have to make sure, I have to wake up and look over, make sure she's still breathing and I can go back to sleep, but it takes a lot of getting used to. • [The apnea monitor] was a nightmare sometimes because it doesn't stick . . . the electrodes, and it would go off and then I was up [and wide awake] until the next feeding.
Determination	<ul style="list-style-type: none"> • It's [been] a roller coaster, and that's ok. • We brought her home and she lost weight between the first and second appointment . . . Our challenge was keeping her awake long enough so she would take enough of her bottle. So we had to go to 2 hr feeds for awhile [which] was hard . . . but we did it. • I know she can do better and I can work with her more. • I just can't imagine her going back there [hospital] again so it's hard but

	you do whatever to see that that doesn't happen.
Thankfulness	<ul style="list-style-type: none">• You just forget about everything that's happened . . . you just forget about it.• It's [was] a long bumpy road, but it will be ok. Of course we were very lucky with [him].• I love my daughter and I didn't expect it to be the way that it was but I wouldn't trade her.• I consider myself to be very lucky that she's here and alive . . . a lot of babies just die because of it [abruptio] and she didn't and neither did I.

Table 3. Infant Demographic Information

Name (Pseudonyms)	GA (Wks)	Birth Weight¹	Days in NICU	Time Since Discharge²
Francis	24	1 lb. 10 ozs.	90	5 months
Tanya	24	1 lb. 4ozs.	150	5 months
Serena	25	1 lb. 14 ozs.	80	5 months
Tina	26	2 lbs. 2 ozs.	96	3 months
Keith	27	1 lb. 4 ozs.	90	2 months
Elizabeth	28	1 lb. 14 ozs.	77	4 months
Seth	28	2 lbs. 12 ozs.	61	4 months
Orson	32	6 lbs.	60	4 months

¹ As reported by mother

² Length of time after discharge at time of interview

Table 4. Textural and Structural Descriptions by Study Participant

Name (Pseudonyms)	Textural Description	Structural Description
Francis	<p>Sadness</p> <p>Fear</p> <p>Joy</p> <p>Spirituality</p>	<p>“I would sit and think ‘did I do something wrong with the whole finding out so late that I was even pregnant . . . there must have been something I did wrong. . . .’”</p> <p>“He came home with all these wires and my mom kept telling me that he shouldn’t be home yet, that they should have kept him in the hospital until his wires were gone.”</p> <p>“We set up his room and felt really good because it was showing me that it was real . . . he was really here . . . and we put his name on the wall, and it felt really, really good.”</p> <p>“Miracles do exist.”</p>
Tanya	<p>Grief</p> <p>Fear</p> <p>Exhaustion</p> <p>Advocacy</p>	<p>“Knowing that <i>your</i> infant might not survive.”</p> <p>“I have to wake up and feel her . . . look over at her to be sure she’s still breathing.”</p> <p>“Working fulltime [2 jobs] and then waking up every 2-3 hours for feeding . . . or when the monitor alarm sounds.”</p> <p>“Every preemie is different and whatever preconceived notions we have in our head about our baby being perfect, with a perfect future, we have to dispel all that because we have to let our children be individuals of who they are.”</p>
Serena	Positivity	<p>“There are no guarantees in life so I would suggest stay[ing] positive.”</p>

	<p>Fear</p> <p>Thankfulness</p>	<p>“We [were told] that it takes longer than they would like for her to feed, but the let her go still.”</p> <p>“And yeah, so 25 weeks is not that scary compared to what could have happened . . . to her and to me.</p>
Tina	<p>Fear</p> <p>Family disruption</p> <p>Exhaustion</p>	<p>“Every day it’s just you feel like ‘I’m waiting for disaster to happen,’ every day.”</p> <p>“I think we really didn’t put her on a schedule, she put us on a schedule.”</p> <p>“We went to <i>a lot</i> of appointments at the beginning.”</p>
Keith	<p>Sorrow</p> <p>Confusion based on inexperience</p> <p>Fear</p> <p>Sense of belonging</p>	<p>“I’m HIV positive and I didn’t want to, you know, pass it on to my child.”</p> <p>“He was at home about a month, eating fine and gaining weight, but just his lungs . . . they said he had fluid on his lungs . . . they put him back in the hospital”</p> <p>“Right now we’re supposed to be trying to wean him off his oxygen, but I’m a little scared to do it.”</p> <p>“I can sit and have a whole conversation with him . . . he’s my best friend.”</p>
Elizabeth	<p>Fear</p> <p>Frustration</p> <p>Thankfulness</p>	<p>“We brought her home and she lost weight . . . so we had to go to two hour feedings for awhile.”</p> <p>“If she spit up after eating I tried to figure out did she eat too fast? Did I eat something that disagreed with her? Finally we read that it had to do with her sphincter . . . and one day she just stopped.”</p> <p>“It’s [been] a roller coaster, and that’s ok.”</p>

Seth	<p>Sadness</p> <p>Exhaustion</p> <p>Fear</p> <p>Guilt</p>	<p>“It would take all his energy to breathe and so he didn’t have any left to eat . . . so he would desat.”</p> <p>“I don’t think there was anywhere in the house you could go to get away from the monitor.”</p> <p>“He was so tiny . . . I was scared to hold him for too long.”</p> <p>“I felt bad that he had to be born early because there was nothing wrong with him and he was just fine hanging out inside of me.”</p>
Orson	<p>Fear</p> <p>Exhaustion</p> <p>Disruption to family</p> <p>Isolation</p>	<p>“I was in an absolute panic” [administering medication.</p> <p>“The first week was just a blur of trying to do what needed doing and snatch sleep and maybe get a shower.”</p> <p>“It was just a circus, but not in a good way.” [when the apnea monitor would alarmed in the middle of the night]</p> <p>“I looked at it as this horrible thing and it was all my problem. That he had gone back to work and so now it was my problem.”</p>

Table 5 Research Associated with Transition to Home for NICU Infants and Families

Author	Method	Findings
Berns, S.D., Boyle, M.D., Popper, B., & Gooding, J. S., 2007.	<ul style="list-style-type: none"> Survey of 502 parents of preterm infants born at ≤ 36 weeks GA; currently at ≤ 30 months old 	<ul style="list-style-type: none"> 65% of parents were reasonably satisfied with access, attention and information received in NICU; 25% were moderately satisfied; 10% were dissatisfied
Brissaud, O., Pedespan, B.F., Feghali, L., Esquerre, F., & Sarlangue, J., 2005.	<ul style="list-style-type: none"> Retrospective study comparing rehospitalization rates of preterm infants at two time-periods, 1997 (n=55), and 2002 (n=73) Participants were born at ≤ 33 weeks GA 	<ul style="list-style-type: none"> 1997 cohort: 29.1% of infants were rehospitalized at least once for an average of 11.8 days 2002 cohort: 20.1% were rehospitalized for an average of 16.8 days Factors associated with rehospitalization included: Low birth weight (<1000grams), chronic lung disease, and GA ≤ 28 weeks at birth
Broedsgaard, A., & Wagner, L., 2005.	<ul style="list-style-type: none"> Mixed methods: semi-structured questionnaires (n=37) and focus groups (n=18) about new education-based intervention, which included follow-up home care 	<ul style="list-style-type: none"> Survey group: 95% of parents felt supported; 94% felt the new intervention was beneficial to them; 90% felt secure when returning home Focus group themes: Frustration with the NICU not being on the obstetrics floor; important information needed repeating and follow-up with written copy; rooming-in periods helped prepare for home Both groups: Hospital coordinators helped parents understand what was going on, navigate the NICU and prepare for discharge
Escobar, G. J., Joffe, S., Gardner, M.N., Armstrong, M. A., Folck, B.F., & Carpenter, D. M., 1999.	<ul style="list-style-type: none"> Chart review of 6054 infants readmitted to a Kaiser Permanente facility after discharge from the NICU 	<ul style="list-style-type: none"> Two most common reasons for rehospitalization were jaundice and feeding problems Infants born at 33-36 weeks GA and those admitted to NICU for <4 days rehospitalized at a rate significantly higher than cohort, most (71%) for jaundice
Feeley, N., Zelkowitz, P., Cormier, C., Charbonneau, L., Lacroix, A., Papageorgiou, A., 2009.	<ul style="list-style-type: none"> Descriptive, correlational study of 21 mothers of VLBW (<1500 grams) infants at 6 months (corrected) age Convenience sample 	<ul style="list-style-type: none"> 24% of mothers attained scores on Perinatal PTSD Questionnaire (PPQ) consistent with diagnoses of PTSD Mothers reporting more concurrent symptoms of PTSD were also less sensitive to infant needs and less effective at structured play
Jackson, K., Ternestedt, B. M., & Schollin, J., 2003	<ul style="list-style-type: none"> Phenomenological study of 7 sets of parents of infants born ≤ 34 weeks GA Interviewed at 2 weeks, 2, 6 & 18 months 	<ul style="list-style-type: none"> Learning to parent a preterm progresses through four stages: alienation, responsibility, confidence and familiarity One of the first important milestones for parents occurred in the NICU when they could remove the neonate from the incubator and hold the infant Mothers feel greater responsibility for care and wanting to be acknowledged as the mother Going home without the infant was especially difficult for mothers Some mothers reported being so afraid their infant would not survive that they struggled to visit the NICU Fathers struggled for balance between work/home

Author	Method	Findings
		<ul style="list-style-type: none"> Each factor listed by parent was influenced by culture
Kowalski, W. J., Leef, K. H., Mackley, A., Spear, M. L., & Paul, D. A., 2006.	<ul style="list-style-type: none"> 19-item questionnaire given to 110 parents of infants born ≤ 32 weeks GA, prior to NICU discharge 	<ul style="list-style-type: none"> 96% felt they received needed information about their infant NICU nurse was recognized as the person who spent the most time with parents discussing infant's condition
Meynyk, B. M., Crean, H. F., Feinstein, N. F., & Fairbanks, E., 2008.	<ul style="list-style-type: none"> Secondary analysis of RTC with 246 mothers of preterm infants Measure of intervention outcomes for Creating Opportunities for Parent Empowerment (COPE) 	<ul style="list-style-type: none"> Participation in COPE was related to decreased maternal depression and anxiety post-NICU Participation was positively associated with higher mother-infant interaction scores
Olshtain-Mann, O., & Auslander, G. K., 2008.	<ul style="list-style-type: none"> Questionnaire; 320 parents who had a preterm infant admitted to a NICU Comparison of depression and competence among parents of full term and parents of preterm infants at 2 months post discharge Infants weighed ≤ 1750 grams; ≤ 36 weeks GA; admitted to the NICU for ≥ 1 week 	<ul style="list-style-type: none"> There were significant differences between stress experienced by mothers and fathers and the stress experienced by parents of preterm infants differed significantly from parents of full term infants High levels of parental stress and low levels of confidence were observable at two months post discharge indicating the need for continued availability of professional help for parents
Poehlman, J., Miller-Schwichtenberg, A.J., Bolt, D., & Dilworth-Bart, J., 2009	<ul style="list-style-type: none"> Longitudinal study of depressive symptoms in 181 mothers of preterm infants, prior to NICU discharge 	<ul style="list-style-type: none"> Depressive symptoms negatively associated with family support Variables such as poverty, being a single mother, other children at home, etc., associated with vulnerability to chronic depression Different ethnic groups experience significantly different depressive trajectories than white counterparts
Ruchala, P. L., 1999.	<ul style="list-style-type: none"> Descriptive, survey of post partum nurses (n=124) and new mothers (103) about discharge teaching they gave/received 	<ul style="list-style-type: none"> Significant differences were noted between what mothers want to know and what nurses taught New mothers wanted to know more about how to care for themselves whereas nurses wanted mothers to know how to care for their newborn Evidenced based practices need to be implemented in patient education areas
Saigal, S., Pinelli, J., Streiner, D.L., Boyle, M., & Stoskopf, B., 2009.	<ul style="list-style-type: none"> Longitudinal, cohort study, 130 mothers of ELBW infants and 126 mothers of normal birth weight (NBW) infants Data collection began at birth and continued through early-adulthood Self-administered questionnaires measured maternal mood; marital disharmony; anxiety; overall health of family; amount of social/family support 	<ul style="list-style-type: none"> A significant, positive association between SES and social support but not between SES and family harmony Mothers of ELBW infants reported closer family unity and greater support from family/friends Mothers of ELBW infants with neurosensory impairments reported feelings of satisfaction in being able to provide the care their infant needed No differences between groups on maternal physical, mental health
Smith, V.C., Young, S., Pursley, D. M., McCormick, M. C., &	<ul style="list-style-type: none"> Prospective study of 867 NICU nurses and families of NICU infants from November 2003 until April 2007 Families were asked to rate their level of preparedness for NICU discharge 	<ul style="list-style-type: none"> Differences in ratings were significant Unclear how this could affect long-term outcomes for preterm infants and their parents

Author	Method	Findings
Zupancic, J. F., 2009.	<ul style="list-style-type: none"> Nurses were asked to rate the family's level of preparedness 	
Spicer, A., Pinelli, J., Saigal, S., Wu, Y., Cunningham, C., & DiCenso, A., 2008.	<ul style="list-style-type: none"> Longitudinal, descriptive study of 152 mothers of preterm infants Self-report questionnaire focusing on family function during the first year of life at 3, 6, and 12 month markers 	<ul style="list-style-type: none"> Majority of mothers described their health status as excellent or very good at all three time points This finding was not related to or dependent on the health of the infant at the same points in time
Underwood, M.A., Danielsen, B., & Gilbert, W. M., 2007.	<ul style="list-style-type: none"> Retrospective study of 263,000 preterm infants born from 1992-2000 Focus was on rehospitalizations during the first year of life; length of stays and associated costs by birth weights and GAs 	<ul style="list-style-type: none"> 15% of infants born <36 weeks GA required rehospitalization during first year – this is recognized as much lower than other studies (at 27% to 47%) Average annual cost in California for infants weighing <2500 grams at birth was \$28.2(M) Percentage of infants readmitted was negatively related to GA and birth weight, except for the late preterm infant (LPI) cohort. LPIs (birth weight >2500 g) represented a significant portion of readmissions (32%) and had the highest costs <i>per cohort</i> Smallest infants (born <1000 g) accounted for 16% of total costs of rehospitalization. have the highest cost <i>per readmission</i>

Table 6.

Themes from Research and Published Papers

Themes	Findings	References
<p><i>The NICU environment is highly stressful for families of preterm infants and that stress does not abate once the infant is discharged to home</i></p>	<ul style="list-style-type: none"> ▪ NICU discharge includes feelings of joy, fear, anxiety for parents ▪ Parents question their ability to duplicate NICU care once home ▪ Infants are being discharge while still requiring care such as Oxygen administration or tube feedings ▪ Preterm birth continues to be the leading cause of death among newborns ▪ These continuing needs of the newborn can overwhelm families ▪ In families with lower SES or where neurological sensory injury has occurred, high levels of stress are reported up to adolescence ▪ Parents who have a good relationship with their pediatrician or who felt confident about the health and maturity of their infant felt prepared to make a successful transition to home 	<p>Wade, et al., 2008; Willis, 2008; Griffin & Abraham, 2006; Bakewell-Sachs & Gennaro, 2004</p> <p>Saigal, et al., 2010; American Academy of Pediatrics, 2009; March of Dimes, 2009; Lasby, Newton & Platen, 2004</p> <p>Saigal, et al., 2009</p> <p>Smith, et al., 2009</p>
<p><i>Clinically depressive symptoms and PTSD in mothers of preterm infants is more common and lasts longer than originally thought</i></p>	<ul style="list-style-type: none"> ▪ Depression and PTSD which begins during NICU admission can extend into the months and years post discharge ▪ 32% of mothers expressed clinically significant depressive symptoms just prior to NICU discharge; 12% continued to experience these symptoms at 24 months post term ▪ Mothers related feelings of continued incompetence in caring for their infant two months after NICU discharge ▪ Mothers of VLBW infants reported continuing PTSD symptoms at six-months post discharge 	<p>Gennaro & Hennessy, 2003; Feeley, et al., 2009; Jackson, Ternestedt & Schoolin, 2003</p> <p>Poehlmann et al., 2009; Olshtain-Mann & Auslander, 2008</p> <p>Feeley, et al., 2009</p>

Themes	Findings	References
<p><i>The maternal-infant bond, postponed during NICU admission, can be more difficult to establish post discharge</i></p>	<ul style="list-style-type: none"> ▪ Mothers of preterm infants admitted to the NICU have their parental role replaced by others caring for their infant ▪ This interruption negatively impacts her ability to develop an early bond with the infant ▪ After discharge, mother's exhaustion can undermine the bonding experience ▪ Exhaustion is exacerbated by the number of doctor and pharmacy visits necessary after discharge ▪ A preterm infant's CNS immaturity and disorganized behaviors can result in less responsiveness to parents' attempts to develop a bond 	<p>Shin & White-Traut, 2007; Griffin & Abraham, 2006; Broedsgaard & Wagner, 2005; Jackson, Ternstedt & Schollin, 2003</p> <p>Wade, et al., 2008; Jackson, Ternstedt & Schollin, 2003</p> <p>Muller-Nix & Forcada-Guez, 2009; Wade, et al., 2008; Broedsgaard & Wagner, 200: Bakewell-Sachs & Gennaro, 2004</p>

Table 7. The Moustakas Method Applied – Orson’s Mother

Horizontalization

I. Significant Statements:

a. Going home

- i. A little scary at first
- ii. Absolute panic;
- iii. Frustrating (meds)

b. First days and weeks at home

- i. They (first days) were horrible
- ii. It was horrible
- iii. We’ve blocked it all out because of course we’ve moved on and now we have him and he’s healthy and he going off his monitor this week so we had forgotten, so this weekend we just tried to refresh my memory and we found that it was a little stressful for us because the first few weeks after his birth (1/13/11) were just awful.
- iv. We had him in our room, of course lights off, no noise, we didn’t think about he had spent all that time in the NICU and he was used to lights, noise and we just couldn’t figure out why he wouldn’t go to sleep and when we turned the light on to get him, he’d go to sleep (laughing).
- v. I guess we were brain dead
- vi. Then we couldn’t sleep (lights on/noise machine)

vii. The monitor is horrible

1. It goes off all the time and it's so scary because you're afraid it's a . . . you know until you get used to what the different sounds are, you assume the baby's not breathing and or they're having an episode of bradycardia, but really it's just the leads have come off. So that's just a nightmare.

viii. it wasn't just one of us getting up with the baby, one of us had to go and get our toddler and settle him back down and tell him 'everything's ok, it's just a noise, don't worry about it' while one of us would tend to the baby.

ix. We'd actually take turns sleeping (during the day)

x. Unfortunately, part of having a preemie is, you're at the doctor's constantly, especially the first few weeks they're home

1. We had about 1-2 appointments each day during that first week

xi. She (home health nurse) was nice but when you've gotten two hrs sleep, no one can be nice enough

1. She helped us with the leads on the heart monitor and that was wonderful

2. (She) said to me 'Have you made an appointment with the apnea clinic yet?' (and I said) 'Well we've been trying to call them (clinic in Fairfax) but no one answers the phones when we call and no one calls us back

3. And so we called the apnea clinic (at Georgetown), someone answered the phone immediately and now I'm on a first name basis with that lady who answers the phones. She knows both of my kid's names. It's just . . . I cannot say enough good things about that clinic.

xii. They (apnea clinic) changed our lives

1. (What we learned was) wonderful, terrific, they're just really nice
2. They assured us that he would outgrow it
3. The NP was amazing, the best. She understood everything.

xiii. The first week was really just a blur of trying to do what needed doing and snatch sleep and maybe get a shower. I mean I know it's like that for all parents of newborns but this is to the nth degree.

1. He was up every 2 hours feeding
2. (My toddler) basically reverted back to his newborn schedule because even once we were all home, with the heart monitor going off and the baby up, he couldn't sleep.
3. You know for the first six weeks, even with the adjustments of the leads where he wasn't having the false alarms, he had a lot of episodes, which of course was scary
4. There was a period that even if I could get them both to sleep at the same time, any time he'd go into that heavy sleep, he'd almost always have an episode of bradycardia which of course would scare me to death because this was still in the stage of we had to physically stimulate him
5. When she (family dog) heard the monitor at first she would bark, go insane, which would wake everybody up.
6. It was just a circus, but not in a good way

- xiv. Once we got used to the heart monitor it was wonderful because I could sleep but it's just that extra worry of, you know, I remember just constantly reading the baby CPR cards to make sure I knew how to do it. Because I was just terrified something would happen and of course, I never needed it. Everybody says you'll never need it.
- xv. I would say it took at least 6 weeks (to get used to being at home with the baby). It was just hard.
- xvi. Relationship challenges – husband
1. That was hard. Disappointing. Very disappointing (only taking 2 weeks off)
 2. We feel that extra pressure and want to be sure that his employer is happy with him, so that was scary
 3. I don't think it would have necessarily been so hard for me if we hadn't had a toddler
 4. They never slept at the same time and it was just hard
 5. My husband and I are at each other's throats because we're exhausted and mad and oh, mad at the situation
 6. So. I don't know how I made it through those first days and weeks. I do not know. It was hard on our marriage.
 7. When advising other mothers I'd tell them that to be prepared that this kid will take a toll, not that it will be everlasting and it's not that you can't work through it but it will be hard because you know for me, and I'm sure a lot of

it had to do with hormones, but I looked at it as this horrible thing and it was all my problem. That he had gone back to work and now it was my problem.

8. I think if it had just been the two kids I might have just been annoyed that he didn't take the time off from work. But it was the two kids, one of them sick, all the doctor's appointments, because at this point I'm still taking him at least 2 times a week to the doctor. This continued through the first month or so. I, of course, was not supposed to be driving but I broke the rules and started driving as soon as I was better and I was no longer taking pain medication.
9. My husband would get up and do some of the night time feedings because he felt horrible and of course, I felt horrible and so I cut him no slack. I made sure he was as miserable as me, I took care of that

xvii. That began to change around the 6 weeks at home mark (and I called the apnea clinic)

1. He still had episodes, but not every night,
2. Good grief, it was a nightmare
3. (After about a week or so – self-talk) Ok, just because he's having an episode, doesn't mean he's going to die
4. It was terrifying and the worst part was nobody really got it
5. It's a big deal. I mean it's the heart and the brain, you know? Everything else you could pretty much live with.

xviii. Family support

1. So when the baby finally was home everybody else was back at work

c. Advice to other mothers

i. This is a terrible thing, but you know social workers sometimes get that stigma . . .

‘Oh I don’t need a social worker, I have insurance, I’m employed, I’m educated.

Thank you very much for the free onesies even, but whatever. Leave me alone. I’m trying to pump here. Thanks but no thanks. And she, of course, gave me the best thing anyone can give you which is the preemie parent groups info.

1. I went to this pediatricians’ appointment and I was just sobbing. My husband is back at work and my kid’s having all these episodes. I have the toddler with me and the baby in the waiting room. I’m exhausted, I’m covered in barf and I just started crying because his lead came off and his monitor is screaming and all these parents are staring at me like I have lobsters coming out of my ears and this mother of twins with her husband came up to me and said ‘When was he born?’ and she knew that obviously he was a preemie. She played with my toddler, letting me take care of Graham and she handed me a business card that said you know, “Preemies Today” and said . . . oh, and I remembered that was the group the social worker told me about, and I mean, it’s wonderful. It’s wonderful to talk to people who understand what you’re going through. And it IS different.

ii. If there is a preemie group, don’t blow it off because it’s wonderful. Go while your baby is still in the NICU if you can. Because I think if someone had said, to just talk to someone about what it’s like to bring a baby home on a heart monitor.

1. I don’t care how many friends you have and how many babies they’ve had, if you didn’t have a baby in the NICU, you don’t get it.

- iii. We were dummies and didn't think about trying to replicate the NICU environment for Graham so he could sleep better. We could have avoided 48 hours of absolute misery
- iv. I wish before he'd come home maybe my husband and I, even if it wasn't a fancy dinner, maybe just sat down and had a couple glasses of wine and just did the "This is going to be really hard but we can do it."
- v. I didn't realize how hard it was going to be, not just physically and emotionally but it's difficult financially and we were in really good position, and we had planned for this baby. We have a comfortable life style and excellent health insurance, and you know, it's still really hard. The hardest thing I've ever done.

II. Invariant qualities and Themes:³

- a. Fear of assuming full responsibility for the infant following NICU discharge
 - i. Wanting to do the best possible job
 - ii. Realizing that it took a team of experts to provide care in the hospital
 - iii. Feeling unsure of being able to provide emergency care if required
- b. Anxiety related to working with the apnea monitor
 - i. Wondering whether the monitor alarm meant an actual problem or a loose electrode
 - ii. Trying to sleep and work with the monitor alarm going off
 - iii. Not understanding what she (mom) was doing wrong to make it alarm

³ Moustakas recommends analyzing the verbatim comments and determining the "significant, relevant, and invariant meanings that provide living descriptions or highlights of the experience" (Moustakas, 1994, p. 130).

c. Sleep deprivation

- i. Expected loss of sleep due to feedings every two hours
- ii. Unexpected loss related to not being able to get the infant to sleep when he first came home
- iii. Unexpected loss due to the household being disrupted each time the monitor alarm went off
- iv. If the alarm was truly reflecting a period of apnea where the infant had to be stimulated, it was difficult to settle back down to sleep

d. Exhaustion due to appointments

- i. Needing to see a doctor every other day
- ii. Mom recovering from abdominal surgery
- iii. Each visit required mom taking her toddler along

e. Disruption to the family structure

- i. When the monitor alarmed it woke the entire household, including a toddler and the dog who responded by barking
- ii. Financial/job-related concerns

f. Feelings of isolation

- i. Once everyone went back to work, care of the infant became my responsibility
- ii. Everyone else was back at work (by the time the infant had discharged from the NICU)

- iii. No one understands it unless they've been through it
- g. Finding a measure of peace
 - i. Being able to rely on the monitor to only alarm during true apneic periods
 - ii. Realizing that each time the monitor alarmed it didn't mean he was going to die
 - iii. Trusting the monitor to alarm when the infant was in distress, allowing me to rest when the monitor was quiet

Clustering of statements into themes or meaning units

I. Fear of the unknown

- a. Will I be able to provide the necessary care for my infant
- b. What does this constant alarming of the monitor mean
- c. Will I be able to do this by myself since no one else is around most of the time
- d. If I am unable to arouse my infant, will I remember how to perform CPR

II. Physical and emotional energy required

- a. Loss of sleep due to the monitor alarm going off
- b. Sleeplessness following an episode when the infant needed to be stimulated
- c. Most doctor visits entailed taking the infant and the toddler
- d. Loss of sleep due to the household being awakened each time the alarm sounded in the middle of the night
- e. Even with a good job and good insurance, it was tight financially

III. The surprising importance of support

- a. Apnea clinic
- b. Home-health nurse
- c. Other mothers of preterm infants
- d. Groups for mothers of preterm infants
- e. Husband taking middle-night feedings
- f. Even close friends who never experienced a preterm birth didn't 'get it'

IV. Finding peace and acceptance

- a. The ability to block out the difficulty of the past and focus on the here and now
- b. Accepting the problems associated with the birth as being part of who this infant is

Imaginative variation⁴

Textural description – What was experienced

Fear and anxiety

Exhaustion

Disruption of family structure

Feelings of isolation

Structural – How it was experienced

⁴ During this step imagination and intuition are applied and replace empirical knowledge. This is necessary in order to accept participants' descriptions of the phenomenon without making adjustments based on personal knowledge of the researcher

Fear

- iv. “It was a little scary at first” (going home)
- v. “I was in an absolute panic” (administering meds)
- vi. “You assume the baby’s not breathing or they’re having an episode of bradycardia, so it was a nightmare” (when the apnea monitor goes off)
- vii. “He had a lot of episodes and that was scary”
- viii. “. . . he’d almost always have an episode of bradycardia (whenever he fell into a deep sleep) which of course would scare me to death because this was the stage where we still had to physically stimulate him”
- ix. “I remember just constantly reading the CPR cards to make sure I knew how to do it because I was terrified something would happen”
- x. “It was terrifying” (apneic episodes)

h. Exhaustion

- i. “The first few days were horrible”
- ii. “Then we couldn’t sleep” (with lights on and a sound machine going to accommodate the baby)
- iii. “It wasn’t just one of us getting up with the baby, one of use had to go and get our toddler and settle him back down while the other tended to the baby” (after a monitor alarm)
- iv. “The first week was really just a blur of trying to do what needed doing and snatch sleep and maybe get a shower.”

- v. “He was up every 2 hours for feeding”
 - vi. “We’d actually take turns sleeping” (during the day)
 - vii. “But it was two kids (one toddler, one infant), one of them sick, all the doctor’s appointments because at this point I’m still taking him at least 2 times a week to the doctor”
 - viii. “We were dummies and didn’t think about trying to replicate the NICU environment for Graham so he could sleep better”
 - ix. “We have a comfortable life style and excellent health insurance, and you know, it’s still really hard. The hardest thing I’ve ever done”
- i. Disruption to family structure
- i. “When she (family dog) heard the monitor at first, she would bark, go insane, which would wake everybody up”
 - ii. “It was just a circus, but not in a good way”
 - iii. “My husband and I are at each other’s throats because we’re exhausted and mad and oh, mad at the situation”
 - iv. “It was hard on our marriage”
 - v. “My husband would get up and do some of the night time feedings because he felt so horrible and of course, I felt horrible and so I cut him no slack. I made sure he was a miserable as me, I took care of that”

vi. “I didn’t realize how hard it was going to be, not just physically and emotionally but it’s difficult financial and we were in a really good position, and we had planned for this baby”

j. Isolation

i. “I looked at it as this horrible thing and it was all my problem. That he had gone back to work and so now it was my problem”

ii. “It was terrifying and the worst part was nobody really got it”

iii. “So when the baby finally was home everybody else was back at work”

iv. “I went to this pediatrician’s appointment and I was just sobbing. My husband is back at work and my kid’s having all these episodes. I have the toddler with me and the baby in the waiting room. I’m exhausted, I’m covered in barf and I just started crying because his lead came off and his monitor was screaming and all these parents are staring at me like I have lobsters coming out of my ears”

v. “I don’t care how many friends you have and how many babies they’ve had, if you didn’t have a baby in the NICU, you don’t get it”

vi. “It’s the hardest thing I’ve ever done”

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Licensure:

- Registered nurse, licensed to practice in MD, VA, DC

Education:

- **Doctoral candidate for PhD in nursing** at Virginia Commonwealth University, Richmond, VA - Expected graduation, August 2011
- **Masters of Science in Nursing**, with focus on nursing education, Marymount University, Arlington, VA - May 2007
- **Bachelor of Science in Nursing (with honors)**, Marymount University, Arlington, VA - May 2002

Career History:

- Teaching assistant, 2009-11, Virginia Commonwealth University for Maternal/child health; Community health; Pharmacology for NPs
- Assistant Professor, 2007-2009, Northern Virginia Community College, Springfield, VA. Didactic and clinical instructor for maternal/child health (OB), pediatrics and geriatrics. Student advisor; chair of simulation committee.
- Lab & Technology Coordinator, 2005-2007, School of Health Professions, Marymount University, Arlington, VA. Managed nursing labs, scheduled instructors, developed simulation scenarios for mid-term and final check-offs for students and wrote/managed the lab budget.
- RN-II, INOVA Fairfax Hospital, Fairfax, VA. Provided bedside care in postpartum unit and newborn nursery.
- RN-II Clinic Nurse, Children's National Medical Center, Washington, D.C. – Cardiology/Nephrology/Pulmonary clinic nurse; assessed patients and families during initial and follow-up visits; managed conscious sedation unit and afternoon/evening telephone triage.
- Assistant Director, Media and Public Relations, BellSouth Corporation, Atlanta, GA/Washington, D.C. Worked on 7-company team to secure passage of the 1996 Telecom bill; managed corporate Crisis Communication Plan; chaired the web design committee; wrote/maintained ~ \$12(M) annual budget.

Memberships:

- National League for Nursing
- Southern Nursing Research Society (SNRS)
- Sigma Theta Tau – Eta Alpha Chapter
- Virginia Nurses Association

Awards:

- Poster presentations for SNRS annual meetings, 2010 & 2011
- VA Department of Health Scholarship, 2009-10; Lettie Pate Whitehead Scholarship, 2000-02
- Chosen “Outstanding Nursing Student,” class of 2002
- Awarded MC (major contributor) award and bonus, 12 consecutive years

Community:

- Previous secretary Sigma Theta Tau, Eta Alpha
- Previous delegate, Sigma Theta Tau International
- Delegate, Virginia Nurses Association
- Health advisor to Children’s International School, Arlington, VA (2005-07)
- Previous board member, UNICEF International
- Welfare nurse for local church group

Publications:

- Phillips-Pula, L., Strunk, J., Pickler, R.H. (2011). Understanding phenomenological approaches to data analysis. *Journal of Pediatric Health Care, (25)1*, 67-71.
- (One additional publication is in preparation.)

Research focus:

- Parents of preterm infants
 - Day-to-day survival for mothers of preterm infant during the transition from NICU to home