“It’s Like Going Home to Emptiness.”

Becoming A Mother And Providing Mother’s Milk To Premature Infants In The Neonatal Intensive Care Unit, A Latina Mother’s Perspective

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ABSTRACT

"It's Like Going Home To Emptiness." Becoming A Mother And Providing Mother's Own Milk To Premature Infants In The Neonatal Intensive Care Unit: A Latina Mother's Perspective

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Preterm birth occurs in 12% of US births and Latinas have preterm rates close to national levels. Becoming a mother in the neonatal intensive care unit (NICU) is considered an altered transition experience impacted by psychosocial and cultural factors. Providing mother's own milk (MoM) to a preterm is challenging due to immaturity and or illness. Despite being the fastest growing, largest minority culture in the US, few studies focus on the experience of Latina mothers in the NICU. The purpose of this mixed methods study was to examine mothers' experience of becoming a mother in NICU and factors that influence infant feeding decisions in the first month of life and to determine what distinguishes this experience for Latina mothers. Research on breastfeeding in NICU has focused primarily on white, married, middle class women. Despite the benefits of human milk, only one third of all NICUs in the US report routine use of human milk.

A convenience sample of 30 mothers with infants ranging from 23 to 35 completed weeks gestational age participated in this study. Data analyses were conducted using NVIVO software for qualitative data and SPSS statistical software version 22 for the quantitative data. There were two primary research questions asked in this study. The first was central to the larger qualitative piece of this work and focused on becoming a mother and providing MoM in the NICU. The second was quantitative in nature and explored the relationship between infant feeding attitudes

and key processes with regard to MoM provision outcomes as modified by culture. This mixed methods study is set in a major northeastern perinatal regional center. The dominant qualitative portion used a semi – structured interview guide developed from the main theoretical concepts of becoming a mother (BAM) and the current literature on parenting in the NICU and providing mother's own milk. The supplementary exploratory descriptive quantitative strand used six standardized measurement tools to explore the relationships between selected psychosocial and cultural factors (maternal moods, decisional conflict, coping strategies, neonatal stressors, infant feeding attitudes and behaviors and psychological acculturation) and continuation of MoM. Data analysis consisted of directed content analysis to describe major themes for the qualitative portion and descriptive statistics and non-parametric tests to identify relationships and group differences. Multivariate analysis using binary logistic regression to describe the strongest relationships was conducted. The data were integrated and discussed for this sample of women.

Qualitative results indicated that Latina mothers did fit into the framework described by Hurst and colleagues that proposed that BAM was interrupted with mothers having a paradoxical experience which included negotiations about pumping and the feeling that pumping created a wedge instead of a connection between them and their infants. Cultural themes that emerged included generational differences with Latina mothers less likely to have social support for breastfeeding and to feel uncertain about their decision and transitioning to their maternal role in the NICU. Cultural values, such as familismo, respeto and fatalism, provided a nuanced response to the experience of BAM in the NICU perceived by mothers, leading to an increased sense of uncertainty. Latina mothers described being in a state of parental liminality related to a sense of powerlessness and uncertainty, a theme that was not identified in the original BAM nor previous framework for providing milk in the NICU.

Quantitative exploratory analyses revealed that there was a significant difference between Latina and non-Latina groups with Latina mothers demonstrating higher levels of self – efficacy about ability to successfully produce MoM for their infants. For this sample of Latina women, anxiety made a statistically significant contribution indicating that mothers who were anxious were 1.35 times less likely to continue to provide MoM. Decision uncertainty approached significance and mothers who were uncertain about decision to provide breast milk feeds were 1.14 times less likely to continue to provide MoM in the first month of neonatal life in the NICU.

It is essential for healthcare providers to be aware that mothers who are anxious, experience decisional uncertainty, perceive alterations in their maternal role, and express a high degree of stress related to the overall NICU environment may be at risk for discontinuing to provide MoM for their premature infants. More research is needed to explore culturally relevant intervention methods aimed at decreasing maternal stress and anxiety and addressing decisional conflict with mothers of premature infants in the NICU.

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DEDICATION

For my mother, Aida Estella Harrison Hendricks (1937-2005), who encouraged me to pursue all my dreams and showed daily by her strength and perseverance that her worth was above rubies and for that her children indeed continue to rise up and call her blessed.

For the almost 500,000 families that have a NICU experience in the United States every year and to their brave and graceful journey through a very unpredictable landscape.

CHAPTER 1

BACKGROUND

Birth is a major transitional event in a society and specifically in the life of a woman. The transition to the mothering role signifies a major shift in relationships, responsibilities and societal expectations. It also requires a woman to modify behaviors and redefine herself within her personal and social contexts. (Meleis, 2010). The normal transition to becoming a mother has incipient developmental challenges which are compounded when a woman has a premature birth. Furthermore cultural and ethnic determinants may impact this crucial transition period.

Preterm birth, classified as delivery of an infant at less than 37 completed weeks gestation, is a major national and worldwide public health problem (Engle, Tomaschek, Wallman & Committee on Fetus & Newborn, 2007; Perrine & Scanlon, 2013). Globally, fifteen million children are born prematurely every year and 1 million will die of preterm morbidities (March of Dimes, PMNCH, Save the Children & WHO, 2012). In the United States (US), approximately 12 percent of the 4 million infants born every year are premature (Perrine & Scanlon, 2013) and more than 70 % will be admitted to a Neonatal Intensive Care Unit (NICU) (Kornhauser & Schniederman, 2010).

Persistent racial and ethnic disparities exist among the nearly half million infants born premature in the United States (Lau, Hurst, Smith and Shandler, 2007). Although the care and survival of preterm infants has been enhanced by the proliferation of NICU care with improved technological advancements; these advancements have set up conditions in which mothers must transition to parenthood within a very stressful, highly technological environment (Miles,1993; Raines, 1999).

Mercer (2006) describes the process of becoming a mother as a four phase progression beginning during pregnancy with a period of commitment and attachment to the fetus and preparation for the infant's birth. This phase is followed by acquaintance, learning about infant and physical restoration of mother immediately after birth. The third phase involves moving towards a new normal, and finally the achievement of maternal identity by 4 months after the birth (Mercer, 2006). Circumstances that may alter the preparatory period include a high risk pregnancy which ends in a premature birth and subsequent admission to the NICU. The premature birth also impacts the period of physical restoration of the mother and her ability to become acquainted with her infant's cues and behavior.

Therefore, becoming a mother in the NICU may be described as an altered maternal transition experience, which may be further impacted by psychosocial and cultural factors (Lee, Long & Boore, 2008; Raines & Brustad, 2012; Shin & White-Traut, 2007). The NICU hospital stay has recently been characterized as a traumatic stressor in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR), with elements of the NICU parent experience likened to a post- traumatic stress response, including symptoms of hyper-arousal, reliving the experience, avoidance of circumstances reminding them of the event and negative moods and feelings (Grosik, Snyder, Cleary, Breckenridge & Tidwell, 2013; Shaw, Bernard, Storfer-Isser, Rhine and Horwitz, 2012).

Relative to this traumatic stress perspective on maternal role experience, mothers in the NICU must also contend with their infant's physical appearance, uncertain survival and the potential deleterious effects of parenting in the NICU environment (Raines et al, 2012, Watson, 2010, Perrine & Scanlon, 2013). In addition, the act of breastfeeding or the provision of mother's own milk (MoM), felt by many mothers to be a critical demonstration of their maternal role, is

changed when an infant is admitted to the NICU (Flacking, Ewald, Nyquist & Starrin, 2005).Milk production is known to be affected by the level of stress a woman is experiencing, and women often express concerns about their ability to provide sufficient amounts of MoM. (Flacking, et al, 2005; Rossman, Kratovil, Greene, Engstrom & Meier, 2013). At the same time mothers acknowledge the importance of providing something that only they can do for their infant during a time when most other aspects of care, nurture and protection of their infant are out of their control (Raines et al, 2012)

The birth of a premature infant may cause sufficient parental role alterations and may delay successful transition to the mother role (Mercer, 2004). Although maternal transition has been widely studied with mothers of healthy full term infants (Lupton & Fenwick, 2001), the concept of becoming a mother in the NICU is not well understood (Cleveland & Horner, 2012; Shin & White-Traut, 2007; Zahr, 1991). Additionally, Latinos are the fastest growing and largest minority in the US, with the highest fertility rates and preterm birth rates equal to national levels (11.7%)(Centers for Disease Control, 2012). Yet in a recent review of the literature only 2 studies focused on the experience of Latina mothers in the NICU, and these studies specifically focused on women of Mexican descent (Cleveland, 2009; Cleveland & Horner, 2012). Furthermore, little research has been conducted on the other heterogeneous mix of Latino cultures found in the northeast, (Lessen & Crivelli-Kovach, 2007), and almost none in New York City despite its reputation as a center of multiculturalism (Foner, 2007).

This lack of culturally grounded research is significant in that there is evidence that culture as a social determinant, greatly affects how a woman deals with crises and traumatic events, such as the unexpected delivery of a premature infant (Cleveland, 2009; Shin & White-Traut, 2007). Culture which is defined in this study “refers to learned, shared, and transmitted

values, beliefs, norms, and lifeways of a specific individual or group that guide their thinking, decisions, actions, and patterned ways of living" (Leininger, 1987). Consideration of issues such as the degree of psychological acculturation, effects of traditional cultural values associated with Latino culture, such as *familismo, fatalismo,* and *respeto* have likewise been rarely examined in the context of the NICU (Cleveland & Horner, 2012).

Breastfeeding is considered for many a major physiologic function during the transition to the mothering role (Bell, Erickson & Carter, 2014).There is extensive research demonstrating that mother's own milk (MoM), also described in the literature as human or breast milk, is the preferred food for human infants and provides superior immunologic and psychological benefits to both mother and infant (Cricco-Lizza, 2006; Flacking, Ewald & Wallin, 2011). This is especially true for the preterm infant, as it further reduces morbidities specific to premature infants, such as "feeding intolerance, necrotizing enterocolitis (NEC), chronic lung disease (CLD), retinopathy of prematurity (ROP) and neurodevelopmental delays" when provided in dose specific amounts during the first month of life. (Meier, Patel, Bigger, Rossman & Engstrom, 2013, p.209-10). It also, promotes parent-infant attachment and subsequent maternal role transition (Myers & Rubarth, 2013).

Moreover, the use of breast milk for preterm infants is promoted by major health organizations and experts such as, the American Academy of Pediatrics, The Centers for Disease Control and Prevention, The Surgeon General and The World Health Organization (Daelmans, Dewey & Arimond, 2009; Perrine & Scanlon, 2013). However, despite awareness of the benefits of human milk, only about one third of all NICUs in the United States report routine use of human milk feeding in NICUs, (CDC, 2013) and the incidence has remained unchanged at about 10% for the past decade (Perrine & Scanlon, 2013).

A major study conducted in a northeast NICU demonstrated that only 29% of infants are discharged from the NICU on exclusive human milk feeds (Gartner, et al, 2005), and in the NICU under study the incidence of mothers providing exclusive MoM at discharge is currently at 5 percent (M. Garland, internal communication, 2014).

Mothers in the NICU face additional barriers when their infant is very premature (for example if born at less than 32 weeks completed gestation age) (Rossman, Kravotil, Greene, Engstrom & Meier, 2013). Physiological immaturity renders these infants unable to directly breastfeed at the breast, requiring a mother to express her own milk using an electric breast pump. The breast milk is then fed to her infant, often through a nasogastric tube and many times by the NICU nurse caregiver (Cricco- Lizza, 2006; McGrath, et al, 2013; Perrine & Scanlon, 2013; Rossman, et al, 2013).

The experience of expressing human milk and maintaining an adequate supply, usually greater than 500- 800 ml/day (Hurst, 2007; Meier, 2007), by 14 days of birth for an undetermined period of time to support the nutritional needs of their infants can be very stressful for mothers in the NICU (Lessen & Crivelli-Kovach, 2007). Current research by Meier and colleagues (2010) has proposed that there are critical time periods when breast milk feeding support are crucial. These include the two week time period after birth and one month after birth, during which time it is very important to support mothers in producing an adequate milk supply. Duration of breast milk feeds (BMF) is dependent on establishment of adequate volumes in the early postpartum period (Rossman, et al, 2013).

Mothers may make the decision to initiate the expression of MoM but as evidenced by the low rates of exclusive breastfeeding over the past decade, (CDC, 2012), many do not sustain this decision to provide MoM throughout their infant's hospital stay in the NICU (Swanson,

Nicol, McInnes, Cheyne, Marcier & Callender, 2012), with many deciding to discontinue expression in the first month of life (Perrine & Scanlon, 2013).

Currently we have little knowledge of possible racial or ethnic differences with respect to these data as most research on optimizing breastfeeding in the NICU has centered on a homogeneous group of mothers who are of primarily European descent, white, married, with middle class or higher SES (Dall'Oglio, Salvatori, Bonci, Nantini, D'Agostino & Dotta, 2007; Lessen & Crivelli, 2007). In addition, the sparse studies that have focused on Hispanic or Latina mothers have mostly been focused largely on women of Mexican descent (Cleveland, 2009).

Social support during transition from family and health professionals is seen as an important confidence enhancer during the process of becoming a mother (Pridham, 1991; Mercer, 2006). Indeed, patient-provider partnerships are an essential component of health promotion behaviors such as breastfeeding (Cleveland, 2009; Flacking, et al, 2006). The incorporation of principles of family centered care into the NICU have emphasized the importance of communication, respect, trust and collaboration in care and decision making, yet research has shown that these principles are inconsistently practiced (Harrison, 1993).

Mistrust of providers and the health care system further destabilize patient-provider partnerships. A study of patient-provider interactions revealed that physicians tended to perceive members of low socioeconomic status (SES) more negatively than those of higher SES; and minorities tended to be more negatively viewed than Caucasian patients (vanRyn and Burke 2000).

Neonatal nurses play a key role in facilitating role transition and interactivity between mother and infant in the NICU (Bell, et al, 2014). Flacking and colleagues argue that a nurse is in the position to encourage "trustful" or distrustful" bonds with mothers which in turn can

enhance or impede maternal confidence, competence and identity (Flacking, et al, 2006). In an urban setting similar to this study, Cricco-Lizza (2009) found that nurses identified several barriers to effective breastfeeding promotion and support in the NICU. They included 1) inconsistent support from all health care providers in the unit; 2) breastfeeding not seen as part of the job description of the NICU nurse, to be deferred instead to lactation consultants or other expert resources and 3) unit practices that did not support the breastfeeding message promoted by the unit. It is important to determine if these concepts apply to Latina women in the context of messaging around providing mother's own milk and support of their becoming a mother in the NICU.

Parents became increasingly involved in decision making in the NICU with the introduction of the concepts of family centered care in the 1980s. Family centered care espouses respect and dignity for families, collaboration in care, and involvement in decision making (Berns, et al, 2007; Harrison, 1993). Within this model of care, it is acknowledged that parents are integral members of the health care team, and as such, need adequate information to participate in decision making (Higgins, 2001). Decision making in this study is defined as choosing between several choices regarding courses of action or inaction (O'Connor, Jacobsen & Stacey, 2002). The decision making obligations of parents, considered surrogate decision makers for their infants, becomes increasingly more complex and emotionally charged in the NICU environment with uncertainty about outcomes and often made within rushed time constraints (Klein, 2008).

Decisional conflict defined as being uncertain about which course of action to take if there is a risk of loss or feeling regret, or values are tested (O'Connor, 1995) may occur as a result of this complex interplay of factors. Further, the NICU can be described as a "liminal

space" wherein a mother may not have yet assumed the independent role of parent/caregiver for this infant, yet is placed in the position of surrogate decision maker for her infant (Watson, 2010). It is in this context, a mother in the " liminal space" of the NICU, can be said to be spinning in a transitional loop (Turner 1977) and must make decisions in "a complex medical landscape characterized by varied and evolving perspective and practices….with enormous amounts of new and unfamiliar information that bring substantial uncertainty." (Kearney & Byrne, 2011, p. 368)

During this critical time period, although there is initially a high initiation rate of breast milk expression in the NICU, many mothers do not continue to express their milk until the infant is physiologically stable to latch on to the breast and breastfeed, often discontinuing expression within the first four weeks, (Perrine & Scanlon, 2013). This may indicate the presence of a high degree of decisional uncertainty contributing to decisional conflict (O'Connor, 1995).

Gap in the Literature

Few studies have examined the specific psychosocial and cultural factors including decision making that may impact the experience of becoming a mother in the NICU from the Latina mothers' perspective. Further, factors influencing the decision making of Latina mothers in subgroups other than Mexican heritage around infant feeding and specifically providing MoM have not been explicitly investigated during the early postpartum period of the NICU stay. This mixed methods study, with a dominant qualitative strand and a concurrent exploratory quantitative sub strand, will explore this issue with a sample of women in the NICU of a large northeastern metropolitan regional academic medical center.

Problem Statement

The purpose of this concurrent mixed methods study is to examine the experience of becoming a mother (BAM) among Latina as distinguished from their non-Latina counterparts in the NICU. This will be the first study to investigate the influence of these psychological and cultural factors in a subgroup of very early postpartum Latina mothers other than those of Mexican heritage, whose infants are still hospitalized in the NICU. Factors to be examined include demographic characteristics, maternal mood, psychological acculturation, decisional conflict, coping strategies, infant feeding attitudes specifically, influence of social support and maternal self- efficacy, influence of the NICU stressors including: NICU environment/infant illness, parental role alteration, social and practical stress and overall NICU stress, on maintaining the decision to provide MoM through the first month of life in the NICU.

Specific Aims

Aim 1: To qualitatively explore the BAM experience of Latina mothers of a premature infant and providing MoM during the first month in the NICU.

Qualitative Research Aim

Aim 1: To qualitatively explore the becoming a mother (BAM) experience of Latina mothers of a premature infant and providing MoM during the first month.

Qualitative Research Questions

The primary research question is:

1) How do Latina women experience the BAM transition in the NICU in the first month of life?

The secondary research question is:

2) How do the perspectives of BAM and providing MoM experiences of Latina and non-

Latina women compare?

Aim 2: To quantitatively measure selected psychosocial and cultural factors that the BAM in NICU model suggests may influence sustaining the decision to provide MoM and to determine if these factors differ for Latina and non-Latina mothers of preterm infants in the NICU in the first month of life

Quantitative Research Questions

The following research questions were explored:

1.) For Latina and non-Latina mothers of premature infants during the first month of life in the NICU, is there a relationship between infant feeding attitudes and behaviors, neonatal stressors, maternal moods, decisional conflict, acculturation and coping strategies?

Hypothesis 1a: Infant feeding attitudes, coping strategies, neonatal stressors, maternal negative mood, and decisional conflict will be positively related.

Hypothesis 1b: Acculturation will be related to the other psychosocial variables of interest to this study but given the paucity of published data, the direction is not hypothesized.

2.) For Latina and non-Latina mothers of premature infants during the first month of life in the NICU, are there different relationships between infant feeding attitudes and behaviors, neonatal stressors, maternal moods, decisional conflict, acculturation and coping strategies for those who maintain and those who stop providing MoM?

Hypothesis 2: Latina and non-Latina mothers will vary in the existence and strength of relationships among the psychosocial variables of interest to this study but given the paucity of published data, the directions are not hypothesized.

3.) Do the psychosocial factors identified as components of BAM in NICU predict sustaining the maternal decision to provide MoM?

Hypothesis 3: Infant feeding attitudes and behaviors, neonatal stressors, maternal moods, decisional conflict, acculturation and coping strategies will predict the decision to sustain MoM during the first month of infant viability following admission into the NICU.

Mixed Methods Research Question. How do the qualitative and quantitative data strands converge to support, or expand the framework of BAM and pumping MoM for Latina and non-Latina mothers during the first month in the NICU?

It is the short term goal of this mixed methods study to describe the Latina mothers' experience of BAM in the NICU and to identify selected psychosocial and cultural factors that may influence that experience for Latina and compared with? non-Latina mothers and their decision making regarding infant feeding. The long term goals of this study are to add to the gaps in the knowledge base about how this cultural subgroup of women transition to motherhood in this extremely vulnerable period and to describe influences to direct the development of hypotheses that will inform future research.

Additionally study findings have the potential to assist nurses to create culturally relevant interventions to assess and support mothers as they transition and to help them maintain their decisions to provide mother's own milk (MoM) throughout their infants' stay in the NICU.

Conceptual Contribution to the Field

To date the theory of becoming a mother (BAM) has rarely been applied to the Latina mothers of premature infants. Yet Latino mothers deliver up to 25% of all preterm infants in the

US (March of Dimes, 2014). Mercer (1995) did contemplate the effects of prematurity on the NICU mother, but did not address cultural aspects. Holditch-Davis and colleagues, (2011) conducted two studies which primarily focused on African American mothers. Cleveland has begun to address the needs of women of Mexican heritage (2008, 2009). However, more studies are needed if interventions are to be developed that will address the needs of a more heterogeneous group of Latina mothers.

A small pilot study conducted by this investigator comprised interviews of a small sample similar to those in other studies of married, well educated women usually reported in the literature. Participants were Black professional women, representative of an ethnic group with one of the largest rates of admission to the NICU. Similar to larger, non-minority samples studied, the women in the pilot study also identified their family unit as one under stress, both during the pregnancy and after the premature birth. Further investigation of the levels of internal and external stressors which may have a relationship to outcomes of the group with the second largest admissions in the NICU, Latina women, bears examination.

Implications for Clinical Practice

Prematurity disproportionately affects Black and Hispanic women across all SES, but especially in lower SES, and the psychological and developmental impact can endure beyond the neonatal period (Barfield, et al, 2006). This mixed methods study examined selected psychosocial and cultural perceptions of BAM and decision making about infant feeding in the early postpartum period and during the first month of the NICU stay, with specific attention to Latina mothers, specifically for a population of Latina and non-Latina mothers. Understanding determinants that impact BAM and factors that influence decision making about infant feeding in a lesser studied subgroup of Latina women will inform policies, and focus nursing care both in

the NICU and into the community to maximize growth and minimize the long term sequelae of prematurity for this group of women.

Theoretical Framework

Becoming a Mother. Mercer's nursing theory of "Becoming a Mother" (BAM), provides a historical milieu that has influenced recent researchers studying this transitional phenomenon in the NICU. Initially called the theory of maternal role attainment, (Mercer, 1986, 1995), Mercer expounded on the work of her mentor Rubin. Rubin (1967) identified four stages of acquisition of maternal identity using the work of Thornton & Nardi (1975). For further elaboration see Table 1.

Mercer (1986) first proposed that maternal role attainment occurred in the following four stages that followed the trajectory of a pregnancy and birth of an infant. These included: 1) the anticipatory phase which occurs during pregnancy; 2) the formal phase around the period of birth, which progressed to 3) the informal phase, during which the mother seeks and follows advice from experts, especially her own mother; and the final phase 4) which involved the eventual acceptance of her ability to make her own judgments related to her infant's care signifying a mother's personal integration of maternal identity role.

The theory was later modified based on intervening research which led Mercer (2004) to argue for a more dynamic interpretation of the transition to motherhood process in a woman's life. The theory of maternal role attainment was renamed "Becoming a Mother" (BAM) to reflect this dynamism. Table 1 highlights the reclassification of the four stages. In the evolving theory the phases are now labelled: 1) Pregnancy: representing commitment, attachment to fetus and preparation for delivery and motherhood; 2) Acquaintance/ Attachment: a period from Birth to approximately 6 weeks postpartum described as a period of becoming acquainted with and

attached to her infant; learning to care for infant, by recognizing infant cues & maternal physical restoration, 3) Postpartum: moving towards a new normal and finally occurring between 2 weeks and 4 months after birth and finally, 4) Achievement of Maternal Identity: the internalization of the maternal role. Mercer felt that his period began four months after birth. It is considered the optimal period for incorporating motherhood (Mercer, 2004).

These stages are taking place within the context of three concentric systems, the most intimate is the family microsystem, the community mesosystem and a larger cultural macrosystem. The family microsystem is the most intimate and contains the parental relationship and the interplay of maternal, child and maternal role expectations. Important constructs in this microsystem include social support, family functioning and stressors. The maternal role or identity is identified by the level of confidence or competence in performing practical caregiving aspects such as feeding, satisfaction in her role and attachment to her infant.

Maternal factors may impact assimilation of the maternal role identity including previous exposure to the parental role, a woman's attitudes toward parenting, the pregnancy and birth experience, her sensitivity to and ability to interpret her infant's cues, and her perception of role strain or conflict. Infant factors influencing the process of BAM include the infant's appearance, responsiveness to mothers' attempts at interaction, infant's ability to give cues. The Community mesosystem is characterized by factors outside the immediate family that may interfere with the role transition including, child care decisions, parent's work settings and or school. Finally, the cultural macrosystem involves all aspects of shared cultural values (Mercer & Walker, 2006).

Table 1: Comparison of Rubin's, Mercer's "Maternal Role Attainment and "Becoming a Mother" Theory.

Rubin (1967) **Maternal Identity**	**Mercer (1980,1981,1985,1986)** **Maternal Role Attainment**
Stages • Mimicry • Role-play • Fantasy • Introjections-projection-rejection • Maternal Identity - end-point	Stages • Anticipatory (pregnancy) • Formal (birth) • Informal (follows advice → own judgment) • Personal – integrating maternal identity (@ 4 months postpartum)
Rubin (1984) **Maternal Identity – Stages Renamed**	**Mercer (2004) Becoming a Mother**
• Replication - Mimicry and Role – play (combined) • Fantasy • Dedifferentiation - shifting from expert models to self as model • Identity *evolves* related to the notion of "binding-in" to infant	• Commitment, attachment & preparation (pregnancy) • Acquaintance, learning, physical restoration (2-6 wks after birth) • Moving to new normal (2 wks to 4 months) • Achievement of maternal identity (4 months)

Building on the work of Mercer, Miles and colleagues (1999) further synthesized Mercer's work around maternal role attainment and demonstrated that three characteristics of maternal role attainment are present also for mothers of medically fragile infants such as a premature infant. Miles and colleagues noted that "maternal role attainment was defined as the process by which a mother, […] achieves an identity as a parent, establishes their presence with the child, and becomes competent in parental caregiving" (p.131). Using these three constructs as predictor variables, the researchers confirmed that maternal role attainment for mothers of high risk infants included the development of 1) maternal identity, which is the mother's sense that she is her infant's mother; 2)maternal presence, or the degree of involvement in caregiving (such as infant feeding) and a sense of closeness or connection to her infant and finally, 3)maternal

competence referring to a mother's sense of effectiveness in her mothering role in activities such as caregiving and infant feeding.

A recent qualitative study conducted at a Level 3 NICU and Level 2 Special Care Nursery in the southwestern United States by Hurst and collaborators (2013), led to the development of a framework that described a mother's transition to becoming a mother *and* providing breast milk in the setting of the NICU environment (See Figure 1). Hurst, et al (2013) conducted interviews with fourteen primarily Caucasian women and identified five main themes.

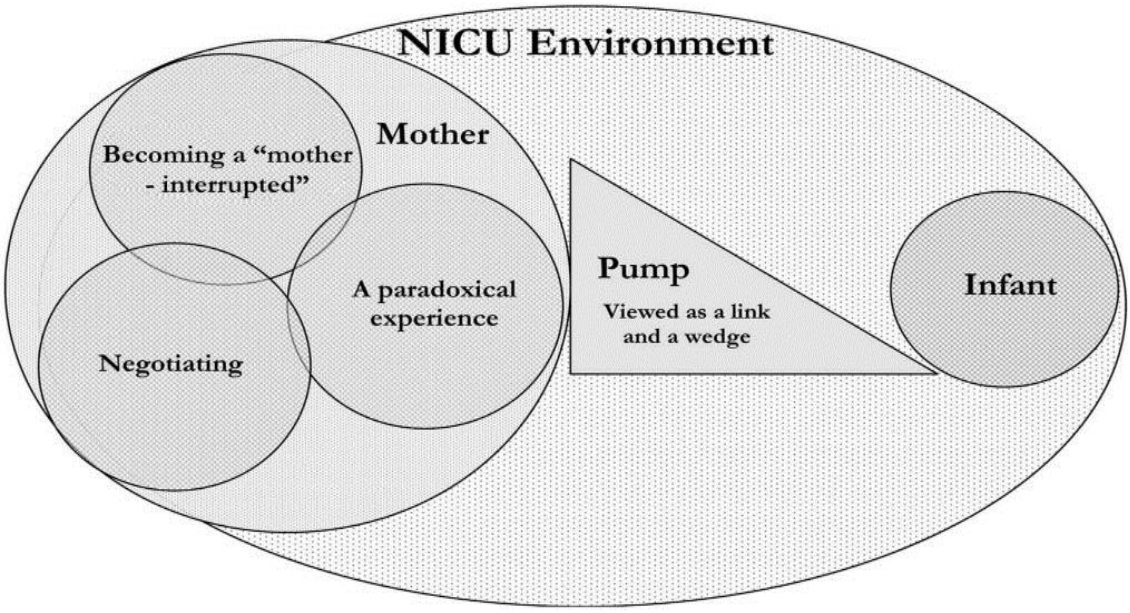
The first theme posits that there is a disturbance in the process of becoming a mother which is interrupted due to the delivery of a preterm infant and admission to the NICU. Second, the experience of BAM is described as a paradoxical one with feelings of both separation and the need to connect with their infant dominating their descriptions. Third, the need for "negotiating their way through the pumping process" (p. 369) in order to develop and maintain their milk supply was described. Fourth, pumping was seen as both a link and a wedge between them and their infant. Finally, the NICU environment was seen as impinging on the mothers ability to continue to provide mother's own milk (MoM) for her infant (Hurst, Engebretson & Mahoney, 2013). The framework conceptualized in Hurst and colleague's study (see Figure 1), will be adapted for use in this study.

The adapted framework for this study (see Figure 2) expands the model proposed by Hurst and her fellow researchers, which incorporated the theoretical underpinnings of BAM as proposed by Mercer and Holditch and colleagues (2011) relating to BAM for mothers of fragile infants such as preterm infants.

Selected psychosocial and cultural factors as well as the role of decisional conflict have been added to the framework from the sparse and evolving literature describing the process of

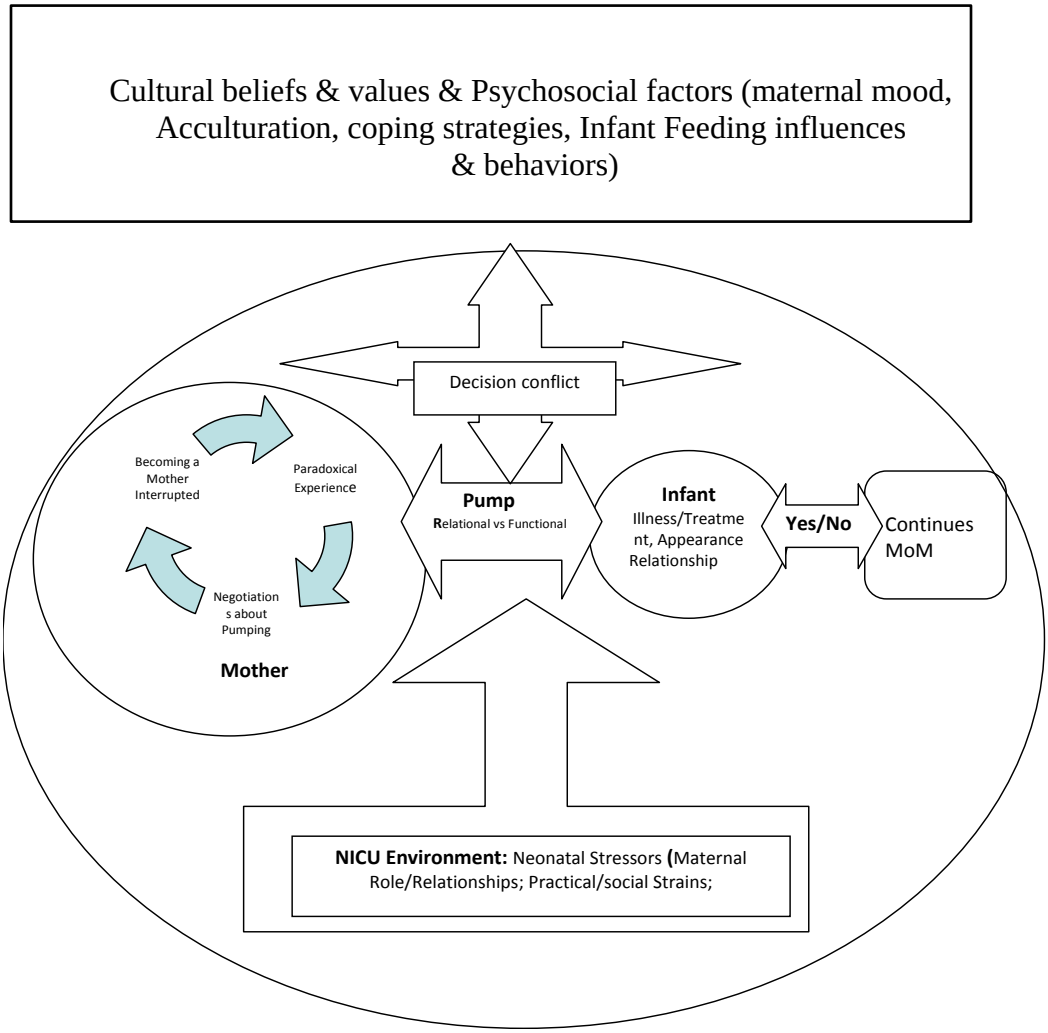
BAM in the NICU. This study will investigate both qualitatively and quantitatively, the existence and influence of the factors influencing the process of becoming a mother and providing MoM in the NICU in Latina mothers.

FIGURE 1: CONCEPTUAL FRAMEWORK OF PROVIDING MOTHER'S OWN MILK IN THE NEONATAL INTENSIVE CARE UNIT



Hurst, Engebretson & Mahoney, 2013

Figure 2: BECOMING A MOTHER AND PROVIDING MOTHER'S OWN MILK IN THE NICU (Adapted Conceptual Framework)



Concepts, Variables and Definitions

The quantitative predictor and outcome variables are found in Table 2. It describes each predictor variable along with the type of data to be produced. For this study the following theoretical and operational definitions will be used:

Definitions

Prematurity Categories

Premature (or Preterm) Infant - an infant born before 37 completed weeks of gestation

Late Preterm Infant - an infant born between 34 weeks 0/7 days – 36 weeks 6/7 days of gestation

Moderate Preterm - an infant born between 32 weeks 0/7 days – 33 weeks 6/7 days of gestation

Very Preterm Infant - an infant born at less than 32 completed weeks of gestation

Birth weight Categories

Low Birth Weight - infant born at less than 2.5 kg (2,500 grams)

Very Low Birthweight - and infant born at less than 1.5 kg (1,500 grams)

Extremely Low Birthweight - an infant born at less than 1 kg (1,000 grams)

Infant Feeding Classifications

Exclusive breast milk feeds (EBMF) - one hundred percent breast milk fed (at breast or expressed mothers' milk feeds by bottle), or 100% of feeds directly at breast. Adapted from (Labbok and Krasovec, 1990)

Partial breast milk feeds (PBMF). Up to 80 percent breast milk fed (with expressed mother's milk feeds via bottle or supplemental feeding device) or directly at the breast, with the rest formula feeds by the bottle or supplemental feeding device. Adapted from (Labbok and Krasovec, 1990)

Formula feeds - infant is receiving no BMF

Latino - This term describes all individuals residing in the United States who originated from Latin America, which consists of Mexico, Central and South America and the Caribbean islands. Operationally, a Latina mother is a woman who acknowledges her heritage from one of these areas. The term Hispanic will be used occasionally in the text to keep it in context to the research literature.

Study Variable Definitions

Maternal Moods

Stress. A negative emotional state classified by "difficulty relaxing, nervous arousal and being easily upset, irritable, over – reactive and impatient" (Lovibond & Lovibond, 1995, p.1). In this study maternal stress was measured by the Depression, Anxiety and Stress Scale (DASS – 21) Stress subscale. Operationally, the higher the score on the DASS – 21 subscale the more affected by the mood or emotional state.

Anxiety. A negative emotional state characterized by "autonomic arousal, skeletal muscle effects, situational anxiety and subjective experience of anxious affect" (Lovibond & Lovibond, 1995, p.1). In this study maternal anxiety was measured by the DASS – 21 Anxiety subscale. Operationally, the higher the score on DASS – 21 subscale the more affected by the mood or emotional state.

Depression. A negative emotional state characterized by "dysphoria, hopelessness, devaluation of life, self – deprecation, lack of interest and involvement, anhedonia and inertia" (Lovibond & Lovibond, 1995, p.1). In this study maternal depression was measured by the DASS – 21 Depression subscale. Operationally, the higher the score on the DASS – 21 subscale the more affected by the mood or emotional state.

Decisional Conflict. Uncertainty about a course of action when outcome is unknown and values and cost of decision may lead to decisional regret. (O'Connor, 1995). In this study decisional conflict was measured using the Decisional Conflict Scale (DCS). Operationally, the higher the score, the more decisional conflict exists.

Coping Strategies. Adaptive and maladaptive responses to a stressor or a situation. (Carver, 1997). The Brief COPE Inventory (BCI) was used to assess maternal maladaptive or adaptive coping strategies in this study. Operationally, adaptive and maladaptive coping strategies are grouped and a higher score on the BCI indicates more use of that particular coping strategy.

Neonatal Stressors

Social and practical relationship stress. Identifies the strain of relating to family, friends and partners and domestic pressures and concerns about future coping (Reid, Bramwell, Booth & Weindling, 2007). Operationally, the higher a mother's scores in this subscale, the more stressed she is by this particular neonatal stressor.

NICU Environment, Infant Illness and Treatments stress. Is related to concerns about illness, treatments, future health worries, their infants' vulnerabilities, and parents' powerlessness to help. (Reid, et al, 2007). Operationally, the higher a mother's scores in this subscale, the more stressed she is by this particular neonatal stressor.

Maternal Role/relationships stress. Is related to problems with parents' inability to interact with their infant, and uncertainties about their role. Issues involving parents' personal space when at the infant's bedside and emotions of anger, guilt and jealousy (Reid, et al, 2007, p.). Operationally, the higher a mother's scores in this subscale, the more stressed she is by this particular neonatal stressor.

Infant Feeding Attitudes and Behaviors

Social Support. A belief that breastfeeding behaviors are valued by significant people. Operationally, higher scores on the Preterm Infant Feeding Survey (PIFS) social support subscale indicates mother feels she has adequate support and her choice is valued. (Dowling, Madigan, Anthony, Elfettoh & Graham, 2009)

Self - efficacy – A belief that breastfeeding or providing breast milk is something that a mother is capable of doing and will be successful in performing. Operationally, higher scores on the PIFS self – efficacy subscale indicate that the mother is confident she can supply breast milk for her preterm infant. (Dowling, et al, 2009).

Acculturation. "An individual's psychological negotiation of two cultural entities" (Tropp, Erkut, Garcia Coll, Alarcon & Vazquez Garcia, 1999, p. 353). Maternal acculturation will be examined using the Psychological Acculturation Scale (PAS) to determine level of cultural identification. (Tropp, et al, 1999). Operationally, low acculturation will be identified as scoring between 1.00 – 4.99, bicultural scores are 5.00-5.99 and high acculturation scores are 6.00 – 9.00 on the Psychological Acculturation Scale (PAS).

Table 2: Description of Concepts, Variables and measurement

Concept	Variable	Measurement	Type of Data (Descriptive statistics)
OUTCOME VARIABLE			
BMF in first month of life		Demographic Form (T1 & T2)	Dichotomous: (n, %)
PREDICTOR VARIABLES			
Maternal identity	Maternal role	NUPS (role/ relationships subscale)	Continuous: Range, (Mean, SD)
Infant Feeding Self-Efficacy	Maternal Self - Efficacy	PIFS: Feeding Self-Efficacy Subscale	Continuous: Range, (Mean, SD)
Social Support	Social support	PIFS Subscale:	Continuous: Range, (Mean, SD)
Maternal Moods	Depression, Anxiety, Stress	DASS -21 subscales	Continuous: Range (Mean, SD)
Coping	Maladaptive & adaptive strategies	BCI Subscales	Continuous: Range, (Mean, SD)
Decisional Conflict	Uncertainty	DCS Subscales & Total	Continuous: Range,(Sum)
Neonatal Stressors	NICU Environment/Illness & treatments; social/relational strain	NUPS Subscales	Continuous: Range, (Mean, SD)
Acculturation	Psychological Acculturation	PAS	Continuous (Mean, SD)

Notes: BMF= Breast Milk Feeds milk; T1 = Time 1 (time of interview/questionnaire); T2 = 2 weeks after T1 or at discharge; n = sample; SD = standard deviation; NUPS – Neonatal Unit Parental Stressor Scale; PIFS = Premature Infant Feeding Survey; DASS – 21 = Depression Anxiety and Stress Scale; DCS = Decisional Conflict Scale; NICU – Neonatal Intensive Care Unit; PAS – Psychological Acculturation Scale

CHAPTER 2: LITERATURE REVIEW

Prematurity

A premature birth is a highly stressful event in a mother's life and premature infants are born at higher rates to Hispanic and Black women in the United States which has the highest rates of premature births amongst developed countries (Barfield, Manning, Kroelinger, Martin & Barradas, 2006; Lasswell, Barfield, Rochat & Blackmon, 2010; Engle, Tomashek, Wallman & the Committee on Fetus and Newborn, 2007). Social determinants such as socioeconomic status, access to health care, and the allostatic load of stress caused by discrimination and racism disproportionally affect Black and Hispanic women and have been implicated as additive elements in the disparities in premature outcomes in the United States (Lu & Halfon, 2003). Moreover, their infants are at increased risk for short term morbidities of all biological systems, as well as poor feeding and poor growth. Of concern as well, are the long term morbidities that very low birth-weight , i.e. VLBW,(infants born at less than 1,500 grams birth weight), and premature infants in general face. These include neurological and sensory complications, lung disease, as well as learning difficulties at school age and beyond which the family and society continues to bear beyond the neonatal period (Barfield, et al, 2006; Engle, et al, 2007).

Moreover, there is an enormous and increasing societal cost, conservatively estimated to be $26.2 billion a year in 2005,(Cuevas, Silver, Brooten , Youngblut & Bobo, 2005) which does not include added costs of specialized education or loss of productivity over a lifetime for these premature infants and their families (March of Dimes, 2012). Mothers must assume their parental role when their infants are admitted into this technologically driven, high stress environment (Holditch-Davis, Miles, Burchinal & Goldman, 2011).

Becoming a Mother

A transition is a complex process that signals the movement from one phase, condition or status in life to another. It occurs along a time trajectory, and usually begins with a distinct event such as the birth of an infant. Achievement of a successful transition is considered to have occurred when stability in the new role is achieved (Meleis, Sawyer, Im, Hilfinger, DeAnne and Schumacher, 2000). Events that signal a transition may be expected or unexpected, as is the case with a premature birth, and are therefore part of a process of movement from one point in time to another. Most parents don't enter a pregnancy anticipating that it will be interrupted by a preterm delivery experience (Hurst, et al, 2013). Another characteristic of a transition involves a sense of disconnectedness. There is disruption of a known reality into an unknown and uncertain future (Hurst, et al, 2013).

Transitions require the attribution of meaning to events and may be influenced by sociocultural determinants (Meleis, et al, 2000). Awareness of the transition process, the level of engagement in the transition event over a specified time trajectory, during critical time points influences the response to a transition (Meleis, et al, 2000). The transition to becoming a mother of a premature infant is such a critical time period. Becoming a mother in the NICU is very stressful transition with high levels of stress and uncertainty (Hurst, et al, 2013). Holditch-Davis and colleagues (2011) further posit that the birth of a premature infant may delay successful attainment of maternal identity, competence in caregiving, and a sense of presence in the infant's life, all of which are outcomes of the successful transition to becoming a mother in the NICU.

The phenomenon of becoming a mother in the NICU has been widely studied in various cultures abroad (Aagard & Hall, 2008; Flacking, Ewald & Starrin, 2007; Hall, 2005; Heerman, Wilson & Wilhelm, 2005; Schenk & Kelley,2010; Lee, Long & Boore, 2008; Nelson, 2003;

Pridham & Chang, 1991; Pridham, Harrison, Brown, Krolikowsdi, Limbo & Schroeder, 2012; Lupton & Fenwick, 2001; Sweet,, 2007, 2008; Wiggert, Johansson, Berg & Hellstrom, 2006; Zahr, 1991), but not as frequently in the Unites States with Latina mothers (Cleveland, 2008)

The theory of becoming a mother has not been extensively studied in the NICU environment (Holditch – Davis, et al, 2011), and data are virtually absent about Latina mothers of premature infants in the NICU (Hurst et al, 2013). The conceptual validity of the theory of becoming a mother as applied to the Latina woman with a premature baby in the NICU will be explored in this under-studied group in the NICU to determine if the experience varies as a result of cultural differences.

Providing Mother's Own Milk

Breastfeeding is a culturally normed event in a mother's role (Flacking, et al, 2006) which may be impacted by the messages a woman receives from societal and personal influences (Cricco-Lizza, 2006, Mahon- Daly & Andrews, 2002). As such, it is not only a means of providing for the growth and development needs of an infant, it also has emotional, cognitive and sexual context for both a mother, her support systems and her health care providers (Marshall, Godfrey & Renfrew, 2007). These mixed inferences can result in confusing and often contradictory messages to mothers, potentially leading to an increase in decision conflict and shortening of the duration of breastfeeding for those who chose this method of infant feeding.

Additionally, earlier research suggested that a mother's own definitions of being a "good mother" may require that she attempt to breastfeed, however if she is unable to sustain an adequate volume or perceives that she is not providing sufficient amounts for her preterm infant's growth she may discontinue her provision of her own milk (Mahon- Daly & Andrews, 2002). Furthermore, conflicts and real life challenges such as the need to return to work, non -

supportive friends and relatives influence a mother's decision to discontinue providing MoM (Marshall, Godfrey & Renfrew, 2007).

Most research and recommendations for breastfeeding initiation and duration have been aimed at term and otherwise healthy infants and have demonstrated rising rates of breastfeeding among women in the United States (US). This is particularly true among Hispanic/Latina women (Faraz, 2010). Furthermore, the American Academy of Pediatrics (AAP) recommends that, "all preterm infants should receive human milk. Mother's own milk, fresh or frozen should be the primary diet…and if mother's own milk is unavailable despite significant lactation support, pasteurized donor milk should be used" (AAP Section on Breastfeeding, 2012, p.). However, a recent study by Perrine and Scanlon (2013) on the prevalence of human milk use in NICUs found that only one-third of all NICU's in the US consistently give human milk to ≥ 90% of their patients. A recent review of the literature by Faraz (2010) showed that no state in the US met the national 2010 Healthy People objectives for exclusive breastfeeding in the early postpartum period, nor at 6 months for full term infants. Furthermore, despite the CDC citing of breastfeeding rates exceeding 80% in 2006 for Hispanic women, further investigation revealed that less than 1/3 were still breastfeeding at 3 months and only 11.6% continued at 6 months of age (Faraz, 2010).

Despite recommendations from medical experts, studies have shown that many women choose not to provide their own milk to their infants, and that this decision is made early in the pregnancy (Mahon-Daly & Andrews, 2006). In contrast, Meier and colleagues (2010) have shown that despite having made a decision not to breastfeed prior to delivering, on admission to the NICU with a consistent message, peer support and encouragement from health care providers

at all levels, high risk mothers have changed their minds and provided and maintained mother's own milk production for their infants (Meier, Miracle, 2004).

Psychosocial Factors

Risk factors, such as maternal mood and coping strategies, are implicated in the decision of certain women not to provide breast milk or to shorten the duration of milk provision. Maternal stress is a known barrier to providing breast milk (Purdy, Singh, Bell, Whiteside and Collins, 2012). Gill and colleagues (2004) found that stress was cited as a reason by many low income Mexican American mothers who chose not to breastfeed. Their cultural belief was that, "if you're stressed while breastfeeding, the baby will get it "(p.46). In addition, in the study of Mexican American women researchers found that social barriers such as embarrassment, the perceived inconvenience of breastfeeding, and pain and lack of social support for breastfeeding factored into low income Mexican American women's decision not to breastfeed. (Gill, Reifsnider, Mann, Villareal and Tinkle, 2004).

It has been suggested that women suffer from depression in the postpartum period at rates ranging from 13 % (Miller, Pallant & Negri, 2006) to as high as 46% for inner city black and Latina mothers studied in New York City. (Howell, Balbierz, Wang, Parides, Zlotnick & Leventhal, 2012) Anxiety has not been as extensively studied, and more frequently has been subsumed under the larger postpartum depression banner. Nevertheless, a few recent studies (Miller, et al, 20106; Rallis, Skouteris, McCabe & Milgrom, 2014) have determined that anxiety and stress have a larger role to play in both pregnancy and the postpartum period than was previously considered. Both studies were conducted in Australia. Miller and colleagues (2006) found that up to 10% of first time mothers ranging in age from 18 -44 showed symptoms of both anxiety and stress without depression, while Rallis, et al (2014) showed that anxiety, stress and

depressive levels changed over the course of a pregnancy. Mothers who showed higher stress scores during the midpoint (second trimester) of their pregnancies demonstrated higher levels of anxiety as the pregnancy advanced to the third trimester. It is unknown if these patterns of anxiety and stress are found among Latina women.

However, several researchers postulate that maternal emotional states of anxiety and stress are given lesser focus and may be underreported in this population of mothers. (Brandon, Tully, Silva, Malcolm, Murtha, Turner & Holditch-Davis, 2014; Rallis, et al, 2014).

Parental Decision Making

Parents are identified as "surrogate decision makers" for their infants during neonatal hospitalization and their decision making obligations have become increasingly complex . Parental decision making is defined in the literature as making choices between alternatives on a proxy level by parents for their children (Klein, 2008). Studies have shown that parents making decisions in real time situations often don't utilize rational normative decision making techniques. Instead, they engage in more intuitive naturalistic decision making in which they assess the information given and attempt to match it to previous experiences, while integrating their personal values and beliefs (Bijma, et al 2005; Klein, 2008). Therefore parents are making a choice, then seeking to assemble reasons to validate their choice. They may not necessarily use the information provided to them by their health care provider because many times, information is incomplete, fragmented or inconsistent (Cote-Arsenault, 2003). If a woman is a first time mother and gave birth to a premature infant, her previous life experiences may not have prepared her to for the high stakes, high stress decision making required in the NICU and may promote decisional conflict.

Decisional conflict can result as a consequence of a decision hastily made during a stress filled time such as admission to the NICU. Decisional conflict, defined as "the simultaneous opposing tendencies within the individual to accept and reject a given course of action" (Janis & Mann (1977) as cited in O'Connor, Jacobsen & Stacey, 2002, p.571), may be a factor in a mother's decision to stop providing her own milk (MoM) for her premature infant in the early postpartum period.

Most studies of parental decision making (PDM) have been conducted outside of the United States, among homogenous populations of mostly white, married, middle to upper income women. They include decision making about pregnancy issues, such as deciding to continue a pregnancy in which a lethal anomaly has been diagnosed, to treatment and end of life decisions in the NICU and to decide on delivery room resuscitation of VLBW infants. Few studies have examined PDM of multiethnic women following admission to the NICU, and none have examined combined psychosocial and ethno-cultural factors that may impact the decision making process. To examine decisional conflict, components of the Ottawa Decision Support framework (O'Connor, et al, 2002) will be used. The Ottowa Decision Support Framework (O'Connor, et al, 2002) evaluates both the quality and the outcomes of an individual's decision making process. It also identifies modifiable factors related to inadequate information, values clarification and feeling supported. Assisting mothers in the NICU with better decision making may strengthen their decisions to maintain providing MoM throughout their infant's hospital stay.

Furthermore, given the World Health Organization's and CDC's identification of prematurity as a major national and global health public health concern, addressing decision making in this study also aligns with the National Institute of Nursing Research's 2011 mission to invest in the

promotion of health and innovation by: 1)studying the behavior of systems, including families, that promote the development of personalized interventions; 2) improving the understanding of behavioral patterns such as parental decision making (PDM) and the incentives for behavioral change; 3) creating and or utilizing innovative communication strategies for individuals, families, clinicians and communities that promote health and improve health literacy and 4) expanding knowledge and application of technologies to facilitate decision support and self-management.

Cultural Factors

According to the US Census report (2011), Hispanic, Latino or Spanish ethnicity is described as anyone identifying their heritage nationality, or their parent's country of origin before immigrating to the United States in one of five categories representing Central and South America, Mexico and Cuba or any other Spanish country. Those who self-identify as Hispanic, Latino or Spanish may be of any race (Ennis, Rios- Vargas & Albert, 2011). The 2010 US Census identifies Hispanics as the largest growing ethnic group in the country with 16.6% of the current US population belonging to this category. This accounts for more than 50 million people in the US. Moreover, 66% are women of childbearing age (Ennis, et al, 2011) with the highest fertility rate and a prematurity rate of 11.6%, roughly equal to the national rate (March of Dimes, 2012). Currently in the United States, one fourth of all premature births are to Hispanic/Latina women. (March of Dimes, 2012).

Researchers have documented a phenomenon called the Hispanic(Stein, Savits, Janevic, Ananth, Kaufman, Herring & Engel, 2009) or Latina epidemiologic paradox in describing the generally positive perinatal outcomes of Hispanic women despite disadvantages such as lower socioeconomic status and factors such as being foreign born and having lower acculturation

(Hoggatt, Flores, Solorio, Wilhelm & Ritz, 2012). However, Hoggatt and colleagues were also unable to support the hypotheses that Latina women, primarily of Mexican descent would have fewer low birth weight infants.

Cleveland (2009) found in a case study of one Mexican American mother's experience in the NICU, that there was a sense of "anticipating discrimination" (p.183) due to her inability to speak the dominant language of the NICU. This was a previously unidentified response and one which could contribute to the allostatic stress load in these mothers (Lu and Halfon, 2003).

A recent analysis of New York City births has shown however, that, given the heterogeneity of Latina cultures, the protective effects of the "Hispanic paradox" were not found in this population of women (Stein, et al, 2009). Latina women were identified by their region of nativity and classified as 1) South American; 2) Central America, and 3) Hispanic Caribbean. In New York City, Puerto Ricans were three times more likely to have an early preterm birth and almost two times more likely to have a late preterm birth as compared to non- Hispanic whites. Additionally all Hispanic subgroups studied had similar adverse outcomes in comparison to the referent group (Stein, et al, 2009).

Acculturation is defined as a change in cultural values and beliefs between the culture of origin and dominant culture, encompassing categories such as separation, assimilation, biculturalism and cultural marginality (Bacallao, Swokowski, 2005). 'Separated' or individuals with low acculturation, have retained their heritage culture identities, while those who have 'assimilated' or of high acculturation have discarded their cultural identities for the receiving cultures values and beliefs. (Bacallao, Swokowski, 2005).

Bicultural individuals identify with both their original culture and the receiving culture. Psychological acculturation refers to "changes in an individuals' psycho-cultural orientations that

develop through involvement and interaction within new cultural systems" (Tropp, Erkut, Allarcon, Garcia, and Coll, 1999). A scale to measure the degree of low acculturation, biculturalism and high acculturation was developed by Tropp and colleagues and will be used in this study.

In earlier immigration movements to the United States, cultural assimilation was the goal. Assimilation or high acculturation is associated with negative health behaviors, including increased internalization behaviors such as depression (Bacallao, Smokowski, 2005), and decreased incidence of initiation, duration and exclusive breastfeeding in Latina women (Ahluwalia, D'Angelo, Morrow and McDonald, 2012).

More recent immigration waves, such as seen with the influx of Latin Americans from Central America and Mexico, reflect the evolution of a bicultural acculturation pattern (Bacallao, Smokowski, 2005). Biculturalism is seen as protective with studies demonstrating balanced affective states, positive psychological adjustments and a better quality of life (Bacallao, et al, 2005).

The integration of Latin values such as *familismo*, have also been shown to be protective in predicting internalizing behavior**s** in Latino adolescents (Smokowski, Chapman and Bacallao, 2008). Likewise, the ability of the bicultural individual to grasp both sides of a situation may potentially lead to a decrease in decisional conflict and this relationship will be explored in this study.

PURPOSE

The purpose of this mixed methods study was, to complete a qualitative description of the experience of becoming a mother in the NICU for Latina mothers who chose to provide mother's own milk (MoM), and to explore through quantitative instruments for Latina and non- Latina

mothers what factors influence the decision to continue to provide MoM throughout the first month of life in the NICU.

CHAPTER 3: METHODS

This chapter describes the research design and methodology used to explore the experiences of mothers of premature infants in the NICU and their decision to provide MoM, including psychosocial and cultural factors that may influence becoming a mother (BAM) in first month of their infant's life. The methodology also seeks to distinguish the difference between Latina and non-Latina mothers experiencing this complex phenomenon.

Research Design

The study design is mixed methods approach using a core descriptive qualitative design along with an exploratory descriptive quantitative supplementary component often represented by the following notation of design 'QUAL/quant' in such studies (Cresswell & Plano-Clark, 2010). This chapter includes a description of the sample size, sample characteristics, inclusion and exclusion criteria, procedures for sample recruitment, predictor and outcome variables, study instruments, data collection procedures, and data analysis plan. Information about the research setting and human rights protections is provided.

Mixed Methods Study Design.

A mixed - methods study defined by Morse & Niehaus (2009) is "the incorporation of one or more methodological strategies, or techniques drawn from a second method, into a single research study, in order to access some part of the phenomena of interest that cannot be accessed by the use of the first method alone." (p.9). As Morse (2010) further explains, "mixed method design consists of a complete method (the core component) plus one(or more) incomplete methods (the supplementary component) that cannot be published alone." (p.1). This study is an observational mixed methods study with a concurrent qualitative core and an exploratory quantitative supplementary method. The mixed methods study design allows inferences to be

made from both strands of data that describe a "whole that is bigger than the sum of its parts" (Tashakkori, Teddlie and Sines, 2012).

This study design was chosen because the issue of prematurity and the perceptions of parents experiencing the NICU environment is a complex one which benefits from multiple methods of examination (Miles, Holditch-Davis, Burchinal & Nelson, 1999). It "allows for cultural/value relativity" (Tashakkori, et al, 2012), which is an advantage in this study as Latina women from various cultural backgrounds are not represented in substantial numbers in either qualitative nor quantitative research on NICU parents. Moreover, although quantitative methods can provide useful information, they do not capture the in depth richness of qualitative data that can be derived from interviews and participant observations. Therefore, the combination of these streams of research design is seen as necessary in order to build the knowledge base for this population and to inform the development of culturally suitable instruments and interventions (Perez-Escamilla, Garcia & Song, 2010).

A semi –structured interview and on-site observations in the NICU comprised the qualitative portion of this study. The quantitative component consisted of a series of standardized measurement surveys along with a demographic and clinical status questionnaire given to mothers within two to four weeks after the infant's NICU admission and prior to discharge. Data collection was conducted through interview and self- report questionnaires with no intervention conducted. Questionnaires were distributed from August, 2014 until May, 2015 when the targeted sample of 30 mothers were enrolled.

STUDY SETTING

The study was conducted in the 62 bed NICU of an urban Level IV Regional Academic Medical Center in New York City. This academic center serves as a regional perinatal center which accepts transfers of highly acutely ill infants for care by all specialties including cardiac and surgical as well as infants requiring extracorporeal membranous oxygenation (ECMO).

Out of approximately 4,500 total annual births, this NICU has on average 1,100 admissions annually. Infants born premature, at 37 weeks or less completed gestation comprise 4 out of 10 admissions (40%) into the NICU. Approximately 57% of the NICU population is multiethnic.

The Medical Center is located in a predominantly Latino neighborhood with a population of approximately 270,700 (NYC Community Profiles, 2006). Close to 60% of the residents seek care at the Medical Center (Kaplan, 2009), and up to 36% of the patients in the NICU are born to Latina women. All participants were recruited from the NICU at the New York-Presbyterian/Morgan Stanley Children's Hospital in New York City.

SAMPLING

Sample Selection

The target population consisted of a non-probability sample of 30 English speaking women between the ages of 18 – 50 years of age, who gave birth to a premature infant, born at a gestational age less than 37 completed weeks gestation and hospitalized for at least two weeks after birth and before discharge from the NICU. The interviews were planned to be conducted with at least 20 of the mothers, or until theoretical saturation was achieved (Elo, et al, 2014). The quantitative component of this study is exploratory in purpose. The number of mothers recruited equaled the sample size of 30 recommended for a pilot study (Herzog, 2008). The sample is anticipated to be insufficiently powered for statistical analysis, but may suggest previously

unreported patterns that will inform a larger and more adequately powered sample in a future study planned for the same NICU. Thirty mothers completed the questionnaires.

Inclusion Criteria

Inclusion criteria for this study included:

1) Any mother of an infant born less than 37 completed weeks of gestation whose hospitalization is at least 2 weeks
2) Mothers who have indicated intent to provide mother's own milk with subsequent intent to breast feed
3) Mothers who were both successful and unsuccessful at providing breast milk at one month infant age.
4) Mothers of singletons or twins
5) Mothers who speak English
6) Maternal age of 18 years or greater.

Exclusion Criteria

Exclusion criteria for this study included:

1) Mothers of infants with major congenital anomalies and disorders that interfere with feeding
2) Mothers of infants whose survival is in question during the first two weeks of extra-uterine life
3) Mothers who are less than 18 years of age
4) Mothers of infants with equal to or less than 37 weeks gestational age who chose not to provide breast milk.

5) Mothers who are non-English speaking

6) Mothers of higher order multiple pregnancies

Sample Recruitment

Participants were recruited by direct approach by the doctoral student, an attending neonatologist who is also the Director of the NICU Lactation Service and/or one of the two NICU lactation consultants. The attending neonatologist had an existing clinical relationship with some potential subjects and could ascertain their interest in participating in the study. For potential subjects that the attending neonatologist did not have a clinical relationship with, the mothers were first approached by the infant's treating clinician or the NICU research nurse to gain permission for the study team to approach the mother. The lactation consultants had an existing clinical relationship with the potential subjects, but they did not gather data or obtain consents. Their role was only to help identify potential candidate mothers on the unit that fit the study's inclusion criteria.

Potential mothers who fit the criteria were asked for their consent by the study investigator who was a candidate in the Columbia University School of Nursing PhD program in Nursing. Participants were informed that participation in this study would potentially contribute to the knowledge of researchers and health care professionals and could possibly assist in developing interventions to assist future parents of premature infants. They were also advised that participation was totally voluntary and would not adversely affect the care their infant was receiving.

MEASURES

The study instruments include a semi-structured interview guide designed for this study and a battery of established quantitative instruments that reflect the BAM model.

Qualitative Semi-Structured Interview

An interview guide with 7 broad questions, plus additional probes, was developed from and interview draft developed with the assistance of neonatal & psychology experts following a thorough review of the literature on transition theory, becoming a mother and breastfeeding. The interview questions were refined to meet the study aims and align with study variables and themes from the conceptual framework. Table 3 provides a conceptual mapping of the themes and variables. All interview sessions, but one, were digitally recorded. One mother wished to have the interview conducted via telephone. All interviews were transcribed verbatim by the doctoral student- investigator and evaluated for accuracy by comparing against the digital recordings prior to analysis.

Stringent measures were taken to assure trustworthiness of the data. Trustworthiness is described using Lincoln and Guba's methodology to assess the rigor of qualitative research, using the four criteria of credibility, dependability, confirmability and transferability (Lincoln & Guba, 1985, 1995 as cited in Elo, Kaarianinen, Kanste, Polkki, Utrianinen & Kyngas, 2014). Credibility is assured by the accurate and full descriptions of the participants and through commentary during the interviews. Descriptions of mothers who were interviewed are found in Appendix D. Dependability refers to the "stability of data over time and under different conditions" (Elo, et al, 2014, p. 2). Rich descriptions and the verbatim text of the mothers helps to assure dependability in this study.

Confirmability signifies that information presented as the participant's voice is authentic and does not include the researcher's preconceived interpretations. Quotation marks are used to denote the verbatim text of each participant in all reports. Transferability refers to whether the reader can transfer the results into another setting, or use it with other groups other than those

under current study. In this study, the analysis process is presented to aid in transferability. (Elo, et al, 2014) A sample of the interview questions is found in Appendix A.

Table 3: Conceptual mapping of Interview Questions with Conceptual Framework and Variables

Interview Questions	Qualitative Conceptual Framework Themes	Quantitative Variables
Tell me about your pregnancy and your feelings about delivering a preterm infant	Becoming a mother - Interrupted, Paradoxical Experience	Maternal Moods (DASS-21)
Share with me what you remember about your first few days of pumping and what kind of support you received to get started.	Pumping	NICU Environment, Social Support (NUPS, PIFS) Coping Strategies (BCI) Acculturation, (PAS)
For those still pumping: was there a time you considered stopping pumping?	Negotiations about Pumping	Maternal Moods (DASS-21) Acculturation (PAS)
For those who did stop pumping- Please describe the reasons why you decided to stop pumping?	Pumping	Decisional Conflict (DCS) Maternal Moods (DASS-21) Acculturation (PAS)
How would you describe the process of becoming a mother in the NICU?	Becoming a Mother - Interrupted, Infant Factors	NICU Environment (NUPS)
What are your feelings about becoming a mother in the NICU and breastfeeding and breast pumping today? How do you feel about your decisions about feeding and caring for your infant while in the NICU?	Becoming a Mother – Interrupted; Decisional Conflict, Pumping Wedge or Connector	NICU Environment (NUPS)
Is there anything else you would like to tell me about your experience of becoming a mother in the NICU and providing breast milk?	Becoming a Mother – interrupted Pumping	Coping Strategies (BCI)

Notes: DASS-21- Depression, Anxiety, Stress Scale, short form; NUPS- Neonatal Unit Parental Stressors Scale; BCI- Brief COPE Inventory; PAS – Psychological Acculturation Scale; PIFS – Preterm Infant Feeding Survey; DCS – Decisional Conflict Scale

Quantitative Instruments

The following standardized questionnaires were used in the quantitative strand of this study. Permission from the original researchers was obtained to use the following questionnaires

in this study: Premature Infant Feeding Study (PIFS), (Dowling, et al, 2009); The Neonatal Unit Parental Stressors (NUPS), (Reid, Bramwell, Booth & Weindling, 2007); and the Pyschological Acculturation Scale (PAS), (Tropp, Erkut, Garcia- Coll, Alarcon & Garcia, 1999). The Brief COPE, (Carver, et al, 1997), Depression, Anxiety and Stress Scale (DASS-21) , (Lovibond & Lovibond 1995); and the Ottawa Decision Conflict Scale (DCS) (O'Connor, 1995) are available in the public domain for use by researchers without requiring permission from the original investigators.

Premature Infant Feeding Survey (PIFS)

The Premature Infant Feeding Survey (PIFS) is a 71 - item measure that was adapted by Dowling and colleagues (2007) from the Breastfeeding Attrition Prediction Scale for use in investigating the feeding decisions of mothers of premature infants. It includes four subscales; 1) positive breastfeeding sentiment, 2) positive formula feeding sentiment, 3) social supports (subjective norms) and 4) breastfeeding self- efficacy (perceived behavioral concerns). Participants were asked to circle the number that most closely described how they felt about each statement. Items were scored on a Likert-type scale from 1 = strongly disagree or didn't care or was not important to 5 = strongly agreed, cared, was important. Psychometric evaluation of the scale has demonstrated good reliability and validity with individual subscale Cronbach's alpha values ranging from .75 to .82 in a sample of mothers in a level 4 NICU.

Ottawa Decisional Conflict Scale (DCS)

The Ottawa Decisional Conflict Scale (DCS) is a 16 - item measurement tool that measures decisional conflict (O'Connor, 1995). The scale, developed using the Ottawa Decision Support Framework, measures the level of uncertainty, considers the effectiveness of the decision and identifies which modifiable determinants contribute to decision uncertainty.

Participants were asked to choose the statement that best described their response to the following sentence: “when I made the choice to provide my own breast milk for my baby…” Responses are scored on a scale from 0 = strongly agree through 4 = strongly disagree. There are three potentially modifiable determinants measured feeling: 1) uninformed about options 2) unclear about values, and 3) unsupported in decision making. There are five subscales : 1) uncertainty subscale, 2) informed subscale; 3) values clarity subscale; 4) support subscale and the 5) effective decision subscale. Scores range from 0 for no decisional conflict to 100 for extremely high decisional conflict (O’Connor, Jacobsen & Stacey, 2002). A total scale score and scores for each subscale scores are calculated. Psychometric evaluation of the scale has demonstrated good reliability and validity with Cronbach's alpha values above .78 in samples of college aged students and middle aged women screened for breast cancer. (O’Connor, 1995)

Neonatal Unit Parental Stress Scale (NUPS)

The Neonatal Unit Parental Stress scale is a 48-item measure that evaluates a parent’s response to specific stressors of the NICU environment and to the overall experience of having an infant in the NICU. It has four subscales 1) Sights and Sounds, 2) Looks and Behaviors (Baby) and Treatments; 3)Relationship (to baby)/ Role (as a mother) and 4) Hassles and Social Relationship Strains and one question that reflects the overall stress related to the NICU experience. Participants were asked to circle the number that best represented their level of stress related to the sights and sound of the NICU, how their infant looked and behaved; their relationship and role as a parent; hassles and social relationship strains and overall stress. Items were scored on a scale of o = not applicable, 1 = not at all stressful to 5 = extremely stressful. Scores ranged from 1- 240. Means were calculated and assessed, with higher mean scores indicating higher levels of stress. A total score as well as subscale scores were calculated.

Psychometric testing for this new scale demonstrated good validity and internal reliability with a Cronbach's alpha ranging from .89-.93 (Reid, Bramwell, Booth & Weindling, 2007).

Depression, Anxiety and Stress Scale (DASS – 21)

The Depression Anxiety Stress Scale (DASS) is a 21-item self-report measure of anxiety, depression and stress. It was adapted from the 42 item DASS by Lovibond and Lovibond (1995) and since its inception has been used with a variety of populations including young adults and college age students. The Spanish version (Daza, Nevy, Stanley & Avenil, 2002) was studied in a group of bilingual Spanish adults, of whom, 81% were women. Participants were asked to respond to each statement to indicate how much the statement applied to them over the past week. Items were scored from 0- never applied to 3 = almost always applied. A total score as well as subscale scores each for depression, anxiety and stress are calculated. Psychometric testing in a non - clinical population demonstrated high internal reliability with scores for the three subscales as follows: 1) for the anxiety scale the Cronbach's alpha was .897 (95% CI = .890–.904); 2) for the depression scale the Cronbach's alpha was .947 (95% CI = .943–.951); 3) for the stress scale the Cronbach's alpha was .933 (95% CI = .928–.937). For the total scale the Cronbach's alpha was .966 (95% CI = .964–.968). (Crawford & Henry, 2003). Higher total scores indicate more negative moods.

Brief Cope Inventory (BCI)

The brief COPE is a shortened version of the COPE Inventory developed by Carver and colleagues (1997). The brief COPE originally consisted of 14 subscale coping strategies with 2 items per subscale. Participants were asked to describe ways they have been coping with the stress in their lives since their baby was admitted to the NICU. Items were scored on a scale of 1 = didn't do this at all to 4= did this a lot. The names of the coping strategies as described by

Carver (1997) and their reported internal reliabilities, ranging from .50 to .90, are: 1)Self-distraction, α= .71 (items 1 and 17); 2) Active coping, α= .68 (items 2 and 7), 3) Denial, α= .54 (items 3 and 8;4) Substance use, α= .90, (items 4 and 10); 5) Behavioral disengagement, α= .65, (items 6 and 15),; 6) Venting, α= .50, (items 9 and 19; 7) Positive reframing, α= .64, (items 11 and 17); 8) Planning, α= .73, (items 12 and 22); 9) Acceptance, α= .57, (items 16 and 18); 10) Religion, α= .82, (items 20 and 24); 11) Self-blame, α= .69, (items 14 and 23); 12) Use of emotional support, α= .71 (items 5 and 13); 13) Humor, α= .73 and 14) Use of instrumental support, α= .64. Higher mean scores indicated use of the coping strategy. The sample included adults, 46% of whom were women and 17% of the sample were Hispanic, interviewed following a natural disaster.

Only 12 subscales were examined in this study. Subscales 13 (humor) and 14 (instrumental support) were not used in this study because they were considered inappropriate for this setting. Moreover, there was an ethical consideration regarding the creation of distress in already stressed parents by appearing to make light of their situation As an example, this was a clear risk when reviewing such scale items as “I found the situation funny”, on the Humor subscale. According to Carver (1997), there is no overall total score for this measure, nor should it be used to designate an ascendant coping style. Rather it is recommended that each scale be examined independently in relationship to the other variables used in a study. For this study the styles were grouped as maladaptive and adaptive coping strategies for purposes of certain analysis. (Geddes & Harmann, 2013). Maladaptive coping strategies included: behavioral disengagement, self - blame, denial, substance abuse and self – distraction, while adaptive coping strategies included: planning, positive reframing, venting, emotional support, religion, active coping and acceptance.

Psychological Acculturation Scale (PAS)

The Psychological Acculturation Scale (PAS) is an 10-item tool that measures the degree of acculturation, (low, high or bicultural), of an individual (Tropp, Erkut, Garcia- Coll, Alarcon & Garcia, 1999). Participants were asked to circle the number closest to the answer in the chart which represented the culture they related to most. Items are scored on a scale of 1 (only Hispanic/Latino acculturation) to 9 (only Anglo/American acculturation). Individuals who were not Hispanic/Latino were asked to insert their own cultural background. Only one mother indicated a culture other than Hispanic/Latino and inserted African. An individual is considered bicultural when they have a midpoint mean score of 5, indicating a sense of connection to both cultures. Studies conducted by Tropp and colleagues (1999) demonstrated a Cronbach alpha value of .85 for the entire scale in a sample of Puerto Ricans, which included Puerto Rican women with a mean age of 28.6.

Demographic Form

Maternal. The following maternal demographics and clinical information were collected: 1) age, 2) marital status, 3) parity, 4) mother's educational level, 5) employment status, 6) income, 7) pregnancy complications, 8) type of delivery, 9) timing of infant feeding decision (prenatally or after admission to NICU), 10) if mother continued or stopped providing MoM given to infant at T1 and T2.

Infant. The following infant demographics and clinical information were collected: 1) gestational age (GA) in completed weeks and days; 2) gender, whether male or female; 3) birth weight (BW) in grams; 4) admitting diagnosis; 5) length of stay in NICU in days (LOS), 6) morbidities: intraventricular hemorrhage (IVH), respiratory distress syndrome (RDS), necrotizing enterocolitis (NEC), sepsis; 7) feeding patterns (EBMF – exclusive breast milk feeds;

PBMF – partial breast milk feeds or FF – full formula feeds).

STUDY PROCEDURES

Twenty mothers were interviewed in person by the principal investigator using a semi-structured interview guide, until theoretical saturation in responses was achieved. These mothers also completed the quantitative questionnaires. An additional 10 mothers completed only the questionnaires, at least two weeks following the birth of her premature infant. Once a mother agreed to participate and informed consent was signed, additional clinical information was retrieved from clinical records of the infant. The interview and completion of the questionnaires lasted approximately 1 to 1.5 hours. If a mother required assistance to complete the questionnaires the process could have taken longer, at which time the protocol provided that the mother be given the option to continue, stop, or reschedule to finish at another time. Four mothers opted to reschedule and finish completing the questionnaire at another time because they were due to pump MoM on completion of the interviews.

Human Rights Protection

Request for human rights protection approval was obtained from the institutional review board (IRB) of the Columbia University & Columbia University Medical Center (Protocol – AAAL9701). Informed consent in the form of written and signed consent was obtained from every participant along with a HIPAA clinical research authorization for non-sponsored research form. The consent form included consent for completion of the questionnaires, medical record review and the interview. It also indicated that the interview was to be recorded, and noted that quotes from de-identified transcripts may be used for publication as part of doctoral research, for in-house discussion and presentation for educational purposes of other health professionals.

After the mother had been identified as meeting study criteria and before any questionnaire was distributed or an interview conducted, the consent process was conducted and written informed consent was obtained by the investigator, a doctoral student and advanced practice nurse with many years' experience interviewing NICU parents. A copy of the signed consent was provided to the participant. See Appendix C for a copy of the informed consent and the HIPAA Research Clinical Authorization for non-sponsored research form.

A mother would not normally be expected to complete questionnaires or a semi-structured interview as part of her usual clinical experience; however, as such the questionnaires and interview do not pose additional risk for either the mother or the infant. No interventions or devices were used in this study

Confidentiality of Study Data

The data was collected and stored as a coded data set. All data forms, questionnaires, interviews notes and transcripts as well as the digital recordings of the interviews were marked only with the code number assigned to each participant. The master list of names and code numbers were placed on an encrypted computer, backed up to ensure confidentiality and available only to the investigator? All notes and recording transcripts were kept in a locked cabinet, and the digital recorder was with a study team member at all times when it was needed and secured in a locked file in the doctoral student's office when it was not. Downloaded recordings and transcripts were stored on an encrypted computer. Only the investigator and research assistant had access to the locked cabinet and only the investigator had access to the computer. No recordings or whole transcripts were or will be shared. Any excerpts of transcripts shared, such as for publication or educational purposes, will be brief and not contain either the

mother's name or the code number. In addition, any words within the content that might identify the mother (such as infant's name or destinations) will be removed.

Data Collection

Qualitative data collection. For those mothers who agreed to be interviewed, the interview was conducted using the semi- structured interview guide (see Appendix A). The interviews were conducted in a location of the mother's choosing. Mothers were given the option of having the interview in a quiet space adjacent to the unit but away from the bedside to minimize interruptions. However, only one mother agreed to this option. All the other mothers chose to be interviewed at their infant's bedside. The initial data collection period was proposed to take between one – 1 ½ hours to complete.

Quantitative data collection. Data were collected at two time periods: Time one (T1) data collection included completion of interviews and questionnaires as well as collection of maternal and infant demographic data. Finally, infant feeding patterns such as EBMF –exclusive breast milk feeds, PBMF – partial breast mild feeds and FF – full formula feeds were collected. Time 2 (T2) data on feeding patterns only, were collected 2 weeks after the first encounter and or at discharge from the unit, whichever occurred first. The sole purpose of T2 data collection was to determine if initial MoM feeding decision was maintained.

Study mothers completed the demographic information and standardized questionnaires which were bound into one booklet for her convenience (See Appendix B). Mothers were given the option to have the doctoral investigator or a research assistant help them to complete the questionnaires if they required assistance. Only one mother requested assistance, and she was aided by the doctoral candidate. Subsequent follow up was in person (if infant remained

hospitalized), through review of the clinical record, or by phone, text or email to ascertain if mother maintained her feeding decision from T1.

Data Analysis Plan

Qualitative Analysis. Following data immersion through repeated reading of transcripts and listening to recorded interviews and consideration of mother's affect and behaviors as observed during the interview, directed content analysis techniques were used to identify congruent theoretical themes and identify new and emerging themes. These were discussed and verified with an expert in qualitative research methods.

Then the qualitative interview data was entered into QSR NVivo, version 10, (QSR, International, 2012) software. NVivo has been designed for data analysis of qualitative and mixed methods studies among other uses. Through NVivo, themes and their relationships were refined and visualizations of these themes were produced. These were also discussed to consensus with the qualitative research methods expert.

Quantitative Analysis. Data analysis followed the seven step method proposed by Bannon (2013). The seven steps are to: 1) develop a study map to describe the proposed relationship between the predictor and outcome variables. 2) Attention to data entry. In this study a coding dictionary and appropriate data software were used to assure adequate data entry. The quantitative data were analyzed using IBM SPSS version 22 software (IBM, Chicago, IL). 3) Checking for data integrity. For this study, assumptions were examined, skewness and kurtosis values and Kolgomorov- Smirnov tests were run to determine normality. 4) Univariate analysis. Descriptive analysis was performed using either means, standard deviations for continuous variables and frequencies and or proportions for dichotomous or categorical variables. 5) Bivariate analysis is the next step, which involves analyzing relationships using correlation

matrices. For this study because of violations in assumptions of normality, Spearman's rho correlations were used to assess correlations. Group differences between Latina and non – Latina mothers who continued to provide MoM and those who did not continue were evaluated using students t-tests or Mann-Whitney U and chi-square or Fisher's exact tests. 6) Multivariate analysis involved identifying predictor variable or variables with the strongest relationship to the outcome variable. In this study binary logistic regression was used to identify variables with the strongest relationship with continuation of providing MoM during the first month of life in the NICU. 7) Write- up and report will be the completed dissertation and any future manuscripts developed as a result of the study's findings.

The quantitative and qualitative data were integrated using mixed methods techniques of identification of convergences, divergences and/or contradictions (Morse & Neihaus, 2009). All findings were then compared with the BAM and related theoretical models proposed from the literature at the outset. Particular consideration was given to the Latina experience of becoming a mother in the NICU and to its cultural nuances.

Chapter 4:

Results

The purpose of this mixed methods study was to complete a qualitative description of the experience of becoming a mother in the NICU for Latina mothers who chose to provide mother's own milk (MoM), and to explore through quantitative instruments for Latina and non- Latina mothers what factors influence the decision to continue to provide MoM throughout the first month of life in the NICU. The qualitative aim was the core strand and its related questions were thoroughly analyzed using data immersion and direct content analysis strategies and computer-based software. The quantitative aim was exploratory in nature and its related questions were analyzed using descriptive and non-parametric between-group analyses to suggest patterns for predictors of continuing to sustain the decision to provide MoM. Results from in-depth qualitative and exploratory quantitative approaches were then synthesized and used to adapt to Latina mothers the theoretical BAM / NICU model initially proposed for this study

Findings of Qualitative Analysis

Aim, related questions and results of the qualitative analysis follow.

Aim 1: To qualitatively explore the becoming a mother (BAM) experience of Latina mothers of a premature infant and providing MoM during the first month of life

Qualitative Research Questions

The primary research question is:

1) How do Latina women experience the BAM transition in the NICU in the first month of life?

The secondary research question is:

2) How do the perspectives of BAM and providing MoM experiences of Latina and non-

Latina women compare?

Description of Latina Mother's Sample

Sample. A purposive sample of 20 mothers whose premature infant was currently in the NICU were interviewed for the qualitative portion of this study and also included in the larger sample for the quantitative strand. Each participant was interviewed once interviews lasted between 9 and 58 minutes for an average of 25 minutes. The mothers ranged in age from 20 – 50 years old with an average age of 32.5 years (see Appendix D for an extended description of interview participants' characteristics). Twelve women self –identified as Latina, while 8 self-identified with a race or ethnic group other than Latina and are classified for this study as non-Latina. Of the non- Latina women, their races consisted of: White (5), African American (2) and Other (1, who identified as bi-racial).

Latina Mothers. Eight Latina mothers had a college or graduate degree, while 4 Latina mothers endorsed completion of some HS or HS graduation. Most of the Latina women were employed (69.2%). Six mothers reported a household income of <$25,000, two mothers reported household incomes of $25,000-$49,999 and >$50,000- $74,999 each. Five Latina women reported a household income of >$75,000. One mother did not provide household income information. Geographically, only one of these higher income Latina mothers lived in the neighborhood of the Medical Center. The others traveled from three of the 4 New York City boroughs (Bronx, Staten Island and Queens) to give birth at this Medical Center.

There were 8 first time mothers and 4 mothers with from 1 – 3 children prior to this target pregnancy. Of the Latina women who were interviewed, only one had experienced a previous NICU admission, which occurred at the hospital NICU that was the setting for this study nine years prior to the target pregnancy. All mothers had singleton births, although one mother

experienced an intrauterine fetal demise and the loss of a twin daughter, which was delivered at the same time as her live baby. Infants ranged in age from $23^{3/7}$ - $34^{3/7}$ weeks completed gestational age (GA), with an average GA of $31^{4/7}$ weeks. At the time of the interview infants ranged from 27 weeks GA to 38 weeks GA.The length of stay in the NICU was an average 54.3 days or just under 2 months. At the time of the interviews, a majority of mothers (9) were providing breast milk feeds, either exclusively (EBMF, n= 7) or partial (PBMF, n = 1), while four were providing all formula feeds (FF).

Becoming a Mother and Providing Mother's Own Milk in the NICU

The core descriptive qualitative design portion of this mixed methods study was analyzed using directed content analysis. This method of analysis is recommended when one is using a theoretical concept or a framework such as the one used in this study as described by Hurst and colleagues (2013), which incorporates Mercer's BAM theoretical concepts. This framework comprises five major conceptual ideas that Hurst and colleagues felt encapsulated a NICU mother's experience. The first was that the process of BAM was "interrupted" leading to the second concept a "paradoxical NICU experience". Thirdly, the researchers averred that a mother entered into negotiations about pumping her own milk. The fourth concept postulated that pumping was either a connector or a wedge between the mother and the infant. Finally, the last influence was that of the NICU environment.

The experiences of the women who self-identified as Latina were explored in the context of this framework to determine if this framework can be applied to this cultural subgroup of women. This is followed by a summary of the non-Latina mothers' responses within the context of the same framework. Mothers are identified solely by numerical code to maintain confidentiality.

Conceptual Themes Consistent with Model

Six theoretically congruent and four emerging themes were identified by this sample of Latina mothers. Table 4 provides a summary of the congruent and other themes.

Becoming a Mother (BAM) Interrupted. *"It's like going home to emptiness."*

The experience of having a pregnancy that was either high – risk from its onset, or suddenly became high risk after an uncomplicated start and was then followed by a NICU admission was, for many Latina mothers an unexpected, traumatic, abnormal, frightening and intensely emotional experience. The NICU environment then became the milieu in which the mother advanced in her interrupted process of BAM. The unexpected interruption of their pregnancy was described as follows.

> "No I didn't expect it – my pregnancy was good –I didn't have no trouble only liver […], no problems –he just came – my water broke and he came…" (M# 9)

> The pregnancy was hard from the beginning – it was high risk, I had a cerclage at 3 months then I stayed in bed for the duration of the pregnancy, I had to stop working, everything was done for me…(M# 12)

> "Everything started at 18 weeks when I found out I had ruptured my membranes along ago - I found out I had ruptured my membranes at 14-16 weeks, very early – everything was going perfect up to that moment. (M#11)

> "Ok, so I had a really rough pregnancy – I was pregnant with twins one of the twins passed in November. They were both girls. Since I was 8 weeks it was bad news after bad news…" (M#6)

> The experience of leaving the hospital without her baby was described by a mother as, "It's like you're going home to emptiness … (M#1).

Paradoxical Experience – ***"Did I have or didn't I have a baby?"***

For this mother with 2 other children, experiencing her first NICU stay was an acknowledgement of the distinct difference from her previous pregnancies. The difference for her was summed up by describing the sense of being in a vacuum.

> It was like… ' did I have or didn't I have a baby you know like or did I?'. You don't feel that joy of bringing the baby home – So, It's kinda like sad… it's just sad , it's kinda different (M# 1).

Paradoxical expressions of cautious happiness were communicated, along with a sense of foreboding. Several mothers observed:

> The fact that my baby's here in the hospital it means that something's wrong with him. So when I celebrate every little thing - it reminds me, though you're celebrating, but it's a check and balance; so my attitude is like thank you very much but I will celebrate everyday…(M#11)

> It is hard in general - it's hard because you didn't have the baby at home. I can't feed her anytime I want to -I'm thinking a lot of things… sometimes when I call (the NICU), I hear the machine beeping I think it's her – they said it's not her, she's not bad – the bad thing is she's not there I don't know what she's doing – I sleep I wake up.." (I think)…has she changed? (M#3)

Many mothers expressed intense emotional reactions regarding the process of becoming a mother in the NICU. Mothers identified that they felt the NICU experience was an impediment to mother – infant attachment.

> "Well it kind of impedes that attachment - that bond – because you're not holding your baby day to day."(M#9)

Although many mothers shared a need to be present as much as they could, admitting to a hyper-vigilance.

> "I touch here – I curl my hands inside – I change her diaper I hold her – not KC [kangaroo care] but just hold her and I'm watching her like obsessively. (M# 5)

> "Since they don't throw me out I stay here. From 10 in the morning to 10-1. I stay here – I wish I had a couch to stay here. (M# 12)

The opposite was also experienced with one mother expressing her ambivalence about whether her presence at her infant's side was beneficial to him:

> "The only thing that was a little weird to me – since I'm just sitting, [,,,] then I wonder should I be here? I don't know if I should be just sitting here… 'does he know I'm here'?"(M# 10)

Most mothers identified caregiving tasks such as changing diapers, taking infant's temperature, changing their position in their beds, and especially providing milk as evidence of their growing sense of competence in, and assumption of the caregiving role. One mother described feeling that she still felt she had to ask permission to interact with her infant.

> I would always ask (to hold baby) every day. It would depend on how he was doing that particular day and on the nurses if they knew the baby or not – everything is so complicated here it's not only the baby, it's the nurse and the situation. (M # 11)

Negotiations about Pumping: *"I had to pump milk for someone who I hadn't even touched"*

Few mothers described the experience of getting a breast pump and starting the pumping within the recommended time period of 1-6 hours after birth although this is hospital policy. Many said they received the pump the next day, or as one mother described, she received her breast pump just before she was discharged home, three days after her infant's birth.

> "…like 3 days after (birth) when I got the pump – [for] me like the day when I was discharged… I just pumped one time and then at home." (M # 3)

Many had to make multiple requests and some were unaware that the equipment was available for their use. Mothers identified pumping as unnatural. One mother stated:

> "The first couple of days I was hospitalized I didn't see her, so I had to pump milk for someone who I hadn't even touched." (M# 5)

Another mother was more conflicted and undecided about her preferred feeding method prior to the NICU admission due to concerns about the adequacy of their milk supply. She described it this way. " I was planning both, I didn't know if I was going to produce milk …" (M # 3). However, she was persuaded by the professional staff in the NICU that providing her MoM was best for her baby.

NICU Environment: "*A very complicated place…. I couldn't see his face*"

The NICU environment exerted a tremendous effect on many Latina mothers. Many saw it as a "very complicated place", with the infant attached to many pieces of equipment, "he was on CPAP he had a feeding tube, IVs everywhere." (M # 4).

Seeing their infant's face and touching and holding their infant was very important and often a delayed process which added additional layers of separation between them and their infants, and introduced more anxiety into an already stressful situation which then posed barriers to their pumping abilities. Mothers described this as an impediment to feeling connected.

> "I didn't get to see her- I hope they [mothers of premature infant] get to see her so they'll get connected, so they will pump."(M# 5)

Many revealed that their distress manifested through emotions such as crying, becoming angry at having to be in the NICU, being frightened by their infant's appearance, having increased uncertainty about survival. As these mothers poignantly stated,

> The first time I saw him (in the NICU) I cried- because my first one didn't have the tubes in his face…and he didn't need the breathing tubes. So that was scary. I couldn't see his

face…… it hit me… as a mother you're worried you don't know what to do – you don't want to see your kid – or other kids like that. (M # 9)

"the most stressful thing was the things attached to the baby- CPAP, I know, I really appreciate the CPAP inventor – I bless that person every day…but I would think… please God…go away little monster." (M# 11)

Some mothers expressed uneasiness about the perceived differences in care during the change between levels of care, which may have led to further stress due to tendency to overcompensate by remaining in the unit longer than may have been recommended given the mothers' physical status of fatigue and exhaustion and in the case of many, recently having had major surgery.

It's stressful because in the night time - – I feel that her not being in the NICU (infant was in a step down unit at time of interview), I think now that she not getting undivided attention – the nurses has 4 other kids. There's been times when I've been here but the nurse is taking care of another child… and I don't feel good about it – so I say, I have to be here with my baby, because I want her to come home (talking to baby). I left late yesterday after 2:30 AM. There's come times when I've been here and she needs suction and the nurse has been taking care of another baby, so I say I need to stay here and be with my baby. (M #1)

Role Alteration…"I didn't feel like I was a mom yet".

Because of the NICU environment and the necessary separation, mothers felt a definite sense of alteration in and interruption of their maternal role.

"In the beginning I didn't feel connected because they took her and rushed her to the where they kept the babies. It was weird, I didn't feel like I was a mom yet" (M#9)

This mother of three older children, despite being an experienced mother questioned her maternal status by asking, "At one point I was like, 'did I have or didn't I have a baby you know, like or did I? (M#1). Additionally some mothers were enduring an impossibly difficult emotional

upheaval, wherein they were dealing with the loss of one child while confronting the uncertain status of their surviving infant.

> "I was 5 months in this pregnancy when they told me my cervix was getting shorter and I'd be… [I] was delivering soon. It was really scary not knowing how soon and at that point they felt it would be soon because I'd deliver and he'd only live for a few hours." (M# 10)

> "I didn't know what to think…they were going to transfer her (to the NICU)...I saw somebody had an oxygen tank, that really threw me off – I just went blank – I'd just had a baby and they took her away – then 15 minutes later they brought the baby that died – I was just in shock, day after day it was really hard." (M# 6)

The intense need to connect to confirm her maternal bond was echoed by several mothers. Many found that in the act of holding her infant she was able to recover some sense of 'being a mother' and just how serious the consequences could be if she had not had that encounter.

> But when I got up here – I did kangaroo care - like a week later and I began to feel connected. It felt great – (to hold) – that's when I felt connected – I would probably have gone into depression. I was lost…" (M#9)

The act of providing direct caregiving did begin to resolve for some mothers the sense of disconnectedness, but for others the experience was unsatisfactory.

> I felt it could have been better – it was nice I had him right here – (pointing to upper chest), he was wrapped up so I didn't interfere with the IVs." (M# 10)

> "Her mother? Sometimes I forgot – basically when I don't see her, but when I change the diaper, take the temperature… I see things change… I know she is my daughter… (M# 9)

However there are times that interactions with the nursing staff reinforce that they still have limited control in the NICU setting and would not have full control until they were home and able to do whatever they felt was necessary for their infant's comfort. The sense of

powerlessness did not engender a completely trusting relationship with the infant's nurse caregiver.

> I do the turning myself, then they (nurse) say I just turned her from that – so I turn her back… I don't think you're really a mom till she gets home, cause then you're doing everything for her then. (M#1)

> I learned that whenever I was told he was alright and then I would come, I would see things…it's alright that he has a good saturation, but he's a human baby – he has to be comfortable, his lips have to be cleaned, he has to be positioned well. Oxygen levels are fine…and if there was more continuity of services…but little things that I won't get into details, I know I'm not the only one –but it confirms why I have to be here."(M#11)

Pumping Process: "*I didn't think there would be a connection…I felt I was doing my job*"

The pumping process was described as an exhausting experience by these Latina mothers. One mother stated just that, "pumping is hard…you get tired." (M# 3) Another acknowledged pumping was painful, "when you're pumping you feel like it's hard, it hurts…" (M# 1).

Many felt unsure they would experience the sense of connection that direct breastfeeding was expected to bring. Many felt pumping was intrusive, did not reflect how they expected to feed their infant and was time consuming. Some mothers did not seem to be aware of resources on the unit that could provide support for their challenges, and resorted to the internet for information, which provided conflicting information at times introducing more confusion and uncertainty about their decision to pump and provide MoM for their infants.

> It was painful getting used to it – I pumped in the hospital I had to wait a day (after discharge) to go to WIC for my pump and that night I woke up shivering, feverish, they were hard – they were engorged oh my gosh they felt bad – I kept reading on the internet – that made me more scared b/c I read if there was a clog I was putting using towels with warm water – then I read if they were too engorged not to use heat – so I started putting cold – water – but then I got my pump and it hasn't happened again. ((M# 10)

Connector *"my milk is helping her"*

Although many mothers were unsure if they would be able to produce milk through the pumping process, nevertheless they acknowledged the uniqueness of their contribution, and as one mother stated, "it's the only thing I can do right now as a parent"(M# 12). This same mother also felt encouraged in the knowledge that " my milk is helping her."

Only two mothers definitively acknowledged that pumping their milk allowed them to feel a direct sense of connection to their infant, while acknowledging a knowledge deficit related to the dynamics of pumping.

> I didn't think there was going to be a connection, with just a pump and a bottle, I thought it was going to be more of a latch with the baby and then to see the milk come… but it came. I was surprised… I thought that it didn't happen if she didn't latch.(M# 1)

> I know everyone is doing what they have to do - my baby is doing what she has to do – it's the only thing I can do right now as a parent – I cannot dress her, I cannot hold her - I know that my milk is helping her. (M#2)

Mothers also shared advice they would give to new or future NICU mothers. "Keep trying. I definitely see why people give up – if the baby is in the NICU the baby probably needs the breast milk more,"(M#7)

Wedge. *"I felt I was doing my job".*

More Latina mothers felt pumping was more of a functional activity, a necessary activity performed mostly for the infants' benefit. "I felt I was doing my job… I was physically doing it." (M# 11)

A moving response from some mothers was a sense that their bodies had failed them and their infants.

> I still pump…but I'm not getting a lot of milk, maybe one ounce. It's frustrating, you see other mothers bringing in a lot of milk and I'm trying so hard and I can only get one ounce. (M#8)

Mothers acknowledged fears about their ability to produce, or about the inadequacy of their milk supply once they started to express MoM. One mother admitted, "I'm only getting drops" (M# 2). While another stated, "I didn't think I'd be able to produce enough...' (M# 12). The second mother was able to produce enough milk and expressed her intentions of providing MoM for at least one year to her daughter.

> I can get like 7cc, and that's after hand expressing…sometimes I don't get anything in the pump.. I don't want to victimize myself, but when I'd do it and I don't get it the first few seconds I won't lie – I go aaahh… probably I'm never going to get it. But then I say no I'm going to get when he's able to latch on. (M# 11)

Given the uncertainty about having sufficient milk supply, one mother did acknowledge that she considered providing both forms of infant feeding (formula and breast). "I was planning both, I didn't know if I was going to produce milk." (M # 3)

Many continued to pump, often resorting to suggestions from a variety of sources, who were not health care providers.

> "I did anything anyone said to increase my supply...I had fenugreek tea, mothers milk, oatmeal –everything that somebody tells me I do it. My mother said hot chocolate without milk." (M#11).
>
> "I try everything- anything people tell me. I drink a lot, a lot of water, but I'm still not making a lot of milk." (M# 9)

Infant Factors. *"I never had to think about them not making it"*

Uncertainty about their infant's survival during this phase of the hospital stay compounded by the effects of the NICU environment, distressed many mothers.

> It's very tough- very tough – it's so tough – because I cry when I think about it – I really want to cry - (pauses to compose herself) – it's just…like with my daughters… I never had to think about them not making it"(M# 11)

The uncertain medical course was commented on by one mother with this advice.

> I would just say to have patience because even if you get an answer like how long he might have this or things like that - it all depends on how the baby will respond. You don't get an exact timeframe for everything – just to be patient.(M# 10)

Concerns about long term consequences of the prematurity were also a major source of uneasiness for many Latina mothers, despite assurances from various support sources such as NICU staff and family. At times, these concerns persisted because of information provided during pregnancy.

> "I came to see my doctor on Dec 19 and it was like really bad that visit, every visit was bad – but that was like the worst one… a 50-50 chance of having a mentally retarded child." (M #6)

This same mother then reflected on the continued uncertainty that contributes to the ongoing overlapping sense of paradox after her daughter was born:

> "Sometimes I get really happy but yesterday I found a note attached to her isolette (incubator) for me, that she's going to get this eye exam – but I'm really scared – the nurse came, the nurse who's going to be with the MD came and she told and my husband explained it to me, her initial Neo (neonatologist) she came and spoke to me – but I'm still very scared I don't want my baby to be blind." (M#6)

For other mothers, it was seeing the tangible evidence of their infant's struggle to survive evidenced by their infant's need for technological support for the basic survival and their inability to intervene to protect their infant:

> Then I saw all the tubes… it hit me– he was on CPAP he had a feeding tube, IVs everywhere… *as a mother you're worried you don't know what to do* – you don't want to see your kid – or other kids like that. (M#9)

> "It was very difficult, very depressing.it was hard that she had things in her stomach, she was breathing hard. It was all the machines and how she looked so fragile, helpless and all the stuff around her, she looked uncomfortable." (M# 6)

This worry produced a sense of hyper –vigilance described by this first time mother by her need to be present and initiate activities that connected her to her infant

> "I touch her – I curl my hands inside – I change her diaper I hold her – not kangaroo care but just hold her and I'm watching her like obsessively"(M# 5)

Other Themes Related to the NICU Experience

This feeling of powerlessness and high uncertainty about boundaries is recognized as a liminal state, wherein mothers feel they were unable to assume the maternal role until environmental factors are in control, or once their infant was discharged to home. Thus only at that time would the third and fourth phases of BAM – organizing around a new normal and assumption of maternal role begin. As one mother stated, "I would say – I don't know – I don't think you're really a mom till she gets home – 'cause you're doing everything for her then." (M#1)

Cultural Beliefs. ***"I think my culture, for me, being a good mother is … being there for your kid"***

Mothers often expressed a schism between their NICU experience and their cultural beliefs about mothering and providing breast milk, with their experience denoting not being able to provide their "best" to their premature infant.

> I think my culture, for me, being a good mother is about being there for your kid… When you become a mother, it's all about your children. And breastfeeding (direct breastfeeding) is the best you can do for your baby.(M#8)

> Your mom is there for you –my mom was a stay at home mom. That's what I saw growing up. My mom didn't breastfeed us. She's 71 years old – so I didn't have any sense of breastfeeding. (M#2)

External Stressors: "*It's A Balancing Act – "Checks and Balance*"

The specter of external responsibilities was also evident as a further wedge between exemplifying culturally taught values. "I knew I wasn't going to be a stay at home mom. I'm the one that has to work, there is no second income…" (M#2)

Additionally, external challenges that made it difficult for mothers to be with their babies as often as they wished. Many expressed concerns about socioeconomic issues such as unemployment, inadequacies in housing and daily hassles and challenges about returning to work which made it difficult both to be present to interact with their infants and to have the time necessary to pump to maintain their milk supply.

> I'm kinda glad he's here because yesterday we had no heat, or hot water and it was so cold. My oldest son has asthma and that's not good for him, so if the baby has to stay it's a good thing. (M# 8)

> I feel weird about that I might start a job soon – I don't know how that would interfere – how I will do the breast pump. I accepted it (the job), but I'm not sure. I start –the 13th. But like I said I didn't want to work till he was older…The thing is that they're a little more strict –it's phone calls –so they're coming non- stop –I've seen this bra that holds the thing (pump) there –and they do give, like breaks through out, much better than retail – I get 2 15- no 10 minutes break and then lunch. I guess I'd be able to put it on during the break and then take it off. (M# 10)

Some mothers expressed trepidation about the additive effect of external stressors, and the overwhelming need to juggle so many considerations, and for one of these mothers her other responsibilities proved to be detrimental to her ability to continue to provide milk for her infant. It came at great personal cost to her maternal identity as she felt strongly that providing her milk allowed her to feel like a mom in the NICU.

> I don't think it's fair not to let me have that the time that I would have been out when she gets home I will want to start my disability time. (to return to work) - They tell me it's 8 weeks. I have until the 4th in December – but I don't think I will…Planning to get married to her father – that's stressing me…(M# 1)

> I guess the idea (to stop pumping) has passed thru my mind given my reality, because… I have 2 kids. I have two kids (repeats phrase), I live very far – I have a long commute – and I'm really tired. But I don't want to give up, because I feel if I give up I'm deceiving him. I feel when I give him from the breast I'm doing that special part as a mom that no one else can do – when I pump my breast (begins to cry) – I feel like I'm being a mom.(M# 11)

Generational Divide. ***"the new generation of my age… say 'why would you want your child on your breast?"***

Although two-thirds of the mothers were foreign born, all in the Dominican Republic, they had lived in the United States for longer than 10 years. They related a generational divide in the perception of breastfeeding and the experience of mothering. Many conceded that while the cultural expectation was to remain at home and focus on raising their children, this would not be a practical solution for them and some had already returned to work due to their antennal hospitalizations.

Most were planning to return to work within 2 months of giving birth, with one mother planning to return less than one month after giving birth.

> "For most people from older generations breastfeeding is the number one thing. But the new generation of my age and the generation before me, they feel it's nasty. They say 'why would you want your child on your breast?' My sister said, she says it's nasty." (M # 8)

Cultural Values. In their interviews, mothers alluded to several cultural values recognized as central to many Latina cultures concerning beliefs about a good mother and the role of breastfeeding. Cultural values introduced by mothers included: 1) Familismo - the importance of family; 2) Fatalismo - (fatalism) a sense one's fate is predetermined and 3) Respeto (respect) – treating others and being treated with respect (Chong, 2002).

Familismo. As one mother mentioned, "…when you become a mother, your focus shifts and it becomes, 'all about your baby'" (M# 8) Another felt that becoming a mother meant "…raising your children yourself and with a family" (M# 7). Yet another mother stated that

> "Dominican mothers are tight with their kids- they're every time, so close to them. So I think understanding… giving more time, but breastfeeding like, has things clean…quality time." (M #3)

This group of Latina mothers also identified their husbands, mothers and other family members, such as their sisters, as their primary sources of support. "my husband, mom, sister, yeah, they've been my support." (M#12)

> "My husband has always been at my side and my mother is helping with my girls, so that was a great support because I wouldn't be able to be here." (M#11)

One mother admitted that, although her mother was present, circumstances were not conducive to allow her to be a consistent support and she had no other personal support system, she did reach out to the support provided to her in the unit.

> "I'm not in a personal relationship –I got dumped when I was in the hospital, so from that aspect no – no support. I have family, you're born with family – you don't choose them. I think that says it all… what's good about this facility, they have the psychologist, they're there for you - that's a good thing." (M#2)

However, in certain cases, the support also served to highlight the pragmatic aspect of pumping, sometimes to the detriment of the mother's continuing physical recovery.

> "My husband –he's always saying did you pump? He's always waking me up… and I'm tired." (M#5)

Fatalismo. The loss of control over the pregnancy, birth and subsequent hospitalization of their infant in the NICU led to an expression of the sense that one's (or the baby's) fate is predetermined by God for some mothers.

"I got pregnant by IVF, I didn't think it would stick, but miraculously it did. (M#2)

"This experience was very different –beginning with uncertainty – I believe that God's will, will be done whether I like it or not – but I believe He can do a great miracle – but He can just say that no I want to teach you something – He only knows why…"(M# 11)

Respeto. Respeto is the sense that mutual respect exists between the patient and the healthcare worker. Many mothers alluded to this value by acknowledging that the staff were very helpful, provided adequate information about infant's condition, and involved them in their infant's care. Concerns of abandonment were allayed in certain situations. In contrast, some mothers felt the need to be by the bedside to ensure that their infant was sufficiently cared for.

"They talk about any changes even the little things; if she poops, she don't have high BP (blood pressure), anything…"(M# 3)

"I have a good relationship with them (NICU doctors and nurses). The first thing I do is call and find out how she's doing, but it's not the same as coming in to see your baby." (M #1)

"They're great, I haven't had no bad experience, they're very helpful. I have nothing negative to say about them." (M#5)

One mother felt the need for additional vigilance that had overtones of the infant 'feeling' abandoned because she did not remain watching over him when she felt that the nurses, because of their assignments were forced to be at the bedside of another baby. This mother also demonstrated a sophisticated level of understanding of her infant's behavioral cues of pain.

The tubing is touching his face and you would see his face when the tubing was accommodated and reposition – his face would change from making facial grimaces and hear (points to between eyes) it would smooth – and some nurses would care – then they would say –"oh mom he seems happy" – that would tell me that you're paying attention – you're there providing sensitive care. (M# 11)

One young mother felt that her physical presence was necessary to allay confusion on the baby's part: "…so he can feel me, smell me. He can know who I am because having different womens around they tend to sometimes forget who's who." (M#9)

This mother also discussed her surprise that she was encouraged to interact with her infant, since her expectations were otherwise:

> Well I thought it was going to be like you're not going to be able to hold him – you can't do this you can't do that … but they want you to hold him – to see the baby, what's going on with the , to feel comfortable. You have the right to call whenever you want – to – I can go home and feel fine. That's what I thought, you feel more secure. I can go home and sleep fine. I didn't have to worry. That's what I thought oh my God, what if I go home and they can't reach me. That's what I was more concerned about - They made me feel comfortable – I'm glad I can call and reach anybody. I know he's not suffering or being abandoned or anything. (M# 9)

Table 4: Conceptual and Related Themes from Interviews with Latina Mothers

Latina Mothers Themes	Theoretically Congruent Themes
"It's like going home to emptiness."	Becoming a Mother (BAM) Interrupted
"Did I have or didn't I have a baby?"	Paradoxical Experience
"I had to pump milk for someone who I hadn't even touched"	Negotiations about Pumping
"*A very complicated place…. I couldn't see his face*"	NICU Environment
"*I didn't think there would be a connection…I felt I was doing my job*"	Pumping Process
"As a mother you're worried you don't know what to do"	Infant Factors
Latina Mothers Themes	**Other Themes Related to NICU Experience**
"I didn't feel like I was a mom yet"	Role Alteration
"My culture, for me – being a good mother is about being there for your kid" • *Familismo -"raising your children yourself and with a family"* • *Respeto –" that would tell me that you're paying attention, you're there providing sensitive care."* • *Fatalismo – "I believe that God's will, will be done whether I like it or not"*	Cultural Beliefs & Values
"*It's A Balancing Act – "Checks and Balance*"	External Stressors
"But the new generation of my age...they say 'why would you want your child on your breast?	Generational Divide
"I would say – I don't know – I don't think you're really a mom till she gets home – cause you're doing everything for her then."	Liminal Phase

Summary

For these Latina mothers, the experience of becoming a mother in the NICU was an incomplete transition, characterized by a period of high uncertainty that began during their pregnancy and continued through the early hospital stay of their infant in the NICU. It was characterized by intense conflicting emotional undulations as a result of separation from their infant and the inability to connect physically through touching and seeing their infant because of the tangle of NICU equipment wiring and tubing. In several cases the experience was complicated by periods of intense grieving, for some, over a lost child and for most, over the lost experience of a full term pregnancy.

Pumping became their central focus, as conceptualized in Figure 3, a word cloud illustration generated with NVivo software (QSR International, 2012) which denotes the amount of emphasis and frequency that subjects place on important concepts that describe certain phenomena. “Everything” was about the “breast” and “pumping”. The role of mother was on the periphery with direct breastfeeding an even more distant concept, on the margins of the discussion during this period of the early postpartum. Although it was felt to be a service only they could provide for their infant, it was also felt to be unnatural, and not the best expression of their personal or culturally expected maternal role. It required a large degree of negotiation amongst competing issues including external responsibilities, and stressors that fragmented their time and concentration. It was viewed as uncomfortable and served more as a wedge or a pragmatic activity rather than as a connector or relational enhancer of the parent infant bond.

Figure 3: Latina Mothers Impressions of BAM and Providing MoM Experience in NICU

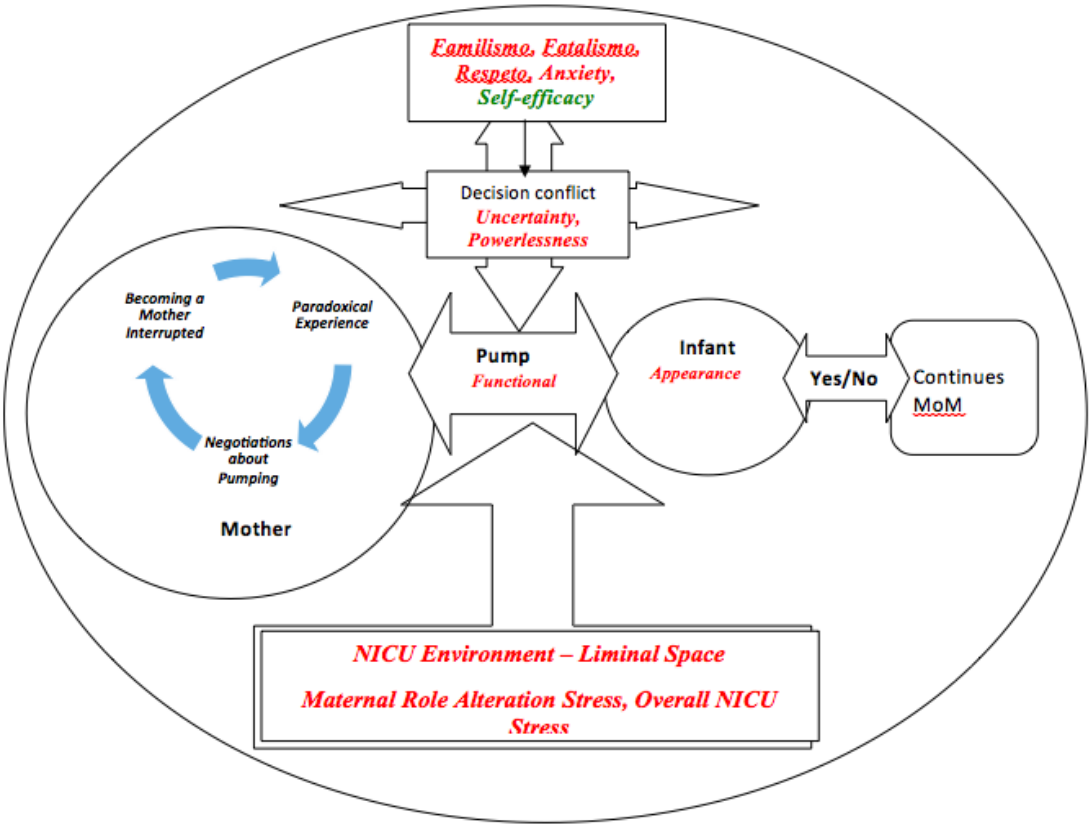
In addition, culturally transferred values such as the family being the unit of protection and caregiving caused conflicts especially for mothers with other children. Mothers were torn between their responsibility to be with their other children and their preterm infant. Moreover, values such as fatalism may have served to unknowingly influence their belief in their ability to provide their MoM for their premature infant by pumping rather than through direct breastfeeding as many anticipated when they made their infant feeding decisions. Their cultural expectations of demonstrated respect may have served to increase their apprehensions in a setting of already heightened anxiety.

Therefore, although the Latina mothers' NICU experience fits the framework of BAM and providing MoM in the NICU, more mothers felt that pumping was a functional process and not a source of connection to their infants. This study highlighted another phase, the liminal phase characterized by high levels of uncertainty about boundaries and roles with high levels of anxiety, and also provided nuances from Latina cultural values. This liminality overshadowed their stay and further delayed the full assumption of the maternal role. Many stated that they would feel like a mom when they were able to hold and interact with their baby whenever they wanted. It also produced some degree of fantastical thinking because mothers who had admitted

to difficulties in producing MoM felt that their milk supply problems would all be resolved once the baby was home and they were able to do direct breastfeeding. As one mother stated, "pumping is OK but I wish I could just feed him at the breast."(M# 11)

The framework therefore is adapted in Figure 4 to include these findings to further expand the concept of becoming a mother from the perspective of this Dominican subgroup of Latina women, and to reflect their perceptions of the relative importance they placed on its different conceptual dimensions

Figure 4: Adapted Framework of The Latina Mother's Experience Becoming a Mother and Providing MoM in the NICU*



*adaptations in italics

Non-Latina Mothers Experiences

Eight non-Latina mothers were interviewed, of whom one half were first time mothers, while the others had at least one other child. This group of mothers were younger than their Latina counterparts with an average age of 30.4 (range 22 – 41) and all were born in the United States (US). They self - identified as White, African/African American and other (biracial). Two reported an income of less than $25,000, 4 reported an income of greater than $75,000 and two did not include information about their income. Four had a college or higher degree while 2 had completed high school. Two did not provide educational information. Three of the non- Latina mothers had twins while 5 had singleton births.

This smaller subset of women were identified as having high risk pregnancies in their second trimesters with the exception of one mother who was identified in her first trimester, as carrying monochorionic- monoamniotic (MCMA) twins with the expectation of a preterm delivery.

Conceptual Themes Consistent with Model

Six theoretically congruent themes, and one other theme were identified by this sample of non-Latina mothers. Table 5 provides a summary of the congruent and other theme

BAM - Interrupted: "*I had sort of an idea how the path would hopefully go"*

Most of the non – Latina mothers indicated that they felt they were adequately prepared or were in the process of preparing themselves cognitively for their early deliveries. As this primiparous mother shared, "I was prepared. I was nervous but I knew they were in good hands, that's why we came out here." (M#17)

Yet another mother felt she was "overwhelmed…to be honest I was still trying to be prepared for anything. She could have problems, and I was trying to mentally prepare myself." (M #13)

Another mother indicated that because she was preparing for an interrupted pregnancy, she had sought additional information from sources outside of the health care staff who were monitoring her pregnancy and delivery, and this allowed her to feel primed for the experience.

> Right, so I had you know googled a lot. Unfortunately I had time (in hospital for one month prior to delivery). I had sort of an idea how the path would hopefully go, yes and in some ways it was even a blessing, because I had an idea about how small they would be. So when I saw them… when they bought them over, I actually thought they looked good, like I thought they would. Everything is relative. (M#18)

Paradoxical Experience. ***"It was sad…but it was happy"***

Only a few non-Latina mothers discussed their NICU experience in contradictory terms mostly related to their emotional response to seeing their infant in the NICU for the first time. This mother stated that, "It was sad (first time seeing baby), , but it was happy. It was a very mixed emotions." (M# 14)

> "It's so hard, it's nothing like you'd expect it to be (mother is crying). You can't hold your baby, which is hard, but that's…she needs what she needs. She doesn't need it (holding baby) as much as I do." (M#16)

One mother recalled being confused regarding her understanding of her hospital admission and the impact of discovering that she was about to deliver a very preterm infant, how she felt she was prepared for a course of action that did not in fact occur.

> "So they prepared me, so I thought they were going to control my BP (blood pressure) and send me back out, so it was a shock when the OB nurse told me I wasn't leaving the hospital without a baby... so I just started crying…so they prepared me mentally…you know we may have to intubate m she may have to get resuscitated, and thought everything was so overwhelming…and then I heard her cry,, and he came and put her on me and all I could think of to be honest…shouldn't you be resuscitating her?" (M #13)

Another mother balked at the seeming contradiction that, despite having recently given birth, her experience did not follow the expected path.

> "I remember walking past the other rooms to go feed and parents with their babies in their rooms and I remember crying– and thinking- it was so unfair because I didn't have my babies with me… every time you leave and you're walking home – without your child – it's heartbreaking" (M #18)

Negotiations about pumping. ***"For me, I'm able to multitask…even now it's difficult things come up"***

Those who had made their decision to provide MoM during their pregnancies appeared to have developed a plan around pumping and were adapting their plan as their life situations changed. Many had considered how they would adapt the pumping into their routines when they returned to work, and how they would involve other family members.

> They (her workplace) have a pumping room, but what I'd do is before I see anybody (medical resident), I'll pump around 8:30 then around 11:30- 12. I'll pump, then I'll see patients in the evening then try to get done early. Or pump before I get home or when I get home. (M#13)

> In a perfect world, I was guesstimating anywhere from 3-5 months (to give BM)…When I do go back to work, we have a lounge and a bathroom that people use to do that (breastfeed)…I work with a mostly female population, so everyone basically respects that we need to do this. (M#20)

Despite mothers pre-planning how to fit pumping into their other life responsibilities, they acknowledged the difficulties in integrating this additional " task" as one mother called it into already busy lifestyles. They admit that it is a draining undertaking and concede to a fair amount of guilt regarding the inability to juggle so many responsibilities.

> "But even now it's difficult because things come up, and I have to go pick up my other son, so basically I just try to…right now it's 1 PM so it's been about 4 hours (since she pumped up. There was a problem with his flight and so I didn't get home until 2 o'clock this morning. And I feel guilty it it's not every 2-3 hours." (M#13)

> "For me, I am able to multitask. Instead of sitting there tethered to a machine, I'm able to do something else...for me I've discovered the hands free pumping bra… I find it to be a

> nuisance factor – 25 minutes of taking time out when I know I have a laundry list of things to do. But I know it's important, and so I do it." (M#16)

A mother of twins described her experience like this.

> Like I wake up I pump, then I try to pump again before I come here – and sometimes I wake up in the middle of the night, sometimes. So I get four or five times in maybe… if I'm home I'll be on my phone – or watching TV since I have the hands free bra It'll be easier to pump when they get home I think.(M#17)

In contrast, one first time mother indicated that she had not made her decision about infant feeding when she delivered prematurely therefore she had no set routines. Consequently she had not established an adequate supply and was supplementing with formula.

> I was still undecided while I was pregnant…I didn't know what breastfeeding was going to feel like…but when he got here they told me breastfeeding was good for preemies... I don't have much of a routine…I pump 1-2 times a day (M#19)

NICU Environment - *"Everything was so overwhelming."*

The experience for these mothers was very emotional tinged with sadness and at times overwhelming. This mother of twins who was breastfeeding one of her daughters during the interview shared about her first visit to the NICU:

> I remember feeling it was so unnatural, and I'm a very natural person… I remember walking past the other rooms to go feed and parents with their babies in their rooms and I remember crying– and thinking- it was so unfair because I didn't have my babies with me…And every time you leave and you're walking home – without your child – it's heartbreaking. (M#18)

Maternal Role Alteration. *"Now I feel such a part – time, minute role as a mother"*

This mother of 2 boys put described so eloquently the diminished role she felt in her daughters NICU experience.

> It's heartbreaking. Every time I think about it I almost start crying….now I feel such a part – time, minute role as a mother in her experience here…I would love to be here to hold her 24 hrs. a day – to do all those things… This is my little girl please take care of

her because I can't right now. (M#13)

Pumping: ***"I fit my day into pumping."***

Although many of these women had other children, they still displayed a knowledge deficit about providing MoM by pumping for their premature infant and described the emotions they felt when they were informed of actions that were less than optimal.

> I was pumping every six hours in the beginning….I was already 4-5 days into pumping when I actually spoke to the LC… I thought I was getting enough milk then the LC came by and said, no, no you have to be pumping every 2-3 hours and I felt like I was a horrible mom. (M#13)

There seemed to be a variance in the amount of breastfeeding support these mothers were given in the initial period right after their deliveries. For example, a first time mother stated, "I started pumping 2-3 days after he was born." (M#19). A new mother of twins offered a refreshing perspective on the action of pumping, indicating that life at this period of time revolved around the pumping process.

> "I think I fit my day into pumping (laughs). That's what it feels like anyway. I think it's pretty amazing." (M# 20)

Infant Factors - ***"She's behind the mask".*** As with the Latina mothers, the superseding separating factor was the equipment in the NICU environment.

> Well the masks, the CPAP (continuous positive airway pressure), and not really being able to see her face and her hair, You know her. She's "behind' the mask. (M#16)

Concerns about their babies suffering were also disconcerting to these mothers.

"I'm not sure if it was more the NICU (environment) or the fact that they were , they seemed to be in some sort of pain and were crying,," (M#20)

"…when we first saw them they were laboring to breather, that was a scary thing to see. Your realize that they are not just small, but they have issues**."** (M#18)

One mother was also concerned about her son's survival chances due to a previous child's death. "I had a child before, but she died when she was four. That's kinda stressful. I hope he will be OK." (M# 19). Her stoic presence at the bedside, the fact that she was facing away from her son and did not interact with him during the entire interview was telling and may have represented a subconscious detachment, raising the specter of previous losses and its impact on the target pregnancy.

Other Themes Related to the NICU Experience

Maternal empowerment emerged as an additional theme not addressed in the initial model for this subgroup of mothers. Several non – Latina mothers alluded to a sense of attempting to get control of the situation by seeking information about their infant, the feeding regimen to make the NICU experience a more manageable situation.

Maternal Empowerment: *" Feeling in control…getting information makes you feel more powerful"*

Non-Latina mothers referred to their pregnancy as a planned experience. A second time mother shared that even though the timing was a "pleasant surprise" they "… had tried unsuccessfully for a long time, and so we were glad when she just showed up." (M#16)

Mothers who had clear infant feeding plans seemed to wrest a measure of control over their situation.

> "After that first experience (not establishing a milk supply with first child), I knew I needed to pump right away, the second I got to the hospital room, I was asking, when would I get a breast pump…it came within the first 3 hours…but I must have asked 6 times. The point is, I knew I had to start immediately." (M#16)

"I always wanted to do pumping or breastfeeding. Since I knew I wouldn't be able to breastfeed immediately because I was in the NICU, so I planned on pumping." (M#19)

"I'm a 'breastfeeding nazi", so to speak. I don't know how it will be with twins and a toddler ...I hope to breastfeed them as long as I can – I hope to at least make it to a year. Thank goodness I'm getting quite a bit of milk – at least there's a reward for my efforts…. I'm still getting milk… I would have tried and tried until I drove myself insane, maybe that's why God said you've got enough (M#18)

Another mother indicated that getting information provided an additional sense of empowerment "Getting information lets you feel...more powerful." (M#16)

Summary

For these non-Latina mothers, the experience of becoming a mother in the NICU was demonstrably different than for the Latina mothers. Many were multiparous with other children and this may have moderated their experience. However even the new mothers indicated a degree of planning and preparation, especially if once they were identified as having a high risk pregnancy. Their responses reflected the BAM framework and fit the framework of BAM and providing MoM in the NICU, however they also displayed a greater sense of preparedness which as Mercer described is a major task of pregnancy in the BAM model. They were clear about their goals to provide MoM for their infants including duration of providing BMF and considering ways to integrate the process into their lifestyles. Although there were more multiparous non-Latina moms, their ability to be prepared was tempered also by concerns about external stressors, such as childcare and workplace concerns.

The non- Latina women also projected a stronger element of maternal empowerment and control over the NICU experience. As one mother declared, "… information, getting information lets you feel more in control – more powerful." She went on to suggest the following advice for future NICU mothers' considerations: "Make sure you get sleep, the less sleep you have the less

likely you are not to process the information and get more upset by it - to let your hormones take control." (M#16).

Table 5: Conceptual Themes from Interviews with non -Latina Mothers

Non-Latina Mother's Themes	Theoretically Congruent Themes
"I had sort of an idea how the path would hopefully go"	Becoming a Mother (BAM) Interrupted
"It was sad…but it was happy"	Paradoxical Experience
"For me, I'm able to multitask…even now it's difficult things come up"	Negotiations about Pumping
"Everything was so overwhelming."	NICU Environment
"I fit my day into pumping."	Pumping Process
"She's behind the mask".	Infant Factors

Non-Latina Mother's Themes Other	Themes Related to the NICU Experience
"Feeling in control…getting information makes you feel more powerful"	Maternal Empowerment

Comparison between Latina and Non-Latina Mothers

Although Latina mothers felt they were getting adequate information from the NICU doctors and nurses and other resource personnel, they still resorted frequently to friends, other mothers and even the internet to augment the information, and were often confused by the

conflicting information presented on internet sites. None mentioned speaking with hospital personnel to alleviate the confusion.

Several of the non-Latina mothers addressed the need to take care of themselves in order to avoid becoming debilitated by the inevitable exhaustion of recently giving birth following a harrowing, disturbed pregnancy. And while most of the benefits of providing MoM were directed to their infants, they recognized the importance of caring for themselves as well in order to have the capacity to maintain their supply. They described the importance of being present, and the increased sense of competence that developed over time in anticipation of taking their baby home. "I think the more time you spend, the more I do the more comfortable I feel. I don't feel like I will hurt her now when I hold her and that helps too." (M#13).

Fewer non – Latina mothers than Latina expressed feeling overwhelmed. Latina mothers who seemed overwhelmed by the NICU experience and seemed willing to bide their time in a more fatalistic way while in the NICU. As one Latina mother said,

> You feel as if the rug has been pulled out from under you…seeing her… in an isolette (incubator), was like you're just thrown into all this. It's like you don't expect [it]… having a preemie is a wake- up call –it's a lot. (M#2)

Another mother advised,

> I would say to have patience because even if you get an answer like how long he might have this or things like that, it all depends on how the baby will respond. You don't get an exact time frame for everything." (M#10)

And though the desire to take their infant home was present as this mother of a toddler noted,

> "I mean the first 3 days you're anxious. OK what wrong? Then another week passes by – you're OK, baby is doing better. Then another week and you're like – [sighs]… and you say OK, I don't want to be here anymore. You see your baby is OK – it's about feeding, it's about breathing, it's about the temperature... Then you realize he's not OK –It's wanting to go home… It's when the baby is ready so you wait – it's kinda hard." (M#9.)

In comparison, the two mothers who admitted to more uncertainty and being unaware of the expectations of a preterm birth, were the two young African – America mothers in their early twenties. They admitted being unprepared for their pregnancies and the subsequent births of their premature infants, and their demographic profiles were similar to the younger Latina women.

Both of these African – American mothers admitted to a higher degree of uncertainty about their role transition in the NICU and admitted to being undecided about infant feeding and being willing to supplement with formula feeds. Their observed behaviors were also telling as neither mother was in direct contact with her infant during the interview sessions. Although both agreed to have the interview conducted at the infant's bedside, neither was interacting with their infant before or during the interview. One was facing away from her infants' bed and the other was seated several feet away from the incubator although she was mindful of the infant's equipment alarms and concerned about his responses, frequently interrupting the interview to ask the infant if 'he was alright' or to get reassurances from the nurse.

Pumping remains a central focus, for the non – Latina mothers as well, as conceptualized in Figure 5. However, pumping was more closely linked to mothering than in the Latina mothers' descriptions. Certain mothers, however, although they had provided MoM to their other children, were not as clear of the requirements of premature infants and the importance of early and frequent pumping, except for the two mothers who had had a previous child in the NICU. Despite early lapses, they were, however, able to readjust their routines and at the time of interview all were providing EBMF to their infants.

This was not the case for the Latina mothers or for the non-Latina African American mothers. Their infrequent pumping schedules did not result in a resetting of their pumping goals and most produced less than 500 ml/day of MoM at two weeks. Instead, more were

supplementing MoM with formula by T2, which was 2 weeks following the interview or at discharge.

Figure 5: Non-Latina Mothers Impressions of BAM and Providing MoM in the NICU

Non-Latina mothers also engaged in more interventions considered to be conducive to promoting pumping, including earlier skin to skin (SSC) care, simultaneous double pumping, for example using the hands free bra and a pumping regimen closer to the recommended 8-10 times per day schedule, In contrast, only one Latina mother mentioned using a hands free bra, and only one other mother indicated that she held her infant in skin to skin care (SSC) within one day of birth. The others all noted that it was close to a week and even longer, before they held their baby in SSC. Finally, many of the Latina mothers admitted that their pumping regimens were suboptimal and that they were not following the recommended schedules with some pumping as infrequently as 1-2 times per day.

In conclusion, results indicated that Latina mothers did fit into the framework described by Hurst and colleagues that proposed that BAM was interrupted with mothers having a paradoxical experience which included negotiations about pumping and the feeling that pumping created a wedge instead of a connection between them and their infants. Cultural themes that

emerged included generational differences with Latina mothers less likely to have social support for breastfeeding and to feel more uncertain about their feeding decision and transitioning to their maternal role in the NICU. However, although values such as familismo, were acknowledged and felt to be helpful during their experience of transitioning to motherhood in the NICU, the cultural value of fatalism expressed by some Latina mothers may have led to an increased sense of decisional uncertainty. This decisional uncertainty about their infant feeding decision may have led to decreased milk supply and need for increased formula supplementation as their infant's feeds were advanced.

While both subgroups of mothers fit the framework of BAM and providing MoM in the NICU, for Latina mothers, further research is needed to examine the emerging theme of liminality in this population. This theme was exhibited by high levels of uncertainty about the maternal role, the decision about providing MoM, questions about the importance of their presence in the NICU and Further research is needed on strategies to enhance maternal empowerment, and support resilient behaviors such as persistence despite having very little MoM production.

Exploratory Quantitative Questions

Analysis of quantitative data proceeds from descriptive to bivariate to multivariate analyses. Descriptive analyses include data screening, calculation of instrument reliability coefficients for this sample, description of sample demographics, and data distributions for each variable. Bivariate and multivariate analyses are used for hypotheses testing. Bivariate analysis includes correlations between variables and identification of between group differences. Multivariate analysis includes logistic regression for preliminary suggestion of a potential predictive model. Details and results of descriptive, relational and predictive analyses are now reported.

Descriptive Data Analysis

Data Screening. Data were coded, entered into an SPSS version 22.0 database and recoded in preparation for data analysis, (Bannon, 2013). Prior to analysis of the data and upon completion of data entry, the data were assessed for accuracy. Minor corrections to the coding of the DCS items to match the user manual numbering of 0 -4 instead of 1 – 5, and the data were further reviewed for outliers. The data were screened in SPSS to identify valid and missing data. Missing data did not show any specific patterns and were less than 5% overall. One mother left the entire Psychological Acculturation Scale blank after identifying her ethnicity as Yiddish. To address missing data, a pairwise deletion procedure was used in this study (Pallant, 2011). This methodology is recommended when the sample size is small to minimize large amounts of data being excluded from analysis (Munro, 2005).

Scale Reliability. Six standardized questionnaires were used to explore selected psychosocial and cultural factors. Internal consistency and reliability of the measurement scales and subscales were calculated for this study sample (see Table 6),and most were found to be within acceptable ranges interpreted as .70 or greater for a new instrument and .80 or greater for a standardized instrument (Pallant, 2011). Only the DASS-21 anxiety subscale fell short of these recommended coefficient values. In the current study, the Cronbach alpha coefficient was .60 for the anxiety subscale of the DASS – 21. The remaining subscales of the DASS – 21 generated the satisfactory Cronbach alpha coefficients, depression (.82) and stress (.81) while the Cronbach alpha for the entire scale was .89. As this was a standardized instrument, it was not recommended to remove the items, since equivalent comparisons with other studies using the scale would not be able to be performed (Pallant, 2011). Lovibond & Lovibond's (1995) original study of a student sample yielded a Cronbach alpha coefficient of .73 for the anxiety subscale.

Miller, Pallant & Negri (2006) used the DASS – 21 in their more recent study on anxiety and stress in postpartum women, and reported a Cronbach alpha coefficient of .77. However, in a very recent study in which Rallis and colleagues (2014) looked at depression anxiety and stress throughout pregnancy, Cronbach alpha levels similar to the current study for the anxiety subscale, (.64 - .74) were obtained.

Table 6: Cronbach alpha Reliability Statistics for Study Scales

Scale	Number of Items	Cronbach alpha (α)
Psychological Acculturation Scale (PAS)	10	.96
Decisional Conflict Scale (DCS)-total	16	.93
DCS – Uncertainty Subscale	3	.92
DCS – Modifiable Factors Subscale	9	.88
DCS – Effectiveness of Decision	4	.73
Depression, Anxiety and Stress Scale (DASS-21) – Total	21	.89
DASS Stress Subscale	7	.81
DASS Anxiety Subscale	7	.60
DASS Depression Subscale	7	.82
Neonatal Unit Parental Stressor Scale (NUPS)-total	48	.96
NUPS –NICU Environment/Infant appearance Subscale	16	.94
NUPS –Maternal Role Subscale	17	.88
NUPS – Social Relationship Strains Subscale	13	.90
Preterm Infant Feeding Survey (PIFS) - total	71	.94
PIFS Social Support (unweighted) Subscale	6	.94
PIFS Self-efficacy Subscale	10	.78
Brief Cope Inventory (BCI)-total	24	.86.

Sample Description. The final participants in this exploratory descriptive quantitative cross-sectional study were 30 mothers and their premature infants from a convenience sample of mothers in the Level 4 NICU at a major academic regional perinatal medical center in New York

City. As this was an exploratory analysis, an a priori power analysis was not performed. However, a sample of 30 is considered adequate for a pilot study (Herzog, 2008). Demographic characteristics of the study sample are found in Table 7.

Maternal Characteristics. Mothers ranged in age from 20-50 with a mean age of 30.9 years (SD = 7.73). Just over thirty six percent (36.7%) were of advanced maternal age, classified as older than 35 years old.

Fifty –six percent (54.3%) self -identified as Latina and forty-seven percent (46.7%) self - identified either as White, African – America/Black and Other race (biracial) and were grouped for analysis as non-Latina. Of the mothers who self - identified as Latina or Hispanic, a large majority (65.5%) were foreign born, all of whom identified their place of birth as the Dominican Republic (DR), an island in the Caribbean whose residents are primary Spanish speakers. These mothers reported spending an average of 22.82 (SD = 10.01) years in the US and more than three fourths (79.3%) reported speaking English at home. More than one – half (56.7%) had a college or higher education and 36.7% reported a high school or lower education level.

More than three – fourths of mothers in this target pregnancy had a pregnancy complication (76.7%) that led to delivery of their premature infant. Sixty percent delivered by cesarean section (CS). Just under one- half (46.7%) of the women were first time mothers. There were just over 51 % female infants. Forty percent (40%) of mothers had more than one child (range 1-3 children). Of those who had other children, 23% had a previous NICU experience. The vast majority intended to provide MoM (93.3%). Mothers were interviewed when their infants were on average 34.5 weeks GA (range 27 – 38 weeks).

Eighty eight percent of the women were married or with a partner, compared to 12% not currently in a relationship. Fifty-three percent reported an income greater than $50,000 and

36.7% reported an income of <$25,000. More than half (56.7%) of all mothers had private insurance and 43.3% were receiving Medicaid assistance.

Infant Characteristics. Infants in this study had a mean birth weight of 1485 grams (SD ± 589.38, range 555 grams and 2805 grams) classified as very low birth weight. The majority were moderate to very premature (83.7%) indicating birth at less than 33 completed weeks GA. Only 16.2% were born late preterm which is a gestational age between $34.^{0/7}$ and$36.^{6/7}$ weeks completed gestational age. These values differ from average national NICU admission in which the majority of admissions are late preterm infants. This may be explained by the comprehensive subspecialty nature of the regional perinatal center which resulted in a high case mix index (CMI) of 4.40 in 2014. Nationally, regional perinatal centers had on average a CMI of 2.8 (NPIC, 2015).

At the time of their enrollment in the study (T1), 73.3% were still providing MoM to their infants. 53.3% percent of infants receiving MoM were having exclusive breast milk feeds (EBMF) while 20% received partial breast milk feeds (PBMF). Another 26.7% were receiving full formula feeds (FF). At time 2 (T2) of the study – only one more mother had stopped providing breast milk feeds to her infant. In total, at T2, 70% mothers continued to provide some MoM feeds for their infants.

Table 7. Demographic Characteristics of Sample Mothers and Infants (N = 30 mother; N = 36 infants)

Maternal Characteristics	**Maternal Descriptors**	
	M (SD)	**Range**
Maternal age (years)	30.9 (7.73)	20-50
Years in U.S.	22.8 (10.00)	
	n (%)	
Delivery Type		
NSVD	12 (40.0%)	
CS	18 (60.0%)	
Pregnancy Complications	23 (73.7%)	
First Time Mother	14 (46.7%)	
Ethnicity/ Race		
Latina	16 (53.3%)	
Black / African American	2 (6.7%)	
White	11 (36.7%)	
Other	1 (3.3%)	
Born outside U.S.	19 (56.7%)	
Education	11 (36.7%)	
High school or less	17 (56.7%)	
College or more		
Employed	20 (66.7%)	
Insurance		
Private	17 (56.7%)	
Medicaid	13 (43.3%)	
Income (annual)		
$25,000 or less	11 (36.7%)	
$50,000 or more	16 (56.3%)	
Continued MoM at T1& T2		
T1	22 (73.3%)	
T2	21 (70.0%)	

Table 7. Demographic Characteristics of Sample Mothers and Infants (N = 30 mother; N = 36 infants)

Infant Characteristics	**Infant Descriptors**	
	M (SD)	**Range**
Gestational Age (weeks)	30.2 (3.3)	23.5-35.0
NICU Length of Stay (days)	50.4 (20.2)	10-120
	n (%)	
Prematurity**		
Less than 34 weeks GA	31 (83.7%)	
Greater than or equal 34 weeks GA	6 (16.2%)	
Infant gender		
Female	19 (51.5%)	
Male	18 (48.5%)	

Notes: NSVD – normal spontaneous vaginal delivery; CS – cesarean section; **Prematurity - includes 4 twins (1 twin excluded b/c medical condition)

Description of Data Distribution for Research Variables

The primary outcome variable for the study was whether a mother sustained her decision to continue providing MoM for her infant in the first month of life in the NICU. Six predictor variables were examined in relation to this outcome. They were: 1) maternal mood; 2) psychological acculturation; 3) coping strategies; 4) infant feeding attitudes and behaviors; 5) decisional conflict and 6) neonatal stressors. Means and SD, medians, skewness and kurtosis are shown in Table 5. Regarding skewness values greater than 0.2 or below – 0.2 indicate severe skewness and a non- normal distribution for the particular variable (Munro, 2005). Mothers (N = 22) who continued to provide MoM to their infants were analyzed. Univariate Analysis of Predictor Variables for NICU Mothers of Premature Infants is found in Table 8.

Maternal mood. Maternal mood was examined using the DASS – 21. Mothers were asked to identify which statements applied over the past week. Mothers averaged a total DASS – 21 score of 12.74 (SD±9.39). The sample distribution was markedly positively skewed with a distinctly leptokurtic peak, indicating narrower distribution of points resulting in a higher kurtosis. This variable did vary substantially from a normal distribution.

Psychological Acculturation. The PAS measured acculturation along a 9 point Likert - type scale of Hispanic association to American association. The mean for the sample was 5.95 (SD = 2.08) indicating that this sample was bicultural in their level of acculturation, that they had incorporated values from both the culture or origin and the current culture. The sample distribution was markedly negatively skewed with a slight platykurtic peak, indicating wider distribution of points resulting in lower kurtosis. This variable did not vary substantially from a normal distribution.

Coping Strategies. The Brief Coping Index consisted of 12 subscales. The 24 items comprised two types of coping strategies: adaptive and maladaptive. Adaptive coping strategies

included active coping, emotional support, positive reframing, planning, acceptance, venting and religion with a mean score of 2.74 (SD = .60). Maladaptive coping strategies included: self - distraction, denial, substance abuse, behavioral disengagement, and self-blame, with a mean score of 1.62 (SD = .51).

Results indicated that mothers in this sample used more adaptive than maladaptive strategies to cope with their NICU experience. Mothers reported using acceptance of the situation as a means of coping along with emotional support and positive reframing of the situation. They used planning and religion the least among the adaptive coping strategies. Of those who indicated they used a maladaptive coping strategy, self – blame, followed by self – distraction and venting were most common and least common was the maladaptive coping strategy of substance abuse. The sample distribution was markedly negatively skewed with a marked platykurtic peak, indicating wider distribution of points resulting in lower kurtosis. This variable did vary substantially from a normal distribution.

Infant Feeding Attitudes and Behaviors. The Preterm Infant Feeding Survey is was comprised of 71 items in 4 subscales. Only two of the subscales, self – efficacy and social support are used in this study. Mean scores for the total scale were 3.78 (SD = .54). Mean scores for the self-efficacy subscale were 4.18 (SD = .58) and for social support were 17.34 (SD = 7.39). Results indicated that mothers felt very confident in their ability to provide MoM for their infants via the pumping process and they reported feeling supported in their decision to provide MoM for their infants by those who they deemed important to them when making their decision. The sample distribution was markedly, negatively skewed with a very leptokurtic peak, indicating narrower distribution of points resulting in higher kurtosis. This variable did vary substantially from a normal distribution.

Decisional conflict. Decisional conflict was examined using the Decisional Conflict Scale with 5 subscales. In this study, parents were asked to respond to the statement, "when I made the choice to provide my own breast milk for my baby…" Responses included: "I knew what options were available to me" and "I felt sure about what to choose." The three modifiable factors subscales, (informed, values clarity and support) were combined into one subscale, therefore 3 subscales, modifiable factors, uncertainty about decision and feeling she made an effective decision, were evaluated. The mean score for the modifiable factors was 10.18 (SD = 12.30) out of a possible 100 points indicating that mothers had no conflict due to lack of information, unclear values or insufficient social support of their decision to provide MoM.

The mean score for the uncertainty about the decision subscale was M = 5.83 (SD =12.02), and the effective decision subscale score was M = 5.21 (SD = 10.39), indicating that the overall sample had no conflict related to decision uncertainty or questions about the effectiveness of their decisions. The sample distribution was markedly, positively skewed with a distinctly leptokurtic peak, indicating narrower distribution of points resulting in higher kurtosis. This variable did vary substantially from a normal distribution.

Neonatal Stressors. The Neonatal Unit Parental Stressors scale was used to measure the effect of neonatal and parental stressors. The 48 item scale had 3 subscales and one question queried the overall NICU stress experience score. Subscales included: the NICU environment and infant appearance and treatments; maternal role alteration and relationship with infant and social and relationship strains and the final question concerning the overall NICU experience stress. Overall mothers who continued to provide MoM reported a moderate level of stress related to the overall NICU experience, the NICU environment, their infant's appearance and treatments and the perceived alteration in their maternal role. However they were less stressed by

social and relationship strains. The sample distribution was markedly, negatively skewed with a marked platykurtic peak, indicating wider distribution of points resulting in lower kurtosis. This variable did vary substantially from a normal distribution.

Table 8: Univariate Analysis Of Predictor Variables for NICU Mothers of Premature Infants

Variables	Median	Mean	SD	Skew	Kurtosis
Coping Strategies- Adaptive					
Adaptive Total	**2.86**	**2.74**	**.60**	**-.38**	**-.72**
Active Coping		3.05	1.0	-.80	-.42
Emotional Support		3.10	.82	-.54	-.62
Positive Reframing		3.08	.87	-.73	-.31
Planning		2.92	1.1	-.62	-1.07
Acceptance		3.17	.821	-.94	.42
Religion		2.90	1.05	-.50	-.89
Venting		1.75	.70	.59	-.41
Coping Strategies- Maladaptive					
Maladaptive Total	**1.53**	**1.62**	**.51**	**1.16¥**	**1.76¥**
Self-distraction		1.77	.83	.67	-1.02
Denial		1.33	.55	1.41	.49
Substance Abuse		1.13	.57	4.78	23.77
Behavioral Disengagement		1.43	.78	1.91	3.29
Self-blame		1.93	1.00	.81	-.43
DCS total		**8.12**	**10.92**	**1.69¥**	**2.39**
DCS Modifiable Factors	2.78	10.18	12.30	1.17¥	.57
DCS Uncertainty	.00	5.83	12.02	2.19¥	4.0¥
DCS Effective Decision	.00	5.21	10.39	2.50¥	6.58¥
DASS Total	**11.00**	**12.74**	**9.39**	**1.27¥**	**2.77¥**
DASS Depression	5.00	6.40	7.19	-.42¥	9.26¥
DASS Anxiety	6.00	6.87	6.00	.94¥	.39
DASS Stress	10.00	12.27	8.17	.41	-.78
NUPS- Maternal Role Stress	3.03	2.70	1.00	-1.07	-.46
NUPS- NICU Environment	2.89	2.77	1.19	-.29	-.89
NUPS- Treatments Stress		2.09	1.07	-.07	-.32
NUPS- Social relationship strains	2.14	2.09	1.07	-.09	-.35
NUPS- Overall NICU experience stress	4.00	3.45	1.38	-.72	-.60
Acculturation*	5.60	5.95	2.08	-.07	.45
PIFS Social Support	19.83	17.34	7.39	-.92	-.28
PIFS Self-efficacy	4.16	4.18	.58	-.99	2.08

Notes: (N = 30) * (N = 29); ¥- > 2 deviations of the standard error (SE)

Bivariate Data Analysis: Relationships and Between-Group Differences

Research Question number one sought to answer the question: for Latina mothers of premature infants during the first month of life in the NICU, is there a relationship between

infant feeding attitudes and behaviors, neonatal stressors, maternal moods, decisional conflict, acculturation and coping strategies. Preliminary data analyses indicated some violations of the assumptions of normality, linearity and homoscedasticity. Therefore the Spearman rho correlation coefficient, recommended for non-parametric data, was used in the analyses. The following correlations were found between the various psychosocial variables for this sample of mothers who continued to provide MoM.

Latina Mothers

Maternal Mood. There were strong positive correlations between anxiety and social and relationship strains, and the emotional states of stress and depression, indicating that higher levels of stress experienced from social and relationship strains were associated with higher levels of anxiety, stress and depression. There was a strong positive correlation between the emotional state of stress and maternal role alteration stress indicating that increased levels of emotional state of stress were associated with an increased experience of maternal role alteration stress. (See Table 9)

Psychological Acculturation. There were no correlations between acculturation and any of the psychosocial variables under study for the subgroup of Latina mothers.

Neonatal Stressors & Decisional Conflict. There was a strong negative correlation between stress due to the NICU environment, infant appearance and treatments. and decision uncertainty indicating that increased stress due to the NICU physical environment, their infant's appearance and treatments, for these mothers, was associated with decreased decision uncertainty.

Infant Feeding attitudes and behaviors. There was a strong negative correlation between social support for infant feeding decision and decisional uncertainty. More social

support for their infant feeding decision was associated with less decision uncertainty (see Table 9).

For this subgroup of Latina women, hypothesis 1a stated that, infant feeding attitudes, coping strategies, neonatal stressors, maternal negative mood, and decisional conflict will be positively related. This hypothesis was partially supported by the results. Maternal moods and parental stressors of social and relationship strain were positively related, however, decisional uncertainty and NICU environment infant appearance and treatments and social support for infant feeding decision were strongly negatively correlated.

The hypothesis that acculturation would be related to the other psychosocial variables of interest was not supported as there were no significant correlations between acculturation and any psychosocial variables.

Table 9: Predictor Variable Correlations for Latina Mothers (N = 16)

	1	2	3	4	5	6	7	8	9	10
1.Acculturation	1.00									
2. Self-Efficacy		1.00								
3. Decision Uncertainty			1.00				-.58*			-.57*
4. Stress (DASS)				1.00	.76**	.72**		.50*	.51*	
5. Depression (DASS)					1.00	.81**				
6. Anxiety (DASS)						1.00			.52*	
7. NICU Environment							1.00		.59*	
8. Maternal Role Alteration (NUPS)								1.00	.52*	
9. Social Strains/Hassles									1.00	
10. Social Support @ Breastfeeding (PIFS)										1.00

Note: * $p \leq 0.05$; ** $p \leq 0.01$

Between-Group Differences

Research Question number two sought to answer the following: for mothers of premature infants who continued MoM, and those who stopped providing MoM during the first month of life in the NICU, are there different relationships between infant feeding attitudes and behaviors,

neonatal stressors, maternal moods, decisional conflict, acculturation and coping strategies for those who maintain and those who stop providing MoM.

Differences between mothers who continued and mothers who stopped providing MoM were examined using Mann – Whitney U (See Table 10). Mann – Whitney U Tests revealed no significant differences between the groups of mothers who stopped providing MoM and mothers who continued to provide MoM with respect to infant feeding attitudes and behaviors, neonatal stressors or acculturation.

However, a significant difference in level of anxiety was found between the groups (U = 39, r = .41, p = .02), indicating a medium effect size for this variable based on Cohen's (1988) criteria. Additionally, there was a significant difference between groups on decision uncertainty (U = 55, r = .36, p=.05), demonstrating a strong effect size for this variable based on Cohen's criteria.

Table 10: Between Group differences between mothers who continued or stopped providing MoM

Variables	Median (n=22)*	Median (n=8)**	U	*p*
DCS Decision Uncertainty	.00	4.17	55.5	**.05**
DASS Anxiety	4.00	11.00	39.0	**.02**
NUPS Maternal Role stress	2.91	3.23	77.5	.06
DCS Modifiable Factors	2.78	19.44	56.5	.13
DCS Depression	4.00	7.00	59.00	.17
DASS Stress	10.00	14.00	61.5	.21
PIFS Social Support	20.45	14.5	67.5	.33
PIFS Self-Efficacy	4.20	3.85	61.5	.25
NUPS Social Strain stress	2.14	2.11	83.0	.81
NUPS NICU environment stress	2.89	2.82	85.5	.91
NUPS Overall NICU experience stress	4.00	4.00	74.5	.89
PAS Acculturation	5.60	5.93	77.0	.73
BCI Adaptive coping	3.00	2.36	60.00	.19
BCI Maladaptive coping	1.58	1.50	84.00	.85

Notes: DASS – depression, anxiety stress scale; DCS – decisional conflict scale; NUPS – neonatal unit parental stressor scale; PIFS – preterm infant feeding survey; BCI – brief cope inventory; PAS – psychological acculturation scale. * = mothers who continued MoM in first month; ** = mothers who stopped MoM in first month.

Ethnicity and Continuation of MoM. When comparing Latina and non – Latina mothers, ethnicity was not related to discontinuation of MoM (χ^2 =.00, df = 1, p = 1.00). There was no difference in frequency of discontinuing MoM as 25% of Latina women and 28.6% of non-Latina women discontinued MoM. Additionally, there were no statistically significant differences in maternal age, infant GA, birth weight or LOS in NICU for Latina and non- Latina mothers. There were no differences by ethnicity for demographic characteristics of GA, maternal age, income, education, NICU LOS or birth weight.

Mann – Whitney U tests revealed a significant difference in infant feeding attitudes and behavior subscale of breastfeeding self – efficacy between Latina mothers (Md = 4.35, n = 16) and non- Latina mothers (Md =4.05, n = 14), U = 58.0, z = - 2.25, p = .024, r = .41) indicating a medium effect size for this variable based on Cohen's (1988) criteria. There was also a statistically significant difference in the acculturation scores between Latina and non- Latina mothers (t = -6.58, p=.00, CI = -4.24, -2.22). No other significant differences were found for the variables of maternal mood, neonatal stressors, coping strategies or decisional conflict between Latina and non – Latina mothers.

Multivariate Analyses: Bivariate Logistic Regression

The third research question asked: do the psychosocial factors identified as components of BAM in NICU predict sustaining the maternal decision to provide MoM? Hypothesis three posits that: Infant feeding attitudes and behaviors, neonatal stressors, maternal moods, decisional conflict, acculturation and coping strategies will predict the decision to sustain MoM during the first month of infant viability following admission into the NICU.

Binary logistic regression was calculated to evaluate the impact of a number of psychosocial and cultural factors drawn from the theoretical framework used in the current study on the

likelihood that mothers would report that they had stopped providing MoM feeds. Factors which were significant or trending towards significance were entered into the model and variables were removed from the final model one by one, until the final model contained two independent variables, DCS decision uncertainty, which was trending towards significance and anxiety, which was significant The model containing the predictor variables was statistically significant, χ^2 (1, n = 30) = 13.74, p .001, suggesting that this model may able to distinguish between mothers who reported that they stopped and those who continued to provide MoM. However, conducting the regression with a larger sample size is strongly recommended to strengthen the predictive value of the model.

The model as a whole explained between 36.8% (Cox and Snell R square) and 53.8% (Nagelkerke R squared) of the variance in feeding status and correctly classified 80% of cases.

Decision uncertainty approached but did not reach significance at p .06. The odds ratio indicated that for every additional point higher on decision uncertainty score, mothers would be 1.14 times less likely to continue providing MoM.

Only anxiety made a unique and statistically significant contribution to the final model (see Table 11). Therefore, for this sample of women the strongest predictor of stopping MoM was anxiety. This model indicated that mothers who reported feeling anxious were over 1.3 times less likely to continue providing MoM than those who reported feeling less anxiety. Thus hypothesis three was partly supported in that maternal mood, specifically anxiety, was able to predict continuation of providing MoM, Decisional uncertainty approached significance and therefore should be addressed when developing interventions to support continuation MoM in the NICU.

Table 11: Regression Model Predicting Likelihood of MoM Continuation in mothers of Premature Infants in the first month of life

							95% CI for Exp (B)	
	B	S.E.	Wald	df	*p*	Exp(B)	Lower	Upper
Anxiety	-.286	.123	5.420	1	.020	.752	.591	.956
Decision Uncertainty	-.139	.073	3.628	1	.057	.870	.754	1.004
Constant	4.142	1.472	7.914	1	.005	62.903		

Chapter 5: Discussion

This chapter will include a summation of the findings of this study, strengths and limitations, and implications for nursing practice and concludes with suggestions for future research.

This mixed methods study was designed to examine the experience of becoming a mother (BAM) and providing mother's own milk (MoM) for mothers of premature infants in the first month of life, with particular emphasis on Latina mothers who are extremely underrepresented in parental research in the NICU. The theoretical framework as proposed by Hurst and colleagues (2013) suggested several conceptual themes including the transition to BAM as an interrupted process, involving paradoxical experiences and emotions, leading a mother to have to negotiate about the provision of MoM for her infant. Next, her perceptions of pumping her own milk using an electric breast pump may have been viewed as a connector to or a wedge between herself and her newborn infant.Additionally, the NICU environment was seen as an additional impact on her transitional experience. This framework was adapted to include the examination of cultural and psychosocial factors that may affect BAM and providing MoM in the NICU. Findings indicated that

Mothers in this study were on average around 30 years old, just under one – half were first time mothers, who had decided to provide breast milk for their preterm infants prior to giving birth. Of the mothers who identified as Latina, over one – half were foreign born, and their stay in the United States which, on average, was over two decades, may have played a factor in the non- significant findings in relationships between acculturation and the other selected psychosocial variables.

Qualitative Findings

Becoming a Mother in the NICU: A Latina Mother's Perspective

Results from the qualitative data analysis showed that Latina mothers expressed the themes of the BAM and providing MoM framework, but a mother's ethnicity showed some differences in how they reacted to becoming a mother in the. Faced with a high risk pregnancy that diverged significantly from expected normal outcomes or from previous birth experiences and may indeed, despite the pre-existence of a high risk pregnancy condition, be a totally unexpected and unknown event, may have propelled the Latina mother into a state with unclear boundaries of her role as a mother within the context f the NICU microsystem..

Additionally, most of the women in the current study delivered a premature infant who was VPT (less than 32 weeks GA) and more than one third were born at less than 28 weeks GA, or less than 7 months gestation. For many of these mothers their pregnancy was only in the second trimester, and thus little of the work on the first phase of the BAM process, preparing for the birth, including making firm decisions about feeding, may not have been done.

Decisions to breastfeed that are made early in the pregnancy or before the pregnancy are shown to result in increased initiation and duration compared with those made later in the pregnancy (National Collaborating Centre for Women's and Children's Health (NCCWCH), 2008), Moreover, providing information about breastfeeding during the antenatal period has been shown to increase breastfeeding initiation and duration, (NCCWCH, 2008). However none of this work specifically addressed mothers of preterm infants who were also ethnic minorities. In particular, all Hispanic cultures are sparsely represented in studies of prematurity and NICU settings.

Further, mothers are placed in a position of powerlessness by the initial passivity of their role at their infants' bedside. They are not free to touch, hold and interact with their infants because of their acute conditions. Indeed, although they may have wanted to interact, the cultural mores of the NICU demand they approach their infant through a "gatekeeper" – their infant's healthcare provider and nurse. Mothers expressed ambivalence about their role, their boundaries in interacting with their newborn, while others felt they had to become extra vigilant in order to overcome the inability to interact with their infant, to soothe and to address their infant's pain and or suffering.

Parental Liminality

The characterization of a liminal phase to the BAM process for Latina mothers may have resulted in lower volumes of MoM production over the first month of life. This phase has been identified by one other researcher. Gill (2010) has described a state of 'parental liminality' which includes the concepts of powerlessness and uncertainty in a group of parents of unidentified ethnicity in the United Kingdom. Although uncertainty about their infants' survival was a main focus of the study, decision making uncertainty was not addressed. Results from the exploratory quantitative analysis demonstrated that decision uncertainty was approaching significance in predicting the likelihood of continued provision of MoM in this sample.

The liminal phase is characterized by high levels of uncertainty about boundaries and roles with high levels of anxiety. This sample of Latina mothers demonstrated this phase while providing cultural nuances about the expected expression of the mother role and their sense of the conflict BAM in the NICU posed. A young mother stated *"My culture, for me – being a good mother is about being there for your kid".* This mother was unable to "be there" because of NICU environmental constraints.

This liminality overshadowed their stay and further delayed the full assumption of the maternal role. Many stated that they would feel like a mom when they were able to hold and interact with their baby whenever they wanted. It also produced some degree of fantastical thinking because mothers who had admitted to difficulties in producing MoM felt that their milk supply problems would all be resolved once the baby was home and they were able to do direct breastfeeding. As one mother stated, "pumping is OK but I wish I could just feed him at the breast."(M# 11).

Although this concept of powerlessness (Gill, 2010) is well known in the NICU parenting literature, this group sample of Latina mothers added another dimension in that they began to question whether their presence was even necessary during this phase of their infant's hospital stay. As one mother lamented, " does he even know I'm here?" Concerns and anxiety about infant survival could be influencing this belief, yet questioning the importance of their physical presence for their infant has important implications for their developing MoM supplies. A sense of usefulness and 'having faith' (Rossman, et al, 2013) that their milk was able to contribute to their infant's well – being and continued growth and development is very important to sustaining satisfactory milk volumes (Rossman, et al, 2013). Questioning the importance of their presence, a key construct of BAM may lead to lower milk volumes as anxiety and the overall NICU experience stressors are increased, the ability to and indeed possibly the desire to pump to provide the milk may be diminished, fueled the cultural value of fatalism and the acceptance that "maybe providing MoM just wasn't meant to be".

Because this study points to a liminal state in the NICU, resulting in a mother's powerlessness to assume the maternal role until environmental factors are in her control, that is once her infant has been discharged, we postulate that the mother of a preterm infant may be

likely to experience a post liminal phase and propose the addition of this phase to the BAM framework as unique to the experience of a mother of a preterm infant. Further research is suggested to determine characteristics of a post liminal period and if assumption of maternal role occurs within or beyond this post –liminal stage.

This current study is the first to suggest that among Latina mothers in a liminal phase, with high degree of decisional uncertainty about continuing MoM feeds, and given the influence of cultural values such as *fatalism*, these mothers may have a decreased likelihood of continuing MoM in the first month of neonatal life because they are waiting for the perfect setting and a sense of control. Latina mothers in this study perceive that the infant's discharge from the NICU will afford them the opportunity to resume behaviors that will achieve their goal of sustaining MoM feeds. Therefore, finding ways to enhance a sense of maternal empowerment throughout the NICU care trajectory is essential in future research agendas.

Providing Mother's Own Milk (MoM) in the NICU

Factors Affecting Pumping of MoM

Mothers reported both intrinsic and extrinsic factors that interrupted their ability to pump for the recommended intervals, leading to concerns about inadequate milk supply. Intrinsic factors included effects of pregnancy complications. More than three-fourths of these mothers self –reported a pregnancy complication. Many reported being unable to visit their infant due to the pain of their cesarean section, ongoing sequelae and treatment of pregnancy complications which delayed pumping initiation. Disrupted lactation due to derangements in biological systems as a result of recovering from pregnancy complications has been shown to impact duration of breast milk feeds (Sluebe, Horton, Chetwynd, Watkins, Grewen, & Meltzer-Brody, 2014). Careful education of these mothers prior to delivery concerning the course of their immediate

postpartum period is important to allay fears and to develop a plan which will maximize a mother's initial efforts to provide MoM.

Another intrinsic factor concerning to mothers was the discomfort of pumping. In the current study, some mothers mentioned that pumping was a painful process, and although they said it would not cause them to stop, they also admitted to pumping less than the recommended time points. Pain has previously been identified as a main reason that women discontinue lactation (Sluebe, et al, 2014).

Many mothers expressed concerns about whether they would be able to provide breast milk. Although not mentioning being fearful about the process, many feared they would not be able to supply sufficient amounts for their babies especially as their feeding volumes increased as their infants matured in the NICU. The perception of inadequate supply has been attributed as a factor for early discontinuation of lactation by mothers of premature infants (Sleube, et al, 2014).

Extrinsic factors included transportation concerns, fatigue and responsibilities for older children or other family members and the time factor to actually perform the pumping of MoM.. Interventions using health information technologies such as decision aids that address decisional conflict uncertainty, maternal moods, expectations of the NICU environment and extrinsic factors would be helpful for mothers in the pre –delivery and early post birth periods.

Information Needs of Mothers in the NICU

The stressful NICU experience compounded by expectations of staff, and unspoken competition with other mothers, possibly bolstered decisional uncertainty about the infant feeding decision. Although the desire and determination are present, for the women in this study, many were unaware of or did not fully utilize the breastfeeding resources in the NICU. Although

breastfeeding support staff, such as lactation consultants were identified as helpful in the early weeks, only two mothers mentioned being given a strategy to augment milk supply. The two mothers described it as "power pumping", increasing the frequency of pumping to every two hours over a specific period of time in order to improve her volume output.

The literature supports the use of evidence based interventions and recommends they are introduced to mothers of preterm infants immediately following birth. Suggestions include the need to pump early and often to ensure maximal volumes are obtained. This requires that mothers pump greater than 6 times a day (at least 45 times a week) and build up a volume of at least 750 ml/day within the first week of life (Geddes, Hartmann & Jones, 2013). What is also reinforced in the literature and was shown in this study, is that women continue to receive inconsistent information (Meier, et al, 2013).

All of the Latina mothers and most of the non – Latina mothers, with the exception of one, reported milk volumes no greater than 480 ml/day at T1 interviews and reviews at T2 did not evidence increased production. Specific strategies that can help some mothers maintain the volume of MoM and increase duration of breast milk feeds have been suggested by Meier and colleagues (2013). They include the early and consistent presence of a breastfeeding coach, expressly a peer counselor, a mother who had been through the NICU experience, who can assist with hands on care such as, monitoring volume and providing encouragement and support to the mother.

Providing information to these mothers immediately after birth may not be the optimal timing as their stress and anxiety levels are notably increased and their focus may not be on information that is not related to their infant's immediate survival. Several mothers mentioned that they were hospitalized for up to two months prior to the birth of their infant and considering

that the NICU trajectory begins for many of these women prior to delivery, the antenatal period appears to be a more effective time to introduce strategies for enhancing MoM production. This may also serve to engender trust which carries through to the NICU experience and may help to allay the inevitable anxiety.

NICU specific informatics have been successfully implemented across various socioeconomic groups and in various regions in the United States (Safran, 2003). Mothers in this current study stated that they used online resources to augment information provided to them by health care providers. However, many sources provided conflicting information according to this sample of mothers. Providing a trusted and reputable means to access information, adjusting the information across the different phases in the NIC trajectory and incorporating matters such as cultural concerns and values would especially be helpful is assisting Latina mothers in decision making.

Supporting remote access of such information would alleviate concerns about extrinsic factors such as transportation, other household responsibilities and maternal fatigue, allowing the mother to have access and reinforcing information needs regarding infant feeding. Indeed, it would also provide a means boost parental empowerment which Latina mothers did not evidence in this study, yet was present in the psyche of non – Latina mothers which may also assist in sustaining production of MoM both during the critical periods in the first month and beyond.

Quantitative Findings

Descriptive analysis of this mothers indicated that this sample was a multiethnic group with a majority of foreign born Latina mothers who had spent on average over two decades in the United States. Most mothers were employed, had private insurance and incomes greater than

$50,000 and educated at the college level or beyond. For most, this was their first premature birth and NICU experience.

Findings from the bivariate analysis of selected psychosocial and cultural factors revealed that for this sample of mothers, increased perceived social support stress and an increased sense of maternal role alteration were associated with increased negative maternal moods, i.e., stress, anxiety and depression. The present research findings are supported those of Leahy-Warren and colleagues (2011), who found that lower levels of perceived support were related to negative maternal mood such as depression in first time mothers of full term infants who were primarily Caucasian living in Ireland. It is likely that mothers of high risk infants may have as great or even greater challenge in dealing with low levels of social support especially in the acute/unstable phase of the NICU trajectory which characterizes the first month of life in the NICU.

Negative maternal moods have been associated with decreased initiation and duration of breastfeeding. (Welch, Halperin, Austin, Start, Hofer Hane & Myers, 2015). Use of maladaptive coping strategies was also related to increased negative maternal moods, especially stress and anxiety. Maternal anxiety in the NICU has been a consistent finding in the literature (Welch, et al, 2015). Welch and colleagues studies mothers at 4 months after birth, and demonstrated that anxiety may be attenuated by early maternal – infant interaction in the form of consistent skin to skin care in a population that had most her other than Hispanic mothers (75%). However, this study is encouraging because it did include a sample of 25% Hispanic mothers and it was conducted in the target NICU. The infants, however were on average moderately preterm and not VLBW. Maternal concerns about a younger, less mature preterm infant may be a factor that must be taken into consideration when determining ways to address maternal mood states during this

first month period, however the exhortation to start early to develop a consistent program of mother – infant interaction is one that is supported by our sample of mothers. Almost all described their feelings on not being able to interact with their infant specifically through touching and being able to see their infant.

Bivariate analysis also demonstrated an inverse association between a mother's sense that she could provide MoM successfully and her decisional uncertainty about her choice to provide MoM.. Study findings showed that there was a significant between group difference in self – efficacy with Latina mothers exhibiting higher levels of self –efficacy. A very recent study of Dominican mothers of full term infants supports this finding in Dominican women. Glassman and colleagues found that self – efficacy was the only factor that predicted increased breastfeeding duration and exclusivity at four to six week follow up (Glassman, McKearney, Saslaw & Sirota, 2014). The current research suggests that for mothers of premature infants this is also a modifiable factor in sustaining MoM throughout the infant's NICU stay.

One unexpected finding was that a similar inverse association was noted between decision uncertainty and the reported stress as a result of physical NICU environment and equipment, and the infant's appearance and treatment. Surprisingly, experiencing higher levels of total NICU experience stress was associated with lower stress due to the actual NICU environment including equipment, and infant's appearance and treatments. This suggests that mothers faced with decreased milk supplies became increasingly uncertain about the decision to provide MoM and their ability to maintain their supply. Mothers faced with an increased demand for milk, the inevitable comparison with other mothers whose supply was not perceived to be affected may have obscured for a time, the stress of the physical NICU environment and even their infant's appearance. Latina and non – Latin mothers alike focused on the activity of

pumping to the exclusion of the potential relational benefits of providing MoM, as shown in both word clouds in the qualitative analysis. The need to produce the commodity of breast milk overshadowed the necessary work of maternal - infant attachment. Finally, as coping strategies were not effectively utilized, the mothers in this current study remained in a highly anxious and stressed state, as shown by the association of increased anxiety and stress with increased use of maladaptive coping strategies.

Despite facing daunting challenges which began prior to and continued after the birth of their infant, close to three–fourths of the mothers in the study continued to provide MoM through the first month of their infant's stay in the NICU. Consistent with previous studies, most of these mothers were older, had higher educational levels, were employed, and made the decision to provide MoM during their pregnancy. The mothers who stopped providing MoM were younger, less educated and undecided on type of feeding method prior to and early in the NICU stay and expressed ambivalence about their feeding decisions.

Strengths of the Study

A mixed methods study was the appropriate design to explore the experiences of mothers whose voices have rarely been heard and to simultaneously objectively gather exploratory data to inform future research. Together these interpretive and quantified approaches can inform each other on a topic about which little is known and can suggest tailored and testable interventions for this group of women.

A second strength of the study was in the use of the theory of BAM to explore if Latina mothers fit the framework of providing MoM in the NICU and their experience of BAM. It was found that a Latina subgroup of Dominican mothers did fit the framework and that themes

identified as germane to Latina mothers can be used to guide development of further studies to test culturally relevant interventions.

A third strength of this study was the use of instruments that were developed specifically for parents in the NICU setting, such as the Neonatal Parental Stressors Scale, that was used to address concepts related to facets of the maternal role and the NICU environment. Additionally, the Preterm Infant Feeding Study, which was developed specifically to address issues of feeding specifically related to premature infants, allowed exploration of concepts of social support and self–efficacy specifically about the ability to pump breast milk for their infants.

Both of these instruments allowed for the juxtaposition of findings

from the quantitative study to be linked to the theoretical framework developed using the theory of BAM and providing breast milk feeds which was explored from the maternal perspective in the qualitative section of the study. Further, the use of an instrument that examined not only depression but also anxiety and stress, provided a statistically significant relationship that has important clinical significance in the care of mothers during the early stages of the NICU trajectory of care. In addition this is the first study to examine decisional conflict in this group of mothers and it also highlighted a key factor – decisional uncertainty - which may decrease duration of breast milk feeds and which is potentially modifiable.

Finally, a major strength of the study was providing the voice of Dominican mothers of premature infants, a Latina subgroup which has not been frequently studied. Cultural mores and values echoed throughout their experiences as they were having to form a maternal identity that transcended negative familial voices and generational differences about their choice to provide MoM to their infants. The study also included mothers with infants in all preterm gestational age

categories from very preterm to late preterm, allowing for a broader picture to be formed of the concerns and influencers in this population of women.

Limitations of the Study

This study was conducted in a single hospital unit, with high acuity patients and conditions that may be less likely to be found in lower level units. Its high case mix may make it unlike other area regional center NICUs thus limiting the generalizability to other NICUs with different patient populations. Additionally, only mothers born in the Dominican Republic were included, therefore results can't be generalized to other Latina mothers for example others of premature infants from Central or South America or Puerto Rico. Furthermore, this study used a convenience sample, while understandable given the vulnerable population and timing of the study, during what for many mothers was the acute phase of the NICU experience, this situation may account for the inability to engage parents in the study thus justifying the use of a convenience sample and a reduced sample size (De Rouck & Leys, 2009).

Recruitment was challenged by Latina mother's comfort level in completing the questionnaires, despite offers to assist in the completion by the researchers. Latina mothers who did not speak English well would initially agree to participate in the study, but when approached for consent would decline to participate. Translation of the NUPS and PIFS into Spanish will allow the instruments to be offered in both languages which might allay some maternal concerns, Additionally, there was a loss of potential subjects, especially late preterm infants (greater than 34 weeks completed gestational age) due to short stays in the NICU. It is recommended that this group be approached earlier in the NICU stay.

Moreover, all of the study instruments relied on maternal self- report of their perceptions about psychosocial and cultural concepts. Interestingly, one mother did not complete the

psychological acculturation scale. She was non – Latina and though they were asked to insert their cultural background if they chose, she preferred to not respond to the acculturation questions for reasons which can only be speculated. There were clear impressions on this and one other instrument, the maternal mood measure (DASS -21), shown by markings next to certain responses that imply she was considering writing a response. Her background as part of an orthodox religious sect, however, may have influenced her desire to respond with answers that may have compromised cultural role representations. Fear of exposure to social criticism may have also been a factor for some mothers who left other random items blank, such as the one just described, although mothers were assured of their confidentiality before and during the data collection. These concerns and possible reactions should be anticipated and planned for in future studies.

Another limitation of this study is that two of the most preterm specific instruments were only available in English, thus we were unable to include Spanish speaking mothers in our sample. These mothers may be less acculturated and experience more distress due to the inability to communicate effectively with the health care providers. Although in this sample of women, most indicated that English was the language spoken in the home, many of the Latina mothers had definite, sometimes strong accents which may have made them reluctant to interact with providers.

Language had long been used as a marker of the degree of acculturation in healthcare studies (Tropp, et al, 1999) and superficial perceptions of health care providers may prevent them from participating in the type of information sharing about infant caregiving topics in a way that mothers have been shown to find helpful, such as chatting (Fenwick, 2001). Gathering specific demographic information such as language spoken in the home may be a way to begin

the development of the trust relationship between health providers and mothers. Bilingual conversational skills in researchers would be a distinct asset. Although this investigator is bilingual, we were limited in our ability to use two of the most crucial instruments because, according to their creators, neither the Preterm Infant Feeding Survey nor the Neonatal Unit Parental Stressors Scale has ever been translated into Spanish. Therefore, the translation and psychometric evaluation of the Preterm Infant Feeding Survey and the Neonatal Unit Parental Stressors Scale into Spanish in order to include Spanish speaking mothers is an area for immediate study being undertaken by this investigator.

Additionally, to reduce the burden of completing the questionnaires, it's recommended that for the Preterm Infant Feeding Survey, the instrument with the highest item count, the scale be reduced to the specific subscales under study, which were the self – efficacy about providing breast milk and the social support of infant feeding decision, thereby reducing the item count from 71 items to 22 items. No other changes to the other scales are recommended. Once the NUPS and PIFS are translated and validated, it will be very beneficial to repeat the study with Spanish speaking mothers.

Because of the use of mixed methods we were able to determine that mothers' experiences of transitioning to BAM in the NICU are indeed interrupted and are highly impacted by feelings of decisional conflict, especially uncertainty about infant feeding option and the negative maternal mood of anxiety. It is unknown if the type of pregnancy complications impacted maternal mood and decision making. A longitudinal study following women through the NICU trajectory from pre–delivery through initial crisis admission phase and then into the stable and convalescent period and before and after discharge phases, may provide information on whether anxiety and uncertainty are diminished and determine if factors such as information

in the form of a decision aid prior to delivery and or early in the post delivery period will ameliorate the impact of stress and anxiety on the transition to BAM and the infant feeding decision.

Implications for Clinical Practice

This study has demonstrated that most mothers in this sample who intend to provide MoM do so throughout the first month of life, but at less than the recommended volumes of greater than 750 ml/day by the second week, to support their infant's growing nutritional needs. As inadequate volumes were a problem for most mothers in this study, with all but one mother producing less than 500 ml/day of breast milk after at least two weeks in the NICU, strategies to increase frequency and volume during the critical periods, with weeks one and two, and around 1 month of lactation are needed.

Monitoring the timing of the first pumping session is another recommendation to be incorporated into clinical practice and should be included in the development of individualized guidelines to support provision of MoM. Guidelines, which address the understanding that cultural beliefs and values may subconsciously impact milk supply and duration, should include the use of peer counselors who may be able to relate culturally relevant factors impacting expression of MoM. Incorporating these steps into clinical practice, may support Latina mothers in the critical periods of early establishment of their breast milk supply.

Furthermore, providing information about the process of BAM may alleviate the sense of powerlessness, thus empowering women to connect with their infants as soon as possible after birth. Measures to reduce anxiety and stress around expressing MoM, such as use of relaxation techniques and music therapy for mothers and techniques to answer these mother' pleas for increased interaction, that is, to see and touch her infant, such as progressive touch and infant

massage may further empower mothers. Nursing staff in the NICU are encouraged to look for ways to assist in making breast milk provision a relational than solely a functional activity. Reconfiguring the environment to allow for more privacy, such as the move to single bedded rooms may address this need.

Recommendations for future research

Information from this study may be used to inform a larger longitudinal study examining the process of BAM and providing MoM throughout the NICU trajectory, which includes the pre – delivery through transition to home periods. In addition, the development and testing of interventions that address decision uncertainty, emotional mood states of the mother including anxiety and stress, and interventions that provide education and social support to women with prolonged hospital stays prior to the birth of this premature infants are areas of focus for future research.

Identification of culturally relevant informational sources and examining the quality of the information that they provide is another area that needs further study, as many of the women in these studies sought out and expressed willingness to take untested and unproven advice about adjuncts to improve their milk supply without thought about consequences to themselves or their infants.

Investigating the development of a resource for mothers accustomed to using online resources is a further area of exploration. Mothers in this study across all age ranges reported using online sources to gather information about the premature infant and to trouble shoot problems about providing MoM. Examination of whether a personal tracking of breast milk production that allows download of data directly to a qualified breastfeeding resource person daily or at critical periods such at 1, 7, 14 and 28 days may allow for earlier intervention if

problems arise. Additional research with multiple sites and a larger sample would allow for enhanced understanding of the process of BAM and continuation of MoM for mothers of premature infants.

Conclusion

Mothers of premature infants fit into the framework of BAM as proposed by Hurst and colleagues. This study adds to the framework description how the interruption of BAM extends into a liminal period as participating Latina mothers described feeling less prepared for the experience of parenting in the NICU and unsure of their role in infant's care This is also the first study of Dominican mothers in the situation of deciding to provide MoM to a premature infant in the NICU. Of note, it would be intriguing to further investigate if a post liminal phase should be added to the BAM to encompass the experiences of mothers of premature infants.

Mothers admitted to more challenges negotiating the pumping process into their lives and as a result were more likely to produce less than the recommended volumes of MoM needed to sustain their infant's needs as feeding volumes advanced. They identified the paradoxical experience of desiring to be connected specifically to see and touch their infant yet were unable to achieve this because of the additive effects of their infant's condition, the NICU environment and staff constraints. Concerns of survivability initially and uncertainty about their infant feeding decision in the first month made it more likely for mothers to discontinue providing MoM to their infants as the NICU stay progressed.

Pumping was not seen as a connector to their infant but was viewed as a functional process that provided a product for their infant and became a central focus of activity in the early experience in the NICU. The exploratory descriptive quantitative results provided corroboration that the higher a mother's decisional conflict and uncertainty about her infant feeding decision,

compounded by high levels of anxiety were the strongest predictors that she was less likely to continue to provide MoM for her neonate in the first month of life.

This study contributes to the literature gap by providing the voices of a subgroup of Latina mothers who have been under represented in the literature on parenting in the NICU. Latina mothers do experience the interrupted BAM experience in the NICU, but cultural nuances such as cultural beliefs and values may color maternal perceptions of their power, presence and ability to provide sufficient amounts of MoM. These mothers also described a potential additional phase for theoretical framework enhancement, that of the parental liminal phase and the possibility that on discharge there is a post-liminal phase. This added evidence that the BAM experience and decision to provide MoM are linked and impacted by a state of suspended role acquisition, bounded by anxiety and uncertainty warrants further research. This study has added to the evidence that factors such as neonatal stressors, negative maternal moods, and decisional uncertainty are potentially modifiable interventions. This knowledge may allow for the development of culturally appropriate and time specific interventions to support mothers as they navigate the incredibly challenging NICU trajectory with their newborns and families.

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Appendix A

QUALITATIVE
Semi- Structured Interview Guide

APPENDIX A: Semi – Structured Interview Guide

Introduction for mothers who are still pumping vs. those who have stopped pumping

Hello, I am Joy Henderson, a doctoral student from the Columbia University School of Nursing, and a co-investigator on this project. Thank you for agreeing to meet with me to complete a few questionnaires, and talk about your experience of becoming a mother in the NICU and with pumping breast milk. We know that pumping can be difficult but you are doing a really good job. Your breast milk is the best thing for your baby and it's wonderful that you can continue to provide that for him/her. We want to support mothers as best we can through pumping, but we don't always know what the specific problems they face. It's going to be very helpful to have your input. We know that having a baby in the NICU can be emotionally difficult, so if there are any questions you would rather not answer, please just tell me.

Introduction for mothers who have stopped pumping

Hello, I am Joy Henderson, a doctoral student from the Columbia University School of Nursing, and a co-investigator on this project. Thank you for agreeing to meet with me to complete a few questionnaires, and talk about your experience of becoming a mother in the NICU and with pumping breast milk. We know that pumping can be difficult but it's wonderful that you were able to provide some breast milk and help get your baby off to the right start. We want to support mothers as best we can through pumping, but we don't always know what the specific problems they face. It's going to be very helpful to have your input. We know that having a baby in the NICU can be emotionally difficult, so if there are any questions you would rather not answer, please just tell me.

Interview Questions:

1. Tell me about your pregnancy and your feelings about delivering a preterm infant

Probe questions may include: A) Can you describe the first time you saw your baby in the NICU? B) What concerned you the most about your baby at the time? How about today? C) I'd like to know your usual routine when you come to see your baby. D)Tell me about what it's like to hold your baby. E)What do you do to feel connected to your baby?

Moving forward in your baby's NICU stay, I'd like to know about your everyday experience of pumping your milk.

2. Share with me what you remember about your first few days of pumping and what kind of support you received to get started.

Probe questions may include: A) Tell me a little bit of what you knew about breastfeeding before your baby was born? B) Please share any cultural beliefs that you have or know about breastfeeding your baby. C) How did you think your baby would be fed in the NICU? D) How did you get a pump and was there a delay in getting one, once you went home? E) Please describe your daily pumping routine. F) How do/did you feel about your body's ability to make milk for your baby? G) Have you run into any issues that have led to your baby getting formula when you thought you had breast milk available? How did that make your feel? H) Who provides you with support/ discouragement to provide breast milk or pumping?

3. <u>For those still pumping</u>: was there a time you considered stopping pumping?

Probe questions may include: A) Please describe why you felt that way. B) What services or staff in the NICU have helped you keep your decision to pump.

4. <u>For those who did stop pumping</u>- Please describe the reasons why you decided to stop pumping?

Probe questions may include: A) What kind of support would you have needed to keep going at that point? B) What things have the hospital staff done that was helpful, or more difficult for you to pump your milk?

5. How would you describe the process of becoming a mother in the NICU?

Probe questions may include: A) What would you say are the characteristics of a " good mother"? B) Could you tell me about things that are going on in your life that make it hard for you to spend as much time as you'd like with your baby? C) Have there been any other things going on that you would say are hassles or major events in your life that have added to your stress at this time? D) Sometimes these things are hard to share so I will understand if you don't want to talk about them. E) Would you tell me about the relationship you have with your baby's nurses?

6. What are your feelings about becoming a mother in the NICU and breast feeding and breast milk pumping today?
Probe questions may include: A) What would you recommend to a mother whose baby has recently been admitted to the NICU about the experience of becoming a mother in the NICU and providing breast milk.

7. Is there anything else you would like to tell me about your experience of becoming a mother in the NICU and providing breast milk?

APPENDIX B

The Experience of NICU Mothers Providing Breast Milk for their Babies

Study Questionnaires Booklet

The Experience of NICU Mothers Providing Breast Milk for their Babies Study Questionnaires

Mother/ Infant Demographics

Please complete the following information, thank you.

1. How many weeks early was your baby (babies) born?) ____ weeks
2. Did you know your baby was going to be admitted to the NICU before birth?
    a. □ Yes □ No
2. Did you have a c-section? □ Yes □ No
3. Did you have any pregnancy complications? □ Yes □ No. Describe_____
    a. □ Complications after the pregnancy? □ Yes □ No. Describe_____
4. How old is your baby now? _____ weeks
5. Did you intend to breastfeed your baby before you knew he/she would stay in the NICU?
    □ Yes □ No
6. Did your plans change once your baby came to the NICU? □ Yes □ No
7. Do you have other children? □ Yes □ No
    a. □ If yes, how many children? _____
    b. □ If yes, were any of them in the NICU? □ Yes □ No
    c. □ If yes, did you breastfeed before? □ Yes □ No
        i. For how long did you breastfeed? _____ weeks/months/years.
8. What is your date of birth:_____ How old you are? ____
9. What race/ethnicity do you consider yourself? (Please check your answer)
    a. □ Hispanic
    b. □ African American or black
    c. □ Native American or Alaska native
    d. □ Asian
    e. □ White
    f. □ Other
10. Were you born in the United States? □ Yes □ No
    a. □ If No: Where were you born?_____
11. How long have you lived in the United States? _____ months/ years
12. Do you speak English at home? □ Yes □ No
    a. (If No:) What language do you speak at home?_____
13. What is the level of school you completed? (Please check your answer)
    a. □ Some high school
    b. □ Graduated high school
    c. □ Associate's degree
    d. □ Bachelor's degree
    e. □ Graduate degree
14. What is your occupation?_____ O None
15. What type of insurance do you have? (Please check your answer)
    a. □ Private
    b. □ Medicaid
    c. □ I don't have insurance
16. What is your household income? (Please check your answer)
    a. □ <$25,000
    b. □ $25,000-$49,999
    c. □ $50,000 - $74,999
    d. □ >$75,000
17. Do you live with your □ husband □ partner
18. Zip Code:_____

19. Contact Information (circled preferred):
Cell phone:_____

email:_____

Home phone:_____

Infant Data – Office Use Only

20. Gestational age : 24-28[] 29-33[] 34-36[]

21. Gender: Male[] Female[]

22. Birth weight : [] <1,000gms []1,001 – 1,499gms [] > 1,500 gms

23. Admitting diagnosis:_____

24. LOS:_____

25. Morbidities: [] IVH [] RDS []NEC []Sepsis (early[] late[])

26. Feeding patterns:

27. T1: EBMF[] PBMF [] FF[]

28. T2: EBMF[] PBMF [] FF[]

[Legend: EBMF – exclusive breast milk feeds; PBMF – partial breast milk feeds; FF- full formula feeds]

PAS

Please circle the number closest to the answers in the chart below to indicate which culture you most relate to.

1	2	3	4	5	6	7	8	9
Only Latino/Hispanic culture (Insert your birth culture)**	.....	.....	___	*Both Latino* & American cultures equally*	.....	.....	___	*Only American culture*

1. With which group(s) of people do you feel you share most of your beliefs and values?
   1 2 3 4 5 6 7 8 9

2. With which group(s) of people do you feel you have the most in common?
   1 2 3 4 5 6 7 8 9

3. With which group(s) of people do you feel the most comfortable?
   1 2 3 4 5 6 7 8 9

4. In your opinion, which group(s) of people best understands your ideas (your way of thinking)?
   1 2 3 4 5 6 7 8 9

5. Which culture(s) do you feel proud to be a part of?
   1 2 3 4 5 6 7 8 9

6. In which culture(s) do you know how things are done and feel that you can do them easily?
   1 2 3 4 5 6 7 8 9

7. In which culture(s) do you feel confident that you know how to act?
   1 2 3 4 5 6 7 8 9

8. With which group(s) of people do you feel you share most of your beliefs and values?
   1 2 3 4 5 6 7 8 9

9. In which culture(s) do you know what is expected of a person in various situations?
   1 2 3 4 5 6 7 8 9

10. Which culture(s) do you know the most about the history, traditions, and customs, and so forth?

    1 2 3 4 5 6 7 8 9

DCS

Please choose the statement that best describes your response to the following sentence:

"When I made the choice to provide my own breast milk for my baby…"

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
1. I knew which options were available to me	☐	☐	☐	☐	☐
2. I knew the benefits of each option	☐	☐	☐	☐	☐
3. I knew the risk and side effects of each option	☐	☐	☐	☐	☐
4. I was clear about which benefits mattered most to me	☐	☐	☐	☐	☐
5. I was clear about which risks and side effects mattered most to me	☐	☐	☐	☐	☐
6. I was clear about which benefits or risks were more important to me	☐	☐	☐	☐	☐
7. I had enough support from others to make the choice to breastfeed	☐	☐	☐	☐	☐
8. I chose without pressure from others	☐	☐	☐	☐	☐
9. I had enough advice to make a choice	☐	☐	☐	☐	☐
10. I am clear about the best choice for me	☐	☐	☐	☐	☐
11. I felt sure about what to choose	☐	☐	☐	☐	☐
12. This decision was easy for me to make	☐	☐	☐	☐	☐
13. I feel I made an informed choice	☐	☐	☐	☐	☐
14. My decision shows what is important to me	☐	☐	☐	☐	☐

15. I expect to stick with my decision	☐	☐	☐	☐	☐
16. I am satisfied with my decision	☐	☐	☐	☐	☐

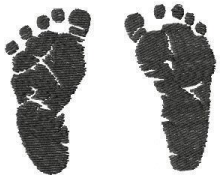
DASS-21 **Please read each statement and check the number which indicates how much the statement applied to you <u>over the past week.</u>**				
	0=Never	**1 = Sometimes**	**2 = Often**	**3 = Almost Always**
1. I found it hard to wind down	☐	☐	☐	☐
2. I was aware of dryness of my mouth	☐	☐	☐	☐
3. I couldn't seem to experience any positive feelings at all	☐	☐	☐	☐
4. I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)	☐	☐	☐	☐
5. I found it difficult to work up the initiative to do things	☐	☐	☐	☐
6. I tended to over-react to situations	☐	☐	☐	☐
7. I experienced trembling (e, in the hands)	☐	☐	☐	☐
8. I felt that I was using a lot of nervous energy	☐	☐	☐	☐
9. I was worried about situations in which I might panic and make a fool of myself	☐	☐	☐	☐
10. I felt that I had nothing to look forward to	☐	☐	☐	☐
11. I found myself getting agitated	☐	☐	☐	☐
12. I found it difficult to relax	☐	☐	☐	☐
13. I felt down-hearted and blue	☐	☐	☐	☐
14. I was intolerant of anything that kept me from getting on with what I was doing	☐	☐	☐	☐
15. I felt I was close to panic	☐	☐	☐	☐
16. I was unable to become enthusiastic about anything	☐	☐	☐	☐
17. I felt I wasn't worth much as a person	☐	☐	☐	☐
18. I felt that I was rather touchy	☐	☐	☐	☐
19. I was aware of the action of my heart in the absence of physical exertion (e.g. send of heart racing, missing a beat)	☐	☐	☐	☐
20. I felt scared without any good reason	☐	☐	☐	☐
21. I felt life was meaningless	☐	☐	☐	☐

NUPS

SIGHTS AND SOUNDS: Circle the number that best represents your level of stress (1= not at all, 5=extremely). If you did not experience the item, circle the NA(not applicable)						
1. The presence of monitors	NA	1	2	3	4	5
2. The constant noises of monitors and equipment	NA	1	2	3	4	5
3. The sudden noise of monitor alarms	NA	1	2	3	4	5
4. the other sick babies in the room	NA	1	2	3	4	5
5. the lack of space around my baby's bed	NA	1	2	3	4	5
LOOKS, BEHAVES (Baby) and TREATMENTS: Circle the number that best represents your level of stress (1= not at all, 5=extremely). If you did not experience the item, circle the NA(not applicable)						
6. tubes and equipment on or near baby	NA	1	2	3	4	5
7. bruises, wounds on my baby	NA	1	2	3	4	5
8. unusual or abnormal breathing of baby	NA	1	2	3	4	5
9. the small size of my baby	NA	1	2	3	4	5
10. seeing needles and tubes put into my baby	NA	1	2	3	4	5
11. my baby having tubes or an IV	NA	1	2	3	4	5
12. when my baby seemed to be in pain	NA	1	2	3	4	5
13. when my baby looked sad	NA	1	2	3	4	5
14. Jerky or restless movements	NA	1	2	3	4	5
15. When my baby looks uncomfortable	NA	1	2	3	4	5
16. My baby not being able to move around properly	NA	1	2	3	4	5
17. Feeling worried about my baby's future health	NA	1	2	3	4	5
RELATIONSHIP (WITH BABY)/ ROLE (AS A PARENT): Circle the number that best represents your level of stress (1= not at all, 5=extremely). If you did not experience the item, circle the NA(not applicable)						
18. Being separated from my baby	NA	1	2	3	4	5
19. Not feeding my baby myself	NA	1	2	3	4	5
20. Not being able to care for my baby myself	NA	1	2	3	4	5
21. Not being able to hold my baby when I want	NA	1	2	3	4	5
22. Feeling helpless and unable to protect my baby from pain and painful procedures	NA	1	2	3	4	5
23. Feeling helpless about how to help my baby at this time	NA	1	2	3	4	5
24. Not being alone with my baby	NA	1	2	3	4	5
25. Feeling worried about how my family will feel about this baby	NA	1	2	3	4	5
26. Feeling worried about how my baby will grow and develop	NA	1	2	3	4	5
27. Feeling angry that my baby has been born early/sick	NA	1	2	3	4	5
28. Feeling guilty that my baby has been born early/sick	NA	1	2	3	4	5
29. Feeling jealous that the nurses are with my baby when I'm not here	NA	1	2	3	4	5
30. Not feeling like a parent yet	NA	1	2	3	4	5
31. Resenting my baby for causing upheaval in my everyday life	NA	1	2	3	4	5
32. Being afraid to be optimistic/hopeful	NA	1	2	3	4	5
33. Feeling worried about going home without my baby	NA	1	2	3	4	5
HASSLES AND SOCIAL RELATIONSHIP STRAINS: Circle the number that best represents your level of stress (1= not at all, 5=extremely). If you did not experience the item, circle the NA(not applicable)						
34. Having to be cheerful when I don't feel like it	NA	1	2	3	4	5

35. Not having enough time to do everything	NA	1	2	3	4	5
36. Feeling that no one knows how I feel	NA	1	2	3	4	5
37. Being unable to get back to normal	NA	1	2	3	4	5
38. Feeling unable to support my partner	NA	1	2	3	4	5
39. The demands of home life and coming to the NICU	NA	1	2	3	4	5
40. Not knowing what to say to family and friends	NA	1	2	3	4	5
41. Having to rely on family and friends for support	NA	1	2	3	4	5
42. Feeling worried about my baby coming home from hospital	NA	1	2	3	4	5
43. Not knowing how to help my partner	NA	1	2	3	4	5
44. Not having enough time to spend with my partner	NA	1	2	3	4	5
45. Not having enough time to myself	NA	1	2	3	4	5
46. Not having as much time as I would like to spend with my baby	NA	1	2	3	4	5
47. Feeling worried about how my other children will feel about this baby	NA	1	2	3	4	5
<u>The overall experience</u>: How stressful has the experience of having your baby in the NICU been for you?		1	2	3	4	5

You're doing great! Just a few more questions ….



PREMATURE INFANT FEEDING SURVEY

You have decided to provide your breast milk for your infant. We are interested in learning more about your thoughts about providing your milk and how you were thinking about feeding your infant before you made this decision. Please answer the following questions by circling the number that is closest to your feelings. There are 5 choices for each statement, from **1 = Strongly Disagree** to **5= Strongly Agree. PLEASE CIRCLE THE NUMBER THAT MOST CLOSELY DESCRIBES HOW YOU FEEL ABOUT EACH STATEMENT.**

	Strongly Disagree				Strongly Agree
1. Formula feeding is easy.	1	2	3	4	5
2. Breastfeeding is easy to do in public	1	2	3	4	5
3. Breastfeeding is natural.	1	2	3	4	5
4. Formula feeding helps the father to feel close to the baby.	1	2	3	4	5
5. It is hard to tell when a breastfed baby is getting enough	1	2	3	4	5
6. Formula fed babies are easily satisfied.	1	2	3	4	5
7. Breastfeeding tires the mother.	1	2	3	4	5
8. Breastfeeding is satisfying.	1	2	3	4	5
9. Breastfeeding is time consuming.	1	2	3	4	5
10. Breastfeeding makes it hard to return to work.	1	2	3	4	5
11. Expressing milk for my baby is uncomfortable.	1	2	3	4	5
12. Formula fed babies tend to get sick.	1	2	3	4	5
13. Breastfed babies are fussy.	1	2	3	4	5
14. Formula fed babies tend to be overweight.	1	2	3	4	5
15. Harder to be close to formula fed babies.	1	2	3	4	5
16. Breastfed babies tend to get sick.	1	2	3	4	5
17. Breastfeeding is easy.	1	2	3	4	5
18. Formula fed babies are fussy.	1	2	3	4	5
19. Breastfed babies tend to be overweight.	1	2	3	4	5
20. Formula fed babies may develop allergies.	1	2	3	4	5
21. Formula fed babies can get constipated.	1	2	3	4	5
22. Breastfeeding helps a mother feel close to her baby.	1	2	3	4	5
23. Breastfeeding is painful.	1	2	3	4	5
24. Breast milk is healthy.	1	2	3	4	5
25. Formula feeding allows more freedom.	1	2	3	4	5
26. Breast milk is best for the baby.	1	2	3	4	5
27. Breastfeeding is less expensive.	1	2	3	4	5
28. Formula feeding allows other people to feed the baby.	1	2	3	4	5

FOR EACH OF THE FOLLOWING INDIVIDUALS INDICATE HOW THEY FEEL ABOUT HOW YOU FEED YOUR INFANT.

	Definitely Not				Definitely
29. My baby's father thinks I should provide breastmilk.	1	2	3	4	5
30. My mother thinks I should provide breastmilk.	1	2	3	4	5

31. My closest friend thinks I should provide breastmilk.	1	2	3	4	5
32. My doctor thinks I should provide breastmilk.	1	2	3	4	5
33. My baby's doctor thinks I should provide breastmilk.	1	2	3	4	5
34. My baby's nurse thinks I should provide breastmilk.	1	2	3	4	5
PLEASE INDICATE THE DEGREE TO WHICH YOU AGREE OR DISAGREE WITH THE FOLLOWING STATEMENTS.					
	Strongly Disagree				**Strongly Agree**
35. I have the necessary skills to express my milk 8 times a day.	1	2	3	4	5
36. Bringing my milk to the NICU is easy.	1	2	3	4	5
37. I am able to fit milk expression into my schedule.	1	2	3	4	5
38. Giving my baby my milk makes me feel good.	1	2	3	4	5
39. I know I will have enough milk for my baby.	1	2	3	4	5
40. I am confident I can provide breast milk for my baby.	1	2	3	4	5
41. I am determined to breastfeed.	1	2	3	4	5
42. I won't need help to breastfeed.	1	2	3	4	5
43. I will emotionally ready to breastfeed my baby when she/he is ready.	1	2	3	4	5
44. I am comfortable breastfeeding with others present.	1	2	3	4	5
HOW MUCH DO YOU CARE ABOUT THE FOLLOWING PEOPLES OPINION ON HOW YOU SHOULD FEED YOUR BABY?					
	Don't Care				**Care A lot**
45. The baby's father	1	2	3	4	5
46. My mother	1	2	3	4	5
47. My closest female friend	1	2	3	4	5
48. My doctor	1	2	3	4	5
49. My baby's doctor	1	2	3	4	5
50. My baby's nurse	1	2	3	4	5
PLEASE INDICATE BELOW HOW IMPORTANT EACH OF THE FOLLOWING STATEMENTS IS TO YOU.					
Using a feeding method that:	**Not Important**				**Important**
51. does not cause me pain.	1	2	3	4	5
52. lets me have some freedom.	1	2	3	4	5
53. will not cause allergies.	1	2	3	4	5
54. is healthy for my baby.	1	2	3	4	5
55. lets someone else feed my baby.	1	2	3	4	5
56. is easy to do in public.	1	2	3	4	5
57. protects my baby from getting sick.	1	2	3	4	5
58. is best for my baby.	1	2	3	4	5
59. keeps my baby from getting constipated.	1	2	3	4	5
60. is easy.	1	2	3	4	5

61. keeps my baby from getting fussy.	1	2	3	4	5
62. lets me be close to my baby.	1	2	3	4	5
63. makes it easy for me to return to work.	1	2	3	4	5
64. lets other people be close to my baby.	1	2	3	4	5
65. keeps my baby from being overweight.	1	2	3	4	5
66. is less expensive.	1	2	3	4	5
67. lets me get lots of rest.	1	2	3	4	5
68. is natural.	1	2	3	4	5
69. is satisfying.	1	2	3	4	5
70. satisfies my baby.	1	2	3	4	5
71. is not time consuming.	1	2	3	4	5

Just a few more questions and you're finished…. 

Brief COPE

These items deal with ways you've been coping with the stress in your life since your baby was admitted to the NICU. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Make your answers as true FOR YOU as you can. Thank you.

	1 = I didn't do this at all	**2 = I did this a little bit**	**3 = I did this a medium amount**	**4 = I did this a lot**
1. I'm turning to work or other activities to take my mind off things.	☐	☐	☐	☐
2. I'm concentrating my efforts on doing something about the situation I'm in.	☐	☐	☐	☐
3. I'm saying to myself "this isn't real."	☐	☐	☐	☐
4. I'm using alcohol or other drugs to make myself feel better.	☐	☐	☐	☐
5. I'm getting emotional support from others.	☐	☐	☐	☐
6. I'm giving up trying to deal with it.	☐	☐	☐	☐
7. I'm taking action to try to make the situation better.	☐	☐	☐	☐
8. I'm refusing to believe that it has happened.	☐	☐	☐	☐
9. I'm saying things to let my unpleasant feelings escape.	☐	☐	☐	☐
10. I'm using alcohol or other drugs to help me get through it.	☐	☐	☐	☐
11. I'm trying tried to see it in a different light, to make it seem more positive.	☐	☐	☐	☐
12. I'm trying to come up with a strategy about what to do.	☐	☐	☐	☐
13. I'm getting comfort and understanding from someone.	☐	☐	☐	☐
14. I'm criticizing myself.	☐	☐	☐	☐
15. I'm giving up the attempt to cope.	☐	☐	☐	☐
16. I'm looking for something good in what is happening.	☐	☐	☐	☐
17. I'm doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	☐	☐	☐	☐
18. I'm accepting the reality of the fact that it has happened.	☐	☐	☐	☐
19. I'm expressing my negative feelings.	☐	☐	☐	☐
20. I'm trying to find comfort in my religion or spiritual beliefs.	☐	☐	☐	☐
21. I'm learning to live with it.	☐	☐	☐	☐
22. I'm thinking hard about what steps to take.	☐	☐	☐	☐

23. I'm blaming myself for things that happened.	☐	☐	☐	☐
24. I'm praying or meditating.	☐	☐	☐	☐

Thank you for your help with this important study!

APPENDIX C

CONSENT FORMS

Columbia University Medical Center Consent Form

ATTACHED TO PROTOCOL: IRB-AAAL9701 PRINCIPAL INVESTIGATOR: MARIANNE GARLAND (MG71)

IRB Protocol Title: Experience of NICU Mothers Providing Breast Milk for their Babies

Consent Number:	**CF-AAAR3779**
Participation Duration:	1.5 hours
Anticipated Number of Subjects:	80

CONTACT:

Marianne Garland

Title: Associate Professor

Contact Type: Principle Investigator

Telephone Number: (212) 305-0952

Joy Henderson

Contact Type: Co Investigator

Telephone Number:

Pager – 84934

Cell – (646) 408-8208 / (646) 341-1593

Telephone – (212) 305-0607

REASEARCH PURPOSE

The purpose of this study is to understand the experience that the mothers of infants in the Neonatal Intensive Care Unit have with the transition to motherhood and providing breast milk to their premature infant by pumping.

INFORMATION ON RESEARCH

This interview is part of a research study on mother's experiences with breast pumping and the transition to motherhood. Providing breast milk for a baby is beneficial but there are many challenges for a mother to do so. The purpose of the study is to better understand the mother's perspective on becoming a mother and providing breast milk for her baby in the NICU in the hope that the hospital can help remove barriers to success. The study consists of completion of

nine standardized questionnaires and an interview, to be completed over 1.5 hours, to discuss the mother's personal experience.

You are being asked to participate because you are the mother of a premature infant that is currently admitted to the Neonatal Intensive Care Unit. About eighty people are expected to be enrolled in this study, all from Columbia Presbyterian's Neonatal ICU. If you decide to be in this study, your part in the research will consist of completing nine questionnaires and you may be asked to be interviewed about your experience providing breast milk and becoming a mother in the NICU. You may also receive a telephone call about two weeks after the interview to check with you how breastfeeding is going. The completion of the interview and questionnaires should take one to one and 1/2 hours.

We are asking for you to allow us to record the interview as part of the research study. The recording will be used to make sure we understand what you say and to later be translated into a transcript of the interview. The recordings and the whole transcripts will not be shared with anyone outside of the research team. Excerpts from the transcripts may be used for educational purposes among NICU staff or in presentations. These excerpts will not have your name, a study ID number, or any other identification. In addition, any words within the content that might identify you will be removed. The recording will be stored on an encrypted computer and will be password protected. The recording will be linked with a study ID number to your name. The "code" linking the study ID number to your name will also be stored on an encrypted computer and password protected. The recordings will be deleted when the researchers have no further use for them.

RISKS

To the best of our knowledge, taking part in this study will not hurt you. Although it is not a risk, taking part in this study involves the inconvenience of give one to one and 1/2 hours of your time in order to participate in an interview and complete nine questionnaires.

There is a small risk that taking part in this study will result in the loss of confidentiality. Loss of confidentiality includes having your personal information shared with someone who is not on the study team and was not supposed to see or know about your information. The study team plans to protect your confidentiality and the details for this is described in the "confidentiality" section of this form. However, there is always a possibility that others may gain access to the information without the study team's permission.

BENEFITS

The are no direct benefits expected. However, if we find out something during the interview that we can help you with, we will try to do so. The information from the interviews and questionnaires will help the NICU provide better care for future infants and mothers. The interviews and questionnaires will identify some of the barriers that NICU mothers face. This information will be used to try and minimize those barriers so that future mothers will have an easier time with becoming a mother in the NICU and providing breast milk for their infants.

CONFIDENTIALITY

Any information collected during this study that can identify you by name will be kept confidential. We will do everything we can to keep your data secure, however, complete confidentiality cannot be promised. Despite all of our efforts, unanticipated problems, such as a stolen computer may occur, although it is highly unlikely. All computers and data storage devices that hold your data are encrypted and have strong password protection. The recording of your interview and questionnaires will be assigned a code number, and separated from your name or any other information that could identify you. The research file that links your name to the code number will be kept on an encrypted computer. The following individuals and/or agencies will be able to look at and copy your research records: the study investigator, the study staff and authorities from Columbia University and New York Presbyterian Hospital, including the Institutional Review Board ("IRB") and the Office of Human Research Protection

Additional Information

If you have any questions or are hurt while taking part in this research study, you should contact Dr. Marianne Garland. She can be reached by email at mg71@columbia.edu, by phone at 212-305-0952 or by pager at 84934.

If you have any questions about your rights as a research subject, you should contact the Columbia University Institutional Review Board by phone at (212) 305-5883 or by email at irboffice@columbia.edu. More information about taking part in a research study can be found on the Columbia University IRB website at: http://www.cumc.columbia.edu/dept/irb.

Voluntary Participation

Taking part in this study is your choice. You can decide not to take part in or stop being in the study at any time. Your choice will not affect the treatment you or your baby receives from doctors and staff at Columbia University Medical Center and New York Presbyterian Hospital.

I have read this consent form which explains the purpose of this study. I have had the chance to ask questions and I will receive a signed and dated copy of this consent form. I voluntarily agree to take part in this research study.

Please read and initial on the line next to the following statements:

"I agree to be interviewed about my NICU experience" _____

"I agree to complete questionnaires relating to my NICU experience"_____

"I agree to a follow-up phone call in two weeks" _____

SIGNATURE

Study Coordinator
Print Name_____Signature_____Date ---

Study Subject
Print Name_____Signature_____Date ----

APPENDIX D

NARRATIVE DESCRIPTION OF MOTHERS PARTICIPATING IN INTERVIEWS

Latina Mothers

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1. Mother is a 43 year old Latina woman, with 2 other children, born in USA, single living with a partner, employed, with a 2 year college degree, with an annual income of $25,000 – $49,999 with private insurance. Her daughter was born at 32 $^{3/7}$weeks GA and spent one and ½ weeks in the NICU for prematurity. She was interviewed 2 weeks after her birth. Infant was feeding exclusively breast milk (EBMF) feeds at time of interview. Cognitive, affective, behavioral.

2. Mother is a 50 year old Latina woman, first time mother, born in the USA, single, employed, with a Bachelor's degree, with an annual income of >$75,000 with private insurance. Her daughter was born at 32 weeks and spent one month in the NICU for prematurity. She was interviewed 2 weeks after her birth Infant was feeding all formula feeds (FF) at time of interview.

3. Mother is a 30 year old Latina woman, a first time mother, born in Dominican Republic, living in USA for 16 years, single living with a partner, employed, with a Bachelor's degree, with an annual income of <$25,000 with Medicaid. Her daughter was born at 24 $^{3/7}$weeks and spent 19.4 weeks in the NICU for prematurity. She was interviewed 3 weeks after her birth. Infant was feeding exclusively breast milk (EBMF) feeds at time of interview.

4. Mother is a 31 year old Latina woman, first time mother, born in Dominican Republic, living in USA for 16 years, single living with partner, employed, with some HS, annual income of <$25,000 and Medicaid insurance. Her son was born at 23 $^{5/7}$ weeks GA and spent 16 weeks in the NICU for prematurity. She was interviewed 9 weeks after his birth due to infant's acute status. Infant was feeding full formula (FF) feeds at time of interview.

5. Mother is a 24 year old Latina woman, first time mother, born in Dominican Republic, living in USA for 20 years, married, unemployed, with a Bachelor's degree, annual income of $50,000 - $74,999 and Medicaid insurance. Her daughter was born at 31 $^{6/7}$ weeks GA and spent 6 weeks in the NICU for prematurity. She was interviewed 3 weeks after her birth. Infant was feeding exclusively breast milk (EBMF) feeds at time of interview.

6. Mother is a 35 year old Latina woman, first time mother, born in Dominican Republic, living in USA for 31 years, Spanish is spoken at home. She is

married, employed, with a Bachelor's degree, annual income of >$75,000 and private insurance. Her daughter was born at 28 $^{2/7}$ weeks GA and spent 8 weeks in the NICU. Infant was feeding exclusively breast milk (EBMF) feeds at time of interview.

7. Mother is a 23 year old Latina woman, first time mother, employed, with a Bachelor's degree, annual income of >$75,000 and private insurance. Her daughter was born at 31 $^{6/7}$ weeks GA and spent 4 weeks in the NICU for prematurity. She was interviewed 3 weeks after her birth. Infant was feeding exclusively breast milk (EBMF) feeds at time of interview.

8. Mother is a 28 year old Latina woman, with 3 other children, born in Dominican Republic, living in USA for 21 years, English is spoken at home. She is married, self - employed, a HS graduate, annual income of <$25,000 and Medicaid insurance. Her son was born at 30 weeks GA and spent 8 weeks in the NICU for prematurity. She was interviewed 4 weeks after his birth. Infant was feeding all formula feeds (FF) at time of interview.

9. Mother is a 20 year old Latina woman, with 1 child, born in USA. She is single with a partner, employed, a HS graduate, annual income of <$25,000 and Medicaid insurance. Her son was born at 34 $^{3/7}$ weeks GA and spent 8 weeks in the NICU for prematurity. She was interviewed 2 weeks after his birth. Infant was feeding exclusively breast milk (EBMF) feeds at time of interview.

10. Mother is a 32 year old Latina woman, first time mother, born in Dominican Republic, living in the US for 23 years. English is spoken in the home. She is single not living with a partner, graduated HS and annual income < $25,000 and Medicaid insurance. Her son was born at 26$^{6/7}$ weeks GA and was in the NICU for over 3 months for prematurity. She was interviewed 3 weeks after his birth. Infant was feeding exclusively breast milk (EBMF) feeds at time of interview.

11. Mother is a 34 year old Latina woman, with 2 other children, born in Dominican Republic, living in USA for 16 years, married, employed, with a graduate degree, with an annual income of >$75,000 and private insurance. Her son was born at 26 weeks GA and spent 11.1 weeks in the NICU for prematurity. She was interviewed 3 weeks after his birth. Infant was feeding partial breast milk (PBMF) feeds at time of interview.

12. Mother is a 38 year old Latina woman, a first time mother, born in Dominican Republic, living in USA for 26 years, married, employed, with a Bachelor's degree, annual income of >$75,000 and private insurance. Her daughter was

born at 30 weeks GA and spent 6.3 weeks in the NICU for prematurity. She was interviewed 3 weeks after her birth. Infant was feeding exclusively breast milk (EBMF) feeds at time of interview.

Non-Latina Mothers

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13. Mother is a 36 year old bi-racial woman, with 2 other children, born in the USA. She is married, employed, with a graduate degree, annual income of >$75,000 and private insurance. Her daughter was born at 31 $^{6/7}$ weeks GA and spent 6 weeks in the NICU for prematurity. She was interviewed 2 weeks after her birth. Infant was feeding exclusively breast milk (EBMF)

14. Mother is a 36 year old White woman, first time mother, born in USA, married, with a graduate degree and annual income >$75,000 and private insurance. Her daughter was born at 32 weeks GA and spent 6 weeks in the NICU for prematurity. She was interviewed 4 weeks after their birth. Infant was feeding exclusively breast milk (EBMF) feeds at time of interview.

15. Mother is a 24 year old African-American woman, first time mother, born in USA, single with a partner, a HS graduate, unemployed, annual income of <$25,000 and Medicaid insurance. Her son were born at 30 weeks GA and spent 8 weeks in the NICU for prematurity. She was interviewed 2 weeks after their birth. Infant was feeding all formula feeds (FF) at time of interview.

16. Mother is a 41 White woman with one child, born in USA, married, employed, with a Bachelor's degree, annual income of >$75,000 and private insurance. Her daughter was born at $25^{6/7}$ weeks GA and spent 10 weeks in the NICU for prematurity. She was interviewed 3 weeks after her birth. Infant was feeding exclusively breast milk (EBMF) feeds at time of interview.

17. Mother is a 23 year old White woman, first time mother, born in USA, single with a partner, with an unknown educational level and annual income; private insurance. Her twin sons were born at 31 weeks GA and spent 6 weeks in the NICU for prematurity. She was interviewed 4 weeks after their birth. Infant was feeding exclusively breast milk (EBMF) feeds at time of interview.

18. Mother is a 31 year old White woman with one child, born in USA, married, a stay at home mom, with a graduate degree, annual income of >$75,000 and private insurance. Her twin daughters were born at $28^{4/7}$ weeks GA and spent 8 weeks in the NICU for prematurity. She was interviewed 5 weeks after their

birth. Infant was feeding exclusively breast milk (EBMF) feeds at time of interview.

19. Mother is a 22 year old African American woman, first time mother, born in USA, currently unemployed, HS graduate, with an annual income of <25,000 on Medicaid. Her son was born at 34 weeks gestational age (GA), and spent 3 weeks in the NICU for prematurity. She was interviewed 3 weeks after his birth. Infant was feeding all formula feeds (FF) at time of interview.

20. Mother is a 31year old White woman, first time mother, born in USA, currently unemployed, no information on education or income provided. She has private insurance Her twin girls were born at 34 weeks gestational age (GA), and spent 3 weeks in the NICU for prematurity. She was interviewed 2 weeks after their birth. Infants were feeding partial BMF at time of interview.

APPENDIX E

COMMUNICATIONS/PERMISSIONS FOR USE OF MEASUREMENT TOOLS

Date: Thu, 1 May 2014 09:16:12 -0400 [09:16:12 AM EDT]
From: Donna Dowling <dad10@case.edu>
To: "jhh46@columbia.edu" <jhh46@columbia.edu>
Subject: Re: Permission to Use the Preterm Infant Feeding Survey
Part(s): 2 PretermInfantFeedingSurveyscoringinstructions031912Fx.docx
3 PRETERMINFANTFEEDINGSURVEY. Download All Attachments (in .zip file)

Dear Joy,
I am pleased to have you use the Preterm Infant Feeding Survey in your research. I have attached the instrument and the instructions for its use. Please let me know if you have any questions.
I ask that you share your findings with me, in particular any reliability testing you may do.
Good Luck!
Donna Dowling

On Tue, Apr 29, 2014 at 12:07 PM, <jhh46@columbia.edu> wrote:

Dear Dr Dowling,

I am a doctoral student at the Columbia University School of Nursing. My dissertation interest is parental decision making in the NICU as it impacts infant feeding decisions.

I am writing to request permission to use the Preterm Infant Feeding Survey as part of my dissertation research project. If permission is granted, I would like to request an official survey form and a user manual. I appreciate your assistance as I work towards successful completion of my doctoral studies.

Sincerely,
Joy Henderson, RNC - NIC, MSN, CPNP
PhD Candidate
Columbia University School of Nursing
212-305-0607
jhh46@columbia.edu

Date: Tue, 22 Apr 2014 13:07:13 +0100 [08:07:13 AM EDT]
From: tilly reid <tillyreid@gmail.com>
To: Joy Henderson <jhh46@columbia.edu>
Subject: Re: Permission to use NUPS in doctoral dissertation
Part(s): 2 tillys thesis.doc [application/msword] 1,383 KB

Download All Attachments (in .zip file)

Headers: Show All Headers

1 unnamed [text/html] 1.67 KB

Hi Joy,
You are very welcome to use the NUPS scale or the related parent-staff communication scale (Journal of Neonatal Nursing 2007 13, 24-35 and 64-74).
However, I have not published anything further as I now work in a different field entirely, which I was a bit sad about as I think it is a much improved scale to Miles et al. All the validation material is in my thesis which I have attached. Please feel free to use it as appropriate, I do not have any issues with intellectual property rights etc but I would be grateful for an acknowledgement if you do any further work with it. There are 5 other researchers using it internationally. Please feel free to contact me to discuss this further if you wish to. Tel 01253 726940 (land line)
best wishes, Tilly

On Wed, Apr 16, 2014 at 8:28 AM, Joy Henderson <jhh46@columbia.edu> wrote:

Dear Dr. Reid,
I am a doctoral student at Columbia University School of Nursing in New York City. My interest are family transitions and decision making in the NICU. I would like permission to use the NUPS as part of my doctoral research. If you grant permission and there is an official version of the NUPS and a user manual(scoring information), I would request that it be forwarded to this email address. I look forward to hearing from you.

Sincerely,
Joy Henderson, RNC- NIC, MSN,CPNP
Sent from my iPad