Maternal Breastfeeding Experiences and Neonatal Breastfeeding Behaviors of Children Later Diagnosed with Autism

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THESIS

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This dissertation is dedicated to the 21 families with children diagnosed with autism spectrum disorder who shared their story.

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LIST OF ABBREVIATIONS

APGAR	Appearance, Pulse, Grimace, Activity, and Respiration
ASD	Autism Spectrum Disorder
BAER	Brainstem Auditory Evoked Response
BSID	*Bayley Scales of Infant Development*
DSM	*Diagnostic and Statistical Manual of Mental Disorders*
EEG	Electroencephalography
ERP	Event-Related Potentials
GA	Gestational Age
HRV	Heart Rate Variability
NBAS	*Neonatal Behavioral Assessment Scale*
NBO	Neurobehavioral Organization
NNBO	Neonatal Neurobehavioral Organization
PMA	Post Menstrual Age

SUMMARY

The two studies presented here describe neonatal breastfeeding as a measure of neonatal processing. The first paper describes the theoretical framework which guides both studies, the Biobehavioral Conception of Neonatal Processing. The first paper also reviews the state of the science for the measurement of neonatal processing, neonatal neurobehavioral organization (NNBO). The second paper is the first study to describe breastfeeding behaviors, a measure of NNBO, of children later diagnosed with Autism Spectrum Disorder (ASD).

The first study describes the Biobehavioral Conception of Neonatal Processing theoretical framework, reviews the science of NNBO biobehavioral measures, and provides a short summary of a descriptive study using breastfeeding as an NNBO measure. The Biobehavioral Conception of Neonatal Processing uses three concepts, a neonate, the environment (maternal factors) and the neonatal mental system. Neonatal processing occurs within the neonatal mental system. The mental system may be assessed by NNBO biobehaviors, specifically breastfeeding. Breastfeeding and other NNBO biobehavioral measures of sleep/wake states, vagal tone and heart rate variability, neurophysiological measures of event-related potential of brain activity, and nutritive sucking and sucking patterns of bottle feeding literature is reviewed. NNBO biobehavioral measures have been found to be predictive of developmental outcomes. Breastfeeding, however, as an NNBO biobehavioral measure, has limited research as a predictive measure for cognitive and social outcomes. A short summary describes maternal breastfeeding experiences of mothers of children later diagnosed with ASD using the Biobehavioral Conception of Neonatal Processing as a guide. Mothers described their breastfeeding experiences and their neonate's breastfeeding behaviors. Many of the neonates' breastfeeding behaviors were described as demonstrating an atypical breastfeeding pattern, "insatiable feeding", which may reflect early alteration in processing.

The second paper applies the Biobehavioral Conception of Neonatal Processing in a retrospective study. The study describes the maternal breastfeeding experiences during the first month after delivery of mothers who breastfed children later diagnosed with ASD. Mothers were interviewed in their homes, offices, libraries, at local shopping malls and restaurants. The interview used three measures created from the three major concepts within the Biobehavioral Conception of Neonatal Processing: a maternal socio-environmental questionnaire, a semi-structured interview, and a post-interview summary.

Participants were a convenience sample of 20 mothers (13 primiparas, 7 multiparas). Maternal age range was 28-60 years of age (M = 43.3, SD = 9.6). Two mothers had more than one son diagnosed with ASD. One mother had two sons and the second mother had three sons diagnosed with ASD for a total sample of 23 breastfed neonates. All 23 children had been full term neonates (38-42 weeks gestation) with birth weight > 2500 grams, diagnosed with ASD between ages of 18 months to 11 years of age (*M* = 4.3, *SD* = 2.4) and age range at the time of the maternal interview was 5-35 years of age (*M* = 11.5, *SD* = 7.6).

Mothers described three types of breastfeeding experiences affected by the maternal environmental factor of professional support. One mother's experience overlapped between the first and second group. The first group (n=4) recalled breastfeeding success with no or limited professional support. The second group (n = 11) breastfed successfully after receiving positive professional support (one mother overlapped with group one), and the third group (n = 6) had variable success with breastfeeding after receiving unfavorable professional support. Support provided to the second and third groups was given for inexperience, anatomical barriers and neonates that demonstrated an "insatiable feeding", i.e., frequent vigorous feeding without ceasing after satiation.

The mothers of neonates later diagnosed with ASD described having similar breastfeeding experiences and challenges compared to the typically developing population. The mothers of neonates also described a triad of neonatal breastfeeding behaviors that merit future research, "insatiable feeding", a vigorous suck that did not stop with satiation, diminished social interaction, and > 70^{th} percentile for weight for many of the infants during the first year.

Taken together, these findings support using the Biobehavioral Conception of Neonatal Processing to guide future studies using NNBO biobehavioral measures. The findings also support future research to quantify the breastfeeding behavior of "insatiable feeding" for a potential screening tool for neonates at-risk for ASD.

I. Maternal Breastfeeding Experiences and Neonatal Breastfeeding Behaviors of Children Later Diagnosed with Autism Spectrum Disorder

Background

In 2011, 75% of all neonates born in the United States initiated breastfeeding during the first few days of life (U.S. Department of Health and Human Services, 2011). Factors that affect successful breastfeeding initiation and duration have been studied extensively (Baby-Friendly USA, 2010; Beilin et al., 2005; J. Britton & Britton, 2008; Collins, 2004; Gibson-Davis & Brooks-Gunn, 2006; Hill & Aldag, 2007; Hill & Johnson, 2007; Li, Fein, Chen, & Grummer-Strawn, 2008; Radzyminski, 2005; Segal, Stephenson, Dawes, & Feldman, 2007; Taveras et al., 2003; Thulier & Mercer, 2009; U.S. Department of Health and Human Services, 2011; Weddig, Baker, & Auld, 2011; Woodworth & Frank, 1996). Maternal factors associated with successful breastfeeding are maternal attributes or environmental factors that support the mother in initiating breastfeeding which include higher maternal education and yearly income, White race, Hispanic ethnicity, prenatal intention, professional support, early initiation of breastfeeding (≤ 1 hour of delivery), and rooming in (Baby-Friendly USA, 2010; Hill & Aldag, 2007; Li et al., 2008; Thulier & Mercer, 2009; U.S. Department of Health and Human Services, 2011; Wambach et al., 2005; Weddig et al., 2011). Neonatal factors that affect initiation and duration of breastfeeding have not been as extensively studied and presently successful neonatal breastfeeding is assessed by satiation after feeding and typical growth and development (American Academy of Pediatrics, 2005; Lampl & Thompson, 2007; Lampl, Veldhuis, & Johnson, 1992).

Neonatal breastfeeding behaviors have been described as a window into neonate's brain activity (Medoff-Cooper & Brooten, 1987; Piaget, 1971; Pieper, 1963; Porges, 1983; Sameroff, 1972; Selley, Ellis, Flack, & Brooks, 1990; Wolff, 1968). Neonatal processing is brain activity which transforms environmental and internal neural signals into meaningful thoughts and ideas which begins in-utero and continues throughout the lifespan (Als et al., 2004; Dalton & Bergenn, 2007; Edelman, 1987; Lewis, 2004; Posner & Peterson, 1990; Thelen & Smith, 1994). Neonatal processing is unique as the brain transitions from control by the autonomic nervous system to cortical control (Goldman-Rakic, 1987; Greenough & Volkmar, 1973; Greenough, Volkmar, & Juraska, 1973; Huttenlocher & Dabholkar, 1997; Kolb & Whishaw, 1989). Any alteration in processing from in utero development through infancy directly impacts the trajectory of typical (expected) development (Als et al., 2004; Edelman, 1987; Feldman & Eidelman, 2009; Gottlieb, 1997; Porges, 1983). This is significant because in 2005, a greater number of children ≥ 2 years of age (5.8% ages 3 to 5 and 9% ages > 5 years of age) were diagnosed in the United States with atypical social, physical, emotional, motor, and cognitive development than during infancy (2.4%) (U.S. Department of Education, 2010). Early intervention during the first year of life is more cost effective than later interventions as neurobiological research shows that early experiences and stimulation are critical for optimal brain development, suggesting considerable capacity for early intervention to support development (Black, 1998; Danaher & Goode, 2007; Greenough & Volkmar, 1973; Hebbeler et al., 2007; Kolb & Metz, 2003; McCormick et al., 2006; C. Nelson, 2000; Ramey & Ramey, 1998; Rolnick & Grunewald, 2003; Spittle, Orton, Doyle, & Boyd, 2007). Early identification of atypical behavior in the first two months of life would allow early interventions (Als et al., 2004; Gottlieb & Blair, 2004; Meisels & Shonkoff, 2000). Atypical development is present at birth but difficult to identify because of a neonate's limited behavioral repertoire (Als, 1983; Brazelton & Nugent, 1995; Kron, Ipsen, & Goddard, 1968; Sameroff, 1972). Neonatal behavior measured at one time point or in one domain has not been predictive of developmental outcomes (Banks & Bennett, 1991; DeCasper & Spence, 1991; Karmel, Gardner, & Magnano, 1991; Rochat & Senders, 1991; Sai, 2005; Slater, Earle, Morison, & Rose, 1985). However, biobehavioral measures of neonatal neurobehavioral organization (NNBO) such as sleep/wake states, heart rate variability, and bottle feeding has been found to be predictive of developmental outcomes (Freudigman & Thoman, 1993; Medoff-Cooper, Shults, & Kaplan, 2009; Mizuno & Uedo, 2005; Porges, Arnold, & Forbes, 1973)

NNBO is defined as a neonate's ability to regulate, to interact, and to respond to environmental stimulation which is the foundation of social and cognitive processing (Aitken & Trevarthen, 1997; Als & Duffy, 1989; Als et al., 2004; Feldman & Eidelman, 2009; Field & Diego, 2008; Greenough, Black, & Wallace, 1987; Huttenlocher, 1999; Lester, Hoffman, & Brazelton, 1985; Trevarthen & Aitken, 1994). Extensive research has documented the maturation of bottle feeding, one NNBO biobehavioral measure, from the emergence of rhythmic cycling of expression and suction at 32 weeks gestation to the demonstration of a mature rhythm of a 1:1:1 ratio of suck:swallow:breathe at 38 weeks gestation (Amaizu, Shulman, Schanler, & Lau, 2008; Crook, 1979; Lau, Alagugurusamy, Schanler, Smith, & Shulman, 2000; Matthew, 1991; Medoff-Cooper, Bilker, & Kaplan, 2001; Medoff-Cooper, McGrath, & Shults, 2002; Mizuno & Uedo, 2003; Sameroff, 1968; Selley et al., 1990; Wolff, 1968). Research has also documented those preterm infants who are unable to create suction while bottle feeding after several weeks had poorer motor and cognitive outcomes at a year and 18 months of age (Medoff-Cooper et al., 2009; Mizuno & Uedo, 2005). These developmental outcomes suggest that bottle feeding patterns over time may be a predictive assessment for atypical development. One research study by Tanoue & Oda (1989) explored breastfeeding and neonates later diagnosed with infantile autism (a severe form of Autism Spectrum Disorder (ASD). The study found that 24.8% (145) neonates later diagnosed with infantile autism in comparison to 7.5% (224) control neonates weaned from breastfeeding to bottle feeding within one week of age (Tanoue & Oda, 1989). The most common cause cited was “breastfeeding failed for no reason” (Tanoue & Oda, 1989, p. 428). No other research has explored breastfeeding as a predictive measure.

Statement of the Problem

Presently, there is no standardized assessment to identify typically developing neonates and infants who are later diagnosed with alterations in cognitive or social disabilities, such as ASD (Bayley, 2006; Brazelton & Nugent, 1995; Kavsek, 2004; Majnemer & Snider, 2005; Prelock, 2006). No study has examined or described neonatal breastfeeding behaviors as a screening tool for atypical behaviors in neonates later diagnosed with developmental disabilities, such as ASD.

Significance of the Study

ASD is a developmental disability which affects verbal and nonverbal communication (eye contact), reciprocal social interactions and motor movement (American Psychiatric Association, 2007; Autism Society, 2008). ASD is the earliest developmental disability to be identified by standardized assessment in children beginning as early as 14 months (American Academy of Pediatrics, 2007; Center for Disease Control and Prevention, 2010; Clifford & Dissanayake, 2008; Kleinman et al., 2008). In 2009, ASD was reported to occur in 1 of 110 (1.1%) children ages 3-17; occurring four times more often in boys, and with an increased odds of occurrence in non-Hispanic White population groups, and with a lifelong cost of caring for families between $3.5 to $5 million (Autism Society, 2008; Center of Disease Control, 2007;

Kogan et al., 2009; Parner, Schendel, & Thorsen, 2008). Retrospective research for ASD identification has found alterations in joint attention (infant and parent experience an object of attention together) and eye contact before one year of age using home video tape recordings (American Academy of Pediatrics, 2007; Auestad et al., 2003; Center of Disease Control, 2007). Research with sibling of children diagnosed with ASD has found that before one year of age, siblings later diagnosed with ASD exhibited atypical sleep, event-related audio and visual potentials, and oral feeding issues (Cortesi, Giannotti, Ivanenko, & Johnson, 2010; Elsabbagh et al., 2009; Hoehl et al., 2009; Keen, 2008; Kodak & Piazza, 2008; Tanoue & Oda, 1989). Describing breastfeeding behaviors of children later diagnosed with ASD may develop a constellation of NNBO behaviors that will identify neonates at-risk for later diagnosis with ASD.

Purpose of the Research Study

The purpose of this research study will be to describe neonatal processing by examining maternal breastfeeding experiences and neonatal breastfeeding behaviors during the first thirty days of life of children later diagnosed with ASD. The retrospective study will be guided by the Biobehavioral Conception of Neonatal Processing which theorizes that neonatal processing may be assessed by neonatal breastfeeding behaviors, a biobehavioral measure of NNBO.

Research Questions

1. The primary aim of this study is to describe maternal breastfeeding experience during the first month of life of mothers of children diagnosed with autism.
2. The secondary aim is to describe neonatal breastfeeding behaviors during the first month of life of a child diagnosed with autism.

II. BIOBEHAVIORAL CONCEPTION OF NEONATAL PROCESSING

Introduction

Early identification of atypical neonatal processing of environmental stimulation would support referral for early intervention (Black, 1998; Gottlieb & Blair, 2004; Huttenlocher, 1990; Huttenlocher & Dabholkar, 1997). Research has found that early intervention is effective for neurobehavioral and social change during the brain's period of global plasticity, the first five years of life (Bruer, 2001; Chugani, 1998; Farran, 2001; Rice & Barone, 2000). A recent National Early Intervention Longitudinal Study found that one-third of infants and preschoolers who received early intervention services because of an identified developmental delay did not need services on entry to kindergarten (Hebbeler et al., 2007). Early intervention is more cost effective than later interventions especially during the first year of life as the brain's global neuroplasticity (ability to make new neuron connections) and rapid synaptic pruning are able to alter emerging atypical behavior and ameliorate atypical behavior (Greenough & Black, 1999; Hebbeler et al., 2007; Kolb & Whishaw, 1989; Marchik, Einspieler, Garzarolli, & Prechtl, 2007; C. Nelson, 2000; Ramey & Ramey, 1998; Rolnick & Grunewald, 2003; Spittle et al., 2007). As early intervention is cost effective and supports typical developmental trajectories for a child diagnosed with atypical development like, Autism Spectrum Disorder (ASD), identification of atypical neonatal behaviors would be beneficial.

Early intervention in the neonatal period (first 30 days of life) is advantageous as the brain is rapidly growing and creating cortical connections (Blackburn, 2003; Farran, 2001; Greenough & Volkmar, 1973; Huttenlocher, 1990; Huttenlocher, 1999; C. Nelson, 2000). During the neonatal period, the brain structure and control is unique as a neonate transitions from the brain being controlled by the autonomic nervous system in the brainstem to cortical control (deRegnier, 2008; Nagy, 2011; Posner & Peterson, 1990; Robbins & Everitt, 1995). Early interventions would support a neonate's typical developmental trajectories and decrease the development of atypical behaviors (Hebbeler et al., 2007; Huttenlocher, 1999).

The ability of the brain to regulate, interact, and respond to the environment while maintaining internal stability is termed the neonate's neurobehavioral organization (NNBO) (Bell, Lucas, & White-Traut, 2007; Brazelton, 1979; Medoff-Cooper et al., 2009; Porges, 1983; Thoman, Korner, & Kraemer, 1975). A neonate's neurobehavioral organization (NBO) is dynamic and sensitive to environmental stimulation and malleable to intervention during this period of global brain plasticity (Magnusson & Cairns, 1996; Magnusson & Stattin, 2006). Several NNBO biobehavioral measures, such as sleep/wake state, heart rate variability, and feeding have been found to be predictive of later cognitive and social outcomes (Freudigman & Thoman, 1993; Medoff-Cooper et al., 2009; Mizuno & Uedo, 2005; Porges, Doussard-Roosevelt, & Maiti, 1994). The neonate's NBO regulates the foundation from which a neonate builds social and cognitive development (Magnusson & Cairns, 1996; Magnusson & Stattin, 2006).

Statement of the Problem

The focus of this paper is on the biobehavioral measures of NNBO, specifically descriptions of breastfeeding behaviors in an atypical developing population, those later diagnosed with ASD.

Purpose of the Study

To investigate the biobehavioral measures of NNBO, a theoretical framework was necessary to guide the study. However, there are few theories focused on the neonatal period (Nagy, 2011). All of the traditional childhood developmental theories, including those of Piaget, Erikson, and Kohlberg, were helpful to explain development in childhood. However, all the theories were discussed in the context of infants after the neonatal period and some after 3 months of age when the brain establishes cortical control (Bukatko & Daehler, 2004; Lamb, Bornstein, & Teti, 2002; Nagy, 2011; Piaget, 1963). Piaget identified neonatal feeding behaviors as a window into the brain, but for many years described a neonate as reflexive and passive in his or her interaction with the world (Piaget, 1963). The Synactive theory by Als (1982) does theorize about the transitional neurobehavioral maturation and development of the preterm infant, beginning at 32 weeks gestation and ending at term (38-42 weeks gestation). However, the Synactive theory is not ecologically focused, and does not discuss the transactional interactions between the infant and the environment as pivotal for the preterm or term infant's growth and development (Als, 1982). The scarcity of neonatal developmental theories is due in part to the fact that up until the 1970's a neonate was assessed either as neurological (Prechtl & Beintema, 1964; Saint-Anne Darassies, 1977) or behavioral (Graham, 1956), but not as an integration of both (Bell et al., 2007; Brazelton, 1979). As the neurological approach only assessed primitive reflexes and the behavioral approach only looked at single behavioral responses, neither of these approaches were predictive of later cognitive or behavioral standardized measures (Sameroff, 1972). When the theoretical paradigm shifted to acknowledge the neonate as an active participant in seeking out environmental experiences for growth and development (Aitken & Trevarthen, 1997; Brazelton, 1979; Lester, 1983; Lester et al., 1985; Tronick, 1989; Turkewitz & Mellon, 1989), then biobehavioral activities, or measures of NNBO, were able to be examined as processing or precognitive behaviors (Als & Duffy, 1989; Brazelton, 1979; Porges, 1983; Prechtl & O'Brien, 1982; Thoman et al., 1975).

Developmental Science Paradigm

In 1987, the Carolina Consortium on Human Development, an advanced institute for the study of development, was formed (Magnusson & Cairns, 1996). The Consortium members came from multiple disciplines spanning human, animal, and genetic studies. Together they created a perspective of developmental science. Within the developmental science paradigm there are some fundamental assumptions. Foremost is that development is the study of change over time (Magnusson & Cairns, 1996). Second, that an individual is a dynamic, open system whose changes occur nested within his or her culture, across the lifespan, and within the context of an individual time period. The individual's dynamic stability maintains an internal balance to adapt to or accommodate each new change. An individual's changes are nonlinear, unique to an individual, who self-organizes after each change using dynamic stability (Magnusson & Cairns, 1996). Third, that an individual is embedded in the environment. The environment is the world surrounding the individual, beginning with the individual's own internal environment, proximal space, and then nested within the community, local area, country, and global community. The individual is part of a complex system with the environment where all change occurs as continuous, reciprocal interactions, influencing and being influenced by each other. The individual interacts with the environment which creates internal neural signals which the individual takes in, responds to, learns from, and adapts to the environment. These responses and adaptations to the environment result in the individual's ongoing growth and development (Magnusson & Cairns, 1996).

One perspective within the developmental science model focuses on how the internal neural signals support dynamic stability. The Holistic Interactionistic Model focuses on how the individual and the mental system of the brain change over time (Magnusson & Cairns, 1996).

Magnusson and Stattin (2006) describe the mental system as the ability of an individual to take in the environment, internalize the environmental stimulation, and then respond to the stimulation. Magnusson and Stattin theorized and tested how the role of the internal biochemical and neuroendrocrine systems affect how the brain activity adapts to the environment while creating new internal stability. In a study of early and late menarche in young women, Magnusson and Stattin (2006) found that young women with early menarche onset, in comparison to later menarche onset, were sought out by, and socially interacted with, older men. The social interactions, driven by the neuroendocrine change, was the catalyst for earlier childbearing, a higher number of children, completing less years of education, and lower income compared to young women with late menarche. The neurophysiological change affected cognitive and social development and lifelong economic outcomes (Magnusson & Stattin, 2006).

Biobehavioral Conception of Neonatal Processing Theory

Using the concepts of the individual, the mental system, and the environment, the Holistic Interactionistic Model was adapted to the Biobehavioral Conception of Neonatal Processing, Figure 1. The Biobehavioral Conception of Neonatal Processing uses the concepts of a neonate, neonatal mental system, and the environment, Table 1.

A neonate. The biobehavioral domain is the integration of the biological and behavioral domains of a neonate. A neonate is defined as a human from birth to 30 days of age (Blackburn, 2003). The biological domain is a neonate's genetic make-up, general health, and gestational age. As a neonate transitions from a fetal environment in-utero to the neonatal environment at birth, atypical gestational age, health history or weight affects the biological transition of birth (American Academy of Pediatrics, 2007; Ballard et al., 1991; Touwen, 1998). Any birth transition that alters typical development will alter a neonate's ability to process the environment

(Casey, McIntire, & Leveno, 2001). The behavioral domain of a neonate is conceptualized as one-dimensional behavior, such as eye contact or hearing. Research has found one dimensional behavior is insightful as to the abilities of a neonate (Dondi, Simion, & Caltran, 1999; Goubet, Strasbaugh, & Chesney, 2007; Kron, Stein, & Goddard, 1967; Rees & Rawson, 2002; Sai, 2005; Sann & Streri, 2007; Simion, Regolin, & Bulf, 2008; Turati, Bulf, & Simion, 2008); however, a single behavior, i.e. eye movement, is not predictive of later cognitive or social developmental outcomes but biobehavioral patterns, i.e. sleep/wake cycles have been found to be predictive (Cohen, 1991; DeCasper & Spence, 1991; Freudigman & Thoman, 1993; Karmel et al., 1991; Kisilevsky, Stack, & Muir, 1991; Slater, 1997; Thoman, 2001).

The environment. The mental system is part of the complex system of a neonate and the environment. The concept of environment is defined as external regulation of a neonate by his or her mother who primarily creates and interactively participates in experiences that support growth and development (Als et al., 2004; Barnard, Bee, & Hammond, 1984; Bernstein et al., 2007; Bowlby, 1969; Bradley et al., 1989; Bradley et al., 2001; Emde, 1980; Klaus, Kennell, Plumb, & Zuehlke, 1970). A neonate actively seeks environmental experiences to promote growth and development (Feldman & Eidelman, 2009). However, a neonate has limited behavioral repertoire and mobility to communicate his or her needs; thus a neonate is dependent on his or her mother for survival (Brazelton, 1979; Feldman, 2006; Stern, 1977). The mother and neonate are a complex system (Ainsworth, 1983; Bowlby, 1969; Feldman, 2006; Field et al., 2008; Stern, 1977; Tronick, Als, & Brazelton, 1977). The mother supports and facilitates a neonate's interaction with the world including increasing or diminishing interactions with a neonate according to a neonate's NNBO biobehaviors of alertness and feeding (Bornstein, 1985; Emde, 1980; Feldman, 2007b; Field, 1977, 1981; Klaus et al., 1970; Lester et al., 1985). The maternal breastfeeding experience and the maternal factors that affect the regulation of neonatal breastfeeding behaviors are the focus of this study. Many maternal factors are pivotal to supporting the initiation of neonatal latch and breastfeeding duration (Field, 1977; Harrison, 2009; Lavelli & Poli, 1998). Maternal factors that positively affect breastfeeding initiation and duration include socio-economic variables such as White ethnicity (Caucasian and/or Hispanic), middle or upper class income, marriage, college educated, age > 25 years of age (Fein et al., 2008; U.S. Department of Health and Human Services, 2011), maternal confidence in breastfeeding (Li et al., 2008; Thulier & Mercer, 2009) and maternal professional breastfeeding support (The Center for Breastfeeding, 2002; Wambach et al., 2005; Weddig et al., 2011). One maternal variable that negatively affects the choice to initiate or sustain breastfeeding is a history of smoking (Amir & Donath, 2002; Bailey & Wright, 2011; Fein et al., 2008). A history of depression or anxiety has been found to have mixed effects on the initiation and duration of breastfeeding (Fairlie, Gillman, & Rich-Edwards, 2009; Kiernana & Pickett, 2006; Pippins, Brawarsky, Jackson, Fuentes-Afflick, & Haas, 2006), but negatively affects infant cognitive and emotional outcomes (Feldman, 2006; Feldman & Eidelman, 2007; Field et al., 2008; Pippins et al., 2006). Breastfeeding success has been found to increase with the environmental support of early initiation of breastfeeding (Baby-Friendly USA, 2010; U.S. Department of Health and Human Services, 2011). Maternal variables that may delay initiation of breastfeeding include cesarean section (Cunningham et al., 2010; Schmied, Beake, Sheehan, McCourt, & Dykes, 2011; Sparks, 2010; Weddig et al., 2011), certain medication received during labor and delivery (Beilin et al., 2005; Radzyminski, 2003), maternal breast and nipple structures (Alexander, Grant, & Campbell, 1992; Cadwell, 2007), hospital routines (Chang & Heaman, 2005; Weddig et al., 2011), and formula supplementation (Bernstein et al., 2007; Hill & Humenick, 1997).

The neonatal mental system. The neonatal mental system's ability to process environmental stimulation has been assessed by NNBO biobehavioral measures. These NNBO biobehavioral measures reflect a neonate's ability to regulate and respond to the environment (Bell et al., 2007; Feldman & Eidelman, 2009; Porges, 1983; Thoman, 1975; Wolff, 1968). The neonatal period is a unique period within lifetime development. A neonate's mental system transitions from being controlled by the autonomic nervous system to being controlled by the maturing cortex through synaptic connections and myelination of neurons (Huttenlocher, 1999; Pieper, 1963; Posner & Peterson, 1990). NNBO measures how the mental system regulates, processes and responds to environmental stimulation over time.

Processing is a set of brain activity patterns which transform environmental and internal neural signals into meaningful thoughts and ideas; a phenomenon which begins in-utero and continues throughout the lifespan (Dalton & Bergenn, 2007; Edelman, 1987; Howe & Lewis, 2004; Posner, 1973; Posner & Peterson, 1990; Vouloumanos & Werker, 2007). During the neonatal period, brain activity patterns observed through diagnostic imaging have found that neonates have largely unmyelinated axons and fewer synaptic connections than adults, so the cortical processing speed of sensory stimuli is slower than the adult or older infants (Casey et al., 2004; Chugani, 1998; Huttenlocher & Dabholkar, 1998; Näätänen & Alho, 2004; Nagy, 2011; Nolte, 2002). Processing during the neonatal period is also characterized by cortical signaling similar to adult brain activity (Nagy, 2011). Even though the cortical processing speed is slower, ERP tracings have measured significantly higher brain wave activity in the cortical somatosensory and motor areas. In addition, as a neonate interacts with the environment, PET scans have measured significantly higher glucose metabolism in the limbic system of the hippocampus, thalamus and brainstem, where the ascending cortical pathways are located between the cortex and brainstem with rapid global synaptogenesis (Chugani & Phelps, 1991; Eyre, Miller, Clowry, Conway, & Watts, 2000; Huttenlocher, 1990; Huttenlocher & Dabholkar, 1998). Other ERP studies have documented neonatal brain activity similar to adult brain activity in the front-central areas and left superior temporal gyrus during processing of phonemes (Dehaene-Lambertz & Pena, 2001; Nagy, 2011; Telkemeyer et al., 2009). All of these brain activity patterns are the foundation of social and cognitive processing and have been assessed by several NNBO biobehavioral measures (Als et al., 2004; Casey & de Hann, 2002; Field & Diego, 2008; Huttenlocher, 1999).

Neonatal Neurobehavioral Organization Biobehavioral Measures

A more in-depth examination of the NNBO biobehavioral measures will support the importance of exploring breastfeeding as a measure of neonatal processing. These NNBO biobehavioral measures include sleep/wake cycles (Prechtl & O'Brien, 1982; Thoman et al., 1975), heart rate variability (Porges et al., 1973; Porter, 2001), *The Neonatal Behavioral Assessment Scale (NBAS)* (Brazelton & Nugent, 1995; Lundqvist & Sabel, 2000; Tronick & Brazelton, 1967), motor movement (Einspieler & Prechtl, 2005; Snider, Majnemer, Mazer, Campbell, & Bos, 2008), direct measurements of brain activity patterns such as event-related potentials (ERP) (Molfese & Molfese, 2001; C. Nelson & Salapatek, 1986), and nutritive sucking organization, which included bottle feeding and breastfeeding (Lucas, 2008; Medoff-Cooper et al., 2009; Mizuno & Uedo, 2005; Wolff, 1968).

Sleep/wake states. As a neonate transitions from brainstem control to cortical control, a neonate's regulation of sleep/wake states is a measure of a neonate's ability to regulate his or her internal NBO (Holditch-Davis & Thoman, 1987; Prechtl, 1974; Sameroff, 1972; Thoman, 1990, 2001; Thoman et al., 1975; Wolff, 1987). Thoman (2001) describes the sleep/wake states as a neonate's ability to interact while mediating environmental stimulation and modulating a neonate's behavioral output response to the environment. Neonates' regulation of their sleep/wake states, communicates to their mothers how much maternal and environment interaction, including care-giving activities, they are able to handle (Thoman, 2001). Sleep/wake states have been found to be present in-utero and continue throughout the lifetime (Feldman, 2006; Field, Diego, & Hernandez-Reif, 2006; Graven, 2006; Pinter & Warshaw, 1979; Salisbury, Fallone, & Lester, 2005; Stanojevic, Perlman, Andonotopo, & Kurjak, 2004). However, research has found that sleep/wake states are unique in a neonate compared to adult sleep/wake states, as a neonate is able to pay attention to external stimulation, assimilate new behaviors, and *learn* while sleeping (Fifer et al., 2010; Tarullo, Balsam, & Fifer, 2011).

There are six sleep/wake states that have standardized descriptions: alert; non-alert waking; fussiness/cry; drowse and sleep-wake transition; active sleep; and quiet sleep (Brazelton & Nugent, 1995; Thoman, 2001; Thoman et al., 1975). For example, a non-alert waking state is, "The infant's eyes are usually open, but dull and unfocused. Motor activity may vary but is typically high. The eyes may be closed during periods of high-level activity. Isolated fuss vocalizations may occur" (Thoman & Whitney, 1990, p. 116). As reported by Berg, Adkinson & Strock (1973), the neonate's time spent in alert, non-crying states (excluding feeding) is brief, with over 90% of alert periods lasting less than 9 minutes (M. Nelson, Clifton, Dowd, & Field, 1978; Thoman & Whitney, 1990). The regulation of sleep/wake states is imperative to growth and development, as periods of alertness and active sleep allow the developing neonate to interact with his or her environment, an interaction which creates new structures and functions (Blackburn, 2003; Fifer et al., 2010), while quiet sleep is restorative to health (Thoman, 1990, 2001; Thoman et al., 1975).

Neonates show individual differences of state regulation at 2 days of age and continue to show individual differences in state regulation throughout the newborn and neonatal period (Gill, Behnke, Conlon, McNeely, & Anderson, 1988; M. Nelson et al., 1978). Freudigman and Thoman (1993) found that behavioral state regulation during the first two days of life are correlated to the *Bayley Scales of Infant Development* (*BSID*) (the gold standard of standardized cognitive and motor assessment from 2 months to 30 months of age) at 6 months (Bayley, 2006). Neonates with good regulation of state on the first day of life have positive correlations to the higher mental development index scores on the *BSID* at 6 months. By day two, none of the behavioral states were correlated to the mental *BSID*; instead only two behavioral states were correlated to the motor *BSID* (Freudigman & Thoman, 1993). Freudigman and Thoman concluded that neonates with better regulation of sleep/wake states on the first day of life demonstrate a well-organized NNBO even with the stress of birth. By day two, most neonates had recovered from birth stress and demonstrated good regulation of sleep/wake states. Thus, the predictive effect was lost with the combined group of neonates by the second day of life. (Thoman, 2001). Thoman and Whitney observed infants over 7 weeks after birth and found behavioral sleep/wake states had a sequentially recurring pattern of stability (Thoman, Deneberg, Sievel, Zeinder, & Becker, 1980; Thoman & Whitney, 1990). An extension of the study found that neonates and infants at 2-5 weeks of age (40-47 weeks PMA) with the lowest state regulation have major developmental problems at later ages (Thoman, 2001; Thoman et al., 1980).

Sleep/wake states may be measured by the electroencephalography (EEG) signals of the brain and by the observation of the range and regulation of behavioral states (Thoman, 2001). Although EEG signals are real time, the EEG recording patterns obtained during active sleep state cannot be distinguished from the alert state (Thoman, 1990, 2001). The EEG recording must be correlated with a record of observed behavioral states. Thoman argues that the gold standard for recording and analyzing sleep/wake states should be behavioral states rather than EEG recordings (Thoman, 2001). Sleep/wake states are a noninvasive measurement of the brain's processing and mediation of the environment instead of the leads needed for EEGs (Thoman, 2001).

Vagal tone and heart rate variability. Heart rate variability (HRV) has been used to measure the regulation of the internal homeostasis, e.g. heart rate and respiration of individuals from the fetus to adults (DiPetro, Bornstein, Hahn, Costigan, & Achy-Brou, 2007; Feldman, 2006; Field & Diego, 2008). HRV is a characteristic pattern of short term beat-to-beat (R-R wave) high frequency oscillations caused by the expiratory phase of the respiratory cycle (Porges, 1983). The regulation of the high frequent oscillations is by the vagus nerve, located in the medulla where it divides into the afferent (sensory) and the efferent (motor) fibers that innervate most of the organs in the body including gastrointestinal and cardiovascular system (Porter, 2001). Vagal activity has been measured by several HRV algorithms which require extensive computer support (Berntson et al., 1997; Field & Diego, 2008; Porges, Doussard-Roosevelt, & Greenspan, 1996; Porter, 2001).

During the neonatal period, Fox and Porges (1985) found that neonates with higher HRV at birth correlated to higher *BSID* mental development index at 8 and 12 months of age; preterm and sick neonates, with lower HRV, had a mixture of *BSID* mental development index scores. The mixed *BSID* mental development index scores were explained by complex system of mother and neonate. Some mothers were able to support and regulate their at-risk neonates to ameliorate the initial stress and damage at birth for typical development. However, some mother and neonates were unable to overcome the initial stress and damage and the neonates had lower mental development scale *BSID* scores (Fox & Porges, 1985). Harrison (2009) found that neonates were likely to have higher HRV in direct proportion to their mothers' sensitivity to their cues. In neonates, increased HRV is correlated with better range and regulation of states that reciprocally elicit or inhibit interaction with the environment (Porter, 2001). Several prospective longitudinal studies in very low birth weight infants have found higher HRV associated with better social competence at 3 years and 6 years of age (Doussard-Roosevelt, McClenny, & Porges, 2001; Doussard-Roosevelt, Porges, Scanlon, Alemi, & Scanlon, 1997). Feldman (2006) has studied preterm infants' maturation of HRV over time compared to term neonates' HRV along with arousal modulation, orientation and sleep-wake cycles. Each variable was predictive of mother-infant synchrony at 3 months of age (Feldman, 2006). Feldman (2006) argues that these biological rhythms contribute "meaningfully to the formation of mother-infant synchrony second by second" (p. 184). Alterations in mother-infant synchrony as measured by lower HRV and decreased serotonin and dopamine levels, have also been found in mothers diagnosed with prenatal depression and in their neonates (Field & Diego, 2008). HRV reflects the early neurobiological balance needed by a neonate to regulate the environment.

Motor assessment. A neonate's NNBO may also be measured by the neonate's motor movements and abilities in response to environmental stimulation (Prechtl, 1982; Snider, Majnemer, Mazer, Campbell, & Bos, 2009). Every neonate undergoes a rudimentary assessment of behavioral movements at birth with the APGAR score: Appearance (color), Pulse (heart rate), Grimace (respiratory effort), Activity (movement), and Respiration (Apgar, 1953). Term and at-risk neonates may be assessed with a more complete assessment of active and passive movement patterns, primitive reflexes, and orienting responses to auditory and visual stimuli (S. Campbell, Kolobe, Wright, & Linacre, 2002; Snider et al., 2009). General motor assessment in the neonatal period has been used to assess standardized typical development at one point or sequentially with several assessments (S. Campbell, 2005; Prechtl, 1979). Atypical spontaneous general movement has prospectively been found to be predictive of cerebral palsy, with the lowest "non-optimality score" of normal and atypical general motor movement to be100 % predictive of cerebral palsy (Prechtl, 1979; Yuge et al., 2011). Establishing typical motor development is fundamental to the typical growth and development as motor movement and motion are part of the continuous interaction between a neonate and the environment supporting typical developmental trajectories (S. Campbell et al., 2002; Yuge et al., 2011).

Neonatal Behavioral Assessment Scale. The *Neonatal Behavioral Assessment Scale (NBAS)* is the gold standard measurement of a neonate behavior and regulation that emerged as a result of the paradigm shift evaluating in neonates in the 1970's. The *NBAS* has been used to establish normal neurobehavioral function for the newborn and neonate (0-28 days of life) (Brazelton & Nugent, 1995). The *NBAS* focuses on assessment and scoring of a neonate's best available response to standardized sensory and motor sensory stimulus. Brazelton recommends that the most effective assessment of the changing neonate (or measuring the full range of adaptation) to his or her environment involves assessing a neonate 2-3 times, such as at 3, 14, and 30 days post partum (Als, 1991; Brazelton & Nugent, 1995; Lester, 1983; Lundqvist & Sabel, 2000; Pressler, Hepworth, Appelbaum, Sevcik, & Hoffman, 1998; Tronick & Brazelton, 1967). The multiple set of scores would give data for individual variability of performance (Brazelton & Nugent, 1995).

The *NBAS*' predictive validity for later development has mixed results. The *NBAS* focus is on obtaining a neonate's best performance. As neonates have a limited time in the alert state, a neonate's best performance is often difficult to elicit. Any poor performance should be replaced with a repeated better performance (Brazelton & Nugent, 1995). The lack of standardized assessment does not allow correlation with later developmental outcomes. Insofar as there are different domains within the *NBAS*, i.e. sleep/wake, attention, non-nutritive sucking, the *NBAS* gives inconsistent results. The use of the *NBAS* is mixed in assessing the preterm infant, as some preterm infants with the best orientation of vision and sound performance demonstrated the poorest developmental outcomes at 18 months (Lester, Boukydis, McGrath, Censullo, & Brazelton, 1990; Lester, Garcia-Coll, Valcarcel, Hoffman, & Brazelton, 1986). The *NBAS*' strength, however, is in its concurrent validity in identifying neonates who are at-risk for developmental sequelae (Lester & Tronick, 2001).

Brain electrical response: the event-related potential (ERP). Assessment of a neonate's ability to process environmental stimulation is limited because of a neonate's limited behavioral repertoire. However, with presentation of audio, visual, or sensory motor stimulation, the brain will respond even if no behavioral activity is observed (Burden et al., 2007). A method to assess the brain's response is an event-related potential (ERP) (deRegnier, 2008). An ERP is a transient synchronized brain wave change in the electroencephalography signal that "measures changes in the brain's electrical activity in response to stimuli, allowing the evaluation of attention and memory in very young infants" (Burden, et al., 2007, p. e337). Although adults and infants respond to environmental stimulation by frontal and prefrontal cortex brain activity, the wave forms are different (Courchesne, 1978; Reynolds & Richards, 2005). A neonate and infant responds with a different brain wave pattern than an adult when paying attention to environmental stimulation (Courchesne, 1977; Luck, 2005). An adult demonstrates a positive P300 wave form (Luck, 2005). A neonate and infant demonstrates a long negative component which is thought to denote attention and a late positive component cortical wave form which is thought to denote memory updating (Burden et al., 2007; Courchesne, 1977). Extensive research has been done in observing and exploring the auditory nervous system evoked potential as neonates may be tested in their sleep (Kushnerenko et al., 2007). The auditory evoked potential has also been used to screen a neonate for auditory nerve function with the brainstem auditory evoked response (BAER) (Lamb et al., 2002; Luck, 2005). Using the BAER, neonates are able to identify patterns of sound and differentiate an “oddball” sound of tone or frequency within an expected pattern (Kushnerenko et al., 2007). The auditory “oddball” paradigm was used in a prospective longitudinal study of neonates with a family history of dyslexia and a low risk control group of neonates. The at-risk neonates were found to demonstrate atypical processing of the auditory sounds in the right hemisphere instead of the typical left hemisphere during testing and later demonstrated poorer receptive language and verbal skills of fluency at 2nd grade in comparison to the control group (Guttorm, Leppänen, Hämäläinen, Eklund, & Lyytinen, 2009; Leppänen et al., 2010). Another auditory study compared a neonate’s ERP response to his or her maternal voice and a stranger’s voice. In comparison, neonates of a diabetic mother demonstrated a delayed response to the stranger’s voice, and preterm infants tested at term did not show any significant difference in their response to a stranger’s voice compared to typically developing neonates (deRegnier, 2008). Neonates diagnosed with Down syndrome have delayed negative and positive wave responses to stimulation and this pattern is consistent throughout the lifetime (Kittler et al., 2009).

Visual evoked potential and sensory evoked potential are neonatal brain waves that are elicited by visual and skin stimulation. Visual evoked potential may be stimulated with a flashing light (stroboscopic lamp), by light-emitting diode using goggles, or by pattern visual stimuli (Kato & Watanabe, 2006). The flashing light and light-emitting diode require specialized equipment and has not been frequently used to assess neonatal behavior in the clinical setting (Richards, 2005). The visual pattern stimuli is a sensitive measure of attention and memory updating but is not reliable before 38 - 42 weeks gestational age (Kato & Watanabe, 2006; Slater, 2000). Visual evoked potential has been found to be a predictive measure for atypical development in term neonates with a history of birth asphyxia (Kato & Watanabe, 2006). Sensory evoked potential has been tested in the adult population and is now being used to develop a neonate's typical responses (Trollmann, Nüsken, & Wenzel, 2010). Sensory evoked potential research has not established enough data to be used as a predictive measure for atypical development (deRegnier, 2008).

Nutritive sucking patterns. The focus of this research is breastfeeding, which uses coordinated nutritive sucking to create and sustain a latch during feeding. Nutritive sucking has been extensively studied, examining the maturation of sucking from 32 weeks gestation to 38 weeks gestation and the presence of individual differences (Amaizu et al., 2008; Crook, 1979; Kron et al., 1968; Medoff-Cooper, 1991; Mizuno & Ueda, 2006; Wolff, 1968). Nutritive sucking is the highly complex coordination of a neonate's autonomic nervous system with sensory and motor systems (Kron, Stein, & Goddard, 1962; Qureshi, Vice, Taciak, Bosma, & Gewolb, 2002). Typical oral sucking and swallowing are the first assessments of "early developmental pathways that are the basis for later communication skills" (Delaney et al., p.106). Coordinated swallowing is innervated by the sensory (afferent) cranial input of cranial nerve V, VII, IX, and X. The oral-pharyngeal region uses the sensory cranial nerves of the senses (taste, smell, tactile, hearing, vision, and vestibular) during nutritive sucking (Delaney & Arvedson, 2008; Peiper, 1963). For swallowing, the primary motor (efferent nerve) for the brain-stem control uses cranial nerve V, VII, IX, X, XII and the upper cervical (C1-C3) nerves. In addition, the central pattern generators in the brain stem coordinate the movements for respiration and swallowing (Delaney & Arvedson, 2008; Pieper, 1963). Together the sensory afferent nerve and motor efferent nerve innervations control and coordinate the mature 1:1:1 ratio of the suck:swallow:breathe cycle needed for effective feeding (Barlow & Estep, 2006; Delaney & Arvedson, 2008; Miller & Kang, 2007). The action of sucking is a cycle of expression and suction (Sameroff, 1968; Wolff, 1968). Expression is the action of the tongue stripping the nipple of milk against the hard palate which develops first around 32 weeks (Lau et al., 2000; Sameroff, 1968). Suction is the negative intraoral pressure that is created when the mouth is sealed around the nipple and the jaw drops as the tongue strips the nipple during bottle feeding with weak pressures emerging as early as 32 weeks, but typically after 34 weeks (Bosma, 1967; Bosma, Hepburn, Josell, & Baker, 1990; Lucas, 2008). A well organized sucking pattern has mathematical precision when measured on an X/Y axis, Figure 2 and Figure 3. A disorganized sucking pattern is random when plotted on an X/Y axis (Qureshi et al., 2002). Nutritive sucking patterns have demonstrated maturational change beginning at 32 weeks gestation with the emergence of the gag reflex to a mature suck:swallow:breathe at 38 weeks gestation (Wolff, 1968). Two studies have found that sucking maturation continues through the first month. Queshi et al (2003) found that the number of bottle feeding sucks increased from a neonate period to 77/min at one month of age, with an increase of 2:1 or 3:1 suck:swallow ratio. Moral et al. (2010) found that the number of sucks per minute at 21-28 days of life was different according to the method of feeding; exclusively breastfeeding neonates had the greatest average number of sucks per minute, followed by neonates who exclusively bottle fed, and the neonates with the lowest average number of sucks had a mixture of breast and bottle feeding. The difference in number of sucks per feeding continued to change over time and at 3-5 months the number of sucks per minute was not significantly different between bottle fed and breastfed infants. However, the bottle fed infants' number of sucks was slightly lower, with shorter pauses between sucks in contract with breastfed infants who had slightly higher number of sucks with longer pauses between sucks (Moral et al., 2010).

Neonates' nutritive sucking patterns are responsive to environmental stimulation. Neonates will change their nutritive sucking to a nonnutritive sucking pattern with a pacifier, at the initiation of breastfeeding, and at the end of feeding with satiation (Geddes, Kent, Mitoulas, & Hartmann, 2008; Mizuno & Ueda, 2006; Moral et al., 2010; Wolff, 1968). The nonnutritive pattern is a more rapid and irregular suck:swallow:breathe ratio with longer pauses between sucking bursts when compared to a nutritive suck (Lau & Kusnierczyk, 2001; Medoff-Cooper, 2005; Mizuno & Ueda, 2006; Sameroff, 1967; Wolff, 1968). Neonates will also change their sucking patterns in response to different fluids such as sugar water, salt water, or formula (Crook, 1978; Crook & Lipsitt, 1976; Kron et al., 1967; Sameroff, 1968). The most effective pattern is demonstrated with formula. Nutritive and nonnutritive sucking have both been used to study the abilities of a neonate to attend to familiar and novel stimuli (Bingham, Abassi, & Sivieri, 2003; Casey et al., 2004; DeCasper & Fifer, 1980; DeCasper & Spence, 1986; Dondi et al., 1999; Dubignon, Campbell, Curtis, & Partington, 1969; Moon, Cooper, & Fifer, 1993; Sameroff, 1970). As new stimuli are introduced, such as sound or color, a change in nutritive sucking patterns is seen. However, these changes in nutritive sucking patterns have not been found to be predictive of later cognition (Crook, 1978, 1979; Crook & Lipsitt, 1976; Elder, 1970; Lipsitt, 1986; Lipsitt, Kaye, & Bosack, 1966; Sameroff, 1972).

Since the 1950's, the sucking cycle has been studied; eight parameters of nutritive sucking were found: number of sucks, number of bursts (a burst having ≥ 3 consecutive sucks), number of sucks per burst, intersuck interval (a pause ≥ 2 seconds between bursts), intrasuck interval (time between each suck in a burst), length of time of each burst, and maximum sucking pressure (da Costa, van den Engel-Hock, & Bos, 2008; Kron et al., 1962; Medoff-Cooper, 2005; Medoff-Cooper et al., 2001). Using these parameters, neonates were found to have individual differences in sucking patterns (Kron et al., 1968). Queshi et al. (2002) found neonate's have individual sucking patterns which begin at birth. These sucking patterns were studied over the first month of life and each individual nutritive sucking patterns was graphed on an X/Y axis demonstrating rhythmically organized or disorganized sucking patterns (Qureshi et al., 2002).

In the preterm infant, nutritive sucking parameters have been correlated with the *NBAS* and the *BSID* mental and motor scales. An early pilot study by Medoff-Cooper & Gennaro (1996) found that in preterm infants with atypical sucking patterns (< 70 sucks in 5 minute feeding) at 34 weeks gestation, the number of sucks (r = .90, p < .05) and the number of bursts (r = .87, p < .05) were significantly correlated with the *BSID* mental and motor development index scores at 6 months (Medoff-Cooper & Gennaro, 1996). In a more recent study, Medoff-Cooper, et al., (2009) developed a z-score, which is a composite number that describes the average maximum pressure, mean number of sucks, and mean number of sucks per burst. Using a cohort of 105 preterm infants born between 28 and 34 weeks post menstrual age (PMA), nutritive sucking data were obtained at 34 and 40 weeks. Each parameter and the composite z-score were correlated to the 6 and 12 month *BSID* mental development index score (Medoff-Cooper et al., 2009). The preterm infants' 40-week PMA nutritive sucking z-score was significantly correlated to the 12 month *BSID* mental development index (r = .42, p = .001) and motor development index (r = .38, p = .002) (Medoff-Cooper et al., 2009). Another research lab found that atypical nutritive sucking in preterm infants at risk, defined as preterm infants unable to create rhythmic suction and expression during sucking after a two weeks of feeding, was found to be correlated at 18 months to poorer mental development index scores on the *BSID* at 18 months of age (Mizuno & Uedo, 2005). Overall, these studies demonstrate maturation of nutritive sucking but more importantly, they showed that typical and atypical patterns of nutritive sucking over time are prospectively predictive of motor and cognitive functions.

As maternal regulation of bottle and breastfeeding is pivotal to a neonate's survival, another aspect of nutritive sucking is the social communication that occurs beyond the nutritive latch. Research has found that feeding is the key early social turn-taking behavior (Alberts, Kalverboer, & Hopkins, 1983; Bowlby, 1969; Csibra, 2010; Dunn & Richards, 1977; Field, 1977; Kaye, 1982; Kaye & Wells, 1980; Newson, 1977; Stern, 1977, 1995; Stevenson, Roach, Ver Hoeve, & Leavitt, 1990). A neonate interacts with his or her mother with behavioral cues of rooting, hand swipes, sucking, and crying to signal a neonate's need for positioning at the breast or bottle, burping, frequency of feedings, and other physical needs (Cadwell, 2007; Kaye, 1977; Kaye & Wells, 1980; Stern, 1977). During feeding a typically developing neonate breaks off sucking not to regulate milk flow but for social interaction (Feldman, 2006; Kaye & Wells, 1980; Stern, 1995). As a neonate feeds, each mother supports her neonate's effort by pacing, gazing, and vocalizing (Barnard, 1979; Hill & Johnson, 2007; Mulder, 2006; Nommsen-Rivers & Dewey, 2009; Winberg, 2005; Wolff, 1968). Kaye and Wells (1980) found that neonates pause during feeding, awaiting a response from their mother before continuing feeding (Field, 1977; Kaye & Wells, 1980).

Breastfeeding. Breastfeeding requires an organized nutritive sucking to transfer breast milk properly. Initiation of neonatal breastfeeding is more challenging than neonatal bottle feeding (Geddes et al., 2008; Matthew & Bharia, 1989; Sameroff, 1968; Selley et al., 1990). In order to breastfeed effectively, neonates must coordinate their suck:swallow:breathe in a 1:1:1 ratio, while maintaining suction at the breast. Recently the intraoral pressure cycle was measured with a pressure transducer during breastfeeding for the first time. Geddes et al.'s (2008) ultrasound study found that the increase in milk volume occurred when the posterior tongue dropped away from the hard palate with increased suction and not while the tongue was stripping the nipple (Bosma et al., 1990; Geddes et al., 2008; Selley et al., 1990). In comparison, neonates use only expression to obtain milk from a commercialized nipple (Crook, 1979; Sameroff, 1968).

As breastfeeding requires greater coordination to create a vacuum seal at the breast for suction, compared to bottle feeding, many typically developing neonates have difficulty with establishing breastfeeding during the first week of life (Cadwell, 2007; Li et al., 2008; The Center for Breastfeeding, 2002). Neonates may encounter difficulty establishing breastfeeding because of maternal and neonatal anatomical barriers, such as flat or inverted nipples and neonatal low muscle tone (Alexander et al., 1992; Rogers & Arvedson, 2005; Segal et al., 2007). Other external factors have been found to affect typically developing neonates from establishing breastfeeding, such as maternal epidural doses using high dose narcotics or disruptive hospital routines (Declercq, Labbok, Sakala, & O'Hara, 2009; Lieberman & O'Donoghue, 2002; Rowe-Murray & Fisher, 2002; Scanlon, Brown, Weiss, & Alper, 1974; Weddig et al., 2011). Maternal epidural dosage has been changed to low dose epidurals and recent studies have found no significant difference in breastfeeding behaviors and neurological assessment in neonates whose mothers received a low dose epidural when compared to those mothers who did not receive a low dose epidural (Radzyminski, 2003, 2005). In addition, the barrier of disruptive hospital routines is also changing as the World Health Organization has published a list of recommendations for acute care setting to practice to support mothers breastfeeding in the first days of life, including rooming-in, and no formula supplementation (Baby-Friendly USA, 2010; Declercq et al., 2009).

However, assessment of neonatal breastfeeding effectiveness is still evaluated by assessing the satiation of a neonate after a feeding, and by evaluation of typical physical growth and weight gain (American Academy of Pediatrics, 2005; Lampl & Thompson, 2007; Lampl et al., 1992). Breastfeeding assessment scales focus on the mechanics of a proper nutritive latch and sucking rhythm or on qualitative maternal report (Baum & Palmer, 1985; Cadwell, 2007; Chambers, Mc Innes, Hoddinott, & Alder, 2007; da Costa & van der Schans, 2008; Hall et al., 2002; Kumer, Mooney, Wieser, & Havstad, 2006; Mulford, 1992; Palmer, Crawley, & Blanco, 1993; Riordan & Koehn, 1997). No one has examined neonatal breastfeeding behaviors as both a *task*, which requires maternal regulation and may be affected by maternal physical properties, *and also* a neonate's first complex processing of environmental stimulation.

At-risk breastfeeding populations. Many neurologically at-risk neonates struggle with initiating breastfeeding, such as neonates who are premature, medically fragile, or born with genetic anomalies (Als, 1982; Danner, 1992; Keen, 2008). Premature infants have difficulty creating a strong seal because of their immature autonomic nervous, sensory, and motor systems and are unable to coordinate their breathing and swallowing (Gewolb & Vice, 2006b; Medoff-Cooper, 1991). The premature infant will change the suck:swallow:breathe ratio to suck for long stretches without breathing (Gewolb & Vice, 2006b; Medoff-Cooper, 1991). Preterm infants diagnosed with bronchopulmonary dysplasia during the neonatal period are characterized by an atypical suck:swallow:breathe ratio with periods of apena during sucking and swallowing (Gewolb & Vice, 2006a). The apneic periods inhibit effective oral feedings, placing a preterm infant with bronchopulmonary dysplasia at-risk for aspiration during feeding and later for affected normal growth and development (Gewolb & Vice, 2006a). Neonates diagnosed with Down syndrome and Prader-Willis syndrome have difficulty creating and maintaining an effective nutritive suck because of low muscle tone which inhibits a neonate's ability to create a seal for vacuum and milk transference (Miller et al., 2011; Mizuno & Ueda, 2001; Pisacane et al., 2003). An ultrasound study during feeding found that neonates diagnosed with Down syndrome demonstrate hypotonicity of the perioral and masticatory muscles, lips, and even the tongue (Mizuno & Ueda, 2001). Neonates exposed to congenital cytomegalovirus infection also have demonstrated lethargy and a poor suck during bottle feeding in the neonatal period (Boppana, Pass, Britt, Stagno, & Alford, 1992). Term neonates of mothers who were gestational diabetic but insulin controlled during pregnancy demonstrated lower number of sucks and number of bursts during a 5-minute feeding in comparison to neonates of mothers with no prenatal complications (Bromiker et al., 2006). The term neonates' lower number of sucks and bursts demonstrated an immature nutritive sucking pattern in comparison to the control neonates (Bromiker et al., 2006). In contrast, neonates who were born to drug dependent mothers had a mildly altered suck:swallow:breathe ratio due to longer periods of sucking followed by apneic swallows (Gewolb, Fishman, Qureshi, & Vice, 2004). As each of these at-risk neonatal populations demonstrate an alteration of the typical suck:swallow:breathe ratio, it is possible that neonates later diagnosed with ASD may have difficulty with initiation of a nutritive suck because of an atypical developing neurological system (Als, 1982; Danner, 1992; Keen, 2008).

Children with Autism Spectrum Disorder (ASD)

ASD is an inclusive term for a spectrum of neurodevelopment disability diagnoses which includes Pervasive Developmental Disorder - Not Otherwise Specified, Asperger's, and Autism (American Psychiatric Association, 2007). ASD is a neurodevelopmental disability that presents with one or more of these symptoms in various levels of severity: persistent deficits in social communication; social interaction; and restricted, repetitive patterns of behavior, interests, or activities (American Academy of Pediatrics, 2007; Hyman & Towbin, 2007). ASD is diagnosed in 1 of 110 (1%) children, occurring in 1 of 70 boys, and 1 of 310 girls (Center for Disease Control, 2009). ASD has standardized assessment tools for identification beginning as early as 14 months (Center for Disease Control and Prevention, 2010; Robins, Fein, Barton, & Green, 2001). Although ASD is most commonly identified between 2-3 years of age because of atypical developing language, the average age of identification is 4.5 - 5.5 years of age (American Academy of Pediatrics, 2007; American Psychiatric Association, 2007; Center for Disease Control and Prevention, 2010; Lord & Bishop, 2010).

ASD diagnosis and research. Although diagnosis occurs after infancy, many children who are ultimately diagnosed with ASD may present atypical developmental findings during the first year of life. Analysis of retrospective home videotapes have found children later diagnosed with ASD demonstrated alterations in social interactions during their first year of life (Clifford & Dissanayake, 2008; Werner, Dawson, Osterling, & Dinno, 2000). In comparison to typically developing children and children diagnosed with mental retardation, the children later diagnosed with ASD had diminished responses to being called by their name; diminished expressive language to communicate what they need; and diminished looking at others (Landa, 2010; Landa & Garrett-Mayer, 2006; Lauritsen, Pedersen, Bøcker, & Preben, 2005). Prospective studies of children after 18 months - 5 years of age found alterations in regulatory, motor, social, language, and sensory domains among the children who were later diagnosed with ASD (American Psychiatric Association, 2007; Landa & Garrett-Mayer, 2006). Population studies have documented a 2% – 10% familial risk for families with a child diagnosed with ASD, having another child with diagnosed with ASD (Barbaresi, Katusic, & Voigt, 2006; Center for Disease Control and Prevention, 2010; Landa, 2010; Lauritsen et al., 2005; Pierce et al., in press). Because of increased prevalence of ASD amongst siblings, studies of siblings have been done for documentation of alterations during early development and for early identification of siblings (American Academy of Pediatrics, 2007; Barbaresi et al., 2006; Center for Disease Control and Prevention, 2010). Among the siblings who were studied, a significant number of those that demonstrated soft neurological signs such as head lag at 6 months were later diagnosed with ASD (Landa, 2010; Landa & Garrett-Mayer, 2006). Siblings that were later diagnosed had significant differences on the Mullen's Scales of Early Learning at 14 months in the domains of Fine Motor ($p <.01$), Gross Motor ($p < .001$), Receptive Language ($p < .001$), and Expressive Language ($p < .001$), but better scores in the Visual Receptive domain compared to unaffected children (Landa & Garrett-Mayer, 2006).

Research on the physiological triggers of ASD include the physiological presentation of enlarged head circumferences at one year of age with children later diagnosed with ASD (Courchesne, Carper, & Akshoomoff, 2003; Dawson, 2008; Landa, 2010; Redcay & Courchesne, 2005; Wass, 2011). The increased head circumference was documented with magnetic resonance imaging and diffusion tensor imaging techniques (an emerging magnetic imaging technique that is being used to examine the structural integrity of white matter tracts within the cortex and has correlates to brain connectivity) (Rodrigues & Grant, 2011; Vasung et al., 2010).

These studies have found atypical increases in the number of synaptic connections in the frontal cortex while synaptic connections from the frontal cortex to other areas of the brain was decreased in older children and adults (D. Campbell et al., 2011; Khazipov, Tyzio, & Ben-Ari, 2007; Tyzio et al., 2006; Wass, 2011). As brain synaptic connections are initiated by neurochemical triggers such as neurotransmitters or neuropeptides, extensive research is being conducted to explore these epigenetic interactions (Amaral, Schumann, & Nordahl, 2008; Bucan et al., 2009; D. Campbell et al., 2011; Courchesne, Yeung-Courchesne, & Pierce, 1999; Elsabbagh et al., 2009).

ASD and NNBO measures. There currently are no NNBO studies among children later diagnosed with ASD. Research suggests that such studies may be worthwhile. Prospective studies of siblings later diagnosed with ASD have documented alteration in sleep regulation and event-related potential responses within the first year (Cortesi et al., 2010; Elsabbagh et al., 2009; Hoehl et al., 2009; Kodak & Piazza, 2008). Prospective studies of children diagnosed with ASD have documented low vagal tone and heart rate variability (Field & Diego, 2008; Ming, Julu, Brimacombe, Connor, & Daniels, 2005). Children diagnosed with ASD, in comparison to typically developing children, have a disproportionate rate of poor sleep regulation patterns, atypical oral sensitivity and motor regulation (American Academy of Pediatrics, 2007; Cortesi et al., 2010; Dziuk et al., 2007; Emond, Emmett, Steer, & Golding, 2010; Keen, 2008; Volkert & Vaz, 2010). In light of these findings, further research of NNBO patterns is indicated among siblings of children diagnosed with ASD.

ASD and breastfeeding. Only one study has examined breastfeeding in neonates later diagnosed with ASD. Tanoue and Oda (1989) found that 24.9% of neonates later diagnosed with infantile autism compared to 7.4% of the control neonates weaned after the first week of life.

The largest reason for weaning was “maternal breastfeeding failure”(Tanoue & Oda, 1989, p. 426). No additional description was given if the reason was because of an inability to create and sustain a nutritive latch, hypotonicity of suck, or ineffective patterns of breastfeeding. As no study has described the neonatal breastfeeding behaviors of children later diagnosed with ASD, the purpose of this study was to explore and compare results with other research on neurologically at-risk neonates.

Application of the Biobehavioral Conception of Neonatal Processing Framework

A retrospective descriptive study was performed using the Biobehavioral Conception of Neonatal Processing as a theoretical framework to guide the development of the measures and data analysis. The mothers were interviewed to describe the neonatal breastfeeding behaviors of their child who was later diagnosed with ASD. The measures used included a socioenvironmental questionnaire, a semi-structured interview, and a post interview summary. The socioenvironmental questionnaire and semi-structured interview were created based on the theoretical framework concepts of neonate, a neonate mental system, and the environment as the maternal role in successful initiation and duration of breastfeeding. These three concepts were used to create specific codes a priori to describe the initiation and duration of breastfeeding including the mechanics of breastfeeding, the introduction of bottle feeding, general neonatal and infant behavior, the time when the child was diagnosed with ASD, and the maternal experience of raising a child diagnosed with ASD. University Institutional Rights Board approval was obtained and research participants were recruited by the primary investigator via posted flyers at two community clinics, ASD parent support meetings, and an occupational therapist office.

Discussion

Maternal description of neonatal behavioral patterns. Mothers of neonates later diagnosed with ASD reported that their neonates were able to create and maintain a nutritive latch. A neonate's ability to create a nutritive latch was accomplished in spite of anatomical barriers, i.e. flat maternal nipples, neonatal hypotonicity, and two-thirds of the mothers being not having breastfed before. The mothers did describe several behaviors. First, there were two neonatal breastfeeding behaviors described by the mothers of children later diagnosed with ASD: typical initiation of a nutritive latch and an atypical breastfeeding pattern. The mothers described a breastfeeding pattern that was a vigorous suck that did not cease with satiation, or an "insatiable feeding" pattern. Another description by the mothers was a perception of diminished social interaction between herself and her neonate. The third maternal description was that many of the neonates had weights that were $\geq 70^{th}$ percentile.

These three behavioral descriptions may be intertwined. A typical neonate may have 8-12 feedings in 24 hours, lasting 5-20 minutes during the first few days of life (American Academy of Pediatrics, 2005; La Leche League International, 1991). Frequent feedings are a normal pattern before a growth spurt which has been found to occur around 10 days, 3 weeks, 6 weeks, 3 months, and 6 months (Lampl & Thompson, 2007; Lampl et al., 1992). Although this normal frequency may be perceived by primiparas as being insatiable, a typical neonate will stop sucking when he or she is satiated. Both multiparas and primiparas in this study described "insatiable feeding" as a frequent feeding pattern that needed to be terminated by the mother in order to prevent physical trauma to the breasts and nipples.

The second pattern the mothers described was a perception of diminished social interaction. Some mothers described the diminished social interaction by lack of eye contact, and some by a diminished sense of interaction. Eye contact has been detected in neonates from birth (Sai, 2005). By a few hours of life typical developing neonates are able to discriminate their mother's face from others (Sai, 2005). The description of diminished social interaction may be related to early feeding patterns. Brown (1973) has reported that humans are the only mammal that pauses during feeding. The pause during feeding allows for socialization between the mother and her neonate (Barnes, Lethin, & Jackson, 1953; Brown, 1973). The mother responds in a conversation of touch, vocalization, or jiggling of the breast and bottle (Brown, 1973; Kaye & Wells, 1980). Taking a break allows a mother to protect her nipples and also allows a neonate during the pause to interact with his or her mother. If a neonate feeds with an "insatiable feeding" pattern, he or she may not have paused while feeding.

The third description was the maternal report that their infants were equal to or above the 70^{th} percentile in weight. During the first 4-6 months of life, the weight of the breastfed infant is generally around the 50^{th} percentile growth curve and then drops below the 50^{th} percentile (Grummer-Strawn, Reinold, & Krebs, 2010). New studies are revising the growth curves to reflect the normal growth curve of a breastfed infant as prior growth curves have been based on infants consuming artificial milk (Li, Scanlon, & Serdula, 2005). It would be expected for breastfed infants to be > 50^{th} percentile for the first 6 months of life, but unexpected to continue after 6 months based on normal breastfeeding infant weight patterns. Thus, it is unexpected that so many neonates and infants would be described to be that large for the entire year.

Together, these three behaviors may describe an atypical breastfeeding pattern presenting a constellation of behaviors. The pattern of "insatiable feeding" may preclude the neonates from pausing for social interaction and potentially leading to excessive weight gain as neonates and infants eat beyond their nutrition needs. As many children with ASD have oral-motor feeding issues, the mothers may be describing an earlier presentation of pervasive feeding. Further investigation is needed to objectively verify these findings.

Limitations. In this study there were several limitations. The first limitation is the small sample size of 20 mothers' descriptions. Second, NNBO was conceptualized as the maternal description of neonatal breastfeeding behaviors. The neonatal breastfeeding behaviors were described and interpreted by their mother's retrospective recall and the behaviors may not have been accurately described. Third, as a retrospective study, maternal recall may have been affected by the reinterpretation of their experience knowing their child's diagnosis. Many of these mothers weaned their children over 10 years ago, with one mother weaning over 30 years ago. The reinterpretation of their experience may have altered the actual events, such as the perception of diminished social interaction or interpreting the "insatiable feeding" pattern as a form of pervasive behaviors which is a diagnostic sign of ASD. However, although accuracy is best within three years of breastfeeding, mothers do recall with accuracy the initiation of breastfeeding.

Implications for future research. Further investigation of the "insatiable feeding" pattern is merited. One option would be to conduct a larger qualitative study that would recruit mothers whose children were just diagnosed so that the time lapse for their recall of their breastfeeding experiences would be shorter. The study would verify if these mothers describe their neonate and infant as an "insatiable feeder". Another option would be to prospectively videotape neonatal breastfeeding behaviors of siblings of children with ASD, to capture and verify the maternal descriptions of neonatal breastfeeding behaviors of children with ASD.

Conclusion. In conclusion, the measures of NNBO are a window into the brain's activity of the neonate's ability to process the environment. The measures of NNBO of breastfeeding and breastfeeding patterns should be investigated further. Breastfeeding behaviors may be a snapshot of how typical or atypical the brain is organizing data. How neonatal data is organized may give insight into later more complex neurobehavioral forms that may be diagnostic of typical development, ASD, or other neurodevelopmental disability.

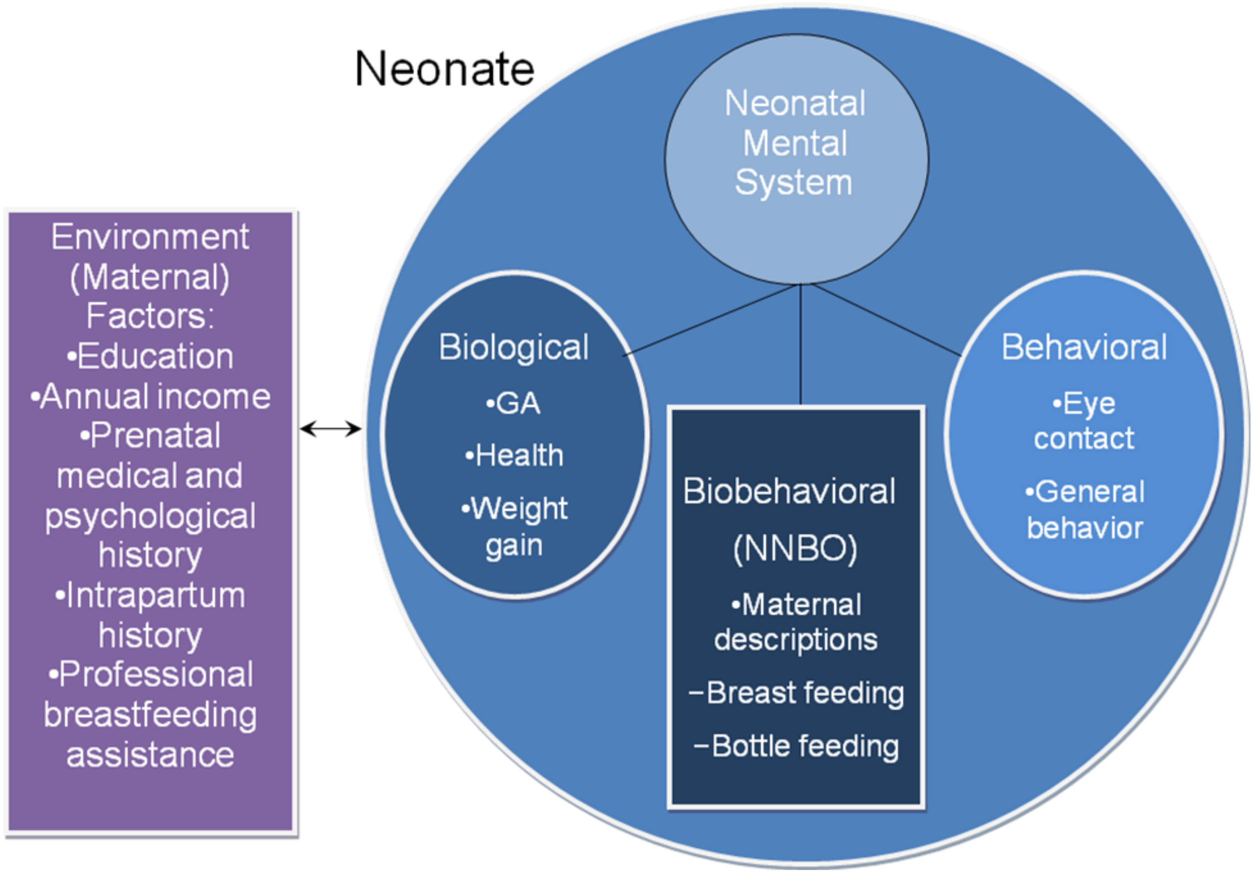

Figure 1. Biobehavioral Conception of Neonatal Processing

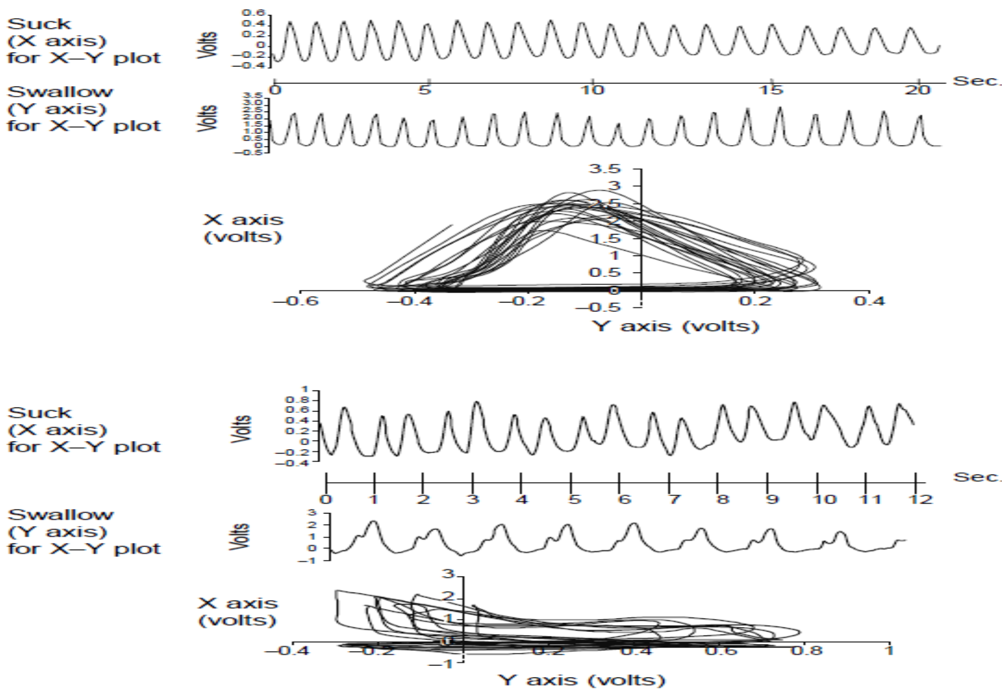

Figure 2. Organized nutritive sucking pattern (Qureshi, et al., 2002).

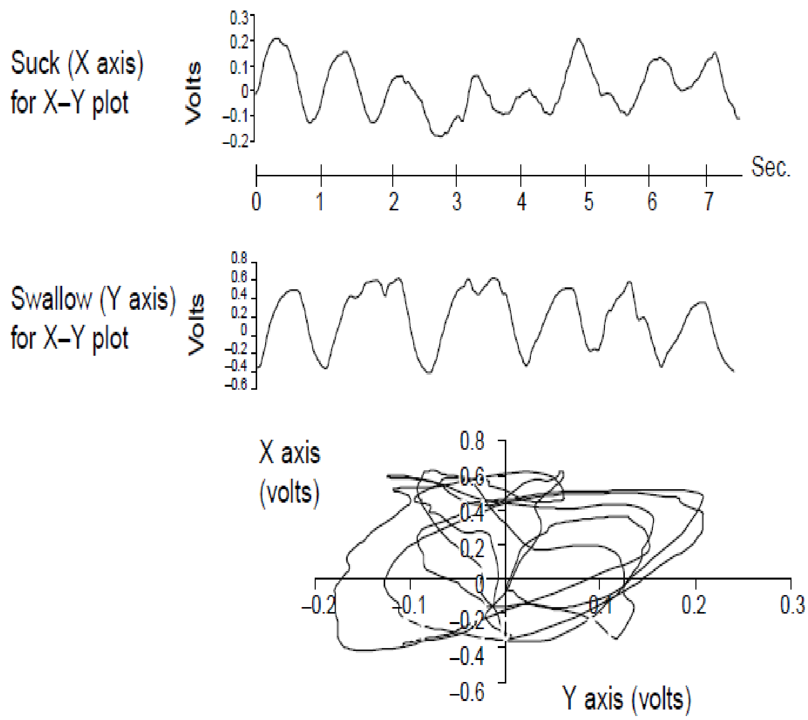

Figure 3. Disorganized nutritive sucking pattern (Qureshi, et al., 2002).

TABLE 1

BIOBEHAVIORAL CONCEPTION OF NEONATAL PROCESSING

Theoretical Definition	Construct Definition	Concept	Variable	Operational Definition
Individual	Full-term Newborn	Human being an open system, epigenetic expression, in-utero and intrapartum experiences	Gestational age Appropriate for gestational age Health from birth to 30 days of age	Maternal description of 38-42 weeks gestational age Maternal description of > 2500gms birth weight, and weight gain during first month Admission to newborn nursery Maternal descriptions of health complications Maternal description of single dimension behavior such as eye contact or temperament

TABLE 1 (continued)
BIOBEHAVIORAL CONCEPTION OF NEONATAL PROCESSING

Theoretical Definition	Construct Definition	Concept	Variable	Operational Definition
Mental System	Neurobehavioral Organization	Mediation of environment Internal coordination of ANS and CNS	Breastfeeding	Maternal description of neonatal latch Description of the pattern of feeding

TABLE 1 (continued)
BIOBEHAVIORAL CONCEPTION OF NEONATAL PROCESSING

Theoretical Definition	Construct Definition	Concept	Variable	Operational Definition
Environment	A neonate's mother as the proximal, distal nested and interactional world surrounding the newborn	External regulation of newborn, experiences that support growth and development Predominantly by a neonate's mother	Annual Income Ethnicity/Race Maternal education Prenatal and intrapartum psychological and medical health history Route of delivery Professional support	Socioenvironmental Questionnaire Semi-Structured Interview

III. MATERNAL BREASTFEEDING EXPERIENCES WITH CHILDREN LATER DIAGNOSED WITH AUTISM SPECTRUM DISORDER

Introduction

Breastfeeding is beneficial for maternal-neonatal interactions (Ainsworth & Bell, 1969; J Britton, Britton, & Gronwaldt, 2006; Stern, 1977; Tronick et al., 1977). To initiate breastfeeding in the first few days of life, a breastfeeding mother needs to observe and respond to a neonate's behavioral cues (Baby-Friendly USA, 2010; Barnard, 1979). Typically developing neonatal behavioral cues such as state of alertness or hand swiping, signal an optimal time for initiating breastfeeding (Barnard, 1979). To initiate and facilitate breastfeeding, a mother may need to optimize behavioral cues to support a neonate's creation of a nutritive latch and sucking pattern (Barnard, 1979; Cadwell, 2007). Breastfeeding for neurodevelopmentally at-risk neonates, such as those with prematurity or Down's syndrome, may be challenging (Danner, 1992; Meier & Pugh, 1985). These neonates may have difficulty communicating clear behavioral cues, and creating and sustaining a nutritive latch because of an immature or disorganized neurological system (Als, 1982; Danner, 1992; McGrath & Bodea-Braescu, 2004; Medoff-Cooper et al., 2009; Meier & Pugh, 1985; Pisacane et al., 2003; Wolff, 1968). A mother's experience breastfeeding a neonate later diagnosed with Autism Spectrum Disorder (ASD), a neurodevelopmental disability, has not been described in the literature.

ASD is diagnosed in 1 of 110 (1%) children, occurring in 1 of 70 boys, and 1 of 310 girls (Center for Disease Control, 2009). ASD is an inclusive term for a spectrum of diagnoses, Pervasive Developmental Disorder - Not Otherwise Specified, Asperger's, and Autism, which presents one or more of these symptoms in various levels of disability: persistent deficits in social communication; social interaction; and restricted, repetitive patterns of behavior, interests, or activities (American Academy of Pediatrics, 2007; Hyman & Towbin, 2007). Presently, children are identified with ASD as early as 18 months of age with standardized assessments (Lord & Bishop, 2010). Little is known about ASD in the neonatal period. Only one group of investigators has described breastfeeding duration in children later diagnosed with ASD (Tanoue & Oda, 1989). In evaluating the maternal reports, weaning was attributed to several factors, such as maternal and neonatal illness. The largest factor was attributed to "maternal breastfeeding failed for no reason" (Tanoue & Oda, 1989, p. 428). No recent study has described the maternal breastfeeding experiences of mothers whose children were later diagnosed with ASD.

Purpose of the Study

This paper describes the maternal breastfeeding experiences during the first month after delivery. This data reported here are from a study on maternal breastfeeding experiences and neonatal breastfeeding behaviors of children later diagnosed with ASD. In this paper, data are reported related to the maternal factors that affected breastfeeding.

Literature Review

Initiation of breastfeeding. Initiation of neonatal breastfeeding is more challenging than neonatal bottle feeding (Geddes et al., 2008; Matthew & Bharia, 1989; Sameroff, 1968; Selley et al., 1990). In order to breastfeed effectively, neonates must coordinate their suck:swallow:breathe in a 1:1:1 ratio, while maintaining suction at the breast so that their tongue can strip the nipple (expression) to obtain milk (Selley et al., 1990; Wolff, 1968). In comparison, the bottle fed neonate only needs expression and not suction in order to obtain milk from a commercialized nipple (Matthew & Bharia, 1989; Sameroff, 1968).

In 2002, 25% of breastfeeding mothers weaned during the first 2 weeks after delivery compared to the first week as found in Tanoue and Oda's study (Tanoue & Oda, 1989; Taveras et al., 2003). The reasons for weaning were perceived inadequate milk supply, breast and nipple trauma, and maternal lack of confidence (Taveras et al., 2003). In 2008, Li, Fein, Chen and Grummer-Strawn reported that 25% of breastfeeding mothers weaned at 1 month and 22% weaned at 2 months (Li et al., 2008). Maternal and neonatal issues were reported as reasons for weaning. Maternal issues were perceived inadequate milk supply and breast and nipple trauma; neonatal issues were the ability of a neonate to create a nutritive latch and a neonate's lack of satisfaction with exclusive breastfeeding (Li et al., 2008). These issues have been identified as barriers to successful breastfeeding in the last 25 years (1986-2011) while there has been an increase in professional lactation support and a greater cultural awareness of breastfeeding (U.S. Department of Health and Human Services, 2011).

Breastfeeding neurodevelopmentally disabled neonates. As many typically developing neonates struggle with initiating breastfeeding, neurodevelopmentally at-risk neonates later diagnosed with ASD may have difficulty because of an atypically developing neurological system (American Academy of Pediatrics, 2007; Danner, 1992; Keen, 2008). Breastfeeding and bottle feeding in neurodevelopmentally at-risk neonates, such as those with Down syndrome or prematurity, have been successful with professional support, peer support, and maternal social support (C. Britton, McCormick, Renfrew, Wade, & King, 2009; Danner, 1992; Medoff-Cooper et al., 2009; Meier & Pugh, 1985; Pisacane et al., 2003; Schmied et al., 2011; Wolff, 1968). Supporting neurodevelopmentally at-risk neonates to breastfeed has given insight into the neurological organization of a neonate and successful maternal breastfeeding behaviors (Bowden, Greenberg, & Donaldson, 2000; Hill, Andersen, & Ledbetter, 1995).

Initiating breastfeeding in neonates later diagnosed with ASD may require similar successful maternal breastfeeding behaviors.

Neonatal Biobehavioral Conception of Processing

The theoretical framework of the Neonatal Biobehavioral Conception of Processing uses three concepts, the neonate (biology and behavior), neonatal biobehavioral activity; and environment. The concept of the neonate has two domains: biology and behavior. The neonate's biological domain is defined as a living human being within the first 30 days of life and operationalized as health, age, and medical complications (Ballard et al., 1991; Blackburn, 2003). The neonate's behavioral domain is defined as observable activity by the neonate in one dimension, sensory or affect, and is operationalized as eye contact, or emotional state (Lester et al., 1985; Sai, 2005; Simion, Farroni, Cassia, Turatie, & Dalla Barba, 2002; Simion et al., 2008; Slater, Morison, & Rose, 1982). Neonatal biobehavioral activity is defined as neonatal neurobehavioral organization (NNBO) (Bell et al., 2007). NNBO is the ability of the neonate to interact and respond to the environment (Bell et al., 2007; Brazelton & Nugent, 1995; Freudigman & Thoman, 1993; Medoff-Cooper et al., 2009; Mizuno & Uedo, 2005; Porges et al., 1973). NNBO is the observable complex behaviors and brain activity as the neonate uses more than one sensory system or affect (Porges et al., 1973; Thoman & Whitney, 1990). The NNBO is the result of the integration of the autonomic, central nervous and sensory systems, such as sleep/wake cycles or feeding (Bell et al., 2007; Porges, 1983; Thoman, 1975; Wolff, 1968). If the neonate has an atypical NNBO, then the neonate's ability to interact with the environment will be altered and may be observed by biobehavioral activities such as feeding (Danner, 1992; Medoff-Cooper et al., 2009; Pisacane et al., 2003; Wolff, 1968). In this study NNBO was operationalized as the mother's description of breastfeeding behaviors. The concept of environment was defined as external regulation of the neonate by his or her mother who primarily creates and participates in experiences that support growth and development, i.e., breastfeeding (Bernstein et al., 2007; Bradley et al., 1989; Bradley et al., 2001; Shiao, Andrews, & Helmreich, 2005; Smithells et al., 1977). The environment was operationalized as **maternal factors** that affect breastfeeding. The neonate is embedded in the environment; as the neonate interacts with the environment, the environment and the neonate both respond and are both changed (Magnusson & Stattin, 2006).

The data reported here focused on the **maternal factors** that affect maternal breastfeeding experiences. The **maternal factors** that positively affect breastfeeding initiation and duration include socio-economic variables such as White ethnicity (Caucasian and/or Hispanic), middle or upper class income, married, college educated, > 25 years of age (Fein et al., 2008; U.S. Department of Health and Human Services, 2011), maternal confidence in breastfeeding (Li et al., 2008; Thulier & Mercer, 2009) and professional breastfeeding support (The Center for Breastfeeding, 2002; Wambach et al., 2005; Weddig et al., 2011). One maternal variable that negatively affects the choice to initiate or sustain breastfeeding is a history of smoking (Amir & Donath, ; Bailey & Wright, 2011; Fein et al., 2008). A history of depression or anxiety has been found to have mixed effects on the initiation and duration of breastfeeding (Fairlie et al., 2009; Kiernana & Pickett, 2006; Pippins et al., 2006), but negatively affects infant cognitive and emotional outcomes (Feldman, 2006, 2007a; Pippins et al., 2006). Breastfeeding success has been found to increase with the environmental support of early initiation of breastfeeding (Baby-Friendly USA, 2010; U.S. Department of Health and Human Services, 2011). Maternal variables that may delay initiation of breastfeeding include cesarean section (Cunningham et al., 2010; Sparks, 2010; Weddig et al., 2011), medication received during labor and delivery (Beilin et al., 2005; Chang & Heaman, 2005; Radzyminski, 2003; Riordan, Gross, Angeron, Krumwiede, & Melin, 2000), maternal breast and nipple structures (Alexander et al., 1992; Cadwell, 2007), hospital routines (Richard & Alade, 1990; Weddig et al., 2011), and formula supplementation (Bernstein et al., 2007; Hill & Humenick, 1997).

Methods

Design. The study design was a retrospective descriptive study.

Sample and setting. Eligible participants were mothers between ages 18-64, who had a full-term delivery (38-42 weeks gestational age), of a child who later received a clinical diagnosis with ASD by a university center using the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM*) and by continuing educational assessment per mothers' description (American Psychiatric Association, 1980, 2003, 2007), and initiated breastfeeding in the hospital setting. Only mothers who could read, write, speak, and understand English, were enrolled. Mothers having a neonate, not admitted to the normal newborn nursery or diagnosed with a genetic anomaly, e.g. Down syndrome were excluded. This study was approved by the University of Illinois Institutional Review Board.

A convenience sample of 21 was recruited; one mother was excluded as her twin sons did not meet the *DSM* criteria of symptoms before 36 months of age (American Psychiatric Association, 1980, 2003, 2007). Recruitment was done via posters and flyers at ASD community events, two community clinics that serve families with ASD, and by the primary investigator being present at ASD community events and clinics at an information table. The location site of the interviews was selected by the participants. Location sites selected by the participants included offices, homes, local restaurants, libraries, and large indoor shopping malls throughout a large Midwestern metropolitan area.

Maternal demographic information is summarized in Table 2. Two mothers had more than one son diagnosed with ASD. One mother had two sons and the second mother had three sons diagnosed with ASD for a total sample of 23 breastfed neonates. Characteristics of maternal breastfeeding experience and duration are summarized in Table 3 and Table 4.

The sample of neonates included 22 boys and one girl, 13 were first-borns and 10 later-born neonates. All neonates were born at 38-42 weeks gestation (*M* = 40; *SD* = .79), with a birth weight from 3033 to 4224 grams (*M* = 3694; *SD* = 446). All children were diagnosed with ASD. Seven neonates received support for temperature instability, low blood sugar, meconium staining or poor oxygenation at birth and the other 17 transitioned at birth with no difficulty. Twenty-two neonates breastfed within 6 hours after delivery.

The age of the children at the time of the interview was 5 to 35 years, (*M* = 11.5; *SD* = 7.6), with 13 (57%) ages 5-9 years, six (26%) ages 10 -20 years, three (13%) between ages 21-30 years, and one (4%) >30 years. The age of the children at the time of their diagnosis ranged from 18 months to 11 years, (*M* = 4.3; *SD* = 2.3).

Data collection, management and analysis procedure. Three measures for this descriptive qualitative study were used: a socio-environmental questionnaire; a semi-structured interview guide; and a post-interview summary. The socio-environmental questionnaire and semi-structured interview used as measures in this study were created based on the maternal variables that affect breastfeeding initiation and duration, as well as neonatal behaviors that affect successful creation of a nutritive latch. The semi-structured interview guide asked about each mother's breastfeeding experience, each neonate's ability to create and sustain a nutritive latch during breastfeeding and bottle feeding, the duration of breastfeeding, each neonate's general behavior during the first month of life, a description of what the child was like at the time of the interview, and a brief history of the child's diagnosis of ASD. Question examples used to interview mothers about their hospital breastfeeding experiences are provided in Table 5. Each interview, which was about one hour in length, was digitally recorded. After each interview a post-interview summary was completed to ensure accuracy, record environmental disturbances, topics and questions that elicited the most response, and establish an audit trail of emerging ideas and categories that occurred as a result of the interview.

Each recording was transcribed verbatim, and the transcript triple checked for accuracy. Data management and analysis were guided by the theoretical framework. The major codes were created from the theoretical framework and used for the analysis: the neonate; the neonate's biobehavioral measure of breastfeeding; and the environment as the maternal factors that positively or negatively affect successful breastfeeding. The sub-codes were created with reading of the transcripts. The first five interviews were double coded by the primary investigator, RL and a research assistant, CPM; then the code book definitions were finalized. The code book was reviewed by both PM, a breastfeeding research expert and KK, a qualitative methods expert for content validity. Thirty percent of the first five interview codes were randomly compared for an inter-rater reliability of 95%. Every fifth interview was double coded by RL and CMP with an inter-rater reliability of 95%. All of the coded interviews were transferred to ATLAS-ti, 6.2, a software program for qualitative analysis which stores and retrieves coded text (ATLAS.ti, 2010).

The ATLAS-ti*, 6.2* program supports analysis of categorical coding within and across subjects. The analysis focus was to differentiate between maternal breastfeeding experiences and neonatal breastfeeding behaviors and what part each brings to the initiation of breastfeeding.

Three major coded categories labeled, “maternal breastfeeding experiences”, “neonatal breastfeeding”, and “neonatal general behaviors” were analyzed. RL read through each mother’s statements and compared mutual coded ideas unique to each interview and common between the 20 mothers’ interviews. The analysis continued as an individual maternal summary of the major categories was written. The 20 individual summaries were peer reviewed by a breastfeeding expert, PH. The next step of abstraction was to use the summaries to begin the within and across subject comparison of ideas and themes. As more ideas emerged the summaries were referred back to verify each individual mother’s experiences. An analysis summary of the data was completed and peer reviewed; a paragraph synopsis of the study’s results was written. The synopsis along with each mother’s individual summary was sent to all 20 mothers for a member check. A member check verifies that the data reported are congruent with the participant and increases the validity and trustworthiness of the data (Lincoln & Guba, 1985). Sixteen of the 20 mothers responded and agreed that their individual summary was accurate. The other four mothers were not able to be reached.

Results

The findings reported here focus on the **maternal factors** that affect maternal breastfeeding experiences. One maternal factor, role of professional support, was a major theme. Other maternal factors such as socioeconomic variables are presented where relevant.

The mothers described three types of professional support which one mother’s experience overlapped between the first and second group. One group (n = 4) recalled breastfeeding success with no or limited professional support. The second group (n = 11) breastfed successfully after receiving positive professional support and the third group (n = 6) had variable success with breastfeeding after receiving unfavorable professional support. Support provided to the second and third groups was given for breastfeeding inexperience, anatomical barriers, and neonates that demonstrated an "insatiable feeding", i.e., frequent vigorous feeding without stopping.

Maternal success at breastfeeding with limited or no professional support. One group of four mothers described initiating breastfeeding six neonates with limited or no professional support. All four mothers initiated breastfeeding at delivery. Two of the four mothers had multiple sons with ASD. A multipara mother said, "As soon as he was delivered…they checked him out first and then they [nurses] put him to my breast… with a little bit of help and just helping getting the latch on it was fine."

The second mother had two sons diagnosed with ASD. At the birth of her first son, she described receiving positive professional support and breastfed for 18 months. She described initiating breastfeeding with her second son, "When I compare them, [my second son] was a lot quicker, I mean, he got it right away…and I was a lot more efficient."

The third mother also had no difficulty initiating breastfeeding; however, after she was discharged she described her daughter as being an 'insatiable feeder', i.e., frequent vigorous feeding without stopping. "It seemed like she still wanted to be breastfed even though she was full." The fourth mother was the mother with three sons diagnosed with ASD. She had no difficulty initiating breastfeeding, she said, "My three children could have taught the class." However, her first son demonstrated "insatiable feeding"; beginning at the second week of life until she went back to work at six weeks. "He was nursing 45 minute stretches, every two hours on the hour. So I was not sleeping and I chose at that time to end the breastfeeding."

Positive professional support for breastfeeding challenges. The second group consisted of 11 mothers. Nine of the mothers were primiparas who described receiving support for breastfeeding inexperience; one of them was the mother of two sons with ASD whose experience overlapped the two groups of mothers who described maternal success at breastfeeding with limited or no professional support and receiving positive professional support for breastfeeding challenges. Five of the nine primiparas described receiving support to manage their neonates' "insatiable feeding". The remaining two mothers in this group were multiparas, who described receiving support, one for sustaining a successful latch and the other to manage the "insatiable feeding".

The nine primiparas described receiving positive support to position their neonate to create and sustain a nutritive latch. The mother of two sons with ASD described her first breastfeeding experience as "The postpartum nurses are very good at knowing what to do too… they would come in when, when I was going to nurse him… [they were] coaching me." One of the primiparas had extended hospitalization due to complications with preeclampsia, but she was motivated to be successful at breastfeeding. "I wanted him to get that colostrum." She described how she actively sought lactation support during her first hospitalization after delivery and again after being readmitted. She described being followed by the lactation staff during both hospitalizations and being coached about how to reestablish breastfeeding after discharge.

Four of 11 mothers (one multipara and three primiparas) described receiving support for maternal anatomical barriers. One multipara described being coached to facilitate latching her son's small mouth around her nipple, but was successfully breastfeeding at discharge. The three primiparas reported having flat or inverted nipples. Two mothers described creating a nutritive latch for their neonates with professional support and the assistance of a nipple shield. One mother said "I remember one woman that helped me that she was like. 'Think of it as like a hamburger' and when she said that to me, that seemed like the magic words."

Although the third mother did not have access to a nipple shield, her son "latched beautifully, the first time around;" however, after his circumcision "He was a beast to nurse." She and a lactation consultant spent 5 hours the night before she went home trying to establish breastfeeding. The lactation consultant was concerned about sending them home and negotiated an additional hospital day. By discharge, she and her son had established a nutritive latch. She spent the next 2 weeks at home spending hours working with him. "I didn't let any formula come in the front door…he probably brought the nipple out on his own with the multiple attempts."

Four mothers, three primiparas and one multipara, described their experience of positive support from the postpartum staff by coaching them on how to manage the "insatiable feeding" with a proper anatomical latch, emotional support, formula supplementation or supplemental nursing system. One primipara described how she perceived her neonate's "insatiable feeding" was milk insufficiency. "So, he would just suck and suck and suck and suck. I can't pee…like I have got him on my boppee and I'm like eating, you know with both hands." She described how a staff nurse intervened by supplementing her son with formula because he wanted 'Thanksgiving dinner'. Later, another staff nurse coached her to use a supplemental nursing system (SNS) for his "insatiable feeding".

Two multiparas described how they managed their neonates' "insatiable feeding" with lactation support. One mother described how she had experienced previous breastfeeding difficulty with her first premature neonate. Based on that experience she described how she actively sought support and was seen by the lactation consultant three times before discharge. She described supporting her neonate's nutritive latch and "insatiable feeding" as:

Having gone through that whole, learning to breastfeed procedure once before, I was a little more confident with my ability to hold him correctly and know that he was latching on…and then he would just go and go and go and go… And eventually he would fall asleep but he would keep sucking.… I think that that was probably the one thing I noticed that he doesn't seem to have an on/off as it were, in terms of saying.

By discharge, all 11 mothers who had described receiving beneficial professional support were confident in initiating breastfeeding with their neonates and to call for help if they needed assistance. "So, just, just a little bit of help. I think it was more like, could you just help me so we could get it going right from the start. So, I wasn't afraid to ask for help." Or another mother stated, "It was good. That is all I can say. I had no problems and he was swallowing, he was drinking, everything was fine. "

Unfavorable professional support for breastfeeding challenges. The third maternal factor was described by 6 of the 20 mothers who perceived their professional support as not helpful. Three of the six mothers were primiparas; three were multiparas. The primiparas described receiving support for many breastfeeding challenges: low muscle tone, maternal inexperience, ankyloglossia (short frenulum), maternal flat nipples, and neonatal "insatiable feeding". The multiparas received support for "insatiable feeding".

The first primipara described having difficulty breastfeeding her son who was diagnosed with low muscle tone at one year. She said,

The lactation nurse, almost like yelling at me, you have to stick the whole nipple in. I was like, 'He doesn't want it!' She was like, 'It doesn't work otherwise.' 'But he's eating, so like, it's working'… It was like the night before we went home; yeah I was up crying a lot, because he wasn't eating and he was crying and unhappy…. When they said he's got low muscle tone…after age one, I said to my husband, well maybe the low muscle tone was there at birth and that was why he couldn't, why he wasn't a good breastfeeder.

Two other primiparas described receiving unfavorable professional support during their hospital stay. One mother had a son with a short frenulum. She described being able to latch her son on one side, "With somebody's assistance. I think—now, because it was so new to me at the time, I don't even remember—did he even latch on?" She described being discharged without being confident of her breastfeeding latch. After her neonate lost one pound during the first week after discharge, her pediatrician prescribed a visit by a lactation consultant and prescribed a frenotomy for her son. The second primipara described her son wanting to feed frequently without satisfaction. "I think he was just so hungry… maybe I wasn't producing enough milk at that time." She was unable to latch her son on one breast and asked for help several times a day. When she couldn't get her son to latch by herself, she described supplementing her son with formula which was handed to her with each feeding. "I almost felt like they saw my frustration and because they saw that he was having formula they decided well… we're not gonna do our best to help her." She described weaning at discharge.

Three multiparas had neonates they described who created a nutritive latch but with an "insatiable feeding" who experienced unfavorable support. One mother was uncomfortable with the professional support, "He feed til I bled… When the lactation consultant came in, you know, she told me, 'Oh you're bleeding!' and they tried to put…shields on, but, that just felt so unnatural...and I wasn't comfortable with the pump either."

The last multipara delivered 34 years ago when professional breastfeeding support was minimal. She was coached by her sister to breastfeed, not by a professional. She said, "Nobody taught me… it wasn't even popular to breastfeed your children [34 years ago]… I'm sure they slipped him a bottle before they ever brought him to me."

Discussion

No previous study has described the breastfeeding experiences of mothers whose neonates were later diagnosed with ASD. In exploring the breastfeeding experiences of mothers whose neonate were later diagnosed with ASD, the hope was to discover if atypical patterns of breastfeeding emerged. The atypical pattern of breastfeeding may assist in early screening.

The 20 mothers in this sample were able to create and sustain a nutritive latch while breastfeeding. Only one mother reported weaning at discharge compared to 25% of mothers in another study population (Tanoue & Oda, 1989). In this study, 78% of the mothers reported exclusively breastfeeding at discharge, 73% reported exclusively breastfeeding to 3 months, and 43% reported exclusively breastfeeding to 6 months.

The descriptions of maternal breastfeeding experience reflect the literature regarding how maternal factors positively and negatively affect breastfeeding success. In this study, 15 mothers were Caucasian and/or Hispanic, had an average of 16.2 years of education, 80% had > $50,000/year income, described a prenatal intention of breastfeeding an average of 10.2 months, and 11 mothers described being confident to breastfeed at discharge (Lawson & Tulloch, 1995; Li, Ogden, Ballew, Gilliespie, & Grummer-Strawn, 2002; U.S. Department of Health and Human Services, 2011). Eleven mothers (nine primiparas and two multiparas) received positive support from the professional staff while in the hospital which is one maternal factor of the environment as conceptualized in the framework. The supportive interventions included early initiation of breastfeeding, rooming-in, and professional support for maternal inexperience and anatomical barriers (Baby-Friendly USA, 2010; Declercq et al., 2009; Li et al., 2008). In this study all of the mothers described how important breastfeeding was for their neonates' health and how they were motivated to succeed at breastfeeding.

In contrast to the positive professional support, seven mothers described their professional support as unfavorable. Six of the 7 mothers described initiating breastfeeding at delivery as per The Baby Friendly Hospital guidelines (Baby-Friendly USA, 2010). All seven mothers described experiencing breastfeeding challenges that required professional support. These mothers desired the support, but during the interchange the professional missed the importance of supporting each mother as she perceived her need (Li et al., 2008; Taveras et al., 2003). The mothers quickly perceived when the professionals gave up on them. A clinical implication of this study is the importance of professional support for successful breastfeeding. Although professional support was not always positive, the mothers needed the support to overcome breastfeeding inexperience, anatomical barriers, to identify vigorous sucking patterns, and to learn how to protect themselves from nipple trauma. Professional support may also increase the duration of breastfeeding if at-risk mother-neonate breastfeeding couples are identified at discharge for follow-up support at home (Baby-Friendly USA, 2010).

The mothers in this study delivered neonates who were admitted to the newborn nursery and assumed to be typical neonates. Yet all three groups of mothers described neonates who demonstrated "insatiable feeding". The 'insatiable feeder' was described by the mother and her professional support to be a successful breastfeeder which is a measure of typical NBO. Typical neonates feed frequently, 8-12 feedings in 24 hours, lasting 5-20 minutes per feeding session during the first weeks of life, terminate feeding at the breast, and typically fall asleep (American Academy of Pediatrics, 2005). The "insatiable feeder" neonates in this study were described as breastfeeding until their mothers stopped them. For neonates later diagnosed with ASD, “insatiable feeding” may be a soft neurological sign of atypical development and a potential predecessor of repetitive behaviors that are the hallmark of ASD.

Finally, the mothers’ descriptions of breastfeeding demonstrated greater success than Tanoue & Oda’s population because the populations differed in three ways. First, in Tanoue & Oda’s study neonatal inclusion criteria used the *DSM-III* diagnosis for infantile autism (American Psychiatric Association, 1980). Infantile autism is characterized by significant neurodevelopmental disorganization compared to the broader *DSM-IV*, *DSM-IV-TR* diagnosis of ASD (American Academy of Pediatrics, 2007; American Psychiatric Association, 1980, 2003). The children and adults described in the present study were diagnosed under several *DSM* criteria because of their broad age range (5-34 years of age). The diagnosis of ASD encompasses a spectrum range of atypical neurodevelopment and many of the children and adults were less affected than those neonates diagnosed with infantile autism. Second, Tanoue & Oda’s population also included neonates treated in the intensive care unit which were excluded in the present study. A third difference is that breastfeeding in Japan, the site of the Tanoue & Oda’s study, may be culturally different than in the United States. A fourth difference between the two studies is the significant change in the World Health Organization’s focus on breastfeeding—the large group of mothers who had “breastfeeding failures” may today have received additional support and been successful at breastfeeding (World Health Organization, 2007).

Limitations. The limitations of this study include a small sample size, maternal bias towards breastfeeding which may have motivated them to participate in the study, potentially skewing their recall of their breastfeeding experience, and altering their recall after the large time gap (5-34 years) since breastfeeding. This bias may account for a larger proportion of mothers in this study reporting a higher breastfeeding success rate and duration rate compared with the average population (Emond et al., 2010; U.S. Department of Health and Human Services, 2011). The focus of this study was the initiation of breastfeeding; research has found that women recall with accuracy the initiation of breastfeeding up to 50 years later, but with best accuracy within 3 years of initiating breastfeeding (Li et al., 2005; Tomeo, Rich-Edwards, & Michels, 1999). However, many of the mothers in this study stopped breastfeeding over 10 years ago and they may have interpreted their breastfeeding experience differently now, than if they were closer to the event. A final limitation is that NNBO was operationalized as the mother's description of breastfeeding, thus precluding other interpretation of the neonate's behaviors.

Future research. Future research is needed to establish how common "insatiable feeding" is within breastfeeding and bottle feeding populations. A larger qualitative study is needed to describe if the "insatiable feeding" is prevalent in children with ASD, or if "insatiable feeding" is present in bottle feeding within the ASD diagnostic spectrum.

Conclusion. In summary, the mothers of children later diagnosed with ASD reported breastfeeding experiences similar to mothers with typical developing children. The mothers described their breastfeeding as successful with minimal support and some professional support. However, further in-depth study is needed to determine if mothers of neonates later diagnosed with ASD report similar "insatiable feeding" behaviors as reported in this study, and how mothers of neonates not diagnosed with ASD describe their neonate's feeding behaviors.

TABLE 2

MATERNAL CHARACTERISTICS *(N = 20)*

Maternal Variable	Delivery			Diagnosis			Interview		
	Range	*M*	*(SD)*	Range	*M*	*(SD)*	Range	*M*	*(SD)*
Maternal age, yrs	22-39	30.8	(3.9)	28-45	35.1	(4.7)	28-60	43.3	(9.6)
Maternal Education, yrs	10-18	16.2	(2.0)				10-18	16.2	(2.1)
Paternal Education, yrs							12-18	15.8	(2.8)
Maternal Intention Breastfeeding, months	6-18	10.6	(3.8)						
Breastfeeding Duration, months							3-18+	9.0	(5.6)

TABLE 2 (continued)

MATERNAL CHARACTERISTICS

Maternal Variable	Delivery	Diagnosis	Interview
Marital Status	N (%)	N (%)	N (%)
Married	19 (95%)	19 (95)	18 (85%)
Stable partner	1 (5%)	1 (5%)	0
Single	0	0	0
Divorced	0	0	2 (10%)
Ethnicity			
Asian	1 (4%)		
Black	3 (15%)		
Hispanic	4 (20%)		
Caucasian	12 (60%)		

TABLE 3

MATERNAL BREASTFEEDING DURATION *(N = 23)*

Duration	Number weaned *n*	(%)	Breastfeeding *n*	(%)	Difficulty with Breastfeeding
Hospital	1	(4%)	22	(96%)	Latch
3 months	3	(13%)	17	(73%)	Flat nipples, "insatiable feeding"
6 months	3	(13%)	10	(43%)	Two neonates weaned on own, both with "insatiable feeding"; short frenulum
9 months	7	(30%)	9	(39%)	Milk insufficiency, neonate weaned on own, mother returning to work
12 months	2	(9%)	7	(30%)	Maternal plan
18 months	4	(17%)	3	(13%)	Maternal plan, maternal difficulty with weaning neonates with "insatiable feeding"

TABLE 4

MATERNAL BREASTFEEDING EXPERIENCES

Subject	Age of child at interview	Prior breastfeeding experience	Breastfed < 1 hour delivery	Breastfeeding challenges	Professional support strategy or intervention	Maternal Perception	Duration Reason for weaning
1	16	Yes	No	Insatiable feeding, cracked and bleeding nipples	Pumping, nipple shields	Unfavorable, uncomfortable with intervention	2 months Nipple trauma
2	14	No	No	Maternal inexperience and mixed breast and bottle feeding because of maternal complications, facilitating latch	Pumping, positioning, six lactation visits	Positive	9 months Return to work
3	7	No	No	Maternal inexperience facilitating latch with poor muscle tone	Positioning	Unfavorable uncomfortable with intervention	9 month Return to work, infant weaned

TABLE 4 (continued)

MATERNAL BREASTFEEDING EXPERIENCES

Subject	Age of child at interview	Prior breastfeeding experience	Breastfed < 1 hour delivery	Breastfeeding challenges	Professional support strategy or intervention	Maternal Perception	Duration Reason for weaning
5	12	1st No	Yes	Insatiable feeding, maternal inexperience	Initial Assessment	Minimal Positive	2 months Nipple trauma
	7	2nd Yes	Yes	None	Initial Assessment	Minimal Positive	14 months Maternal choice
	5	3rd Yes	Yes	Mild nipple trauma, maternal complications	Initial Assessment	Minimal Positive	18 months Maternal choice, professional recommendation

TABLE 4 (continued)

MATERNAL BREASTFEEDING EXPERIENCES

Subject	Age of child at interview	Prior breastfeeding experience	Breastfed < 1 hour delivery	Breastfeeding challenges	Professional support strategy or intervention	Maternal Perception	Duration Reason for weaning
6	34	Yes	Yes	Insatiable feeding	None, no culture of breastfeeding support	Unfavorable	18+ months? Continued to breastfed after birth of sibling
7	24	No	No	Flat nipples, facilitating latch, maternal inexperience and maternal complications	Positioning, nipple shield, pumping, 2 weeks after discharge spent 12 hours at lactation consultant home	Positive	7 months Milk insufficiency

TABLE 4 (continued)

MATERNAL BREASTFEEDING EXPERIENCES

Subject	Age of child at interview	Prior breastfeeding experience	Breastfed < 1 hour delivery	Breastfeeding challenges	Professional support strategy or intervention	Maternal Perception	Duration Reason for weaning
8	9	1st No	Yes	Inexperience	Positioning	Positive	18 months Maternal choice
	5	2nd Yes	Yes	None	None	Minimal Positive	18 months Maternal choice
9	21	No	Yes	Facilitating latch, maternal inexperience, Neonate had difficulty regulating milk flow after milk letdown	Positioning, quiet and darkened room	Positive	9 months Maternal choice, return to work, infant weaned

TABLE 4 (continued)

MATERNAL BREASTFEEDING EXPERIENCES

Subject	Age of child at interview	Prior breastfeeding experience	Breastfed < 1 hour delivery	Breastfeeding challenges	Professional support strategy or intervention	Maternal Perception	Duration Reason for weaning
10	7	No	No	Insatiable feeding, facilitating latch, unable to latch on one side, maternal inexperience, maternal complications	Positioning, pumping	Unfavorable felt impatience of and judgment by staff	3 days Maternal choice
11	7	No	Yes	Insatiable feeding Facilitating latch, flat nipples, maternal inexperience	Positioning, pumping, nipple shield, quiet and darkened room	Positive, helpful with positioning	3 months Maternal choice, nipple trauma, return to work

TABLE 4 (continued)

MATERNAL BREASTFEEDING EXPERIENCES

Subject	Age of child at interview	Prior breastfeeding experience	Breastfed < 1 hour delivery	Breastfeeding challenges	Professional support strategy or intervention	Maternal Perception	Duration Reason for weaning
12	8	Yes	Yes	Insatiable feeding, facilitating latch, nipple trauma	Refused help based on two negative breastfeeding experience with older siblings	Unfavorable	10 months Maternal choice
13	21	Yes	No	Facilitating latch with small neonatal mouth	Positioning	Positive	9 months Return to work
14	16	Yes	No	Insatiable feeding	Emotional support	Positive	5 months Infant weaned

TABLE 4 (continued)

MATERNAL BREASTFEEDING EXPERIENCES

Subject	Age of child at interview	Prior breastfeeding experience	Breastfed < 1 hour delivery	Breastfeeding challenges	Professional support strategy or intervention	Maternal Perception	Duration Reason for weaning
15	5	No	Yes	Short frenulum, maternal inexperience	Positioning, pumping	Unfavorable, never confident	4 months Never established effective latch
16	10	Yes	Yes	None	Initial assessment with alternate positioning	Minimal uncomfortable with intervention	12 months Maternal choice
17	6	No	Yes	Insatiable feeding, maternal inexperience	Positioning	Positive with positioning	9 months Return to work, milk insufficiency

TABLE 4 (continued)

MATERNAL BREASTFEEDING EXPERIENCES

Subject	Age of child at interview	Prior breastfeeding experience	Breastfed < 1 hour delivery	Breastfeeding challenges	Professional support strategy or intervention	Maternal Perception	Duration Reason for weaning
18	5	No	Yes	Insatiable feeding, maternal inexperience	Positioning, supplemental nursing system, pumping	Positive	14 months Maternal choice
19	6	No	Yes	Insatiable feeding, maternal inexperience	Initial assessment	Positive, mother worked on latch alone	9 months Infant weaned
20	6	Yes	Yes	Insatiable feeding	Initial assessment	Minimal positive	4 months Infant weaned

Table 5

SEMI-STRUCTURED INTERVIEW QUESTION EXAMPLES

Breastfeeding Following Birth and During Hospitalization

1) Please describe for me your first breastfeeding experience with NAME
    a. How did it go?
    b. When did it occur?
    c. Were there any concerns?
2) How would you describe NAME's sucking behavior?
3) Do you remember hearing NAME swallow your milk while breastfeeding?
4) Did NAME have any trouble latching-on to the breast?
5) Did NAME have any trouble opening mouth wide?
6) If you had trouble with NAME latching did you have any breast or nipple tissue trauma?
7) Do you recall NAME having any difficulty such as?
    a. Latching-on to the breast?
    b. Placement of his or her tongue?
    c. Placement of his or her lips?
    d. Creating suction?
8) Did NAME need help with stimulation to the palate, tongue, lips?
9) Did you experience any trauma during breastfeeding such as pain, cracked nipples, bleeding, bruising?
10) Did you ask for lactation consultant help?
11) Did staff recommend a lactation consultant help?
12) Did you use a nipple shield during breastfeeding with NAME?

Table 5 (continued)

SEMI-STRUCTURED INTERVIEW QUESTION EXAMPLES

Breastfeeding Following Birth and During Hospitalization
13) Did you have to pump?
14) What do you recall about your breastfeeding experience during the remainder of your hospitalization?
15) Do you recall NAME getting other nutrition besides your own milk, such as formula?
16) If yes, do you know why NAME was given formula?
17) If yes, do you remember how often NAME had formula while in the hospital?
18) When you and NAME left the hospital, how would you describe your health and the health of NAME?

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APPENDICES

Appendix A

UNIVERSITY OF ILLINOIS
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice
Initial Review (Response To Modifications)

April 21, 2010

Ruth Lucas, RN
Nursing
845 S Damen Avenue, Room 838
M/C 820
Chicago, IL 60612
Phone: (630) 738-4113 / Fax: (312) 996-8871

RE: **Protocol # 2010-0348**
"Maternal Breastfeeding Experiences and Neonatal Breastfeeding Behaviors of Children Diagnosed with Autism"

Dear Ms. Lucas:

Your Initial Review application (Response To Modifications) was reviewed and approved by the Expedited review process on April 21, 2010. You may now begin your research.

Please note the following information about your approved research protocol:

Protocol Approval Period: April 21, 2010 - April 20, 2011
Approved Subject Enrollment #: 30
Additional Determinations for Research Involving Minors: The Board determined that this research satisfies 45CFR46.404, research not involving greater than minimal risk. Therefore, in accordance with 45CFR46.408, the IRB determined that only one parent's/legal guardian's permission/signature is needed. Please see "Assent" below.
Performance Sites: UIC, Chicagoland Autism Connection, Easter Seals DuPage and the Fox Valley Region, One Place for Special Needs
Sponsor: None
Research Protocol:

a) Maternal Breastfeeding Experiences and Neonatal Breastfeeding Behaviors of Children Diagnosed with Autism;02/26/2010

Recruitment Materials:

a) Second F-to-F Contact Script; Version 1; 04/16/2010
b) Third F-t-F Contact Script; Version 1; 04/16/2010
c) Second Contact Telephone Script; Version 1; 04/16/2010

APPENDIX A (continued)

d) Third Contact Telephone Script; Version 1; 04/16/2010
e) Recruitment Flyer; Version 2; 04/16/2010
f) Web Advertisement; Version 1; 04/16/2010
g) Public Announcement; Version 1; 04/16/2010
h) Breastfeeding Recruitment Poster; Version 1; 04/16/2010
i) Fourth Telephone Contact Script; Version 1; 04/16/2010
j) Revised Telephone Script; Version 3; 04/20/2010
k) Revised Face-to-Face Script; Version 3; 04/20/2010
l) Business Cards (no footer)

Informed Consent:

a) A waiver of documentation has been granted under 45 CFR 46.117 for recruitment/screening purposes only (verbal consent will be obtained at screening, written permission/consent will be subsequently obtained, private contact information for potential subjects will be destroyed if those potential subjects subsequently decline to enroll in the research)

Assent:

a) A waiver of child assent has been granted under 45 CFR 46.116(d) for infants as secondary subjects (mother will be disclosing data regarding the infant; written parent permission/consent will be obtained)

Parental Permission:

a) Maternal Breastfeeding Consent; Version 3; 04/20/2010

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.,
(7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
04/01/2010	Initial Review	Expedited	04/07/2010	Modifications Required
04/16/2010	Response To Modifications	Expedited	04/19/2010	Modifications Required
04/20/2010	Response To Modifications	Expedited	04/21/2010	Approved

Please remember to:

→ Use your **research protocol number** (2010-0348) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the enclosure,
"UIC Investigator Responsibilities, Protection of Human Research Subjects"

APPENDIX A (continued)

2010-0348 Page 3 of 3 4/21/2010

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-2014. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Sandra Costello
Assistant Director, IRB # 2
Office for the Protection of Research Subjects

Enclosures:

1. **UIC Investigator Responsibilities, Protection of Human Research Subjects**
2. **Parental Permission:**
   a) Maternal Breastfeeding Consent; Version 3; 04/20/2010
3. **Recruiting Materials:**
   a) Second F-to-F Contact Script; Version 1; 04/16/2010
   b) Third F-t-F Contact Script; Version 1; 04/16/2010
   c) Second Contact Telephone Script; Version 1; 04/16/2010
   d) Third Contact Telephone Script; Version 1; 04/16/2010
   e) Recruitment Flyer; Version 2; 04/16/2010
   f) Web Advertisement; Version 1; 04/16/2010
   g) Public Announcement; Version 1; 04/16/2010
   h) Breastfeeding Recruitment Poster; Version 1; 04/16/2010
   i) Fourth Telephone Contact Script; Version 1; 04/16/2010
   j) Revised Telephone Script; Version 3; 04/20/2010
   k) Revised Face-to-Face Script; Version 3; 04/20/2010
   l) Business Cards (no footer)

cc: Joan Shaver, Nursing, M/C 802
Pamela D. Hill, Maternal Child Nursing, M/C 802

APPENDIX B

UNIVERSITY OF ILLINOIS
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice
Continuing Review

March 3, 2011

Ruth Lucas, RN
Nursing
845 S Damen Avenue, Room 838
M/C 820
Chicago, IL 60612
Phone: (630) 738-4113 / Fax: (312) 996-8871

RE: Protocol # 2010-0348
"Maternal Breastfeeding Experiences and Neonatal Breastfeeding Behaviors of Children Diagnosed with Autism"

Dear Ms. Lucas:

Your Continuing Review was reviewed and approved by the Expedited review process on February 24, 2011. You may now continue your research.

Please note the following information about your approved research protocol:

Protocol Approval Period: February 24, 2011 - February 23, 2012
Approved Subject Enrollment #: 30 (limited to data analysis only for 21 subjects)
Additional Determinations for Research Involving Minors: The Board determined that this research satisfies 45CFR46, research not involving greater than minimal risk.
Performance Sites: UIC, Chicagoland Autism Connection, Easter Seals DuPage and the Fox Valley Region, One Place for Special Needs, UIC Disability and Human Development Family Clinic
Sponsor: None
Research Protocol(s):

a) Maternal Breastfeeding Experiences and Neonatal Breastfeeding Behaviors of Children Diagnosed with Autism;02/26/2010

Recruitment Material(s):

a) Not applicable – limited to data analysis only.

Informed Consent(s):

a) Not applicable – limited to data analysis only.

Phone: 312-996-1711 http://www.uic.edu/depts/ovcr/oprs/ FAX: 312-413-2929

APPENDIX B (continued)

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific category(ies):

(6) Collection of data from voice, video, digital, or image recordings made for research purposes., (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
02/17/2011	Continuing Review	Expedited	02/24/2011	Approved

Please remember to:

→ Use your **research protocol number** (2010-0348) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the enclosure,
"UIC Investigator Responsibilities, Protection of Human Research Subjects"

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 355-0816. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Chijioke G. Ogbuka, M.A.
IRB Coordinator, IRB # 2
Office for the Protection of Research Subjects

Enclosure(s):

1. **UIC Investigator Responsibilities, Protection of Human Research Subjects**

cc: Joan Shaver, Nursing, M/C 802
Pamela D. Hill, Maternal child Nursing, M/C 802

APPENDIX C

SOCIOENVIRONMENTAL QUESTIONNAIRE

Date _________

ID ___________

I. Background Questionnaire

Please read each item and fill in the blank as requested, circle the appropriate response, or check a box that best represents you.

1) What is your age and birth date? Age _______ Date of birth: ____________
(Month) (Day) (Year)

2) What was your age at the birth of your child diagnosed with autism?___

3) What is your marital status?
a. Married to father who lives in our household
b. Living with father but not married to him
c. Married to father who is involved but living elsewhere
d. Not married to father who is involved but living elsewhere
e. Father of infant not involved at this time

4) What was your marital status when your child was born?
a. Married to father who lives in our household
b. Living with father but not married to him
c. Married to father who is involved but living elsewhere
d. Not married to father who is involved but living elsewhere
e. Father of infant not involved at this time

5) How many years of education have you had? (Circle the highest grade)

a. Grade School ………1	2	3	4	5	6	7	8	
b. High School …………………9		10	11	12				
c. College or Vocational School …………..…….				13	14	15	16	
d. Some Graduate School …………………….			17					
e. Graduate School or beyond …………..…			18					

APPENDIX C (continued)

6) How many years of education did you have when your child was born? (Circle the highest grade)

a. Grade School ………1	2	3	4	5	6	7	8
b. High School …………………9		10	11	12			
c. College or Vocational School …………..…….				13	14	15	16
d. Some Graduate School ……………………			17				
e. Graduate School or beyond ………….…			18				

7) How many years of education does the father of your child have? (Circle the highest grade)

a. Grade School ………1	2	3	4	5	6	7	8
b. High School …………………9		10	11	12			
c. College or Vocational School …………..…….				13	14	15	16
d. Some Graduate School ……………………			17				
e. Graduate School or beyond ………….…			18				

8) Check the groups with which you identify. Please check a box for each category.

i. Ethnic Category: ☐ Hispanic or Latino ☐ Not Hispanic or Latino ☐ Unknown

ii. Racial Categories:

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Native Hawaiian
- ☐ Pacific Islander
- ☐ White
- ☐ More than one race
- ☐ Unknown

iii. Where were you born?

- ☐ US
- ☐ Mexico
- ☐ South America
- ☐ Central America
- ☐ Europe
- ☐ Asia
- ☐ Africa
- ☐ Other _____

APPENDIX C (continued)

9) What is your occupation?

____

10) What was your occupation when your child was born?

____

11) What is your child diagnosed with autism father's occupation?

____

12) Check below your gross annual household income last year –

☐ Under $ 10,000	☐ $ 10,000 to $ 19,999
☐ $ 20,000 to $ 29,999	☐ $ 30,000 to $ 39,999
☐ $ 40,000 to $ 49,999	☐ $ 50,000 and over

13) Check below your gross annual household income when your child was born –

☐ Under $ 10,000	☐ $ 10,000 to $ 19,999
☐ $ 20,000 to $ 29,999	☐ $ 30,000 to $ 39,999
☐ $ 40,000 to $ 49,999	☐ $ 50,000 and over

14) How tall are you? ________ ft. ________ inches

15) What was your weight at the time of delivery? ________pounds

16) How much weight did you gain with this pregnancy? ____________pounds

17) Including this child, how many pregnancies have you had _______

APPENDIX C (continued)

18) Including your child diagnosed with autism how many living children do have?

a. **_____Boys _____Girls**

19) What is your child's birthday?

20) Is your child:

- ☐ Boy
- ☐ Girl

21) Birth Weight: _____pounds ____ounces

22) G**estational age at birth (Please circle one)?**

a. 38 weeks
b. 39 weeks
c. 40 weeks
d. 41 weeks
e. 42 weeks

23) What type of delivery did you have with your child diagnosed with autism?

a. Cesarean
b. Vaginal
c. Vaginal Birth After Cesarean

24) Have you ever previously breastfed an infant? ☐ Yes ☐ No

25) Have you been told you have inverted or flat nipples? Inverted: ☐ Yes ☐ No

Flat: ☐ Yes ☐ No

26) Were you breastfed as an infant? ☐ Yes ☐ No

APPENDIX C (continued)

27) When did you first initiate breastfeeding with your child diagnosed with autism?

a. at delivery
b. First 6 hours
c. Between 7-12 hours of age
d. Between 13 – 24 hours of age
e. > 24 hours after birth

28) How long did you plan to breastfeed this child? _____________weeks/months (circle)

29) How old was your child when you stopped breastfeeding altogether? ________

APPENDIX D

Semi-structured Interview Guide

Maternal Breastfeeding Experiences and Neonatal Breastfeeding Behaviors of Children Diagnosed with Autism

(To identify neonatal breastfeeding behaviors as a description of neonatal processing)

I. Introduction of Breastfeeding Questionnaire

The reason why we are having this interview is because I am interested in learning about maternal breastfeeding experiences and neonatal breastfeeding behaviors of children diagnosed with autism. Because you are a mother of a child diagnosed with autism that breastfeed your full term newborn, we are interested in your breastfeeding experience.

As you are aware as a mother of a child diagnosed with autism, the number of children diagnosed with autism has risen dramatically in the last ten years. As health care providers we want to have a greater understanding of autism to support your family and other families like you now and in the future. Identifying autism as early as possible will allow early intervention of children diagnosed with autism. The earlier the identification of autism, the earlier support and interventions to help families will begin. Many infants later diagnosed with autism had difficulty with feeding during the first year. Many normal newborns have difficulty feeding during the first month of life. No one has studied early breastfeeding behaviors in children later diagnosed with autism.

During this interview, I will ask you a series of questions to find out when you decided to breastfeed, your breastfeeding experience, any interventions you used to help with breastfeeding, and any neonatal breastfeeding behaviors you experienced during your child's first month of life. In particular, I am interested in hearing about what you did as a mother to support breastfeeding and how your newborn responded during the first month of life. We hope the information that we learn from your experiences will give insight into neonatal behavior in the first month of life that might help identify infants with autism in the future. Please do not hesitate to ask me any questions or express any concerns you have during our conversation.

First, I would like to learn more about your reason for participating in this study and learn about your experience of having a child diagnosed with autism.

APPENDIX D (continued)

Interview Guide

II. Infant History of Autism

1) **How did you find out about this study?**

2) **Tell me what made you choose to participate in this study?**

3) **I want to get to know your child (NAME). Tell me about the time when NAME was diagnosed with autism?**

4) **Did you as a parent suspect that something was wrong?**

5) **If yes, when did you suspect something?**

6) **Did you have any concerns about NAME and you looking at one another, paying attention to objects together or just being together at any time?**

7) **If yes, when was this and what were you feeling?**

8) **How much longer after that did you start to be concerned something might be different with NAME?**

9) **Do you recall why you felt that something was not right with NAME?**

10) **What sensory thing or action does your child (NAME) like to experience?**

11) **What have you found to be helpful for NAME to organize his/her day, (such as a schedule, one task at a time, etc.)?**

12) **What have you found to be helpful for NAME to learn a new behavior?**

13) **If NAME has been in therapy, what has been helpful for him/her to learn new things?**

III. Maternal Medical and Prenatal History

I want to talk about your breastfeeding experience, but I first want to learn about your medical and prenatal history. I want to have an understanding about pregnancy of NAME of child

APPENDIX D (continued)

14) **In your medical history do you have any of the following**:

  a. Diabetes
  b. Metabolic disease (thyroid)
  c. Hypertension
  d. Did you smoke before or during your pregnancy? How many years? ______
  e. Did you drink alcohol before or during your pregnancy?
  f. How often during pregnancy? _______________

15) **In your prenatal history, did you experience?**

  a. In Vitro Fertilization
  b. Hormonal support
  c. Gestational diabetes
  d. Preeclampsia or Pregnancy Induced Hypertension

16) **Did you experience any complications during pregnancy with NAME?**

17) **Did you take any medications during your pregnancy? What were the medications?**

18) **Did you experience any complications during delivery?**

19) **What medications, if any, did you take during delivery?**

20) **Did you experience any complications after delivery for you or for NAME?**

21) **What medications, if any, did you take during the hospitalization following delivery?**

22) **How long did you remain in hospital following delivery? _____________**

23) **What medications, if any, did you take during the first week at home?**

24) **Was there any time after you delivered NAME, when you felt depressed?**

I am now going to ask you questions about your breastfeeding experience and NAME's breastfeeding behaviors in the hospital. I want you to describe what you did to breastfeed and how well NAME breastfed. Please do not hesitate to share what you know or ask me any questions. I would like to know about your experience.

APPENDIX D (continued)

IV. Breastfeeding following Birth and during Hospital

25) Please describe for me your first breastfeeding experience with NAME –

a. How did it go?
b. When did it occur
c. Were there any concerns?

26) How would you describe NAME's sucking behavior?

27) Do you remember hearing NAME swallow your milk while breastfeeding?

28) Did NAME have any trouble latching-on to the breast?

29) Did NAME have any trouble opening mouth wide?

30) If you had trouble with NAME latching did you have any breast or nipple tissue trauma?

31) Do you recall NAME having any difficulty such as:
a. Latching-on to the breast?
b. Placement of his or her tongue?
c. Placement of his or her lips?
d. Creating suction?
e. Stimulation to the palate, tongue, lips?

30) Did you experience any trauma during breastfeeding:
a. Pain
b. Cracked nipples
c. Bleeding
d. Bruising

31) Did you ask for lactation consultant help?

32) Did staff recommend a lactation consultant help?

33) Did you use a nipple shield during breastfeeding with NAME?

34) Did you have to pump?

35) What do you recall about your breastfeeding experience during the remainder of your hospitalization?

APPENDIX D (continued)

36) **Do you recall NAME getting other nutrition besides your own milk, such as formula?**

37) **If yes, do you know why NAME was given formula?**

38) **If yes, do you remember how often NAME had formula while in the hospital?**

39) **When you and NAME left the hospital, how would you describe your health and the health of NAME?**

I am now going to ask you questions about your breastfeeding experience and NAME's breastfeeding behaviors the first week you were at home. I want you to describe what you did to breastfeed and how well NAME breastfed. Please do not hesitate to share what you know or ask me any questions. I would like to know about your experience.

V. Breastfeeding Post-Hospitalization

40) **Once you were home, what do you recall about your breastfeeding experience that first week?**

41) **Once you were home did NAME continue to have any trouble latching-on to the breast?**

a. Breast or nipple tissue trauma?
b. Difficulty with placement of his or her tongue?
c. Placement of his or her lips?
d. Creating suction?
e. Stimulation to the palate, tongue, lips?

42) **Did you experience any trauma during breastfeeding:**

a. Pain
b. Cracked Nipples
c. Bleeding
d. Bruising

43) **Did you use a nipple shield during breastfeeding with NAME?**

44) **Did you have lactation support from anyone when you got home from the hospital?**

APPENDIX D (continued)

45) Did you experience concern with your milk supply?

46) If yes, did anyone diagnosis this as a problem?

47) If yes, from whom?

48) If yes, what types of interventions, if any, did this individual do?

49) If yes, was this individual helpful with the problem?

50) Did you need any pharmacologic help, such as Reglan, herbal tea, fenugreek?

51) During the first week at home, did you supplement with formula?

52) If yes, do you recall the reason for using formula and how frequently formula was used?

I am now going to ask you questions about your breastfeeding experience and NAME's breastfeeding behaviors after your first week at home. I want you to describe what you did to breastfeed and how well NAME breastfed. Please do not hesitate to share what you know or ask me any questions. I would like to know about your experience.

VI. Breastfeeding after the First Week at Home

53) After the first week at home with NAME, what do you recall about your breastfeeding experience?

54) How was your health and NAME's health after the first week at home?

55) During the entire time that you were breastfeeding, did NAME experience any problems with weight gain?

We are almost done. I have some last questions before we end today's interview.

APPENDIX D (continued)

VII. Summary, Questionnaire, and Closing Questions

56) **Is there anything else that you want to tell me about NAME and your breastfeeding experience that I have not asked?**

57) **How was it today being interviewed?**

58) **How was it today being part of the study?**

Now that we have completed the interview, I need you to fill out a questionnaire about you, your background, your child's birth information and some general breastfeeding questions. When you have finished I will tell you about the next step in the study.

59) **The next step in the study is for me to listen to our interview and put into words. After I have interviewed all of the mothers in the study, I will write a summary of everyone's experience and your own experience. I will send you back your summary and everyone's summary. I will ask that you tell me if you think I wrote what you meant today. After I get back from all of the mothers their thoughts I will write up the study.**

60) **Do you have any questions about the next step?**

61) **Thank mother for her time and participation.**

APPENDIX E

Date _________

ID ___________

The Post-Interview Summary Form

Interview setting

Behaviors of mother during written questionnaire

Behaviors during child's history

Behaviors during hospitalization

Behaviors during post-hospitalization

Questions that received the strongest response

Consistent maternal breastfeeding experiences

Consistent neonatal breastfeeding behaviors

Emerging ideas

Length of interview

APPENDIX E (continued)

Interruptions during interview

Distractions during interview

My response to the interview

APPENDIX F

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