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Maternal Experiences Breastfeeding Infants Later Diagnosed with Autism: A Qualitative Approach

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Maternal experiences breastfeeding infants later diagnosed with autism:
A qualitative approach

by

Leslie J. Dooley

A thesis submitted to the graduate faculty
in partial fulfillment of the requirements for the degree of

MASTER OF SCIENCE

Major: Human Development and Family Studies

Program of Study Committee:
Carla Peterson, Co-major Professor
Amy Popillion, Co-major Professor
Gayle Luze

The student author and the program of study committee are solely responsible for the content of this thesis. The Graduate College will ensure this thesis is globally accessible and will not permit alterations after a degree is conferred.

Iowa State University
Ames, Iowa

2017

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DEDICATION

This thesis is dedicated to my beloved children, Ayden and Madelin.

Becoming a mother has made me stronger, more fulfilled than I could have ever imagined,

    connected me to a love that I barely have words to describe,

    And you both are my inspiration every day.

“The most beautiful things in the world cannot be seen or touched, they are felt with the heart.”

— Antoine de Saint-Exupéry, The Little Prince
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ABSTRACT

Being a parent of a young child is both challenging and rewarding. Families who have a child who is diagnosed with an autism spectrum disorder (ASD) may face unique challenges based on early infant feeding behaviors. There are currently more people diagnosed with ASD than at any other time, making ASD the fastest-growing developmental disability, yet diagnosis often does not occur until a child is 4 years old. The increasing rates highlight the need to find accurate diagnosis and effective treatment at an early age for those who have increased risk of ASD. The earlier assessment and diagnosis can occur, the sooner a child and family can begin to receive treatment and support. The purpose of this study is to learn more about the infancy of children who are diagnosed with ASD, including breastfeeding and other behaviors, based on maternal recall of experiences during the first years of their child’s life. This study examined the networks of both formal and informal support that mothers accessed when breastfeeding their infants and provides a better understanding of the relationship between maternal observations, development, and infant feeding behaviors. Five women who have a child with an ASD diagnosis were interviewed. The analysis, findings, and interpretation provide a description of the infancy of children diagnosed with ASD based on the participants’ experiences. Six themes were constructed: (a) Breastfeeding as an intervention, (b) Suspicions, (c) Inexperience: First-time mothers, (d) Disposition, (e) Need for Support, and (f) Perseverance. Findings are consistent with prior studies on early indicators of ASD and provide new insight into the feeding behaviors of infants later diagnosed with ASD.
CHAPTER 1. INTRODUCTION

Introduction

Prevalence rates of autism have increased at an astonishing rate over the past decade, which has led researchers and practitioners to speculate that we are in the midst of an autism epidemic (Liu et al., 2010). One of every 68 children born in the United States will be diagnosed with an autism spectrum disorder (ASD) (Baio, 2014). The prevalence rate of ASD among children in the U.S. has increased 119.4 percent from 1 in 150, in 2000, to the current rate of 1 in 68 (Baio, 2014). Currently, more than 3.5 million Americans live with ASD and more people are diagnosed with ASD than at any other time, making ASD the fastest-growing developmental disability (Buescher et al., 2014). Yet, diagnosis often does not occur until a child is 4 years old (Baio, 2014).

Early intervention, services, and support have been associated with better outcomes for children who have been diagnosed with ASD (Corsello, 2005; Green et al., 2015; Greenspan, 2011; Woods & Wetherby, 2003; Zwaigenbaum et al., 2015). However, despite the presence of atypical behaviors during infant/toddler years, diagnosis typically coincides with preschool enrollment resulting in a lack of intervention, services, and support for children and their families. Mothers are often the primary caregiver for infants; as such they are the best source of information regarding their child’s patterns of behavior and development including atypical behaviors or early indicators that might point to the need for developmental assessment. Maternal reports could identify infants who might need further assessment based on atypical patterns of behavior. While several studies have found atypical patterns of behaviors in infants later diagnosed with ASD, little is known about the maternal observations and interpretations of those atypical behaviors (Kishore & Basu, 2011; Talbott et al., 2015).
In addition, feeding difficulties commonly occur in children diagnosed with ASD, yet there is little research exploring breastfeeding patterns and infant feeding behaviors during infancy before diagnosis occurs. Burd (1988) compared breastfeeding rates for children with pervasive developmental disorders to a control group matched for age, sex, and IQ. Results indicate that the rates between groups were not significantly different but both were significantly lower than the national average (Burd, 1988). According to Burd (1988), the mothers who participated in his study reported the low rates of breastfeeding were due to prolonged illnesses during infancy in both groups. National breastfeeding rates are climbing as national initiatives designed to support breastfeeding rates and duration increase (CDC, 2016). As breastfeeding rates and access to support for breastfeeding increase, it is important to explore infant feeding in a contemporary context in order to provide current information about infant feeding. While the method that a mother uses to feed her baby may vary, the frequency and duration of atypical behaviors during infant feeding may allow care providers a reference point to address the need for further developmental screening. This study will provide the field with more information about early indicators of ASD and the factors that are inhibiting access to assessment and services.

**Purpose of the Study**

The purpose of this study is to learn more about the infant behaviors of children later diagnosed with ASD, including breastfeeding and other behaviors, based on maternal recall of experiences during the first years of their child’s life. The focus will be on mothers who have a child diagnosed with ASD who also breastfed for at least the first six weeks of their child’s life. The central questions of the study will focus on maternal observations of infant feeding cues and behaviors.
Mothers, typically the primary caregiver for infants, provide the best source of information regarding their child’s patterns of behavior and development. Mothers are the gatekeepers of information, including atypical feeding behaviors or early indicators that might point to the need for developmental assessment. While parental report survey data are beneficial to create standardized checklists of symptoms, qualitative data can help explore the unique lived experiences, obstacles, and challenges that occur before a child receives a diagnosis. These experiences may help illuminate possibilities for early diagnosis as well as potential opportunities for support and intervention. Qualitative exploration can illuminate whether mothers were concerned about their baby’s development during infancy or if atypical behaviors were not observed until later in the child’s life. Additionally, participant responses will clarify whether they felt that breastfeeding was successful, and provide insight regarding whether the process was inhibited by atypical behaviors that may be associated with ASD. The focus of this study will be early indicators of ASD learned through mothers’ reports of their experiences, observations, and perceptions. Each interview question will be examined from the mother’s perspective.

**Research Approach**

This study received approval from Iowa State University Institutional Review Board (IRB) to examine the experiences of mothers with respect to their breastfeeding experiences, observations of infant behavior, and the factors that affect the nature of their interactions based on maternal recall of past events. Each mother who participated in this study breastfed their child who was diagnosed with ASD at the time the data were collected. A qualitative approach was used to describe the participants’ lived experiences. A descriptive phenomenological approach allows the lived experiences of participants to be explored from their own perspectives and
observations. The goal of descriptive phenomenology is to maintain the individual participant’s thoughts, impressions, feelings and understanding without abstracting their viewpoint through in depth data collection without reducing the experiences of the phenomenon being studied (Giorgi, 2009). This method allows for a rich description of the participants’ experiences in order to better understand the complexities of the phenomenon.

A comprehensive review of existing literature guided the data collection method, in depth interviews. The interview process began with recruitment through local agencies and interventionists who provide support to families of children diagnosed with ASD. Data for this study were collected during five individual tape recorded interviews that were transcribed verbatim. The study’s conceptual framework provided a structure from which to develop and refine codes based on collected data to describe and provide a comprehensive understanding of the phenomenon.

**Rationale and Significance of the Study**

The rationale for this study originates from my desire to find ways to describe early infant feeding behaviors. Atypical behaviors may signal the need for developmental screening, which would also increase lactation support for mothers of infants who may have undiagnosed developmental disabilities. There is a gap in current research regarding breastfeeding infants who are later diagnosed with ASD. The networks of both formal and informal support that mothers accessed when breastfeeding their infant, such as lactation consultants and pediatricians or family and friends, were examined to provide a better understanding of the relations between development and infant feeding behaviors. Aspects of both breastfeeding support and pediatrician’s awareness of development may be challenged by highlighting the need for better understanding of the complex ways that development and infant feeding behaviors intersect.
Researchers have found early indicators of ASD, across multiple domains of development in children diagnosed with ASD, that might be observable during the breastfeeding process. Increased understanding of mothers’ breastfeeding experiences and their observations of atypical infant behavior may lead to multiple benefits for mothers and infants. Early lactation support for mothers of infants who may be vulnerable might increase the duration of breastfeeding and allow infants and families to receive developmental screening and support services at an earlier age. Access to support, services, and interventions at an early age has the potential to improve children’s developmental outcomes.

**My Role as a Researcher**

Parenting a child with ASD is associated with unique challenges and stressors for parents (Meirsschaut et al., 2010; Midence & O’Neill, 1999; Schieve et al., 2007). Parents may encounter a diverse range of experiences before their child receives a diagnosis. Some may meet with frustration trying to get a diagnosis, accessing social, educational and health services, while others resist diagnosis outright (Mansell & Morris, 2004; Russell & Norwich, 2012). Parents may strive for vindication of their child’s challenges and their experiences raising an infant later diagnosed with ASD yet struggle with the denial of that disability (Russell & Norwich, 2012). The period before diagnosis occurs can be tumultuous and marked by strong emotions. As a mother of a child diagnosed with ASD, I understand this unique time period. I struggled to understand the behaviors and experiences that occurred during my son’s first years of life. My first experiences as a mother involved an intricate process of meeting my son’s needs while observing, comparing, and reporting his unique and often confusing behaviors. I consulted pediatricians, pediatric specialists, and lactation consultants, seeking explanations for my son’s atypical behaviors. As his behaviors became increasingly atypical, I found myself in a state of
constant comparison as he did not meet developmental milestones and his behaviors became increasingly different from those of similar aged children. I began to research development and lactation. My breastfeeding challenges led me to an eventual career as an International Board Certified Lactation Consultant (IBCLC), and my attempts to understand and meet the needs of my son, in turn, influenced my career as a researcher.

As a mother, I wanted my son’s voice to be heard even when he was silent. As a researcher, I bring an ability to demonstrate patience and respect while participants recall their experiences during interviews as they give voice to their own stories during the inquiry process. I am in a unique position to approach participants from a perspective of sensitivity and empathy based on personal experience. Additionally, my training as an IBCLC provided a foundation to conduct interviews effectively, delve deeper into scenarios from a clinical perspective, and decipher themes that emerge from the data.

I was fortunate to have access to area education agency support as my family progressed through the process of my son’s eventual diagnosis, but I understand that each mother-infant dyad has a unique journey, and each child widely varying severity of ASD symptoms. I feel it is crucial to examine the factors that benefit mother-infant dyads and the processes that may inhibit access to support. Furthermore, understanding more about these early experiences will help to clarify when interventions are warranted.

My interdisciplinary approach will allow me to explore a phenomenon with little existing research from a synthesis of both clinical and developmental perspectives. This study offers a unique opportunity to explore the intersection of infant behaviors and maternal experiences navigating the complexities of the breastfeeding relationship framed within the context of ASD.
CHAPTER 2. LITERATURE REVIEW

Theoretical Framework

Bronfenbrenner’s ecological theory of human development provides the framework for this study. Sontag (1996) acknowledged ecological theory of human development as a comprehensive framework for the study of children with disabilities, examining the complexity of their lives, and the contexts that influence development. Ecological theory clarifies the contribution of the individual to the developmental process as a function of both individual characteristics and environmental influences over time. Ecological theory views the child as influencing and contributing to the environmental context in a reciprocal nature (Bronfenbrenner, 1986). For children with ASD, the severity of symptoms influences how children interact with others directly impacting the nature of relationships among individuals in their environment (Beurkens et al., 2013).

Development occurs through processes of complex reciprocal interactions between a child and their environment that occur on a regular basis over extended periods of time (Bronfenbrenner, 1994). Proximal processes are bidirectional interactions that occur in the immediate environment (Bronfenbrenner, 1994). These processes occur in the mother-infant dyad during early interactions that shape social dynamic and behavior patterns over time and influence later development (Feldman et al., 1997; Wan et al., 2012).

The family is the principal context in which human development takes place. In order to understand human development, it is essential to consider the entire ecological system within which growth occurs (Bronfenbrenner, 1994). Ecological theory provides a framework to interpret participant’s references to characteristics and behaviors of the child during infancy, both formal and informal supports such as extended family, lactation consultants, pediatricians or
other interventionists and the roles of these interactions and relationships in relation to maternal experiences (Bronfenbrenner, 1981). Ecological theory conceptualizes the distinct attributes of the family systems in which mothers and infants later diagnosed with ASD exist.

**Autism Spectrum Disorder**

Over the past decade, the prevalence rates of developmental disabilities have increased. The National Institutes of Health define developmental disabilities as disorders that are present at birth and can cause severe, long-term problems (Wicks-Nelson & Israel, 2013). Developmental disabilities negatively affect physical, cognitive, and emotional development or a combination of all three (Saulnier & Ventola, 2012). The problems are persistent, life-long, and can interfere with activities of daily life (Wicks-Nelson & Israel, 2013). Among individual developmental disorders, rates of ASD have had significant and successive increases over time (Boyle et al., 2011). The number of children diagnosed with autism in the U.S. has increased 119.4 percent over the past decade from 1 in 150 children having a diagnosis of ASD in 2000, to the current rate of 1 in 68 (Baio, 2014). Changes in both diagnostic criteria and reporting practices, as well as increases in public awareness are factors associated with increased rates of children diagnosed with ASD (Baio, 2014; Hansen et al., 2015; Polyak et al., 2015; Zwaigenbaum et al., 2015). More than 3.5 million Americans live with ASD (Buescher et al., 2014). Currently, more people are diagnosed with ASD than at any other time, making ASD the fastest-growing developmental disability.

ASD is a neurobiological disorder characterized by impairments in communication and social interaction as well as restricted, repetitive, and stereotyped patterns of behavior, interests, and activities (Wicks-Nelson & Israel, 2013). ASD can cause significant social, communication, and behavioral challenges (Saulnier & Ventola, 2012). There are no obvious outward physical
differences that make ASD apparent in a child, which contributes to the challenges of early diagnosis. ASD is considered a spectrum disorder because a wide degree of variation in the severity and presentation of symptoms exists (Wicks-Nelson & Israel, 2013).

Symptoms of ASD include impairments in social interaction, such as lack of social or emotional reciprocity, as well as impaired nonverbal behaviors, such as limited facial expressions or inhibited eye contact (Wicks-Nelson & Israel, 2013). Children diagnosed with ASD often have impairments in communication, such as delayed or total lack of development of verbal speech (Saulnier & Ventola, 2012). Children with ASD exhibit stereotyped patterns of behavior, interests, and activities that can include inflexible adherence to routines, repetitive rituals, or preoccupation with parts of objects such as only focusing on the wheels of a toy car (Saulnier & Ventola, 2012). The degree of severity to which these symptoms are present will influence the impact on activities of daily living.

Risk factors and characteristics. While the root cause of increased ASD prevalence rates has yet to be determined, certain factors are linked to increased risk of diagnosis. ASD tends to be more prevalent in families who already have one child diagnosed with ASD (Hallmayer et al., 2011). Parents who have one a child with ASD have a 2%–18% chance of having a second child who also has ASD (Hallmayer et al., 2011). In addition, ASD is more common in twins, with identical twins having the greatest risk; if one twin has ASD the other will be affected 36-95% of the time. In non-identical twins, if one twin has ASD the other is affected up to 31% of the time (Hallmayer et al., 2011). ASD tends to occur more often in people who have certain genetic or chromosomal conditions and commonly co-occurs with other developmental, psychiatric, neurologic, chromosomal, and genetic diagnoses (Levy et al., 2010). A small percentage of children born prematurely or with low birth weight are at greater risk for
having ASD (Schendel & Bhasin, 2008). Another risk factor is parental age: children born to older parents have an increased risk of ASD (Durkin et al., 2008). These risk factors for ASD can help identify specific children who would benefit from early monitoring and assessment.

**Early intervention for autism spectrum disorders.** The increasing prevalence rates point to a trend that warrants finding accurate and effective diagnosis and treatment at an early age for those at increased risk of ASD. The earlier assessment and diagnosis can occur, the sooner a child can begin to receive treatment and support. Early intervention during the first years of life can promote healthy development and provide infants with necessary support to ensure the best possible future outcomes (Boyd et al., 2010; Corsello, 2005; Green et al., 2015; Greenspan, 2007). Unfortunately, ASDs are typically not diagnosed or treated until a child enters preschool (Baio, 2014).

**Early assessment.** Early screening for ASD can be based on both caregiver observations and health care assessments to determine if an infant displays patterns of atypical development that warrant further evaluation. It is essential that caregivers and health care providers are aware of the first signs of abnormal development and have adequate tools for early identification of ASD, namely, tools based on patterns of atypical physical, emotional, and social development during infancy. Research has shown that children can be diagnosed with ASD as early as age 2 (Baio, 2014; Mandell et al., 2005). When a school age child is screened for ASD, retrospective data regarding behaviors during the first years of life are collected. Researchers have found specific infant behaviors and atypical patterns of development, across multiple developmental domains, associated with later diagnosis of ASD. Parents of children with ASD often report observing atypical development and behaviors during infancy and toddler years including but not
limited to restricted and repetitive behaviors, communication delays, deficits in social skills, and challenging behaviors (Kozlowski et al., 2011; Talbott et al., 2015).

In addition, parents of children with ASD frequently report a variety of meal time problems and feeding difficulties. Patterns of food selectivity frequently reported include, but are not limited to, food preferences restricted by food category or by texture, skill-based feeding difficulties such as chewing and swallowing difficulties, and frequent food or liquid refusal (Ahearn, 2001; Beighley et al., 2013; Schreck et al., 2004). Parents report that children with ASD exhibit unusual mealtime behaviors such as requiring specific presentations of food and specific utensils, food texture preferences, and a narrow variety of types of food that the children will eat when compared to typically developing children, despite parental attempts and opportunities to provide a variety of food choices (Ahearn, 2001; Schrek et al., 2004).

It is crucial to provide both practitioners and parents with opportunities for early assessment and intervention. Infants whose siblings are diagnosed with ASD are at greater risk and would benefit from being assessed across developmental domains on a regular basis. Early assessment and intervention is the key to helping lessen the impact of symptoms and improve outcomes for children who have ASD, as early symptoms may be apparent based on feeding behaviors.

**Early Indicators of Autism Spectrum Disorders**

**Atypical physical and motor development.** Infants who are later diagnosed with ASD tend to have difficulty in many aspects of motor control such as difficulty controlling head movement, low muscle tone in arms resulting in flopping, uncoordinated movements and difficulty sitting up unassisted. Many of these behaviors are evident in the first few months of life (Green et al., 2009). Several studies have linked specific patterns of physical and motor
development to later diagnosis of ASD. These studies have highlighted this as an area of development that would benefit from further research to develop assessment for early diagnosis, as atypical physical and motor development is not currently in the diagnostic criteria. Movement disturbances, however, often occur in children who are diagnosed with ASD. In addition, the symptoms are often present at birth and provide an opportunity to diagnose the presence of ASD in the first few months of life (Teitelbaum, 1998).

Infants who are later diagnosed with ASD are slower to learn how to sit and stand and are less likely to spontaneously change positions than their typically developing peers (Nickel et al., 2013). Asymmetry of posture or movement, which can be assessed as young as three to five months of age, suggest disrupted neural pathways linked to ASD (Teitelbaum, 1998; Espisito et al., 2009; Nickel et al., 2013). Symmetrical posture can be assessed based on how an infant’s body is positioned such that the arms and legs are similar relative to the corresponding limb. For example, symmetrical posture in the lying position where both arms are bent at the elbow up towards the head in typically developing infants as opposed to the one arm bent up and the other arm straight along the torso in infants later diagnosed with ASD (Espisito et al., 2009). These atypical patterns of movement and posture may impact other aspects of infant development.

Atypical physical and motor development such as uncoordinated movements and difficulty controlling head movements might disrupt the breastfeeding process. To breastfeed successfully, an infant must control movement of their head. In addition, a breastfed infant must maintain specific posture (in relation to the mother’s body) to feed effectively, and asymmetrical posture and atypical reflexes may interfere with the positions in which an infant is held (Teitelbaum, 1998; Espisito et al., 2009).
Infants may fail to roll over on their own, or are unable to roll over using typical pattern of body rotation, and instead use an abnormal sequence such as laying on their side arching their back and using their leg to pull their body over (Teitelbaum, 1998). When unsteady in a specific position, the infant may lack protective reflexes when falling, and may fall over more easily than typically developing infants (Teitelbaum, 1998). Researchers have highlighted patterns of deviations from the normal pattern of crawling, with infants exhibiting asymmetrical leg movements, lack of symmetrical arm support, or other patterns such as crawling with one leg in the crawling position and using the other leg in a flat foot stepping pattern. These physical behaviors, which are less abstract than social, emotional, or communication patterns, would allow for simple assessment by a health care provider, early interventionist, or other trained diagnostician based on observations that could be used to determine the need for intervention.

While there are not major physical abnormalities consistent with ASD, researchers have noted abnormal patterns of growth during the first year of life and atypical physical characteristics. Children who are diagnosed with ASD tend to be born with significantly smaller head circumference that persists during the first two weeks after birth and a significantly larger head circumference by 10 to 14 months (Davidovitch et. al, 1996; Mraz, et al., 2007). Teitelbaum et al. (1998) observed a characteristic shape of the mouth that can be seen the first few days after birth and may persist past infancy. The lower lip is flat, but the upper lip is arched in a shape characteristic of Moebius Syndrome (Teitelbaum et al., 1998). Though no studies to date explore the characteristic mouth shape observed by Teitelbaum et al. in relation to breastfeeding, the physical shape of an infant’s mouth directly impacts breastfeeding. To form a seal around the mother’s nipple, the breastfed infant must flange out both upper and lower lip, allowing the tongue to come out of the mouth past the gum line. If the infant has an atypical
mouth shape, it might be challenging to form the proper mouth shape allowing a complete seal around the mother’s nipple, feeding may be ineffective, and the mother may experience discomfort when breastfeeding due to compression of the nipple.

**Atypical emotional development.** Several patterns of atypical emotional development have been associated with later diagnosis of ASD. Infants later diagnosed with ASD smile less often than those who do not develop the disorder (Filliter et al., 2014; Zwaigenbaum et. al, 2005). In addition, retrospective data collected from parents who have a child with ASD reported that during infancy their children had a more negative or neutral affect and were often passive or disengaged especially in response to a caregiver’s emotions (Cassel, 2007; Zwaigenbaum et. al, 2005). Infants later diagnosed with ASD exhibit poor emotional modulation and tend to behave in an extremely distressed manner that differs from the reactions of typically developing infants in response to situations and environments (Esposito et al., 2013; Maestro et al., 2005). These emotional responses may be the first cues that parents observe and report to health care providers, and these parental observations and reports should warrant specific attention from health care providers.

**Atypical social development.** Researchers have found several patterns of atypical social development that can be observed during infancy. During the first year of life, infants tend to show a preference for the faces, gaze, and voices of others but infants later diagnosed with ASD display poor social initiative and have difficulty regulating attention to complex social scenes (Maestro et al., 2005; Shic et al., 2013). Children and adults with ASD look less at people's eyes and faces than their typically developing peers do (Jones & Klin, 2013; Osterling & Dawson, 1994; Shic et al., 2013). These patterns of interaction may cause infants to miss the social cues that would help them understand social interactions and emotional expressions. Researchers have
found that infants who hear talking in a social situation restrict and focus their gaze towards the sound. The presence of speech might interrupt the attention of infants who later develop ASD at a critical developmental point when other infants are acquiring language and learning about their social world (Shic et al., 2013). In addition, researchers have found that infants later diagnosed with ASD tend to not respond when their name is called and exhibit fewer social and joint attention behaviors such as pointing, showing objects, and looking at others (Osterling & Dawson, 1994; Woods & Wetherby, 2003; Zwaigenbaum et al., 2005).

**Atypical communication.** Communication skills and competency are closely related to social skills and behaviors, and are a primary factor in developing relationships. Deficits and delays in receptive and expressive communication skills that commonly occur in children diagnosed with ASD are a component of diagnostic criteria and predictive of later outcomes (Woods & Wetherby, 2003; Zwaigenbaum et al., 2005). Infants later diagnosed with ASD exhibit infrequent attempts to solicit attention from a care provider, have difficulty acquiring language skills and communicating verbally, struggle with their ability to respond appropriately to parent initiated communication, and use limited nonverbal gestures such as reaching or pointing (Mitchell et al., 2006). These infants also tend not to use complex gestures such as motioning to be picked up or pointing for toys (Mitchell et al., 2006). Infants later diagnosed with ASD were found to have an inability to generate reciprocal interactions or make purposeful attempts to communicate. These atypical patterns of communication can directly affect parent child interactions. Parents reported that they struggled to determine or understand what their baby wanted or needed (Mitchell et al., 2006). Many infants later diagnosed with ASD show limited understanding and production of simple verbal communication such as single words, tend
to understand significantly fewer phrases, and have limited overall use of gestures, which may overlap with atypical physical or motor development (Mitchell et al., 2006).

**Feeding Issues and ASD**

Childhood is a period of rapid growth and development, and often a time of challenging behaviors as children learn about the world in which they live. Many children have strong preferences and dislikes for a multitude of scenarios. These preferences can lead to behaviors that may prove to be challenging for parents, especially when the behaviors directly impact aspects of daily life. Parents often describe young children as having patterns of “picky eating,” a common occurrence when children begin to feed themselves, that can lead to mealtime struggles. Picky eating tends to peak between the ages of two and six years but tends to decrease after preschool in most children (Suarez & Nelson, 2012). While not consistently operationally defined, food selectivity encompasses picky eating and the consumption of an abnormally limited variety of food (Bandini et al., 2010; Cermak, et al., 2010). Food selectivity can include a child who eats a decreased variety of foods, a child who avoids or refuses specific foods, or has excessive intake of a limited variety of food categories (Bandini et al., 2010; Cermak, et al., 2010). For typically developing children, these preferences are a normal part of development; however, for children with developmental disabilities food selectivity is a common occurrence that can be exacerbated by the symptoms of their disability and can persist past the age at which feeding problems usually resolve for typically developing children (Cermak et al., 2010; Schreck et al., 2004).

Abnormal patterns of eating and behavior problems associated with feeding were previously included in the original diagnostic criteria for ASD (Ahearn, 2001). Despite not being included in the current criteria for diagnosis of ASD, parents commonly report food selectivity
behaviors in children diagnosed with ASD (Bandini et al., 2010; Beighley et al., 2013; Sharp et al., 2013). Although the feeding issues that occur in children with ASD are similar to those of typically developing children, such as food selectivity and food preferences, the severity and duration tend to differ. Current prevalence estimates suggest a substantial proportion, between 46-89%, of children with ASD exhibit abnormal feeding behaviors and problems (Allen et al., 2015). Children with ASD are five times more likely to have both behavioral and skill based feeding problems than typically developing children and often exhibit feeding issues as early as infancy, though it is often most noticeable towards the end of the second year of life (Allen et al., 2015; Emond et al., 2010; Keen, 2008; Nadon et al., 2011). Parents who report higher levels of feeding problems were also more likely to report that their children have more severe ASD symptoms, increased levels of disorder in other aspects of self-regulation such as sleep disturbances, and generally higher levels of internalizing and externalizing behaviors (Allen et al., 2015).

**Medical conditions related to food selectivity.** Various factors may contribute to food selectivity in children with ASD, such as physiological dysfunction, age of the child, and sensory sensitivity (Suarez & Nelson, 2012). Biological disorders that cause discomfort such as reflux, constipation, or food allergies may lead to food selectivity (Suarez & Nelson, 2012). In addition, children with ASD are more likely to have gastrointestinal problems than children who do not have a developmental disorder (Suarez & Nelson, 2012). When additional medical conditions that cause physical discomfort are present in conjunction with a diagnosis of ASD, interest in food may decrease and children may exhibit protective behaviors that attempt to avoid or diminish discomfort associated with mealtime and eating (Suarez & Nelson, 2012).
**Sensory processing and feeding issues.** In addition to medical conditions that may contribute to increased rates of food selectivity, researchers have found that sensory issues occur often in children who have ASD. Sensory processing issues are very common and found across a range of severity in children with ASD (Cermak et al., 2010). Sensory over responsivity is defined as a response to a sensation that is longer in duration, faster, more intense, and inconsistent with the demands of the immediate environment (Suarez & Nelson, 2012). For example, tactile defensiveness and oral defensiveness are both forms of sensory over responsivity. Tactile defensiveness is an abnormal overreaction to certain physical touch sensations causing observable aversions or negative behavioral responses to stimuli (Cermak et al., 2010). This response to stimuli can influence touch, taste, and smell which may negatively affect eating. Oral defensiveness is defined as an aversion to specific sensations in the mouth or avoidance of certain food textures. This atypical response may be caused by an underlying issue with sensory input, and potentially linked to tactile defensiveness, which can result in selective eating (Cermak et al., 2010).

**Food selectivity and development.** Food selectivity and food refusal can adversely affect children’s health, growth, development, and overall functioning. Food selectivity can lead to inadequate nutrition, malnourishment, and failure to thrive, posing a serious health concern for the child (Ahearn, 2001; Johnson et al., 2008). Food selectivity, when untreated or mismanaged, can lead to chronic behavior patterns that can interfere with daily activities as well as create added stress for the family (Allen et al., 2015). Children with ASD, despite feeding difficulties, tend to have comparable height and weight when compared with typically developing peers suggesting that the volume of food consumed is adequate to support growth. However, children with ASD have higher rates of nutritional deficits and consume less protein and calcium than
their typically developing peers (Sharp et al., 2013). The increased needs for nutrients that support physical growth and development during childhood combined with a lack of nutrient intake in children with ASD may lead to increased risk of health complications later in life (Sharp et al., 2013).

**Infant Feeding Patterns**

Similar to developmental milestones, there are feeding patterns and behaviors that can be observed, assessed, and monitored to determine if intervention is needed. While there is individual variation in the frequency and duration of feeding sessions among infants, there are multiple ways to assess effective feeding, including, but not limited to growth and weight gain, stool and urine output, and quantity consumed during bottle feeding. Changes in infant feeding patterns can occur for multiple reasons such as acquisition of new developmental skills, periods of rapid growth, or illness (Dahl, 2015).

**Infant nutrition.** After birth, newborn human babies are relatively helpless when compared to other mammals. Unable to effectively move or protect themselves, newborns rely on a caretaker for survival. An essential part of survival is access to nourishment. While the method a mother chooses to feed her baby is considered a personal choice, the need for infants to be fed is not debatable. Infant breast milk substitute (formula) is widely available and competitive companies conduct exhaustive research to generate advances in ingredients and formula components. However, many benefits to breastfeeding cannot be duplicated in a synthetic formula.

**Benefits of breastfeeding.** Breastfeeding has protective benefits for both mother and baby, providing infants with essential nutrients and immunological benefits as well as decreasing maternal risk for multiple illnesses (DHHS, 2011). Breastfeeding is associated with decreased
risk for many early-life diseases and medical conditions. Breastfed infants have lower rates of ear infections, respiratory tract infections, atopic dermatitis, gastroenteritis, type 2 diabetes, sudden infant death syndrome, and obesity (Chung et al., 2007). Breastfeeding also is associated with health benefits to women, including decreased risk for type 2 diabetes, ovarian cancer, and breast cancer (Chung et al., 2007).

Based on the numerous positive outcomes associated with breastfeeding across mother and infant lifespan, the U.S. Surgeon General issued a Call to Action specifically focused on the importance of supporting breastfeeding mothers and their infants (DHHS, 2011). The Healthy People initiative provides a framework for disease prevention and health promotion in the United States, including several breastfeeding objectives (DHHS, 2011). The Healthy People 2020 goals include a target of 60% of infants breastfeeding at 6 months of age (DHHS, 2011). In addition to these numerous health benefits, breastfeeding provides a unique opportunity for observation of early development across multiple domains outside of indicators of adequate nutrition and physical growth. Yet little research examining patterns of atypical breastfeeding behaviors or their relations with the need for developmental assessment has been undertaken yet.

**Rates of breastfeeding.** The majority of mothers in the U.S. initiate breastfeeding after giving birth; 81.1% of mother’s initiate breastfeeding. However, despite the national initiative to encourage and support breastfeeding mothers, only 22.3% of babies are exclusively breastfed after six months (CDC, 2016). Multiple factors contribute to breastfeeding cessation including factors attributed to the mother (e.g., physical illness requiring medication contraindicated to breastfeeding, low milk volume, discomfort or pain while breastfeeding, perception that the baby is not getting enough breast milk), factors attributed to the infant (e.g. physical illness or genetic disorder present at birth), and external factors (e.g. returning to the workforce, lack of access to
evidence based information and support) (Ahluwalia, et al., 2005). It can be a challenge to reach national breastfeeding goals given so many factors contributing to early cessation, but the result is that both mother and baby are not able to experience the benefits of breastfeeding.

**Dynamics of breastfeeding.** Breastfeeding is a biological process reliant on internal and external stimuli, hormonal processes within the mother, and physical processes related to direct stimulation of the mother’s nipple. During pregnancy, a woman’s body begins the process of making milk based on hormonal changes related to pregnancy (Dahl, 2015; Wambach & Riordan, 2016). After birth, the combination of hormones and physical stimulation from a suckling infant continue the process. Milk production is a supply and demand process, requiring frequent breastfeeding to establish a full milk supply that can support infant nutritional needs (Dahl, 2015; Wambach & Riordan, 2016). Mothers rely on infant feeding cues to know when their baby is hungry such as rooting (a reflex in which an infant will turn their face towards a stimulus when cheek or lip is touched and make sucking motions), moving their head from side to side, licking lips, and crying which is a late feeding cue (USDA, 2009). If an infant is having trouble communicating hunger and is missing feedings, the mother’s milk supply will be impacted directly and eventually decrease (Dahl, 2015; Wambach & Riordan, 2016). In addition, an infant who is not able to breastfeed effectively due to poor oral motor skills, sensory defensiveness, or disrupted physical coordination, will be unable to gain weight and the mother’s milk supply will be compromised (Dahl, 2015; Wambach & Riordan, 2016).

The breastfeeding relationship of the mother-infant dyad is reciprocal: the mother’s body will not be able to make milk without the interaction with the baby and likewise the infant will not be sufficiently nourished without the mother’s attention, awareness, and responsiveness to feeding cues (Dahl, 2015; Wambach & Riordan, 2016). When an infant is developing atypically,
the breastfeeding process may be negatively affected. Early feeding problems that present during infancy can result in a diagnosis of failure to thrive, meaning an infant has insufficient weight gain (Keen, 2008). Early feeding behaviors include the process of self-regulation, sucking, swallowing and the ability to communicate both hunger and satiety (Keen, 2008; Williams et al., 2000). Disruption of these processes or inability to master a specific aspect of these early feeding behaviors will result in ineffective feeding and inability to gain weight (Keen, 2008). Researchers have found an association between failure to thrive and both abnormal biological and social responsiveness, as well as early manifestations of impaired social communication (Keen, 2008). Persistent and severe feeding problems during infancy, including failure to thrive, warrant further evaluation and monitoring for later potential diagnosis of ASD (Keen, 2008).

**Typical infant feeding and hunger cues.** Newborn infants require frequent feedings based on their small stomach size and the speed at which the stomach empties. These frequent feedings also protect against dehydration (Dahl, 2015; Wambach & Riordan, 2016). Newborns communicate hunger through a variety of feeding cues including increased movement of arms and legs, rooting, fast breathing, clenched fists, and sucking on fingers and hands (Dahl, 2015; USDA, 2009; Wambach & Riordan, 2016). Crying is viewed as a late feeding cue that typically occurs after early feeding cues are not noticed by care providers. A newborn infant will typically breastfeed at least 10 to 12 times in 24 hours. Successful breastfeeding in the first months of life is related to how much weight an infant is gaining, as well as urine and bowel movements, related to increased maternal milk supply (Dahl, 2015; Wambach & Riordan, 2016). Mothers of formula-fed infants are typically encouraged to feed their baby on demand in the early weeks of life but may be instructed to provide larger, less frequent feedings when compared to breastfeeding patterns (USDA, 2009).
As infants grow, their feeding patterns change. For breastfed infants, feedings become more efficient, the amount of time between feedings increases and the feedings occur at increasingly regular intervals (Dahl, 2015; Wambach & Riordan, 2016). Unlike the newborn, older infants are better able to express hunger through additional feeding cues such as getting into a feeding position and smiling, gazing at, or reaching for a caregiver (USDA, 2009). Recommendations for formula-fed infants involve increasing the amount of formula per feeding gradually until reaching seven to eight ounces at regular intervals with daily total amounts based on infant weight (USDA, 2009). In addition to hunger cues, infants exhibit patterns of behavior to indicate satiety and fullness after a successful feeding session, such as extended arms and legs, relaxed and extended fingers, pushing away, falling asleep, slow or decreased sucking, and back arching away from the breast or bottle.

**Summary**

Infants later diagnosed with ASD may exhibit atypical hunger cues, disorganized feeding, and behaviors that indicate satiety may be disrupted based on behaviors associated with early indicators of ASD. The breastfeeding process may allow observations of early indicators of ASD across multiple domains of development in children later diagnosed with ASD. Figure 1 provides a conceptual literature review as a literature map depicting the relations among ASD, infant feeding patterns, and maternal observations on research in ASD and infant feeding.

Atypical physical and motor development, such as uncoordinated movements and difficulty controlling head movements, might disrupt the breastfeeding process. In addition to physical indicators that might disrupt feeding, several early indicators of atypical emotional development such as a negative affect or extreme distress responses may make observing and interpreting infant feeding cues challenging for mothers or may lead mothers to question whether they are
making enough breast milk to feed their baby. Breastfed infants during the early months communicate hunger through feeding cues that may be disrupted if an infant is not looking at the faces of others. In addition, if an infant is communicating hunger in an atypical pattern or is unable to use complex gestures to signal hunger a mother may struggle to meet the nutritional needs of her infant.

The feeding issues and increased prevalence of food selectivity that have been observed in older children may also play a role in breastfeeding behaviors. Sensory over responsivity, tactile or oral defensiveness would be directly impacted by the multiple sensory experiences that occur during breastfeeding. Not only are breastfed infants in close proximity to their mothers during the feeding process which might trigger sensory over-responsivity, the rate of milk flow varies during a feeding and throughout the day as well as changes in both consistency and flavor based on maternal diet (Dahl, 2015; Cermak et al., 2010; Suarez & Nelson, 2012). Oral and tactile defensiveness would directly impact a mother’s ability to breastfeed her infant but may be overlooked by professionals.

The variety of early indicators across multiple developmental domains combined with the individual differences associated with ASD can make identification during infancy challenging. However, early intervention may help to support development in children at risk. Exploring maternal experiences and observations of breastfeeding will provide an opportunity to observe early indicators of ASD that may also impact infant breastfeeding behaviors. Findings from this study can inform early interventionists, health care providers, and lactation counselors with more effective ways to assess and support mothers and infants who exhibit atypical breastfeeding behaviors.
Figure 1. Conceptual literature review as a literature map. This literature map shows the relationship between ASD, infant feeding patterns, and maternal observations on research in ASD and Infant Feeding.
CHAPTER 3. METHOD

Overview of Methodology

The purpose of this study was to learn more about the infancy of children who are diagnosed with autism, based on mother’s memories of experiences during the first years of their child’s life. This study focused on maternal observations of early infant feeding behaviors, physical development, and social behaviors during infancy. There is limited research on the maternal experiences, observations, and perceptions of the phenomenon of early infant feeding behaviors in children diagnosed with ASD. Further research into maternal experiences can provide a better understanding of the early infancy of children who are diagnosed with ASD allowing professionals who work with mother-infant dyads to have a more informed approach when addressing maternal reports of atypical infant behaviors. This research seeks to understand this phenomenon and explored the following three questions:

1) What experiences do mothers remember breastfeeding and raising infants who were later diagnosed with ASD

2) What are maternal perceptions and observations of physical development, social behaviors, and feeding behaviors of infants who were later diagnosed with ASD

3) What experiences that mothers had accessing and finding support for their infants before diagnosis of ASD.

This chapter describes the research method including the rationale for the approach, description of the research sample, an overview of the research design, the methods of data collection that were used, analysis of the data, ethical considerations, trustworthiness, and limitations of the current study.
Rationale for Qualitative Design

A growing body of quantitative research focuses on early indicators of ASD during infancy; however, there are limited qualitative studies examining maternal observations during this critical time period. Qualitative research is an approach to inquiry based on and grounded in descriptions of observations (LeCompte & Preissle, 1994). Qualitative inquiry allows a researcher to explore in depth aspects of a phenomenon based on individual experiences to fill in gaps in research or expand on existing knowledge. Using a qualitative research approach provides the researcher the opportunity to explore the depth of lived experiences based on participant’s responses to inquiry and garner rich data to help fully examine the phenomenon of interest. Qualitative inquiry approaches research from a descriptive viewpoint, centered on discovery and elaboration, as opposed to testing a hypothesis. A qualitative approach allows researchers to examine human experiences from the participant’s point of view, and in this case, allows maternal experiences to be brought to light that may otherwise not have been explored. In order to best examine a phenomenon that has little existing prior research and also spans multiple fields of study, a qualitative approach can provide detailed data that may otherwise be missed using a quantitative approach.

When exploring a phenomenon that intersects both maternal experiences and infant behavior, a quantitative approach may not elicit the depth of descriptive data necessary to fully explore the intricacies of the phenomenon. Qualitative inquiry allows for flexibility within the design while allowing the researcher to have close interactions with participants, leading to a deeper contextual and descriptive understanding of the phenomenon of interest. Additionally, qualitative inquiry provides researchers with an awareness of the processes involved in participant’s experiences, including passage of time and locations within which the context of the
phenomenon unfolds. While it is important to be able to assess an infant who may be exhibiting atypical patterns of behavior, it is the mother’s experiences and observations through which those behaviors may be brought to light. Qualitative inquiry can explore what happens during early feeding experiences and the nature of these early interactions.

**Rationale for Descriptive Phenomenology**

In order to understand the meaning of the events, experiences, and interactions that occur between a mother and her infant, a descriptive phenomenological approach is best suited to meet the goals of the current study. Descriptive phenomenology is used to identify the general structure of the underlying lived experiences of a specific phenomenon. Descriptive phenomenology is a research method of discovery rather than validation, allowing for different general structures to emerge from the analysis of data (Giori, 1985). Descriptive phenomenology explores the individual’s unique circumstances to capture the underlying meaning and essential components describing lived experiences (Vagle, 2014). This study examined the experiences of mother-infant dyads with respect to early infant behaviors, breastfeeding experiences, and the factors that affect the nature of their interactions based on maternal recall of past events. The interrelated experiences of the mother-infant dyad are important to the interpretation of the data.

The purpose of this study is to gain an in-depth understanding of the breastfeeding experiences of mothers raising infants later diagnosed with ASD. Descriptive phenomenology can provide insight into the lived experiences of mother-infant dyads and illuminate situations that impact both mother and infant. The goal of a phenomenological study is not to explain or discover the cause of a specific phenomenon, instead the focus is to clarify the nature of the lived experience in order to build an understanding of the most essential meaning of a specific phenomenon of interest from the perspective of those who directly experience it (Giorgi, 1997).
Descriptive phenomenology posits that individuals create their own truth and sense of reality based on their experiences. Participants are selected specifically because they have lived the phenomenon of interest.

**Retrospective Data**

Guided by Bronfenbrenner’s ecological theory, a retrospective qualitative study was conducted to explore the breastfeeding experiences and observations of mothers with children diagnosed with ASD. When an assessment for ASD is conducted, retrospective data are collected based on atypical behaviors during the first years of life, including atypical feeding patterns, behaviors, and preferences (Ozonoff et al. 2009; Green et al. 2015). Previous studies regarding maternal recall of breastfeeding duration within populations having short breastfeeding durations showed that accurate recall of the actual duration of breastfeeding is diminished over time. However, for the purposes of this study duration of breastfeeding is used as a minimum requirement for inclusion to help clarify the distinction between factors related to ASD and breastfeeding behaviors (Li et al., 2005; Vobecky et al., 1998). The focus of retrospective data collected in this study examined maternal recall of experiences breastfeeding and observations of infant behaviors associated with breastfeeding as opposed to specific time frames or duration.

**Research Sample**

Purposeful sampling was used in this study to gain information-rich cases and provide the most information about the phenomenon of interest (Merriam, 2002). Criterion sampling was used to ensure that all participants met a specific set of criteria. According to Giorgi (2009), there is not specific requirement for sample size, however, a minimum of at least three participants is recommended. Mothers of children currently diagnosed with ASD were recruited through ASD
early intervention agencies, breastfeeding support groups, ASD support groups, early interventionists, and online support groups.

Inclusion criteria. The inclusion criteria for participants in this study were as follows: 1) mothers of children less than twelve years of age who have a formal diagnosis of ASD (including but not limited to diagnosis of ASD, Asperger’s Syndrome, Pervasive Developmental Disorder), 2) who breastfed exclusively for a minimum of 6 weeks, and 3) who did not have any preexisting health or medical issues that might disrupt breastfeeding. Additionally, the child who is currently diagnosed with ASD met the following criteria: 1) was born full term (after 39 weeks) and 2) did not have any other physical conditions that would disrupt feeding.

Including participants who breastfed for at least 6 weeks allowed the study to capture the breastfeeding experience after a full milk supply is established but before most women return to the workforce, to ensure that external factors are not influencing the breastfeeding relationship between mother and infant. Participants must be the primary caregiver of the child with ASD because the goal of the current study is to gain an understanding the experiences, feelings, and perceptions of breastfeeding and observations raising an infant who is later diagnosed with ASD. In addition, the nature of successful breastfeeding revolves around frequent feeding in the first weeks after birth in order to establish a full milk supply, thus, when the mother is not the primary caregiver, lactation is difficult to establish. Limiting the study to participants whose infants did not have other physical conditions that could impact the process of breastfeeding helped to provide an accurate portrayal of the breastfeeding behaviors of infants who are later diagnosed with ASD. Participants whose child was less than twelve years of age allowed for recall of experiences from their child’s infancy to be more salient.
Participants

Five mothers of children currently diagnosed with ASD were recruited for this study (See Table 1). Mothers ranged in age from 28 to 39 and all resided in Iowa. Education levels ranged from high school diplomas to master’s degree. All the mothers who participated in this study had only one child diagnosed with ASD. Though not a requirement for inclusion in the study, all the children diagnosed with ASD were the first-born child. Three of the mothers had two children and the remaining two participants each had three children. Four of the five participants were married. Three of the five participants were stay at home mothers.

Table 1

Mother’s Demographics

<table>
<thead>
<tr>
<th>N= 5</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>4</td>
<td>80%</td>
</tr>
<tr>
<td>Divorced</td>
<td>1</td>
<td>20%</td>
</tr>
<tr>
<td>Number of Children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>2.4</td>
<td></td>
</tr>
<tr>
<td>Min</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Max</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Breastfeeding Duration (months)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Min</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Max</td>
<td>28</td>
<td></td>
</tr>
<tr>
<td>Education Attainment:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some College</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>College degree</td>
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<td></td>
</tr>
<tr>
<td>Graduate Degree</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Age:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>32.6</td>
<td></td>
</tr>
<tr>
<td>Min</td>
<td>28</td>
<td></td>
</tr>
<tr>
<td>Max</td>
<td>39</td>
<td></td>
</tr>
</tbody>
</table>

There were a total of 12 children represented in this study, and 42% had a diagnosis of ASD (see Table 2). The children of participants in this study ranged in age from two to nine
years old. The mean age of the children diagnosed with ASD was six years old, with a median age of five years old. The siblings of the children diagnosed with ASD ranged in age from two to six years old, with a mean age of three years old and a median age of two years old.

Table 2

*Children’s Characteristics*

<table>
<thead>
<tr>
<th></th>
<th>Target Children with ASD</th>
<th>Siblings N= 7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Female</td>
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<td>5</td>
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<tr>
<td>ASD Diagnosis:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autism</td>
<td>4</td>
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</tr>
<tr>
<td>PDD NOS*</td>
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<td></td>
</tr>
<tr>
<td>Age in years:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Median</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Min</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Max</td>
<td>9</td>
<td>6</td>
</tr>
</tbody>
</table>

*PDD NOS = Pervasive Developmental Disorder Not Otherwise Specified*

Procedure

*Research design.* Before collecting data for this study, an in depth literature review was conducted to identify existing research contributing to the understanding of early indicators of ASD from a broad range of fields of study. Prior to data collection, a detailed outline of the research procedure outlining all process that were needed to complete the research was provided to the Iowa State University Institutional Review Board (IRB). IRB approval ensures that the study adheres to specific standards for the study of human participants including confidentiality and informed consent. The Iowa State University IRB granted approval to conduct the study and approved the process of interviewing participants (See Appendix A). After IRB granted approval
to conduct the study, the process of recruiting and interviewing participants began using the process outlined below.

**Recruitment process.** Upon receiving approval, central Iowa lactation counselors, ASD support group leaders, AEA providers, and early interventionists were contacted via phone and email to begin the recruitment process. A summary of the research process was discussed and recruitment flyer, research summary, and informed consent documents were emailed to all contact persons who were willing to help recruit participants. Flyers were posted on Facebook support group pages, in person at ASD early intervention agencies, and at local libraries. This process made it possible to find participants that fit the inclusion criteria for this study. A research summary was available for both contact person and potential participant to learn more about the study prior to consent to participate or share recruitment flyers (Appendix D).

Recruitment emails and phone calls were used to screen potential participants to ensure that potential participants met eligibility criteria (Appendix B). Of the 22 potential participants, five met all the eligibility criteria. 17 participants were determined to be ineligible to participate based on specific ineligibility criteria that are known to both impact breastfeeding and are correlated with a higher likelihood of having a child diagnosed with ASD such as having a Cesarean section or Polycystic Ovarian Syndrome (PCOS). Participants were offered compensation of $45.00 gift card to Wal-Mart in appreciation for participation in the study as well as to help defray potential childcare costs. Funding support was provided through The Kappa Omicron Nu Eileen C. Maddex Fellowship.

When conducting research with human participants, it is essential to ensure ethical treatment of all participants while building an honest and trusting relationship between all enrolled participants and the principal investigator and other involved researchers. In order to
maintain transparency, the research intentions were clearly stated in the IRB approved letter of informed consent including information regarding anonymity and participant rights to privacy (See Appendix C). Each participant received the letter of informed consent to read, and sign prior to the onset of data collection via email. A second copy was provided at the face to face interviews. A signed copy of the letter of consent was maintained for the research records and an additional copy of the consent form was provided for each participant to keep. All participants were informed, prior to the beginning of the interviews, that involvement in this study was voluntary. Participants reserved the right to not answer any question, and were informed that they may leave an interview at any time without providing a reason. These actions maintained both the quality and integrity of the study through the duration of the research process.

**Data collection methods.** A qualitative approach was used to examine participants’ retrospective perceptions of their experiences. In-person interviews were chosen as the primary means of data collection because they can elicit detailed descriptive accounts of lived experiences, allowing for the collection of rich data. Additionally, interviews provide researchers with an opportunity to clarify concepts, address information that needs further explanation, and delve deeper into the topics of interest. Researchers have an opportunity to gain information about an individual’s unique perceptions, observations, and feelings in relation to a lived experience, that might otherwise be missed in alternate data collection methods, when conducting in- person interviews (Creswell 2013). Interviews provide researchers an opportunity learn about what cannot be obtained directly through observation alone while providing participants an opportunity to explain their lived experiences (Glesne, 2011).

**Interview process.** Potential participants were sent individual emails describing the purpose of the study and an invitation to participate. Follow up emails requested a date, time, and
location to conduct the interview. Confirmation emails were sent prior to the interview. The interviews took place during November 2016. Semi-structured interviews were conducted with five mothers in face-to-face environments such as a participant’s home or private meeting room at a public library. Before commencement of the interview, all participants were provided the informed consent document (See Appendix C). The researcher read the informed consent document out loud to each participant to ensure that participants understood the goals of the research study, the research process, and their rights as a participant. Reading the document out loud allowed for review of the process and provided the participant an opportunity to ask questions prior to the beginning of the interview. After the informed consent document was read, the participant was asked to sign the informed consent document. Interviews began with open-ended questions and followed a semi-structured interview protocol (Appendix E). The interviews were 90 to 120 minutes in duration. The following is an example of interview questions in relation to the research questions and theoretical framework of this study (See Table 3).

Table 3

Interview Questions in relation to Research Questions and Theoretical Framework

<table>
<thead>
<tr>
<th>Related RQ or Framework</th>
<th>Example of Interview Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research Question 1</td>
<td>1. Tell me about your experiences breastfeeding your child diagnosed with ASD</td>
</tr>
<tr>
<td>Research Question 2</td>
<td>2. Were there any behaviors, symptoms, or signs that there was something different about your baby?</td>
</tr>
<tr>
<td>Research Question 3</td>
<td>3. Describe your experiences trying to get information about your baby’s behaviors that concerned you, assistance for assessment, or support of your child with ASD</td>
</tr>
<tr>
<td>Theoretical Framework</td>
<td>4. Tell me about the kind of support that you received or needed</td>
</tr>
</tbody>
</table>

Observational field notes were collected by the researcher during the interview to document each participant’s nonverbal responses (See Appendix H). All interviews were audio
recorded for later transcription and analysis. A digital voice recorder was used to record each participant interview.

**Ethical considerations.** Conducting research with human participants requires researchers to make deliberate and intentional ethical decisions that will protect the participants. Informed consent and confidentiality are essential to protect participants during and after the research process. Participation in this study was completely voluntary; therefore, it was essential to provide all potential participants with information about the purpose of the study prior to data collection and at any point during or after interviews were conducted. Once interviews were completed, multiple measures were taken to ensure that the collected information was treated in a manner that ensured the rights and confidentiality of all participants were safeguarded.

Informed consent was a priority at all points of the research process. All potential participants received an emailed copy of the informed consent document as a part of the screening email to maintain transparency. Additionally, before the interviews began, participant’s questions about the research process were addressed, then written informed consent was obtained from all participants. The topics discussed during interviews were sensitive and personal, therefore deliberate decisions were made regarding the reporting and dissemination of data. All names, locations, and other identifying information was altered to maintain and protect participants’ confidentiality. All data was stored on password protected devices and in separate locations to prevent unauthorized access to the data.

**Analysis**

The analytic process began upon completion of data collection from interviews with participants through audio recordings, analytic memos, and observational field notes. The first step consisted of the transcription of the audio recordings of each interview. A transcription
service was used to transcribe each interview in its entirety. The transcription service signed a
nondisclosure agreement to protect the anonymity of participants. In order to protect the
confidentiality of each participant specific steps were taken to maintain participant anonymity.
As part of the data analysis process, all participants and their children, spouses, services
providers such as doctors or lactations consultants, and other family members were assigned
pseudonyms. Additionally, all discussion of locations, agencies, colleges or other places that
could reveal a participant’s identity were replaced with pseudonyms or other fictitious
representations to maintain the privacy of the participants. These modifications were applied to
transcribed interviews before analysis began.

Based on the theoretical framework, transcriptions and field notes were analyzed to
explore maternal attitudes and responses to describe mothers lived breastfeeding experiences.
Data were analyzed for emergent significant statements, recurring patterns and themes. Using a
descriptive phenomenological approach, the transcribed text was analyzed and conceptual codes
of meaning units were developed, the meaning units were transformed into emergent descriptive
statements grounded in the research questions, which finally leads to a synthesis of the general
structure of the participants’ lived experiences (Giorgi, 2009; Bloomberg & Volpe, 2016).

Descriptive phenomenology allows for a systematic exploration of mothers’ lived
experiences from their own unique perspectives. Based on Giorgi’s (1985, 1997) descriptive
phenomenology approach, a sequence of five steps was used to analyze the data (Figure 2). The
data analysis process began by a verbal account of lived experiences collected through audio
recorded participant interviews (step 1), reading the interview transcripts in their entirety (step
2), coding the data into descriptive meaning units (step 3), organizing and transforming data into
third person descriptions of general structures of lived experiences from a disciplinary perspective (step 4), and synthesizing data to disseminate findings and results (step 5).

*Figure 2.* Graphic representation of data analysis steps used to interpret results as detailed in the analysis description based on the descriptive phenomenology method.
The goal of descriptive phenomenology is to explore participants’ reports of their lived experiences, from their unique perspectives, framed within the context of phenomenological scientific reduction to reveal essential descriptions of a phenomenon (Giorgi, 2009). Phenomenological scientific reduction involves reducing the participants’ experiences to illuminate the lived reality of the phenomenon (Giorgi, 2009). Interviews were transcribed by a professional transcription service. Accuracy of transcripts was verified by listening to the audio recorded interviews while reading the transcripts. Reading the transcripts in their entirety provides a sense of the entire description of a phenomenon allowing the analysis to articulate an accurate description of the phenomenon. The main emphasis is on description, differing from other interpretative perspectives.

Each transcript was coded into meaning units using MAXQDA (version 12) through a process of free imaginative variation. Coding using imaginative variation involves using varying frames of reference to approach a phenomenon from different positions and perspectives resulting in the emergence of the essential structures of a phenomenon (Giorgi, 2009). Each meaning unit is considered a specific example or instance that is essential to describe the phenomenon of interest. Meaning units allow the transcripts to be broken down into more manageable units as opposed to analyzing large amounts of data holistically (Giorgi, 2009). Meaning units were coded from the interview data based on a shift of focus or meaning in the participant’s response to interview questions. For example, a participant’s first sentence may answer a question about her child’s food preferences and the following sentence may be discussing her family’s inability to dine at restaurants which would be a response that has significant shift in meaning. The previous example would be coded into two separate meaning units. The meaning units were then coded into themes across all transcripts.
Meaning units were then further analyzed into themes that provide detailed descriptive summary to represent aspects of lived experiences that are essential to the general structure of the phenomenon. This process was repeated across all transcripts, and analysis of both meaning units and themes were repeatedly analyzed until unified themes emerged. According to Giorgi (1997), the resulting themes can be used to disseminate descriptive information about the phenomenon of interest to the scholarly community. An example of the analytic process is illustrated in Table 4.

Table 4

Example of analytic process.

<table>
<thead>
<tr>
<th>Meaning Unit</th>
<th>Transferable, General Structure</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Basically if X didn't breastfeed to sleep, then X never slept. Even if X fell asleep on me, if I tried to lay X down, as soon as X got horizontal X would wake up and cry. X ended up being a super fat baby because of that. X basically breastfed all the time and all night long, and X was co-sleeping.”</td>
<td>Mother felt that breastfeeding was one of the few things that kept her child calm and content. The mother used breastfeeding as more than a source of nutrition which also meant her child breastfed frequently.</td>
<td>Breastfeeding as Intervention</td>
</tr>
<tr>
<td>‘I would notice other things, like when we’d go in the nurse would be like, “Touch your nose! Is X able to do it?” I remember saying to my husband, “Oh, those check-ups are really stressful, because the doctor keeps asking me these questions and I have to be like, ‘No’ to them.”</td>
<td>Mother was worried about the infant’s ability to pass certain developmental milestones assessments. She felt infant checkups were stressful because it highlighted aspects of his development that were delayed.</td>
<td>Suspicions</td>
</tr>
<tr>
<td>“I definitely was able to realize not every child is this intense and this on all the time and … had X not been my first, I would have known from probably week two that something was different.”</td>
<td>After the birth of her second child, the mother could compare infant behaviors between her children. She felt that if she had another child before giving birth to her child diagnosed with ASD, she would have known that her infant’s behaviors were atypical.</td>
<td>Inexperience</td>
</tr>
</tbody>
</table>
Table 4 (continued)

<table>
<thead>
<tr>
<th>Meaning Unit</th>
<th>Transferable, General Structure</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Yeah, now, I think the thing that helped me here is my personality, the way that my mind works, is one that is really good at figuring out exactly the thing, narrowing it down to the things that will make a difference, the most important factor here. That’s what I could do with X. I would say, “This is the problem.” I would narrow it down really well, and I’d be like, okay, this. Then I would fix that, and it would solve the problem, but there were so many of those.”</td>
<td>Mother felt that her personality helped her to figure out what her child needed. She described herself as being able to problem solve and focus on an issue until a resolution was determined that would meet her child’s needs.</td>
<td>Disposition</td>
</tr>
<tr>
<td>“I don’t remember the lactation specialist, if I even had one. I don’t remember being given a number, or being told to call if I had problems. That just never occurred to me that I could call… I just thought I’m having pain, so this isn’t going well. X doesn’t seem to be able to do it anyway.”</td>
<td>Mother does not remember receiving lactation support while in the hospital. She was not provided information about who to call if she had problems breastfeeding. She was not aware that services were available. She believed her physical pain was because breastfeeding was not going well and that her infant was unable to breastfeed.</td>
<td>Need for Support</td>
</tr>
<tr>
<td>“Then you have to build your confidence from scratch and when nothing seems to be easy, nothing works out like people say it should. It doesn’t work out like the books say it should and everybody is telling you that... They’re dismissing your concerns.”</td>
<td>Mother talked about needing to build self confidence despite the challenges of atypical infant behaviors. Her experience was unlike anything in the breastfeeding and parenting books that she read. She felt her concerns about her infant were dismissed.</td>
<td>Perseverance</td>
</tr>
</tbody>
</table>
CHAPTER 4. FINDINGS

The purpose of this study was to explore maternal experiences, observations, and perceptions related to breastfeeding an infant later diagnosed with ASD. A descriptive phenomenological approach was used to provide a better understanding of this phenomenon that will allow practitioners, physicians, and lactation consultants to have a more informed perspective when providing support.

Five mothers who have a child diagnosed with ASD, ranging in age from 28 to 39 years old were recruited for this study. All participants breastfed their child for at least eight weeks after birth. Data were gathered using in-depth, semi-structured interviews. The interviews were recorded, transcribed, and analyzed using MAXQDA (version 12). Guided by ecological theory, categories and themes were developed to describe the general structure of the phenomenon.

This chapter provides key findings obtained from five in-depth interviews. Due to the process of refining meaning units into descriptions, the emergent themes are not a summary of all the unique experiences of each participant but rather a descriptive representation of a portion of the many experiences mother’s face when raising an infant later diagnosed with ASD as approached from an ecological perspective. The participants did not have a singular unified experience that can be directly translated into a summary. Just as the presentation of symptoms of ASD vary between individuals, so do the unique experiences mothers face when breastfeeding and raising an infant later diagnosed with ASD. This study describes aspects of mothers’ experiences that can help to illuminate the unmet needs of mothers and infants. Direct quotes from the interviews provide additional insight into the feelings, thoughts, and experiences of the participants. Six themes emerged from the data analysis to form the general structure of mother’s experiences breastfeeding an infant later diagnosed with ASD (see Table 5):
1. Breastfeeding as an Intervention: Breastfeeding was used to manage atypical or challenging behaviors to calm, comfort, and soothe their infant.

2. Suspicions: Participants expressed awareness and concern regarding atypical infant behaviors that became more pronounced as the infant grew.

3. Inexperience: Participants reported that they, as first time parents, lacked preexisting knowledge of development to clearly identify (and bring to the attention of a professional) early indicators of ASD based on infant breastfeeding behaviors.

4. Disposition: The personal characteristics and parenting style of the participants influenced the duration of breastfeeding.

5. Need for Support: Participants reported a lack of professional support related to breastfeeding issues and concerns specific to atypical infant behaviors.

6. Perseverance: Despite the difficulties with breastfeeding, the participants were determined to breastfeed and find ways to meet the unique needs of their infants.

Table 5

*Six themes of mother’s experiences breastfeeding infants later diagnosed with ASD*

<table>
<thead>
<tr>
<th>Breastfeeding as Intervention</th>
<th>Suspicions</th>
<th>Inexperience</th>
<th>Disposition</th>
<th>Need for Support</th>
<th>Perseverance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manage atypical infant behaviors</td>
<td>Atypical Feeding Patterns</td>
<td>Lack of knowledge about development</td>
<td>Personality</td>
<td>Lack of Professional Support</td>
<td>Determined to breastfeed</td>
</tr>
<tr>
<td>Soothe, calm, and comfort</td>
<td>Atypical Sleep Patterns</td>
<td>Unable to identify atypical infant behaviors</td>
<td>Parenting Style</td>
<td>Addressing concerns about development</td>
<td>Meet the needs of the infant</td>
</tr>
</tbody>
</table>
Theme 1: Breastfeeding as an Intervention

While exploring this theme, it is essential to understand the complex relationships between mother and infant from the perspective of the breastfeeding relationship and the impacts of atypical infant behaviors within the context of family and social support networks. The participants described how difficult it was to not know how to meet their infant’s needs before there was an ASD diagnosis that helped to explain atypical behaviors. The impact of atypical behaviors on breastfeeding varied between participants; however, the majority found breastfeeding to be a useful strategy that helped their infant beyond meeting nutritional needs. The majority of the participants used breastfeeding as a way to manage atypical or challenging behaviors in order to calm, comfort, and soothe their infant resulting in frequent feedings in addition to meeting their child’s nutritional needs. Some participants reported that they did not feel an emotional connection from their infant while breastfeeding despite their desire to connect, and that the experience lacked the strong bonding and emotional reciprocity that they had heard about prior to giving birth.

“I was more of a prop to his needs…I don't expect my kids to give back to me but you feel that they are getting something more than nutrition from breastfeeding and I never felt like that with him. I was keeping him happy but I wasn't making him happy.”

Other participants mentioned that breastfeeding was one of the few times that their child could share physical closeness and connect emotionally.

“He was always really snuggly while breastfeeding. It was also like a soothing thing for him. I don’t think I got the soothing thing from my other children while breastfeeding.”

Some participants reported their infant breastfeeding frequently, lasting past the age when most infants can have longer amounts of time between feedings.
“It was like we might have just finished a half an hour ago and we're going to do it again this time or we might have had two hours of happy and now it's time again.”

For the infants who breastfed frequently, frequent breastfeeding was perceived as being a signal of insatiable hunger. Participants reported that their infant had rapid weight gain and growth that was viewed positively by health care providers despite the atypical feeding pattern and other atypical behaviors. Additionally, for some of the infants, the frequent feeding persisted once solid food was introduced.

The majority of the participants reported that in addition to meeting the nutritional needs of their infant, breastfeeding became a way to calm and comfort their infant when no other method of soothing was successful.

“If she started screaming in the car, she would scream so hard and loud that I was worried she was going to hurt herself. The first time I dropped her off at childcare at church, they came and got me, and they said, "We're trying to calm her down, but we're worried that she's going to hurt herself. She’d be screaming, completely red, screaming to the point where she was coughing and gagging, and there was nothing that ... It would go on for as long as you would let it. Only breastfeeding would help to calm her when X was that upset.”

At the time, however, mothers were not necessarily making a conscious connection between using breastfeeding as a strategy to manage their infants’ atypical behaviors. The mothers would use breastfeeding when no other parenting interaction or strategy would help, regardless of whether the infant had breastfed recently.

“He'd start screaming, I've changed his diaper, I've done everything else I can. Let's try to [breastfeed] and so it wasn't even that it was a specific cue. I could tell with my other
two children, they would do the rooting or I could tell it's probably about that time and they were starting to get hungry, I could even catch them before they were actually fussy. With him, we'd go from fine to I'm screaming and let's just try nursing and so there was no real obvious cue.”

The information that mothers received regarding the frequency at which an infant should breastfeed, including the common phrase “breastfeed on demand”, contributed to both the duration of breastfeeding and the use of breastfeeding to soothe and comfort their infant. The phrase “breastfeed on demand” is often used by health care providers, lactation consultations, and many books to encourage mothers to feed their infant every time the infant is hungry and to follow the infant’s hunger cues. Following this doctrine lead many of the participants to breastfeed frequently, though not necessarily in response to the infant’s hunger.

“So it felt to me like all breastfeeding “on demand” meant was as soon as they wake up and start squawking you have to rush in there because they're going to work themselves up into a rage and not be able to settle.”

Several participants reported that their infants did not like to be held or cuddled but would breastfeed in response to overstimulating environments and as a way to stay calm and happy.

“He could always hold his head up but he was not a snugly baby. He was always rigid, he wasn't that baby that curls into you but he was happy nursing and so he nursed all the time. Anytime it was crowded or lights or looking back on it, I look back and say, ‘Oh yeah he was overstimulated’ and so that's what he would do for comfort.”

All the participants described having a strong desire to breastfeed before giving birth. One of the participants simply stated, “It was just always something I was going to do.” Many of the participants had siblings or other family members who also breastfed, and discussed the
influence of family, friends, and educational information that they had received explaining the health benefits of breastfeeding. For the participants whose infant’s fed frequently, they described the information they received before giving birth about how to breastfeed as being useful. However, they did not feel that the information they had prior to giving birth prepared them for their infants feeding behaviors.

“The kind of lumped her feeding issues in with her sensory, like the stimulation and … it was all related… so I guess that’s why when I saw other moms with breastfeeding problems, like tongue-tie problems and mastitis and cracked nipples and stuff, I didn't have anything on that level. All the issues that we had for her breastfeeding seemed to be more sensory… It seemed like if there was any kind of sensory interference that she was having, it would carry over into breastfeeding.”

**Theme 2: Suspicions**

All the participants expressed an awareness that their infant exhibited atypical behaviors during infancy, though not all behaviors were related to feeding. The participants reported atypical behavior across multiple developmental domains. Many participants reported noticing both atypical receptive and expressive communication during infancy, such as a lack of pointing or not responding to their name being said out loud. The communication delays persisted and were often one of the first signs leading to formal assessment when the infant was slow to develop verbal speech. Several participants reported delayed fine and gross motor skills, one participant reported her infant never crawled. Several participants reported atypical social behaviors, such as lack of eye contact, limited amounts of smiling and laughing, or concerns about bonding. The majority of participants reported struggling with infant sleep patterns, with many participants relying on breastfeeding as a way to address sleep issues such as frequent
night waking. Some participants described their infants as being “high needs”, hard to soothe, irritable, quick to be emotionally aroused, and intense.

“He was just on fire, all the time.”

Other participants reported their infants as being generally calm and detached from other people, seldom seeking interaction. These infants were in stark contrast to the “high needs babies”, and were often relaxed but also disconnected from people including parents and caregivers.

“She could just lay somewhere on the blanket on the floor and her bouncer for a long time and just be happy. She wasn't crying out for companionship. She would just play in her Pack and Play and be pretty content.”

The participants reported atypical behavior across multiple developmental domains and emotional regulation, however, since all the participants were first time mothers they were not aware of the extent of the atypical behaviors. Many of the participants reported noticing behaviors that seemed extreme and unsettling while others reported being aware of behaviors that, while not frustrating, still seemed atypical during infancy.

“He would just study things really intently. He would look at things a lot longer. His focus on things seemed to be a lot longer than I would expect for a baby or for a young toddler. Then when I had my second child, it seemed much more what I would expect. He'd look at something for a while, and he'd look at something else. Then he'd get distracted. X would study wheels or flashing lights, or looked at more ceilings. We'd go to Wal-Mart or something, I would think, ‘What is holding your attention... Oh, that is weird!’ I've never even looked up at the ceiling when I was at Wal-Mart before.”

All the participants reported having concerns about their infants’ atypical behaviors, however, these concerns became more specific after they had another child with which to compare
behaviors. The magnitude of the ways in which participants recognized aspects of atypical development during infancy that spanned multiple developmental domains was surprising; however, the lack of siblings or other infants with whom to compare behaviors may account for the participant’s perceptions of inexperience.

Many of the participants had close connections to extended family members, friends, or other support people who witnessed the infants’ atypical behaviors. The influences of these other people ranged from supportive concern regarding atypical behaviors to attempts to reassure mothers that their infant was “normal”.

“I would say, we had a lot of people who probably knew that he had autism, but didn’t want to tell us that, because they probably didn’t feel like it was their place, because they weren’t necessarily qualified to make the diagnosis.”

**Theme 3: Inexperience**

Though not a requirement to participate in this study, all the participant’s first-born children were diagnosed with ASD and all participants had more than one child. All the participants reported that they felt being a “first time mother” made them uncertain as to whether a specific behavior was atypical or normal. Participants reported that, at times, they felt atypical behaviors were “normal” because they had no other frame of reference or information about development.

“I was at home with her when I wasn't working and because she was my first, everything seemed normal. We look back and we feel like she was a very relaxed baby on her own. She could just lay somewhere on the blanket on the floor and her bouncer for a long time and just be happy without any interaction from either one of us.”
These feelings also created a sense of inexperience, that held differing connotations between participants. Some participants felt that being a first-time mother made them unaware of aspects of atypical development that may have caused increased stress or worry if they had other children with whom to compare behaviors.

“We had no idea, because we didn’t have any other kids. We just thought that’s what he did... Luckily, we didn’t know any different.”

Whereas, other aspects of atypical development caused participants to feel frustrated and have self-doubt about their parenting skills when they became overwhelmed by their infant’s behaviors.

“I think I was just insecure enough as a new parent to think, well I think we just both felt, ‘We haven't figured it out. We haven't cracked the code yet of how to co-sleep and breastfeed and also get us some sleep. Maybe we have a particularly hard to soothe baby.’”

Being a first-time mother also influenced decisions on multiple aspects of parenting of their other children, such as parenting interactions or introduction of solid foods. For the participants who had an infant that was content to be alone with little interaction, they realized with subsequent children that they would need to change their parenting interactions. For those who identified their infants as “high needs,” having other children helped the participants identify atypical behaviors that they had not previously understood.

“In his babyhood, into now, that when he gets upset, it takes much longer for him to come back to equilibrium. He gets fight or flight. He gets upset. That was something we noticed with our second kid. It's like "Oh, he can cry as a baby and come back to normal
in 10-15 minutes, or now as a toddler he can complain about something and throw a tantrum, and half an hour later, he's fine."

**Theme 4: Disposition**

Similar to participant beliefs about their desire to breastfeed before giving birth, individual aspects of participant’s personalities and parenting styles played a role in their experiences breastfeeding and meeting the needs of their infant. The majority of participants felt it was important to be responsive to their children’s needs, were persistent in their attempts to figure out how to best meet those needs, and advocate for both themselves and their infant.

Despite being first-time mothers, some participants felt strongly about their own maternal instincts in regards to multiple aspects of their role as a mother, including infant feeding. One participant felt that her ability to intuitively know when her child was hungry helped her to meet his nutritional needs, despite his lack of consistent hunger cues. Another participant felt similarly about her own maternal instincts in regards to breastfeeding frequency and chose to not follow a feeding schedule but instead respond to her infant’s needs through breastfeeding, despite the frequency of feeding.

“No, I gotta trust my gut here, and I just gotta feed her on demand, even though she's a fat kid.”

Several participants discussed attachment parenting, as their personal parenting philosophy, describing the importance of responsive parenting that promotes a strong bond between mother and infant. Participants described reading about attachment parenting and having a strong sense of the importance of responsive parenting from before their child was born. Responsive parenting and following infant’s cues helped participants to meet their infants’ needs, regardless of the frequency or challenging nature of a specific infant behavior.
“I do feel like… maybe this is some protective element, but that continually always having him next to me was already something I was thinking about before he was born, attachment parenting, but then forced upon me by that being the only way he was happy, but I definitely feel like we were super bonded. That's the silver lining of him needing a lot of help regulating himself and figuring out what was going on in the environment, so I think we were very close. We're still very close, but he would use me a lot to see if I was reacting to something.”

All the participants described the processes involved in determining what strategies best met their infants’ needs, often discussed from the perspective of being a detective trying to solve a problem that they did not have a name for before a diagnosis was made. Participants discussed a tenacity and drive to not only determine and provide for their infant’s unmet needs regardless of the intensity or frequency of that need, but strived to understand, predict, and eventually provide a supportive therapeutic home environment after diagnosis occurred.

“I think the thing that helped me here is my personality, the way that my mind works, is one that is really good at figuring out exactly the thing, narrowing it down to the things that will make a difference, the most important factor here. That's what I could do with her. I would say, "This is the problem." I would narrow it down really well, and I'd be like, okay, this. Then I would fix that, and it would solve the problem, but there were so many of those.”

“Then, I just kind of had to get in game mode. It’s like, then you figure out what’s going on with your kid. If you can get educated enough to know what your kid needs, then you have to get on a wait list for everything that they need.”
Theme 5: Need for Support

All participants discussed the need for and importance of support, related to both breastfeeding and information about infant development. From an ecological systems perspective, participants discussed the influence of multiple levels of support based on interactions with spouses, parents, siblings, and trained professionals. Some of the participants felt that they received encouragement from their pediatrician to continue breastfeeding based on their infant’s growth.

“I didn't have a whole lot of friends or anybody else that had already breastfed and Facebook wasn't as prevalent to say, "Is this normal?" I just assumed that whatever he was doing must have been normal and we stuck to it. I had a really good pediatrician that assured me that he was gaining and he did. He easily doubled his birth weight by three months.”

Some participants felt disappointed by their pediatrician’s lack of breastfeeding and developmental knowledge. While other participants felt that while a pediatrician was supportive of breastfeeding, they did not experience their pediatrician to have sufficient breastfeeding knowledge to address their concerns specific to the breastfeeding process. Additionally, several participants reported that their pediatrician was dismissive of developmental concerns and delays.

“He'd been really great and supportive but all of a sudden it clicked like I'm really having to fight to point out that something's not right.”

Some participants felt reassured by the support and information provided by lactation consultants in regard to their ability to breastfeed, though the lactation support mother’s received happened primarily while participants were still in the hospital.
“The nurse taught me how to squeeze colostrum and then just drip it into her mouth, just to make sure she got five to six drops the first few days each feeding.”

Unfortunately, many participants struggled to find effective assistance from lactation consultants regarding their breastfeeding concerns after they went home. The majority of participants discussed conflicts of personality between themselves and the lactation consultant, lactation consultant’s lack of knowledge or successful interventions specific to the issues that their infant was having breastfeeding, and a lack of knowledge about where to find resources. One participant attempted to seek help from a lactation consultant at a breastfeeding support group. She felt frustrated with the lactation consultant’s lack of developmental knowledge and inability to help resolve breastfeeding issues related to atypical behaviors.

“All time anybody had a concern about … [infant behavior that was] not developmentally normal, she [lactation consultant] would either say that's developmentally appropriate or if it's not developmentally appropriate, it's probably not actually the problem you think you're having.”

All participants reported the need for reassurance, support, and information regarding both breastfeeding and infant development. In this study, the two concepts often overlapped with atypical infant behaviors influencing infant feeding behaviors. The mothers expressed a strong desire to have support and that they often turned to others for support and information. Many participants discussed using the internet to find information related to breastfeeding and ASD as well as validation for the experiences and challenges they faced.

“I think just somebody being there and saying, ‘Trust your motherly instinct. Trust that’ I think would have been a big help because I feel like my mom says that and is there but the more you hear it, especially from people who don't have to love you, the better it is
and I just don't feel like that support was really out there ten years ago. I think it's growing a little bit now. People are at least able to share information and not worrying about offending people.”

However, not all of the participants were able to breastfeed for as long as they desired. One participant struggled to breastfeed past two months, she described a combination of several factors impacting her ability to continue breastfeeding based on the need for support from multiple levels. She discussed the need for trained professionals and a support network of friends to help encourage her during challenging times. While she felt that her spouse provided an essential amount of support during the breastfeeding process, she discussed not being aware of lactation specific services in her area. The participant described a desire to have had someone help her with both her understanding of the process of lactation and decipher atypical infant behaviors related to breastfeeding. She felt that had she been able to find support from a trained professional or had an existing network of friends with breastfeeding experience, the duration of breastfeeding her first child would have increased, highlighting the importance of support at multiple ecological system levels.

“I guess it's ... I don't know if it's even possible, but because I was such a young mom, I wish I had somebody or anybody, maybe check up on me just to see how it's going. I don't even know if that type of task exists for somebody's job description, but it would've been nice to just have somebody say, "Call me if you have any trouble, or if you feel like ...if you feel like stopping, think about it and call me. " Whether it was a nurse, or lactation specialist or a friend. I think I was the first of my friends to have a baby, so that was hard.”
Theme 6: Perseverance

In addition to maternal parenting style and disposition, all the participants described situations in which their tenacity and determination lead them to overcome the challenges they faced raising and infant later diagnosed with ASD. Most of the participants overcame multiple obstacles to maintain breastfeeding. While some struggled due to atypical infant behaviors, others had numerous issues related to the breastfeeding process such as problems with the infant latching on to the breast.

“He ended up with thrush, and so did I, so then I was like, “I’m not going to do this [breastfeed].” He wouldn’t do formula. He absolutely rejected formula, like projectile spit it on the wall, like seven different kinds, wouldn’t do it. It was like, “That’s it. We’re going to make it the whole year, and that’s what we’re going to do,” and he did, and we did.”

The majority of participants described struggling to calm and comfort their infant, having to rely on breastfeeding and extensive strategies that would decrease the intensity of their infant’s behaviors. While the behaviors, strategies, and experiences varied among participants, the common theme that emerged was that the mother’s determination to help her infant was a constant process involving endless hours of dedication to her infant, hard work, and thoughtful investigation.

“Inside anywhere else was the worst place to be. Eventually I learned that TV, music, artificial lighting were all kind of problems for her, but I didn't know that at the time. I think that's why the outside was so calming. Luckily, I had her at the end of February, so I had that whole spring and summer when she was “bitty” to go outside, and oh my gosh,
that was wonderful. I don't know what I have done without that. We spent most of our
time on the porch pacing.”

The participants described every day activities, such as going to the store or laying their
infant down for a nap, that required heroic efforts and time devoted to managing behaviors on a
consistent basis. The mothers developed unique solutions to meet their infant’s needs as well as
coping mechanisms to maintain their own ability to function.

“I just came up with this general rule that I wouldn't take him more than one place at a
time, and not for longer than two hours. I remember that being my guideline, and I think
that's because he takes in so much that he gets overwhelmed.”

Participants described extensive routines that were followed religiously to have a desired
behavioral outcome. The infant’s behaviors occurred regardless of who was caring for the child,
and were persisted into the toddler years and beyond.

“He would take easily two hours to settle down and fall asleep. We could rock, we could
nurse, we could read books. Do the whole long bedtime routine over and over and over
again and he would still not fall asleep and finally by about 18 months to two, he was out
of a crib because he wouldn't stay in one and so we just had a bed on his floor and I
would sit there and for two hours, he would be in and out of bed and he would just sit on
his bed and he would talk, to himself, to me, about whatever with his animals until he
finally would just pass out.”

Despite the challenges, most of the participant’s felt that their motivation to breastfeed
and focus on caring for their infant became a source of strength as they realized that despite
feeling exhausted, and frustrated at times, they had overcome obstacles to meet their infant’s
needs.
“Breast feeding to me was not the beautiful, magical thing that they made it out to be at the beginning. I feel like you do that, you get through it, and you do it, and it’s incredible that you did it. It’s sort of an, “All right, I can get through anything” kind of feeling, like childbirth is, so I guess empowering.”

Summary

This chapter presented the six themes revealed by this study. Findings were presented as themes that emerged from individual interviews with participants to reveal their experiences, observations and perceptions breastfeeding and raising and infant later diagnosed with ASD. To illuminate the concepts within each theme, direct quotes from the interviews were included within this chapter. To protect the identities of each participant and their children, the individual respondents are not identified. Direct quotes allow for accurate representation of the lived experiences of participants and their children.

The primary theme of this study revealed that the majority of participants used breastfeeding as an intervention to calm, comfort, and soothe their infant in addition to meeting their infant’s nutritional needs. Although most participants described not being aware of the connection between breastfeeding as a strategy to manage atypical behaviors during infancy, rather that breastfeeding was the only consistent way to soothe and calm their infant. The majority of participants described breastfeeding as one of the few strategies that they used that would consistently work to manage challenging behavior, which lead to both an increase in frequency and duration of breastfeeding, leading some participants to feel a strong bond with their infant. Several participants talked about the impact of atypical infant behaviors on the process of breastfeeding and that these challenges lead to a sense of a lack of connection with their infant. One participant attributed early breastfeeding cessation to her infant’s atypical
feeding behaviors combined with struggles associated with returning to work. For some participants, breastfeeding was the only way that they could have close physical contact with their infant, and for others breastfeeding was an extension of the infant’s need to be in constant close physical contact with the participant. All participants had a strong desire to breastfeed before giving birth, though the information they received prior to giving birth did not prepare them for the challenges they would face.

The second theme that emerged from the data related to participant’s suspicions that their infant had a developmental disability years before receiving an official diagnosis. Participants reported being aware of atypical behaviors and delays across multiple developmental domains during infancy and toddlerhood. Some participants described the difficulty they had managing the intensity of their infant’s behaviors while others perceived their infant’s detached behavior as a being relaxed and calm. All the participants reported having concerns about their infant’s development but at the time did not have other children with which to compare.

The third theme emerged from participant’s inexperience as first-time mothers. Though not a part of the inclusion criteria, all the participant’s first-born children were diagnosed with ASD and all participants had more than one child. All the participants reported having concerns about their infant’s development; however, the participants reported that being a first-time mother impacted their ability to fully realize whether a behavior was atypical or “normal”. While being a first-time mother was reassuring to some participants, because they felt the lack of awareness made them not worry, others reported that their infant’s atypical behaviors made them doubt their abilities as a mother. All participants described a process of comparing behaviors of their other children to the behaviors of the infant later diagnosed with ASD to gain an understanding of typical versus atypical infant behaviors. Participants reported that their
experiences parenting and raising an infant later diagnosed with ASD influenced parenting decisions in raising their other children.

The fourth theme was based on the unique attributes, personal characteristics, and parenting styles of the participants in this study. The majority of the participants believed it was important to be responsive to their infants’ and persistent in their attempts to find ways to meet their infant’s needs. The participants felt strongly about their maternal instincts and the importance of following their infant’s cues, even when those cues seemed confusing or atypical. Several participants specifically discussed attachment parenting as their parenting philosophy, and all participants parenting styles followed closely to the underpinnings of attachment parenting. The participants drive to understand their infants’ behaviors and find ways to support the infant’s needs was tied directly to the responsive nature of their interactions.

The fifth theme was the need for support for both breastfeeding and information about infant development. The participants discussed the various people who supported them during their child’s infancy. There were differing views on professional support regarding developmental information during their child’s infancy ranging from positive experiences to a lack of professional support. A similar pattern emerged regarding access to breastfeeding support, where the majority of participants reported that they received the most breastfeeding support from trained professionals immediately after giving birth while still in the hospital. Many participants described a lack of professional support in relation to the impact of atypical development on breastfeeding.

The sixth theme of persistence evolved from the participants’ descriptions of the numerous strategies, large amounts of time, and tenacity involved in caring for their infants. The participants described experiences that ranged from breastfeeding hourly for months to hours of
non-stop rocking to soothe or comfort their infant. Participants persisted in modifying their own schedules and responding consistently to their infant despite feeling overwhelmed, exhausted, and frustrated. The participants who were able to meet their breastfeeding goals, or those who breastfed out of necessity based on either needing to use breastfeeding as an intervention or because their infant did not respond well to formula, overcame numerous obstacles often without any trained professional assistance from either a lactation consultant, early interventionist, or pediatrician. The participants described having to modify multiple aspects of everyday life such as how long they would be able to leave their own home or where they slept at night to meet their infant’s needs. All participants described multiple settings, situations, and scenarios where their infant’s atypical behaviors required heroic measures to manage on a daily basis. All participants expressed a strong desire to breastfeed before giving birth, however, none of them felt that the education that they had before their infant was born was sufficient to prepare them for the experiences that occurred breastfeeding and raising their infant later diagnosed with ASD.

In conclusion, the findings of this research reveal that mothers of infants later diagnosed with ASD face unique challenges breastfeeding. Many of the obstacles participants faced while breastfeeding were influenced by atypical infant behaviors. Participants reported observing atypical development across multiple domains during infancy and toddlerhood before a diagnosis of ASD occurred. Participants sought help for their struggles from multiple support networks, spouses, health care providers and lactation consultants. However, the outcomes of seeking support varied from beneficial to unhelpful based on the practitioner’s developmental knowledge. Despite the participants’ inexperience with parenting based on being first-time mothers, their personal characteristics, parenting style, desire to breastfeed, and tenacity were protective factors as they overcame obstacles related to their infant’s atypical behaviors.
CHAPTER 5. DISCUSSION AND INTERPRETATION

This qualitative study examined maternal experiences breastfeeding and raising an infant later diagnosed with ASD based on a sample of five mothers of children currently diagnosed with ASD. Guided by ecological systems theory, maternal experiences accessing support for both breastfeeding and atypical infant behaviors were explored. The conclusions and findings from this study address three areas: 1) mother’s experiences breastfeeding and raising infants who were later diagnosed with ASD; 2) mother’s perceptions and observations of physical development, social behaviors, and feeding behaviors of infants who were later diagnosed with ASD; and 3) how mothers accessed and found support for their infants before their child received a diagnosis of ASD. Six themes emerged in response to the research questions, though each theme was unique, the themes were interwoven between and among the research questions. This chapter will discuss the major findings and conclusions from this study, followed by limitations, and implications for future research.

**Interpretation**

**Maternal experiences breastfeeding infants later diagnosed with ASD.** The first major finding of this study was that the majority of participants described using breastfeeding as a strategy to calm, comfort, and soothe their infants in addition to meeting nutritional needs. While there is existing literature that demonstrates breastfeeding provides an infant with more than nutrients alone, this study illuminates the unique ways that mothers used breastfeeding to meet the needs of their infants. This points to the importance of mothers being made aware of the nonnutritive benefits of breastfeeding, both prior to giving birth and while actively breastfeeding, which will help them to be aware that an infant’s need to breastfeed can be caused by more than hunger. The breastfeeding dyad is influenced by the unique qualities of both the mother and
infant. As a biological process, there are certain similarities between all breastfeeding dyads, however individual variation allows for each breastfeeding journey to be unique to the dyad.

The second finding of this study was that each mother had suspicions that her infant’s behaviors were atypical. Although a mother may take classes or read books, breastfeeding her infant may be very different in the real world. These differences may be even more pronounced for mothers of infants later diagnosed with ASD; it may difficult for mothers to explain their struggles to professionals when breastfeeding is used as a strategy to manage atypical behaviors. Mothers may not be able to apply the concepts learned from prior breastfeeding experiences, books, or classes, to infants who exhibit atypical behaviors. These challenges would be exacerbated for first-time mothers with no prior breastfeeding experience.

The study’s third major finding was related to participants’ inexperience breastfeeding and raising an infant as first-time mothers. Several participants described being overwhelmed with the process of breastfeeding. For those whose infants fed frequently, sleep deprivation became a common topic as they struggled to make sense of why breastfeeding seemed so unmanageable. A conclusion that can be drawn from this theme is that inexperience as a first-time breastfeeding mother may mean mothers need more practical information regarding typical breastfeeding behaviors in relation to development.

The fourth finding was that maternal disposition influenced her ability to successfully breastfeed despite the obstacles faced while breastfeeding. Many mothers plan to breastfeed while still pregnant, and there is a positive association between intention to breastfeed and duration of breastfeeding (Wambach & Riordan, 2016). Women who have high confidence and a positive attitude towards breastfeeding tend to initiate and breastfeed for longer than women who don’t share a similar disposition (Wambach & Riordan, 2016). These characteristics also play a
role in the sixth finding of this study that highlighted the mother’s ability to persevere despite challenges with breastfeeding.

Mothers may be unaware of or unable to connect abstract concepts of development to their infants’ breastfeeding behaviors or how other seemingly unrelated atypical behaviors influence breastfeeding. This was highlighted in the finding describing the importance of supports from both informal networks and trained professionals that can bridge multidisciplinary fields of both lactation and development for all new mothers. Women with greater access to social and professional support are more likely to decide to breastfeed and tend to breastfeed longer (Wambach & Riordan, 2016). The intensity at which the participants felt frustrated and overwhelmed highlights the need for access to support by trained professionals in addition to family members (McInnes et al., 2008). There is a need for sensitive and diligent responses to mothers who report concerns about atypical infant feeding behaviors, this finding was especially salient given that the majority of participants breastfed well past the majority of mothers in the U.S.; current rates show only 30.7% of women are still breastfeeding when their child is 12 months old (CDC, 2016).

Maternal observations of atypical behaviors. The findings of this study are consistent with prior research exploring both early indicators of ASD during infancy and maternal observations of atypical infant behaviors, however, this study adds to existing literature by exploring these indicators within the context of infant feeding behaviors and maternal support networks from an ecological perspective. The first finding was that mothers’ used breastfeeding to manage their infant’s atypical behaviors. Breastfeeding was often the only consistent strategy that many mothers had to manage atypical behaviors. While some participants were aware that their infants’ feeding behaviors were atypical, others were reassured by health care providers that
the observed behaviors were not cause for concern. A conclusion that can be drawn from this finding is that infant feeding behaviors may be influenced by other early indicators of ASD. Access to trained professionals with knowledge of both lactation and development can help mothers to connect infant feeding patterns to other atypical behaviors.

The second finding, in relation to mothers’ perceptions and observations of atypical behaviors was that all participants had an awareness and concern that their infant was exhibiting atypical behaviors. Participants reported that though they were aware of atypical behaviors they were uncertain about aspects of development that would help them identify and report their concerns to health care professionals. Several participants discussed using the internet to attempt to find information about their infants’ behaviors. Participants commented that they read about ASD online but did not feel it applied to their child because they presumed that a diagnosis of ASD required a child to exhibit all the symptoms listed on the websites. This finding illuminates the need for parents to better understand the concept of ASD as a spectrum disorder that includes variation in the presentation of symptoms. Another conclusion based on this finding is that there is a lack of information and resources for parents regarding atypical behaviors during infancy, especially online. Internet use is a common way for parents to find information about infant development; therefore, it is essential to have resources with accurate information (Khoo et al., 2008).

In regard to maternal suspicions of atypical infant development, several participants discussed the impact of their infants’ behaviors on their perceptions of bonding with their infant. Bonding is the connection that a mother feels towards her child, whereas attachment refers to the connection an infant has to a caregiver. The mothers who described their infants as not wanting to be held or appearing emotionally detached described an ease of care when their infant could
be left alone without constant interaction or supervision, yet commented on their own struggles to bond with or feel connected to their infant. The participants who had infants that needed constant close physical contact discussed bonding in terms of their connection to their child at an older age. This finding highlights the importance of professionals asking questions about maternal perceptions of bonding to their infants and the importance of exploring and monitoring maternal concerns.

The third finding was that mothers’ inexperience was a key factor in their ability to determine whether a behavior was atypical. Based on this finding, the fundamental foundations new mothers have about infant development may not be sufficient to prepare them to identify and address atypical behaviors. During the first years after their infants were born, many mothers reported being preoccupied with analyzing behaviors to determine what the infant needed. The mothers were unsure if aspects of the immediate environment, something they ate while breastfeeding, or numerous other factors were the cause of atypical behaviors. They became expert detectives striving to find solutions and strategies that would meet the needs of their infant. A conclusion that can be drawn from this finding is that in the absence of formal professional support mothers may tolerate the ambiguity associated with atypical infant behaviors yet need to have a strong desire to understand these behaviors for them to focus on seeking assistance, finding information, and determining parenting strategies. It is important to note that participants reported that the birth of subsequent children was instrumental in their understanding of typical versus atypical infant behavior and development.

The fifth finding describes participants’ needs for support when addressing atypical infant behaviors. Despite the participants’ descriptions of the strategies and extensive amount of time devoted to meeting their infants’ needs, almost all the participants reported feeling
emotionally and physically supported by their spouses in regards to the care of their child with ASD. One participant was divorced, thereby making this sample similar to the rate of divorce for parents of children with ASD in the general population (Hartley et al., 2010). Participants reported seeking help from family members who already had children, such as mothers and sisters, to manage atypical behavior. The majority of participants reported disrupted or challenging sleep patterns leading to sleep deprivation. Many participants turned to their families to help manage their own fatigue and determine a way to help their infant sleep. This finding illuminates the need for professional support to understand, develop strategies, and manage atypical infant behaviors. Without professional guidance and support, mothers and infants struggled daily.

**Maternal access to support before ASD diagnosis.** Maternal attempts to access and find support for atypical infant behaviors were driven by both suspicions about atypical development and inexperience as a first-time mother. The majority of participants reported that the responsibility of finding strategies and learning how to manage their infant’s behaviors was overwhelming and ultimately they relied on themselves. The infants’ atypical behaviors lead the mothers to use breastfeeding as an intervention, and while many mothers described atypical breastfeeding behaviors, they did not always seek support for breastfeeding. Maternal disposition influenced participant’s reactions to healthcare providers’ responses to concerns about atypical behaviors. While some participants trusted their pediatrician’s advice, others felt frustrated with the health care providers’ “wait and see” approach. The ways in which mothers access support varied between informal support from friends and family to seeking specific professional help from lactation consultants, health care providers, and the internet. However, the majority of participants felt they did not receive adequate support from trained professionals in regards to
their infant’s atypical behaviors. The findings point to an overarching breakdown of available professional support for developmental concerns during infancy.

**Limitations**

There were several limitations of this study. One factor is the small sample size, of which only five mother’s experiences were considered in this research. All the participants lived in the Midwest, although aspects of one participant’s experiences were described when her family lived outside of the United States for a period of time. Access to services, for both breastfeeding and ASD services, vary by geographic region within the United States (Sparks, 2010; Thomas et al., 2007). Trends in breastfeeding rates, access to support, as well as social attitudes and beliefs about breastfeeding may vary by region, which may impact participant experiences.

The majority of the participants identified as Caucasian. Disparities exist in breastfeeding rates and use of lactation services based on maternal race/ethnicity, age, education and socioeconomic status (Jones et al., 2015; McDowell et al., 2008; Sparks, 2010; Thomas et al., 2007). For example, African American mothers have the lowest breastfeeding initiation and continuation rates of breastfeeding in the United States compared with all other racial and ethnic groups (Jones et al., 2015). While there is not currently evidence of racial differences in the timing of ASD diagnosis, researchers have found that there are significant racial differences in whether children who meet the criteria for an ASD diagnosis ever receive an actual diagnosis (Shattuck et al., 2009) Additionally, white children are more likely to have a documented ASD diagnosis (Shattuck et al., 2009). These disparities directly impact the availability of mothers to participate in this study.

An additional limitation was that for all the participants in this study, their child with ASD was their first child, which may have limited their ability to discuss their concerns with
health care providers and lactation consultants based on a lack of previous experiences. The majority of the participants, despite their struggles, breastfed longer than the majority of women in the United States, where current rates suggest that only 26.7% of mothers are still breastfeeding at 12 months (this rate includes any amount of breastfeeding) and only 18.8% of mothers are exclusively breastfeeding at 6 months (CDC, 2016). While this may not seem like a limitation, the current study only had one participant that did not breastfeed for as long as she had planned prior to giving birth based on both her infant’s behaviors and the challenges of returning to work after only two weeks. Two of the five participants worked outside of the home, one returned to work after two weeks and the other after 12 weeks, though both had family members to care for their infants in their own home. A sample that included women whose children went to childcare centers and those who were not able to continue breastfeeding based on their infant’s behaviors would help to further explore this topic.

**Implications for Future Research**

Descriptive phenomenology allows for an in-depth exploration of the experiences mothers had breastfeeding and raising infants later diagnosed with ASD to understand how to better meet their needs and illuminate potential early indicators based on feeding behaviors. Based on the findings of this study, breastfeeding became a valuable strategy for participants to use when addressing atypical behaviors. The majority of the participants reported frequent breastfeeding and as a result their infants experienced rapid physical growth. While rapid growth on its own is almost never a cause for increased monitoring of a breastfed infant’s development, given that mothers reported multiple atypical behaviors it is essential for health care providers to inquire about other aspects of an infant’s behavior. Future studies can explore the links between rapid infant growth, frequent feeding, and later diagnosis of ASD.
The number of participants who reported rapid growth and weight gain was a surprising finding along with the duration of breastfeeding reported by participants. There is a possibility that an opposite subset of infant behaviors exists, specifically mothers who report having to cease breastfeeding earlier than planned because of infant behaviors. In those infants, failure to thrive or poor weight gain in addition to other atypical behaviors may be early indicators of ASD. Further research is needed to explore the experiences and observations of mothers whose infants struggled to breastfeed and gain weight and were later diagnosed with ASD.

While all participants reported observations specific to atypical motor development, there were few responses specific to atypical physical development. Mothers may not be aware of subtle variations in physical development which could make reporting concerns to health care providers challenging. Three participants reported that their child had a “high palate”, and described their child as having an abnormally high roof of the mouth. Teitelbaum et al. (1998) noted a characteristic bell shaped mouth, commonly associated with Moebius Syndrome, in children diagnosed with ASD. Moebius Syndrome is a rare condition characterized by congenital facial paralysis resulting in poor or absent sucking due to incomplete closure of the lips, lack of facial mimicking, fixed gaze, incomplete eyelid closure during sleep, low muscle tone and developmental delay (Picciolini et al., 2016). Having a high arched palate is also a common variation of physical development children who are diagnosed with Moebius Syndrome. While the mothers did not associate the difficulty they had breastfeeding with their infant’s high palate, one mother reported that the high palate interfered with her child eating solid foods and another was told by her pediatrician that pacifier use was the cause of her child’s high palate. High arched palates and other palate variations are associated with breastfeeding difficulty (Wambach
& Riordan, 2016). Future research can further explore this anatomical variation in children with ASD in relation to infant feeding.

In addition, three of the participants reported that their infant had above average head circumference, consistent with results of previous researchers (Davidovitch et. al, 1996; Mraz, et al., 2007). Though the participants in this study reported that their infant’s heads were measured with an above average circumference from birth. Several recent studies have found neuroanatomical differences in the brains of children diagnosed with ASD such as brain volume changes over time, altered brain structures, or excess fluid surrounding the brain (Hazlett et al., 2017; Shen et al., 2017; Yang et al., 2016). Future studies can explore the impact of these anatomical variations on infant feeding from a global perspective to identify patterns of behavior that may warrant brain imaging to identify ASD at an early age.

The participants reported observations of atypical motor development; though some mothers described delays in motor development others described motor skills that occurred earlier than they expected. Several participants described delayed motor development. One participant reported that her infant did not begin to crawl until close to one year of age while another participant reported that her infant skipped crawling completely. Several participants reported that their infant exhibited the ability to hold their head up from birth and had rigid muscle tone yet over time developed low muscle tone. Two participants reported that their infants were walking unassisted at eight months of age. Several participants reported that their infant had a postural preference while breastfeeding and disliked laying on their stomach. These patterns of motor development, however, were not discussed in relation to breastfeeding but rather as a description of the mothers’ observations of their infants’ motor skills. Future studies
could further explore atypical motor development and difficulty breastfeeding as well as the influence of atypical motor development on early cessation of breastfeeding.

Though one of the main findings of this study was mothers’ suspicions of atypical development, the specific aspects of development were not described in detail due to the wide degree of variation among participants. Participants reported a variety of atypical behaviors and development that can be further explored in future studies, some described similarities in behaviors between multiple infants and others described a variety of behaviors occurring within a single infant. Several participants reported developmental delays, while others noted aspects of advanced development, and yet others reported a change over time in aspects of development from advanced to delayed. Similarly, several participants reported that their infants did not like to lay flat or be held yet learned to walk at an early age. Additionally, participants reported postural preferences when breastfeeding that required a specific routine or body placement to feed successfully. Future studies can further explore the relationships between these varying aspects of development and behavior in infants later diagnosed with ASD.

Several participants reported using sleep training methods, such as “cry it out” sleep training, to address their infants’ sleep issues. Future studies can examine patterns of disrupted sleep in infants later diagnosed with ASD. Participants reported that their infants had rapid response to sleep training methods and deemed the intervention a success. Future studies can examine whether infants later diagnosed with ASD respond differently to these methods than their typically developing peers. Sleep training methods, however, can vary greatly and there are several methods that have been linked to detrimental outcomes for both infants and mothers (Douglas & Hill, 2013). Future research can help to explore how healthcare providers can best respond to and disseminate information about typical sleep patterns during infancy and provide
suggestions to new parents that do not jeopardize infant health and safety. Unfortunately, infant sleep patterns are not always compatible with parental responsibilities, like returning to work, which can make it challenging for a parent to wake at the same frequency as a young infant.

Future research can explore maternal experiences in other racial and ethnic groups. The disparities in breastfeeding rates and diagnosis of ASD, as well as potential differences in perceptions of “normal” infant behaviors that may vary in different cultural groups, highlight the importance of expanding this research to a more diverse sample. Additional research is needed for practitioners to understand the variations between groups and how to best meet the challenges that may be unique to a specific population.

Previous researchers compared breastfeeding rates for infants later diagnosed with ASD to the national average and found the rates were not statistically different (Burd et al., 1988). Additionally, results of that study showed no difference in both infant responses to the social dynamic of the breastfeeding process and maternal characteristics of nurturing behaviors when compared to control groups (Burd et al., 1988). The parameters of accepted breastfeeding for the study was at least ten days of any portion of an infant’s nutritional intake being breastmilk (Burd, et al., 1988). However, the study was conducted at a time when national rates of initiation and duration of breastfeeding were lower than current national breastfeeding rates (CDC, 2016; Ryan et al., 1991). Revisiting differences between groups based on current national breastfeeding rates, with more specific inclusion criteria related to breastfeeding, will provide a better understanding of potential differences between groups. While the focus of this study was on breastfeeding, there may be early indicators of ASD that are apparent from bottle fed infants as well.

It is important to note that the 22 mothers indicated interest in participation, and of those only five met all the inclusion criteria. The inclusion criteria were designed to isolate the impact
of infant behaviors on breastfeeding. However, an unintended consequence of the exclusion criteria was an overlap of maternal characteristics that both impact breastfeeding and increase the likelihood of a later diagnosis of ASD. Future researchers can further explore the overlap between these two phenomenon and help provide practitioners with better guidelines for identification of children who may benefit from more diligent monitoring.

**Implications for Practice**

As the rates of U.S. women who choose to breastfeed continues to climb, with 51.6% of women breastfeeding for at least 6 months, there is a need for all health care providers who interact with new mothers to have a strong knowledge base of accurate evidence-based breastfeeding information as well as a strong foundation in infant development (CDC, 2016). Over half of all mothers with whom a healthcare provider interacts will breastfeed, and it is essential that healthcare providers have adequate training to meet the demands of the populations they serve. Researchers have found that mothers often view doctors’ breastfeeding support as ineffective and insufficient (McInnes & Chambers, 2008; Taveras et al., 2004). The majority of participants in this study reported that their needs were often unmet in relation to the combination of both breastfeeding and atypical infant behaviors. Adequate breastfeeding knowledge becomes even more important in relation to early indicators of ASD.

Pediatricians are often the only healthcare provider with whom a mother interacts in relation to her infant’s development and as such are the only professionals capable of assessing developmental delays or disabilities. For women who have access to lactation consultants, there is a need for all lactation consultants to have a strong foundation in infant development to distinguish typical versus atypical feeding behaviors that may indicate the need for further developmental screening. With the current rate of ASD, there is a need for training to help both
lactation consultants and pediatricians identify infants who would benefit from further screening. While results of this study did not produce an inventory or checklist for healthcare providers, they highlight the importance of asking mothers about multiple aspects of infant development and feeding behaviors. The results of this study demonstrate that specific behaviors or growth indicators, when viewed separately, did not necessitate the need for further monitoring or developmental screening. However, the descriptions participants provided illuminated a combination of atypical behaviors across multiple developmental domains including but not limited to behaviors related to breastfeeding. The results provided a global description of infant feeding behaviors, that when combined with atypical development, help to show the importance of training health care providers to be aware of early indicators of ASD. There is a need for health care providers to ask questions across multiple developmental domains and most importantly follow up on maternal concerns. It may not be enough for a health care provider to ask a mother how often she breastfeeds her infant; it is important for healthcare providers to be able to ask clarifying questions about the quality of breastfeeding and be prepared to ask questions in a way that does not presume that a mother has a strong knowledge of either typical development or infant feeding behaviors.

From an ecological perspective, the participants in this study described experiences across multiple ecological system levels. Their individual dispositions combined with their beliefs and attitudes towards both parenting and breastfeeding directly impacted their experiences. However, most participants reported that as they sought support and assistance, their experiences receiving consistent, effective, and accurate support decreased as they accessed support within their community and interacted with health care providers. While some participants reported adequate emotional support from spouses, family, or friends none of the
participants felt that the people and resources in their communities’ provided answers to their concerns relating to breastfeeding and their infant’s development or behaviors. Thus, the participants sought help from multiple types of health care providers resulting in varying outcomes. Part of the struggles participants reported stemmed from a lack of resources for both breastfeeding and access to health care providers with adequate knowledge about infant development. From a social and cultural level, because the participants relied on breastfeeding as an intervention, they did not feel encumbered by negative social or cultural views of breastfeeding and instead focused on putting their infant’s needs above their own.

**Final Thoughts**

Limited research has explored maternal experiences and observations of breastfeeding behaviors of infants later diagnosed with ASD. There are numerous benefits to breastfeeding, for both mother and infant, and breastfeeding behaviors may provide health care providers with an opportunity to screen for developmental disabilities during infancy. The opportunity to have access to early intervention and support can lead to both increased duration of breastfeeding and improved developmental outcomes. While a singular pattern of atypical behavior or variation in development during infancy does not necessarily warrant concern, this study helped bring to light maternal observations of infant behaviors across multiple developmental domains and feeding behaviors. Many of the findings that emerged from the data would be missed in a standard visit to the doctor and lactation consultants may not be trained to explore past their focus on breastfeeding to look for potential clues that may be related to breastfeeding challenges.

The participants in this study were candid in the retelling of past experiences, sharing their successes and challenges, and ultimately welcoming me as a researcher into their lives for the duration of our interview. Through each interview, as the mothers talked, their deep love for
their children was evident in more than just their devotion to meeting their infant’s needs but in the small smiles as they recounted memories or shared photographs of their child as an infant. While their experiences may read of heartbreak and challenge, these women were resilient but most importantly devoted mothers who deeply loved their children regardless of a diagnosis or behavior. This research has helped to shine a light on experiences that may have been otherwise left untold, and brought forth the daily sacrifices mothers make raising infants later diagnosed with ASD.
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doi:http://dx.doi.org/10.1097/DBP.0b013e3181d5d03b


Vagle, M. D. (2014). *Crafting phenomenological research*. Walnut Creek, CA: Left Coast Press, Inc.


The project referenced above has received approval from the Institutional Review Board (IRB) at Iowa State University according to the dates shown above. Please refer to the IRB ID number shown above in all correspondence regarding this study.

To ensure compliance with federal regulations (45 CFR 46 & 21 CFR 56), please be sure to:

- Use only the approved study materials in your research, including the recruitment materials and informed consent documents that have the IRB approval stamp.

- Retain signed informed consent documents for 3 years after the close of the study, when documented consent is required.

- Obtain IRB approval prior to implementing any changes to the study by submitting a Modification Form for Non-Exempt Research or Amendment for Personnel Changes form, as necessary.

- Immediately inform the IRB of (1) all serious and/or unexpected adverse experiences involving risks to subjects or others; and (2) any other unanticipated problems involving risks to subjects or others.

- Stop all research activity if IRB approval lapses, unless continuation is necessary to prevent harm to research participants. Research activity can resume once IRB approval is reestablished.

- Complete a new continuing review form at least three to four weeks prior to the date for continuing review as noted above to provide sufficient time for the IRB to review and approve continuation of the study. We will send a courtesy reminder as this data approaches.

Please be aware that IRB approval means that you have met the requirements of federal regulations and ISU policies governing human subjects research. Approval from other entities may also be needed. For example, access to data from private records (e.g., student, medical, or employment records, etc.) that are protected by FERPA, HIPAA, or other confidentiality policies requires permission from the holders of those records. Similarly, for research conducted in institutions other than ISU (e.g., schools, other colleges or universities, medical facilities, companies, etc.), investigators must obtain permission from the institution(s) as required by their policies. IRB approval in no way implies or guarantees that permission from these other entities will be granted.

Upon completion of the project, please submit a Project Closure Form to the Office for Responsible Research, 202 Kingland, to officially close the project.

Please don’t hesitate to contact us if you have questions or concerns at 515-294-4566 or IRB@iastate.edu.
Date: 12/9/2016
To: Leslie Dooley
1319 2nd St.
Nevada, IA 50201

From: Office for Responsible Research

Title: Maternal Experiences Breastfeeding Infants Later Diagnosed with Autism: A Qualitative Approach

IRB ID: 16-251

Approval Date: 12/7/2016
Date for Continuing Review: 7/7/2018

Submission Type: Modification
Review Type: Expedited

The project referenced above has received approval from the Institutional Review Board (IRB) at Iowa State University according to the dates shown above. Please refer to the IRB ID number shown above in all correspondence regarding this study.

To ensure compliance with federal regulations (45 CFR 46 & 21 CFR 56), please be sure to:

• Use only the approved study materials in your research, including the recruitment materials and informed consent documents that have the IRB approval stamp.

• Retain signed informed consent documents for 3 years after the close of the study, when documented consent is required.

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• Immediately inform the IRB of (1) all serious and/or unexpected adverse experiences involving risks to subjects or others; and (2) any other unanticipated problems involving risks to subjects or others.

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Upon completion of the project, please submit a Project Closure Form to the Office for Responsible Research, 202 Kingland, to officially close the project.

Please don’t hesitate to contact us if you have questions or concerns at 515-294-4588 or irb@iastate.edu.
APPENDIX B. RECRUITMENT SCRIPTS

Recruitment Email (Participants in Iowa)

You are invited to participate in a research study exploring the infancy, including breastfeeding and other behaviors, of children who are diagnosed with autism, based on mother’s memories of experiences during the first years of their child’s life. The goal of this study is to learn more about patterns of behavior that a mother may notice during infancy that could indicate the need for a child to receive further assessment, services, and support. This study was approved by the ISU Institutional Review Board.

I am looking for mothers who are:

- Over the age of 18
- Breastfed for at least 6 weeks without formula or solid food supplementation
- Did not have any preexisting health or medical issues that might disrupt breastfeeding including:
  - Breast surgery
  - C-section
  - Flat or Inverted nipples
  - Absence of noticeable breast changes during pregnancy or after birth
  - Hormonal disorders such as Polycystic Ovary Syndrome or Impaired Thyroid Functioning while breastfeeding

Whose child is:

- 12 years of age or younger
- Born at full term (after 39 weeks of pregnancy)
- Has a formal diagnosis of autism
- Does not have any other physical conditions that would disrupt feeding

If you agree to participate in this study, your participation will involve allowing the researcher to interview you about your experiences as a mother of a child with autism focused primarily on the first 3 years of your child’s life. I anticipate that the interview will last between 60 and 90 minutes.

At the end of the interview you will receive a $45.00 gift card to thank you for your participation.

Your participation in this study is completely voluntary.

I have attached the Informed Consent Document for this study that provides additional information regarding the study. If you choose to participate, I will provide a copy for you to sign before the interview begins.

If you are interested in participating, have any questions, or would like more information please contact me at:

Leslie Dooley (researcher) by phone (515-460-2572) or by e-mail at ljdooley@iastate.edu
Recruitment Email (Participants Outside Iowa)

You are invited to participate in a research study exploring the infancy, including breastfeeding and other behaviors, of children who are diagnosed with autism, based on mother’s memories of experiences during the first years of their child’s life. The goal of this study is to learn more about patterns of behavior that a mother may notice during infancy that could indicate the need for a child to receive further assessment, services, and support. This study was approved by the ISU Institutional Review Board.

I am looking for mothers who are:

- Over the age of 18
- Breastfed for at least 6 weeks without formula or solid food supplementation
- Did not have any preexisting health or medical issues that might disrupt breastfeeding including:
  - Breast surgery
  - C-section
  - Flat or Inverted nipples
  - Absence of noticeable breast changes during pregnancy or after birth
  - Hormonal disorders such as Polycystic Ovary Syndrome or Impaired Thyroid Functioning while breastfeeding

Whose child is:

- 12 years of age or younger
- Born at full term (after 39 weeks of pregnancy)
- Has a formal diagnosis of autism
- Does not have any other physical conditions that would disrupt feeding

If you agree to participate in this study, your participation will involve allowing the researcher to interview you via Skype, Google Hangouts, or over the telephone about your experiences as a mother of a child with autism. The interview will be focused primarily on the first 3 years of your child’s life. I anticipate that the interview will last between 60 and 90 minutes.

At the end of the interview you will receive a $45.00 gift card to thank you for your participation.

Your participation in this study is completely voluntary.
I have attached the Informed Consent Document for this study that provides additional information regarding the study. If you choose to participate, I will provide a copy for you to sign before the interview begins.

If you are interested in participating, have any questions, or would like more information please contact me at:

Leslie Dooley (researcher) by phone (515-460-2572) or by e-mail at ljdooley@iastate.edu

Sincerely,

Leslie Dooley, Master’s Student and Carla Peterson, PhD.
Iowa State University
Department of Human Development and Family Studies
Ames, IA 50011

Recruitment Phone Script (Participants in Iowa)

Hi, is this _________(Contact Name)_________? My name is Leslie Dooley a graduate student from Iowa State University- ______(name of person who referred participant)_______ gave me your contact information so that I could connect with you to see if you are interested in participating in a research study about mothers observations of the early feeding patterns and behaviors of children diagnosed with autism. I am asking you to participate because you are over the age of 18 and have a child who is diagnosed with autism that you breastfed.

I am looking for mothers who:

- Breastfed for at least 6 weeks
- Did not have any preexisting health or medical issues that might disrupt breastfeeding including:
  - Breast surgery
  - C-section
  - Flat or Inverted nipples
  - Absence of noticeable breast changes during pregnancy or after birth
  - Hormonal disorders such as Polycystic Ovary Syndrome or Impaired Thyroid Functioning while breastfeeding

Whose child is:

- 12 years of age or younger
- Born at full term (after 39 weeks of pregnancy)
- Has a formal diagnosis of autism
- Does not have any other physical conditions that would disrupt feeding

Participation in this research includes participating in an interview about your breastfeeding experiences and observations during your child’s infancy.
All we need to do is set up a time and place that is comfortable with you, that I could visit with you for about 60 to 90 minutes. If you choose to participate in this study you will receive a $45.00 gift card.

What are some days and times that would work for you?

Would you like to participate at your home or is there another location that would be better for you? We can meet on campus, at the public library or any other place that you feel comfortable.

And do you have any questions about the interview?

I would like to send you a copy of the informed consent document to look over before our meeting, what is the best way for me to get you a copy?

Great, I’ll see you on _____(Date)_____ at _____(Time)_____.

---

**Recruitment Phone Script (Participants Outside of Iowa)**

Hi, is this __________(Contact Name)_________? My name is Leslie Dooley a graduate student from Iowa State University- _____(name of person who referred participant)_____ gave me your contact information so that I could connect with you to see if you are interested in participating in a research study about mothers observations of the early feeding patterns and behaviors of children diagnosed with autism. I am asking you to participate because you are over the age of 18 and have a child who is diagnosed with autism that you breastfed.

I am looking for mothers who:

- Breastfed for at least 6 weeks
- Did not have any preexisting health or medical issues that might disrupt breastfeeding including:
  - Breast surgery
  - C-section
  - Flat or Inverted nipples
  - Absence of noticeable breast changes during pregnancy or after birth
  - Hormonal disorders such as Polycystic Ovary Syndrome or Impaired Thyroid Functioning while breastfeeding

Whose child is:

- 12 years of age or younger
- Born at full term (after 39 weeks of pregnancy)
- Has a formal diagnosis of autism
- Does not have any other physical conditions that would disrupt feeding

Participation in this research includes participating in an interview about your breastfeeding experiences and observations during your child’s infancy.
All we need to do is set up a time that works for you. I can conduct an interview via Skype, Google Hangouts, or over the phone. The interview will last about 60 to 90 minutes.

If you choose to participate in this study you will receive a $45.00 gift card.

What are some days and times that would work for you?

And do you have any questions about the interview?

I would like to send you a copy of the informed consent document to look over before our meeting, what is the best way for me to get you a copy?

Great, I’ll see you on _____(Date)_____ at _____(Time)_____. 
APPENDIX C. INFORMED CONSENT DOCUMENT

INFORMED CONSENT DOCUMENT

Title of Study: Maternal Experiences Breastfeeding Infants Later Diagnosed With Autism: A Qualitative Approach

Investigators: Leslie J. Dooley (researcher)
Dr. Carla Peterson (major professor)
Dr. Amy Popillion (co-major professor)
Dr. Gayle Luze (graduate committee member)

This is a research study. Please take your time in deciding if you would like to participate. Please feel free to ask questions at any time.

INTRODUCTION

Being a parent of a young child is both challenging and rewarding. Families who have a child that is diagnosed with an autism spectrum disorder have unique needs for services and support. In an effort to understand the experiences that occur before a child receives a diagnosis of an autism spectrum disorder, information will be gathered from several mothers of children who have already been diagnosed with an autism spectrum disorder to explore mother’s experiences breastfeeding and observations of infant behaviors.

The purpose of this study is to learn more about the infancy of children who are diagnosed with autism, including breastfeeding and other behaviors, based on mother’s memories of experiences during the first years of their child’s life.

The focus will be on mothers who are:

- Over the age of 18
- Breastfed for at least 6 weeks
- Did not have any preexisting health or medical issues that might disrupt breastfeeding including:
  - Breast surgery
  - C-section
  - Flat or Inverted nipples
  - Absence of noticeable breast changes during pregnancy or after birth
  - Hormonal disorders such as Polycystic Ovary Syndrome or Impaired Thyroid Functioning while breastfeeding

Whose child is:

- 12 years of age or younger
- Born at full term (after 39 weeks of pregnancy)
- Has a formal diagnosis of autism
- Does not have any other physical conditions that would disrupt feeding

The central questions of this study will focus on mother’s breastfeeding experiences and observations of infant behaviors.
Understanding mother’s feelings, perceptions, observations of infant feeding behaviors, and experiences raising an infant who is later diagnosed with an autism spectrum disorder will provide insight into the needs, challenges, and unique situations that occur. These experiences may help to bring to light new possibilities for early diagnosis as well as potential opportunities for support and intervention. You are being invited to participate in this study because you are over the age of 18 and the mother of a child who has an autism spectrum disorder who is 12 years old or younger.

This study is being conducted by a graduate student at Iowa State University for the purposes of a thesis research study required for completing a master’s degree.

DESCRIPTION OF PROCEDURES

If you agree to participate in this study, your participation will last 60 to 90 minutes in the form of a one-on-one interview. It will involve you allowing the researcher to interview you about your experiences raising an infant who was later diagnosed with autism and your feelings about your child’s first years of life. The interview will be audio recorded.

The interview recording will be transcribed by the researcher and will be erased following transcription (within one month). The interview will be conducted as your schedule allows. You may also be contacted later to review the transcript and interpretations to make sure that the researcher is correctly representing your ideas and opinions.

You will be given the opportunity to share photographs or videos of your child during the interview in the following formats:

- Printed picture
- Digital picture
- Digital video

RISKS

The risks of this study are very minimal. While participating in this study you may experience possible discomfort at disclosing information during an interview. However, you are free to not answer any of the questions and to withdraw your participation at any time.

BENEFITS

If you decide to participate in this study, there will be no direct benefit to you. It is hoped that the information gained in this study has the potential to guide further research of early indicators of autism spectrum disorders and support services that will benefit both mother and infant. This information may lead to future research that aids in assessment of early indicators of autism spectrum disorders, early interventions, and support for families.

COSTS AND COMPENSATION

An incentive for your involvement in this study will be a $45.00 gift card following the interview session or any time during the interview in the event that you chose not to complete the entire interview.

PARTICIPANT RIGHTS

Your participation in this study is completely voluntary and you may refuse to participate or leave the study at any time. You may skip any questions you do not wish to answer and you
may stop answering questions at any time. You may decide not to participate in the study or leave the study early for any reason and it will not result in any penalty.

If you have any questions about the rights of research subjects or research-related injury, please contact the IRB Administrator, (515) 294-4566, IRB@iastate.edu, or Director, (515) 294-3115, Office for Responsible Research, 1138 Pearson Hall, Iowa State University, Ames, Iowa 50011.

CONFIDENTIALITY
Records identifying participants will be kept confidential to the extent permitted by applicable laws and regulations and will not be made publicly available. However, federal government regulatory agencies and the Institutional Review Board (a committee that reviews and approves human subject research studies) may inspect and/or copy your records for quality assurance and data analysis purposes. To ensure confidentiality the following measures will be taken: participants will be assigned a pseudonym which will be used in writing the notes, transcriptions, and thesis. All identifying details obtained during an interview or observation will be altered to protect confidentiality. All data gathered will be kept in a password coded USB drive. The contents of the interviews may be used to demonstrate overall themes observed from participants in the write up of the research paper. Pseudonyms will be attached to these quotes and any information that may link the quote to the participant (such as names of people or places) will be changed or excluded. The persons who will have access to the individual data and/or summarized data are the researcher and their major professor.

QUESTIONS OR CONCERNS
You are encouraged to ask questions at any time during this study. For further information about the study, contact

- You may contact me at: Leslie Dooley (researcher) by phone (515-460-2572) or by e-mail at ljdooley@iastate.edu
- Or contact Dr. Carla Peterson (major professor) by email at carlapet@iastate.edu

******************************************************************************
PARTICIPANT SIGNATURE

Your signature indicates that you voluntarily agree to participate in this study, that the study has been explained to you, that you have been given the time to read the document and that your questions have been satisfactorily answered. You will receive a copy of the written informed consent prior to your participation in the study.

Participant’s Name (printed) ____________________________________________

_________________________________________  _____________________________
(Participant’s Signature)  (Date)

INVESTIGATOR STATEMENT

I certify that the participant has been given adequate time to read and learn about the study and all of their questions have been answered. It is my opinion that the participant understands the purpose, risks, benefits and the procedures that will be followed in this study and has voluntarily agreed to participate.

_________________________________________  _____________________________
(Signature of Person Obtaining Informed Consent)  (Date)
APPENDIX D. RESEARCH SUMMARY STATEMENT

Research Summary Statement

Maternal Experiences Breastfeeding Infants Later Diagnosed with Autism: A Qualitative Approach

Introduction

Being a parent of a young child is both challenging and rewarding. Families who have a child that is diagnosed with an autism spectrum disorder (ASD) may face unique challenges based on early infant feeding behaviors. One out of every 68 children born in the United States will later be diagnosed with ASD. The rate of ASD among children in the U.S. has increased by 119.4 percent from 1 in 150, in 2000, to the current rate of 1 in 68 (Baio, 2014). There are currently more people diagnosed with ASD than at any other time, making ASD the fastest-growing developmental disability, yet diagnosis often does not occur until a child is 4 years old (Baio, 2014). The rates of ASD have shown significant and continuous increases over time (Boyle et al., 2011). The increasing rates highlight the need to find accurate diagnosis and effective treatment at an early age for those who have increased risk of ASD. The earlier assessment and diagnosis can occur, the sooner a child and family can begin to receive treatment and support. Many parents report observing abnormal development during infancy (Kozlowski et al., 2011). In addition, parents who have a child with autism reported that during infancy the children had a more negative or neutral temperaments and are often inactive or detached especially in response to caregiver’s emotions (Cassel 2007). Abnormal patterns of eating and behaviors problems associated with feeding were previously included in the original diagnostic criteria for ASD (Ahearn, 2001). Despite not being included in the current criteria for diagnosis of ASD, food selectivity tends to be commonly reported by parents of children who are diagnosed with an autism spectrum disorder yet little is known about how ASD affects early feeding behaviors (Bandini et al., 2010; Beighley et al., 2013).

Purpose

The purpose of this study is to learn more about the infancy of children who are diagnosed with autism, including breastfeeding and other behaviors, based on maternal recall of experiences during the first years of their child’s life. The focus will be on mothers who have a child diagnosed with autism who also breastfed for at least the first 6 weeks of their child’s life. The central questions of this study will focus on maternal experiences breastfeeding and observations of infant behaviors including temperament and crying, feeding cues, and sleep patterns. Understanding mother’s feelings, perceptions, observations of infant feeding behaviors, and experiences raising an infant who is later diagnosed with ASD will provide insight into the needs, challenges, and unique events that occur. These experiences may help to illuminate possibilities for early diagnosis as well as potential opportunities for support and intervention.

Significance of the Study

There is a gap in current research regarding breastfeeding infants who are later diagnosed with ASD. I anticipate that certain aspects of both breastfeeding support and pediatrician’s awareness of development will be challenged. This study will examine the networks of both formal and informal support that mothers accessed when breastfeeding their infant, such as lactation consultants and pediatricians or family and friends, and will provide a better understanding of the relationship between development and infant feeding behaviors.
Participants and Procedures

Mothers are often the primary caregiver for infants and provide the best source of information regarding their child’s patterns of behavior and development. Mothers are the gatekeepers of information, including atypical feeding behaviors or early indicators that might point to the need for developmental assessment. While several studies have found patterns of behaviors in infants who are later diagnosed with ASD, little is known about the maternal experiences breastfeeding, observations of infant’s behaviors, and how mothers attempt to find diagnosis, services, and support for their infants. In an effort to understand the feeding experiences that occur before a child receives a diagnosis of ASD, information will be gathered from several mothers of children who have already been diagnosed with ASD.

The goal of this project will be to examine the experiences of mother-infant dyads with respect to their breastfeeding experiences, observations of infant behavior, and the factors that affect the nature of their interactions based on maternal recall of past events. This study will focus on mothers of children diagnosed with ASD. The inclusion criteria for participants in this study will be: 1) Mothers of a child less than twelve years of age who has a formal diagnosis of ASD (including but not limited to diagnosis of ASD, Asperger’s Syndrome, Pervasive Developmental Disorder), 2) exclusively breastfed for a minimum of 6 weeks with a preference for mothers who breastfed for at least 3 months, 3) did not have any preexisting health or medical issues that might disrupt breastfeeding, and 4) whose child with ASD was born full term (after 39 weeks) and does not have any other physical conditions that would disrupt feeding.

Implications of the Study

This study will help to influence future research to explore patterns of behavior that a mothers may notice during infancy that could indicate the need for a child to receive further assessment, services, and support. There is a need for future research to develop both assessment and interventions for infants who are at risk for diagnosis of ASD or those who are exhibiting symptoms. In addition, this research can help to influence policies that would provide families who have a child with ASD with access to support, services, and interventions at an early age that will improve and support the child’s development.
APPENDIX E. INTERVIEW PROTOCOL

Introductory Protocol

To facilitate my note-taking, I would like to record our conversations today. For your information, only researchers on the project will have access to listen to the recorded interview, this includes 3 HDFS faculty members who are on my graduate committee. In addition, I would like you to sign a consent form that is required by ISU for all research that is conducted with human subjects. Essentially, this document states that: (1) all information will be held confidential, (2) your participation is voluntary and you may stop at any time if you feel uncomfortable, and (3) we do not intend to inflict any harm. Thank you for agreeing to participate.

I have planned this interview to last approximately one hour. During this time, I have several questions that I would like to cover.

Introduction

You have been selected to speak with me today because you have been identified as a mother who breastfed an infant who was later diagnosed with autism. The purpose of this study is to learn more about the infancy of children diagnosed with ASD, including breastfeeding and other behaviors, based on mother’s experiences during the first years of their child’s life. This study does not aim to evaluate your personal breastfeeding techniques or parenting experiences. Rather, I am trying to learn more about early indicators of autism based on breastfeeding behaviors, and hopefully learn about mother’s experiences that will help improve services and opportunities for support during the infancy of children who later are diagnosed with autism.

In Depth Questions

(Will prompt participants to focus answers on infancy and the first 2 years of life of child diagnosed with autism)

1. Demographics) Tell me about your family

Probes specific to family:

a. How many children do you have?
   i. What are their ages?

b. How many of your children have a diagnosis of autism spectrum disorder?
   i. At what age was your child diagnosed with autism?

c. Did you breastfeed your child that was diagnosed with autism?
i. How long did you breastfeed for?

d. (If other children) Did you breastfeed all your children?

e. (If so) Tell me about your experiences breastfeeding children who do not have ASD diagnosis

2. What lead you to breastfeed?

3. Tell me about your experiences breastfeeding child with ASD

*Probes specific to breastfeeding:*

a. What went well for you?

b. What aspects of breastfeeding do you feel did not go well for you?

c. Did you seek assistance?

d. If so, who helped you and what were the suggestions?

e. Tell me about that experience (Related to getting help for breastfeeding)

f. How did you know that your baby was hungry?

g. How did you know when your baby was full?

4. Were there any behaviors, symptoms, or signs that there was something different about your baby?

*Probes specific to symptoms of ASD:*

a. Can you tell me more about that behavior?

i. Tell me how often that occurred

5. Were you ever concerned or worried about your child’s behaviors during breastfeeding or at other times during his/her infancy?

a. If so, what were the behaviors or issues that you noticed
6. Tell me about how you handled those behaviors?

7. Tell me about the kind of support that you received or needed?
   a. If so, was it accessible?
   b. Why or why not

8. How would you describe your experiences trying to get information about your baby’s behaviors that concerned you, assistance for assessment, or support of your child with ASD?
   a. If you did seek help, tell me about your reaction to that experience
   b. Tell me about your thoughts or feelings in reaction to that experience?

9. Is there anything else that you feel would have been helpful for you during your child’s infancy while you were breastfeeding?

10. Tell me about your child’s transition to solid foods
    a. When were solid foods introduced
    b. What (or who) lead you to introduce solid foods
    c. Tell me about your thoughts or feelings in reaction to that experience?

11. Are there any experiences that I didn’t ask about that you would like to share?

**General Questions**

1. Please choose 3 words to describe your experiences breastfeeding your child diagnosed with autism

**Request for Pictures or Videos**

Thank you for taking the time to let me interview you! I really appreciate your participation. Would you be willing to share pictures or videos of your child from the first year of his/her life?
a. If so clarify during first year, picture that clearly shows the child’s face and mouth preferably not smiling in order to observe mouth shape or picture that shows entire body while laying down to check for symmetry of posture

b. Videos that show social interactions between mother and infant to observe infant gaze or infant laying down to observe posture symmetry, coordination/ patterns of movement
APPENDIX F. DATA ANALYSIS EXCERPTS

Leslie: Tell me about your experiences breast feeding Angie.

Samantha: With Angie, I remember in the hospital, I remember the specialist teaching me how to hold her. // she was six pounds, so they were trying to show me ways to hold her, since she was little like a football pose and bring her head to the breast. /I just had... Remember not really just feeling what I thought I was going to feel, like some kind of... She got it and I got it and we were just this wonderful happy mother and baby. // The nurse taught me how to squeeze colostrum and then just drip it into her mouth, just to make sure she got five to six drops the first few days each feeding. //

It wasn't so much of a latch, or sucking, it was just dripping.

Once we brought her home, she would just get so tired, before she would want to feed. // I bring her to the breast and there would just be no movement from her. //

Samantha: Okay go to the table. // Once we brought her home, she would just get so tired, before she would want to feed. // I bring her to the breast and there would just be no movement from her. //

Once we brought her home, she would just get so tired, before she would want to feed. // I bring her to the breast and there would just be no movement from her. // My husband, being that I was just really emotional and just thinking I was doing everything wrong and she's just not getting this. // He would hold her hands. He was just there. He would physically put her on my breast. // It took a lot of teamwork to get her to latch on and nurse, because she just would either fall asleep.

It just seemed like that clicking between I don't know baby and breast, just wasn't naturally there for her. We could ultimately get her to nurse and then we'd switch sides. // He would have to help me with both sides, but it took a lot of effort. // With her (Helen), like I said I was a lot more determined. With her, she nursed right away when she was born, to the point where she was actually, I guess nursing incorrectly. // I had bruise and cracked nipples for a while. // I was so determined. I was like, 'I'm going to get through this.'//

She actually had what they call tongue tie. // They never told me Angie did, so I don't believe she did. // With her they said she did. We never fixed it, because she continued to nurse successfully. // The only thing with her, is I had to physically hold my breast the entire time. I could never just be free handed. I'd have to adjust the breast a little bit, maybe for the position that her mouth... For both sides. It just worked and we just sort of get through it.
<table>
<thead>
<tr>
<th>Meaning Unit, Direct Quote</th>
<th>General Structure</th>
<th>Description of General Structure Code</th>
<th>Topic of General Structure</th>
</tr>
</thead>
<tbody>
<tr>
<td>At this point I was really happy to fill out a questionnaire, because this is when I thought there was something off. There were thing I knew she should be doing like stacking blocks and she wasn't doing it.</td>
<td>The mother was relieved to fill out a developmental assessment because of her concerns regarding her child’s development. The mother observed her child’s developmental delays.</td>
<td>The mother is discusses developmental screening specific to the child. This code is results based information about developmental delays or typical development. It does not refer to the process of getting the screening to be scheduled or events leading up to the screening.</td>
<td>1 Development</td>
</tr>
<tr>
<td>He was mobile really early. He was walking at eight months.</td>
<td>The infant was able to walk at an earlier than expected age based on developmental milestones</td>
<td>The mother discusses a developmental milestone that happened earlier than expected</td>
<td>1.1 Advanced Development</td>
</tr>
<tr>
<td>She would just play in her Pack and Play and be pretty content. Whereas my other daughter, I could never leave alone.</td>
<td>The child with ASD was content playing by herself, whereas her younger sibling needed more interaction and contact with her mother when comparing the two children.</td>
<td>The mother is discussing aspects of the target child's development in comparison to a sibling, this code can be used for both typical and atypical development as long as it is comparing an aspect of development between the child with ASD and a sibling</td>
<td>1.2 Comparison of Sibling Development</td>
</tr>
<tr>
<td>At that time to us, she seemed normal. She seemed perfect size. She was giving lots of smiles for pictures and such.</td>
<td>The mother felt that her child was growing normally and exhibiting typical development based on the infant’s ability to smile for photographs.</td>
<td>The mother describes aspects of the target child's typical Development</td>
<td>1.3 Typical Development</td>
</tr>
<tr>
<td>Meaning Unit, Direct Quote</td>
<td>General Structure</td>
<td>Description of General Structure Code</td>
<td>Topic of General Structure</td>
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<tr>
<td>“I would notice other things, like when we’d go in the nurse would be like, “Touch your nose! Is he touching his nose?” I remember saying to my husband, “Oh, those check-ups are really stressful, because she keeps asking me these questions and I have to be like, ‘No’ to them.””</td>
<td>Mother was worried about the infant’s ability to pass certain developmental milestones assessments. She felt infant checkups were stressful because it highlighted aspects of his development that were delayed.</td>
<td>The mother discusses developmental delays and screening for developmental delays</td>
<td>1.4 Developmental delays</td>
</tr>
<tr>
<td>It was like he didn't seem to settle in for ... I don't know what cycle it is, but he didn't seem to get to that deeper sleep.</td>
<td>The infant didn’t have restful sleep, the mother reported that he never seemed to get into a deep sleep state.</td>
<td>The mother is discussing her child with ASD's sleeping patterns</td>
<td>2 Sleeping Patterns</td>
</tr>
<tr>
<td>&quot;People must be stretching the truth.&quot; Their four-month old baby slept six hours. That can't possibly be true, right? I'm like, &quot;No, they're full of it.&quot;</td>
<td>When a mother talked with other parents about sleep patterns, she didn’t believe that their infant could sleep through the night because her same aged infant did not.</td>
<td>The mother discusses comparisons between sleep patterns of child with ASD to siblings or other children</td>
<td>2.1 Sleep Patterns comparison with Siblings or other children</td>
</tr>
<tr>
<td>Eventually we started swaddling. I think it helped for a short time. I think if I would have started swaddling sooner ... Actually, no, we did swaddle her and it helped. It helped her stay asleep.</td>
<td>The mother used swaddling as a sleep resource, to help her infant sleep for longer amounts of time. Swaddling helped the infant to stay asleep for longer amounts of time.</td>
<td>The mother discusses resources used to address sleep issues including books, internet, doctors, family, or friends</td>
<td>2.2 Sleep resources</td>
</tr>
<tr>
<td>Meaning Unit, Direct Quote</td>
<td>General Structure</td>
<td>Description of General Structure Code</td>
<td>Topic of General Structure</td>
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</tr>
<tr>
<td>Really he didn't spend much time in a crib because he didn't sleep</td>
<td>The infant did not sleep for long amounts of time.</td>
<td>The mother describes challenges or issues related to child with ASD sleeping</td>
<td>2.3 Sleeping issues</td>
</tr>
<tr>
<td>He had had quite a few ear infections that he got with every single tooth that came in.</td>
<td>The infant had frequent ear infections.</td>
<td>The mother describes health issues with her child with ASD</td>
<td>3 Child health issues</td>
</tr>
<tr>
<td>Her sister had a tongue tie.</td>
<td>The sibling of the target child was diagnosed with a tongue tie, a midline abnormality that can cause breastfeeding problems.</td>
<td>The mother describes a sibling's health condition including but not limited to tongue tie</td>
<td>3.1 Sibling Health Issue</td>
</tr>
<tr>
<td>He was in the NICU for a week after he was born. I had a fever during labor and so he was being monitored for an infection and then had jaundice.</td>
<td>The target child was in the NICU the first week after birth due to an infection and jaundice. The mother had a fever during labor.</td>
<td>The mother discusses newborn jaundice.</td>
<td>3.3 Jaundice</td>
</tr>
<tr>
<td>I always had him upright. It was just, when I went to feeding him on just one breast, he seemed to do better. When I cut out dairy for a while, or at least cut down, that seemed to have really helped him.</td>
<td>The mother eliminated dairy from her diet to resolve problems with the infant spitting up and having reflux based on the infant’s reactions after the mother removed dairy from her diet. The mother tried feeding off of only one breast at a time to help resolve reflux issues.</td>
<td>The mother described dietary changes or restrictions that were made to address symptoms related to maternal diet while breastfeeding or ASD symptoms</td>
<td>3.4 Dietary restrictions</td>
</tr>
<tr>
<td>Meaning Unit, Direct Quote</td>
<td>General Structure</td>
<td>Description of General Structure Code</td>
<td>Topic of General Structure</td>
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<tr>
<td>Both him and X had trouble with the cartilage, finishing forming. I think they worried about him aspirating or whatever.</td>
<td>Both children had physical abnormalities associated with tracheomalacia that can cause problems with aspiration and breathing difficulties.</td>
<td>The mother describes problems related to malformed cartilage in infant’s throat related to an increased risk of choking or aspiration</td>
<td>3.5 Tracheomalacia</td>
</tr>
<tr>
<td>He was pretty refluxy for the first six months, and I definitely had one breast that had a much more rapid flow than the other one. I feel like he would nurse and then he’d end up spitting up almost everything.</td>
<td>The infant would frequently spit up after feeding for the first six months of life. The mother described this as being symptomatic of reflux.</td>
<td>The mother describes symptoms associated with reflux exhibited by the child with ASD</td>
<td>3.6 Reflux</td>
</tr>
<tr>
<td>Thinking back to infancy, because of how strong my supply was at first, when my milk first came in, she had a lot of foamy poop and green poop.</td>
<td>The mother had a forceful and abundant milk supply. The infant’s stools were green and foamy as a result of the mother’s milk supply.</td>
<td>The mother described her child's digestive issues including constipation or diarrhea</td>
<td>3.7 Digestive Issues</td>
</tr>
<tr>
<td>He has a fairly high palate and so that soft food would get stuck up there but we would sweep it out and we'd move on and he was fine.</td>
<td>The child has a high palate that caused problems while eating solid foods.</td>
<td>The mother describes a child having a high palate.</td>
<td>3.8 High palate</td>
</tr>
<tr>
<td>She never really made eye contact as an infant, and that was kind of a red flag to me</td>
<td>The infant would not make eye contact with caregivers. This behavior was noticeable to the mother during infancy.</td>
<td>Mothers discuss &quot;suspicions&quot; regarding the child's development, it is used when mother's discuss concerns that they thought their child was atypical</td>
<td>4 &quot;Suspicions&quot;</td>
</tr>
</tbody>
</table>
APPENDIX H. OBSERVATIONAL FIELD NOTES

4.5 yrs

3 (girl)

Tongue tie ->15 gp

Labs:

Head circumference 77.5" 14.5"

Eye contact

Gait, posture, strength

Milk protein

Baby weighing

25 lbs, 0.1

Dr. Sears

On demand -> schedule N7

46 after 6 months

Gavet hormone by Hypo

Ask: did you talk to pediatrician? (0"

Behaviors:

not talking for speaking advice

eye contact 1st noticed

Sensory interface

Hand painting

Touch

Stressed a) frustrating

Past year a) exhausting

Fortune had no sensory

Depressed 2) oral

Sleeping

2) Instrumental in correction (coding)

2 brothers

2.5 yrs ASD - ADHD Anxious

RF mom

attachment

RF 28 months

congenital

problems in beginning

no sleep - large baby

favor one side

left side

Humming cry

15 months 10

Rapid weight gain

Dairy sensitive

having small child

Overnight

Long, loud, whole night

Lactation group

Insufficient, b) criticism. The code.

Books

cry at more frequent feeding

8 lbs, 5 oz, 21 inches

Head circumference

Foot length 5 was

having anxiety