A mixed methods exploration of practitioner knowledge of autism and lactation within the context of maternal experiences

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A mixed methods exploration of practitioner knowledge of autism and lactation within the context of maternal experiences

by

Leslie June Dooley

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

DOCTOR OF PHILOSOPHY

Major: Human Development and Family Studies

Program of Study Committee:
Carla Peterson, Major Professor
  Ji Young Choi
  Tera Jordan
  Gayle Luze
  Donna Winham

The student author, whose presentation of the scholarship herein was approved by the program of study committee, is solely responsible for the content of this dissertation. The Graduate College will ensure this dissertation is globally accessible and will not permit alterations after a degree is conferred.

Iowa State University

Ames, Iowa

2019

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DEDICATION

“…Take your time, think a lot. Think of everything you’ve got, for you will still be here tomorrow but your dreams may not.”

~ Cat Stevens

Childhood memories fade with time, the tragedy of childhood amnesia. My earliest memories of my father swirl into an enveloping cloud of warmth and love, lacking clear form or detail but filled instead with endless joyful emotions. I recall believing that my father could fix anything, knew everything, had the most beautiful signing voice, and played guitar better than any musician on the radio. He taught me to approach the world with curiosity and made me feel like I was the center of his universe, all while indulging my interests with genuine attention. My dad instilled in me the mindset to approach all problems as opportunities to explore, innovate, and grow. Following his example, my approach to parenting follows the same path and I have passed those insights on to my own children. Without my father’s guidance and support, I would never have seen myself as an agent for change, believed I could make a difference, and have the tenacity to seek answers questions that no one else has explored. At the pinnacle of my education, I dedicate my dissertation to my father Roger Broz, my mother Judith Broz, my children Ayden and Madelin, and my husband James.
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ACKNOWLEDGMENTS

During my graduate education, I heard many metaphors for the experience of graduate school, the most accurate representation of my experience was found in the simple phrase: graduate school is a marathon not a sprint. Everyone knows running a marathon takes dedication, training, and copious amounts of effort but there are seldom discussions of the team behind the runner. I was fortunate to have a dedicated team of brilliant professors to illuminate my path and cheer me across the finish line.

I would like to thank my committee chair and mentor, Dr Carla Peterson for her passion, brilliance, and dedication to my education and scholarship. I vividly remember our first meeting, Dr Peterson listened intently, then responded to the description of my research goals with such contagious enthusiasm that it was hard for me to contain my own excitement, she promptly filled my arms with books, and I left that first meeting feeling like I could move mountains. I am honored and beyond thankful for Dr Peterson’s support throughout my graduate school journey.

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Last but not least, I want to also offer my sincerest appreciation to the study participants who were willing to participate in my surveys and interviews, without whom, this dissertation would not have been possible.
ABSTRACT

Currently, one out of every 59 infants born in the United States will be diagnosed with an autism spectrum disorder (ASD) at some point in their future (Baio, 2018). Families may face unique challenges related to atypical infant behaviors and feeding patterns before diagnosis of ASD occurs. There is wide variation of symptoms among children with ASD, yet, children with ASD are five times more likely to have both behavioral and skill-based feeding issues. However, little is known about when feeding issues begin, how atypical behaviors impact infant caretaking needs, and whether practitioners have sufficient training to identify infants for further developmental assessment. As a result, despite identifiable early indicators of ASD during infancy, most children are not diagnosed with ASD until they begin preschool. When practitioner views of infant feeding focus exclusively on nutrition, atypical feeding behaviors may be overlooked as a way to identify atypical development. Infants who have behaviors associated with later diagnosis of ASD may face unique challenges breastfeeding. Practitioners need to have knowledge of development, early indicators of ASD, and infant feeding behaviors to provide support to parents and promote healthy development. The purpose of this study was to better understand practitioners’ knowledge of infant feeding behaviors and early indicators of ASD within the context of mother’s experiences raising infants later diagnosed with ASD. Quantitative measures of lactation consultants' and pediatricians’ knowledge of early indicators of ASD and lactation were integrated with phenomenological analysis of maternal experiences seeking help managing breastfeeding and atypical behaviors in infants later diagnosed with ASD. Individual and professional level influences on maternal access to support and barriers to support were explored.
CHAPTER 1. INTRODUCTION

Introduction

Autism spectrum disorder (ASD) is a developmental disability characterized by stereotyped patterns of behavior and impairments in both communication and social interaction. There is wide variation of symptoms among children with ASD, however, children with ASD are five times more likely to have both behavioral and skill-based feeding issues. Little is known about when feeding issues begin, how atypical behaviors impact infant caretaking needs, and whether practitioners have sufficient training to identify infants for further developmental assessment. As a result, despite evidence based early indicators of ASD during infancy, most children aren't diagnosed with ASD until they begin preschool. Rates of ASD among children have shown significant and continuous increases over time, increasing by 119.4 percent from 1 in 150, in 2000, to the current rate of 1 in 59 (Baio et al., 2018; Boyle et al, 2011). The prevalence rate of ASD among children in U.S. has increased by approximately 150 percent (Baio et al., 2018). 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. Yet diagnosis often does not occur until a child is 4 years old (Baio et al., 2018; Buescher et al., 2014).

Early Indicators of Autism

Researchers have identified early indicators of ASD during infancy across multiple developmental domains including: atypical patterns of motor, social, and emotional development, as well as communication deficits. Infants later diagnosed with ASD can have difficulty with multiple aspects of motor control such as difficulty controlling head movement, uncoordinated movements, low muscle tone in arms, and difficulty sitting up unassisted. Many
of these behaviors are present at birth, providing an opportunity to screen for ASD in the first few months of life (Green et al., 2009; Teitelbaum, 1998). However, it is important to note that atypical patterns of motor development can overlap with other conditions, making early diagnosis of ASD challenging. During the first year of life, infants later diagnosed with ASD have difficulty regulating attention to complex social scenes and display poor social initiative (Maestro et al., 2005; Shic et al., 2013). Researchers have found that infants later diagnosed with ASD exhibit fewer social and joint attention behaviors such as pointing, showing objects, or looking at others, and tend to not respond when their name is called (Osterling & Dawson, 1994; Woods & Wetherby, 2003; Zwaigenbaum et. al, 2005). Infants later diagnosed with ASD may exhibit poor emotional regulation and can behave in an extremely distressed manner in response to external stimuli, such as interactions with others or environmental changes (Esposito et al., 2013; Maestro et al., 2005). Infants later diagnosed with ASD smile less often than their typically developing peers (Filliter et al., 2014; Zwaigenbaum et. al, 2005). These differing patterns of emotional responses may be the first cues that parents observe and report to health care providers. Receptive and expressive communication skill delays or deficits commonly occur in children diagnosed with ASD and are 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). Parents reported that they struggled to determine or understand what their baby wanted or needed exacerbating the challenges of caretaking (Mitchell et al., 2006).
Feeding Issues and ASD

Atypical patterns of development may impact feeding patterns during infancy and can persist throughout childhood. Children with ASD are five times more likely to have skill based and behavioral feeding issues. Parents of children with ASD frequently report a variety of unusual meal time problems and feeding difficulties including food texture preferences, requiring specific presentations of food and specific utensils, and limited variety of food that the children will eat despite parental attempts and opportunities to provide a variety of food choices (Ahearn, 2001; Beighley et al., 2013; Schreck et al., 2004). Feeding difficulties commonly occur in children diagnosed with ASD, yet there is little research exploring infant feeding behaviors, breastfeeding patterns, and maternal experiences seeking help for atypical behaviors during infancy before diagnosis occurs. The feeding issues and increased prevalence of food selectivity that have been observed in older children may also impact breastfeeding behaviors. Despite the frequency at which feeding difficulties occur in children diagnosed with ASD, there is little research exploring infant feeding patterns in children who are later diagnosed with ASD (Burd, 1988). 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 Intervention

Early intervention, services, and support have been associated with better outcomes for children who have been diagnosed with ASD (Clark et al., 2018; Corsello, 2005; Green et al., 2015; Woods & Wetherby, 2003; Zwaigenbaum et. al, 2015). Existing valid and reliable measures can be used to identify children as early as age 2 (Baio et al., 2018; Mandell et al., 2005). 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 (Baio et al., 2018). Accurate diagnosis and effective treatment at an early age for those who have increased risk of ASD is essential to connect families to resources and support best possible developmental outcomes. Infant feeding behaviors may help to identify children at risk for diagnosis of ASD during infancy that would allow families to begin receiving services and support at an early age. Early intervention during the first years of life can promote healthy development and provide infants and their families with necessary support to ensure the best possible developmental trajectory (Boyd et al., 2010; Corsello, 2005; Green et al., 2015; Greenspan, 2007).

**Breastfeeding**

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 strong knowledge of evidence-based breastfeeding information as well as a strong foundation in infant development (CDC, 2016). Mothers can provide practitioners with valuable information about their infant’s development and feeding patterns, however, practitioners must be trained to identify typical versus atypical patterns of development and feeding behavior. Researchers have found that mothers often view doctors’ breastfeeding support as ineffective and insufficient (McInnes & Chambers, 2008; Taveras et al., 2004). 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. Infants later diagnosed with ASD may exhibit atypical hunger cues, disorganized feeding, and behaviors that indicate satiety may be disrupted. The breastfeeding process may allow observations of early indicators of ASD across multiple domains of development.
Practitioner Knowledge

Pediatricians and lactation consultants are practitioners who interact with infants as a part of their professional practice. The American Academy of Pediatrics defines pediatricians as medical practitioners who specialize in the physical, mental, and social health of children from birth to young adulthood (Committee on Pediatric Workforce, 2015). Pediatricians are physicians who undergo specific training focusing on all aspects of medical care for children, adolescents, and young adults (Committee on Pediatric Workforce, 2015). An International Board Certified Lactation Consultant is a healthcare professional specializing in the clinical management of breastfeeding certified by the International Board of Lactation Consultant Examiners (IBLCE), independently accredited by the National Commission for Certifying Agencies of the Institute for Credentialing Excellence (Wambach & Riordan, 2016).

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 available to assess 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 associated with developmental disabilities that may indicate the need for further developmental screening. Early screening for ASD can be based on both caregiver observations and health care provider’s assessment to determine if an infant displays patterns of atypical development that warrant further evaluation. It is essential that health care providers are aware of early indicators of abnormal development and have adequate training and tools for early identification of ASD, namely, tools based on patterns of atypical physical, emotional, and social development during infancy. 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 assessment. There is little systematic information examining practitioner knowledge in relation to early indicators of ASD or breastfeeding.

**Maternal Report**

Mothers are often the primary caregiver for infants and as such provide 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 report could identify infants who might need further assessment based on atypical patterns of behavior. However, practitioners must have a strong understanding of both infant feeding behaviors and early indicators of ASD to identify infants exhibiting patterns of atypical development. While several studies have found atypical patterns of behaviors in infants later diagnosed with ASD, little is known about the maternal observations of those atypical behaviors and their attempts to access professional support (Kishore & Basu, 2011; Talbott et al., 2015).

**Maternal Stress**

Families may face unique stresses and challenges related to atypical infant behaviors and feeding patterns. Mothers of young children with ASD report higher levels of depressive symptoms and stress and lower levels of well-being when compared to parents of children with other disabilities (Padden & James, 2017). Additionally, maternal stress levels have been found to be impacted by child characteristics including dysregulation (Davis & Carter, 2008). Infants who exhibit challenging behaviors associated with a later diagnosis of ASD may be at a greater risk of abuse, maltreatment or neglect, highlighting the importance of identification and early intervention (Sullivan & Knutson, 2000). The sooner a child with ASD begins to receive intervention the better their developmental outcomes across the lifespan and, likewise, the risk of abuse and maltreatment declines.
Purpose Statement

The following section provides an overview of the study, including the relevance, methodological justification, and goals for the study’s expected outcomes.

Statement of the problem

Currently, one out of every 59 infants born in the United States will later be diagnosed with an autism spectrum disorder (ASD) (Baio et al., 2018). Families may face unique challenges related to atypical infant behaviors and feeding patterns before diagnosis of ASD occurs. When practitioner views of infant feeding focus exclusively on nutrition, atypical feeding behaviors may be overlooked as a way to identify atypical development. Infants who have behaviors associated with later diagnosis of ASD may face unique challenges breastfeeding. Practitioners need to have knowledge of development, early indicators of ASD, and infant feeding behaviors to identify infants that can benefit from further developmental evaluation and provide support to parents.

Purpose of the Study

The purpose of this study is to better understand practitioners’ knowledge of infant feeding behaviors and early indicators of ASD. Practitioners’ knowledge base, attitudes, and beliefs specific to both breastfeeding and early indicators of ASD during infancy was assessed and compared between groups. Comparing measures of knowledge between two groups of practitioners, pediatricians and lactation consultants, will pinpoint specific information about areas of knowledge proficiency and deficits. Additionally, this study examined the formal and informal networks of support that mothers of infants later diagnosed with ASD accessed during their child’s infancy, and her observations of infant behaviors before a formal diagnosis of ASD occurred. The impact of practitioner knowledge of lactation and ASD within the context of maternal experiences breastfeeding and caring for infants later diagnosed with ASD has never
been explored directly. This innovative study explored the extent to which maternal experiences seeking and receiving support from practitioners align with, diverge from, or contradict practitioner knowledge of both ASD and lactation. Descriptive phenomenology allowed for an in-depth exploration of mothers’ experiences seeking support for concerns about breastfeeding and raising infants later diagnosed with ASD. Examining maternal experiences illuminates how to better meet the needs, of both mother and infant, and identify potential barriers to services and support. This study adds to the existing knowledge of early indicators of ASD present during the first 2 years of life based on the descriptions of breastfeeding behaviors, maternal experiences, and mothers’ observations of children who have been diagnosed with ASD. The results allow researchers and practitioners to understand more about early indicators of ASD and the factors that are inhibiting access to assessment and services for infants who exhibit atypical behaviors.

**Significance of the Study**

Parents of infants who exhibit atypical behaviors based on a developmental disability may face exceptional caretaking challenges. The stress of parenting an infant who exhibits challenging behaviors may cause mothers to struggle in the absence of formal support (Costa, Steffgen, & Ferring, 2017; Ooi, Ong, Jacob, & Khan, 2016; Ozturk, Riccadonna, & Venuti, 2014; Valicenti-Mcdermott et al., 2015). Examining 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, provides descriptions of beneficial or successful support experiences as well as barriers and deficits in support networks.

There is a little research exploring maternal experiences and observations of breastfeeding behaviors of infants later diagnosed with ASD. Similarly, little is known about practitioner’s knowledge of breastfeeding or early indicators of ASD during infancy, which would potentially impact practitioner ability to provide support and services to families whose
children have ASD. This study is the first to explore practitioner knowledge between pediatricians and lactation consultants, from a systems approach, as experienced by mothers of children with ASD. Assessment of practitioner knowledge allows for the identification of knowledge deficits that may prevent practitioners from providing families with adequate support, accurate assessment, and evidence-based interventions. Aspects of both breastfeeding support and pediatric awareness of development were assessed and examined within the context of maternal experiences.

While there is currently a gap in the literature quantifying practitioner knowledge of early indicators of ASD and breastfeeding, mixed methods approaches have been utilized to separately explore aspects of breastfeeding and ASD. This study utilized a multilevel mixed methods approach to explore practitioner knowledge within the context of maternal experiences related to early indicators of ASD, providing a significant methodological contribution. 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 increased duration of breastfeeding, improved developmental outcomes.

Theoretical Framework

Bronfenbrenner’s bioecological theory of human development provides the framework for this study, providing a comprehensive framework to explore multiple ecological system levels while taking into consideration gene-environment interactions at the individual level. A multilevel mixed methods approach, based on bioecological theory of development, allows this study to capture the impact of practitioner level factors on the experiences of mothers of children with disabilities, examining the complexity of their lives, and the contexts that influence their child’s development (Bronfenbrenner, 1986; Bronfenbrenner & Ceci, 1994; Sontag, 1996).
Bioecological theory views the child as influencing and contributing to the environmental context in a reciprocal nature based on genetically based potentials (Bronfenbrenner, 1986; Bronfenbrenner & Ceci, 1994). 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). Guided by Bronfenbrenner’s bioecological theory of human development, this study approaches practitioner knowledge and practice, maternal experiences and infant feeding from a developmental perspective. This study explores a previously unexamined combination of factors at multiple bioecological levels.

**Research Questions**

A mixed methods research approach is appropriate when the purpose of a research study and research questions require both a quantitative and qualitative approach (Tashakkori & Teddlie, 2010). This study explored the following four research questions:

1.) What knowledge do practitioners have related to lactation and early indicators of ASD?

2.) Are there differences between lactation consultants and pediatrician’s knowledge of lactation and early indicators of ASD?

3.) How do mothers experience receiving professional support caring for and feeding infants later diagnosed with ASD?

4.) To what extent do maternal experiences seeking and receiving support from practitioners align with, diverge from, or contradict practitioner knowledge of ASD and lactation?

**Mixed Methods Rationale**

A mixed methods approach allows for quantitative analysis of measures of knowledge while at the same time provide a qualitative exploration of maternal observations of infant
behaviors and experiences accessing support to clarify factors that may otherwise be unexamined. Comparing practitioners’ knowledge within the context of maternal experiences illuminates how practitioners’ knowledge translates to practice. Conducting mixed methods research allows researchers to collect and analyze data, integrate the findings, and draw inferences across both qualitative and quantitative methods within a single study (Tashakkori & Creswell, 2007). A mixed method approach allows this study to explore the depth and breadth of practitioner knowledge within the context of maternal experiences. This study will utilize a multilevel concurrent mixed methods design, allowing for simultaneous collection of quantitative survey data from practitioners while at the same time conducting in depth qualitative interviews with a smaller sample of mothers to fully explore and describe maternal experiences. Independent analysis of quantitative and qualitative data followed by integration of both quantitative results and qualitative findings provides an interpretation of how practitioner knowledge translates into practice within the context of maternal experiences.

Given that there is little research exploring practitioner knowledge of ASD and lactation, and no studies that have explored practitioner knowledge within the context of maternal experiences, a mixed methods approach allows for both exploration and analysis within one study. A mixed methods approach allows for collection and analysis of comprehensive data that will add insights and in-depth exploration of practitioners’ knowledge of infant feeding behaviors and early indicators of ASD that may otherwise be missed.

**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 failed to meet developmental milestones and his behaviors became increasingly different from those of his peers. I began to research development and lactation. The challenges I experienced breastfeeding led me to a 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.

My experiences helping mothers meet their breastfeeding goals made me realize my early experiences were not unique. Clients reported feeling frustrated with comments their child’s doctors made or being confused by conflicting breastfeeding advice. Mothers whose infants exhibited extreme behaviors would share that they didn’t know what “normal” was, in relation to both breastfeeding feeding and infant behavior. I found myself printing evidence based breastfeeding information to send with mothers as they headed to the doctor, arming them with knowledge, sending them off with renewed hope, and at times taking that extra step to recommend referral for developmental screening.
As a mother, I wanted my son’s voice to be heard even when he was silent. As a breastfeeding counselor, I listened to mothers who felt that every practitioner was saying something different and that they and their baby were somehow getting lost in the process. 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 provides a foundation to conduct interviews with mothers effectively, delve deeper into scenarios from a clinical perspective, and decipher themes that emerge from the qualitative data.

I was fortunate to have access to early intervention 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 clarifies when referrals for interventions are warranted.

When conducting mixed methods research, a personal position statement provides important insight as to how a researcher engages with the practice of research through their own unique intentions and perspectives as an individual (Greene, 2007). Utilizing a mixed methods interdisciplinary approach allows 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 practitioner knowledge, infant behaviors, and the complexities of the breastfeeding relationship framed within the context of maternal experiences.
Summary

This study sought to better understand practitioners’ knowledge of infant feeding behaviors and early indicators of ASD within the context of maternal experiences using a multilevel mixed methods approach. There have been few studies exploring practitioner knowledge of lactation and ASD, and of those studies the focus was on a single group of practitioners without exploring the experiences of the mothers and infants in their care. Currently, there are no studies exploring practitioner knowledge within the context of maternal experiences breastfeeding and seeking services for infants later diagnosed with ASD.

The following four chapters describe in detail the research plan, findings, and conclusions. Chapter Two is a comprehensive review of the literature on practitioner knowledge of ASD and lactation, early indicators of ASD and infant feeding patterns. Chapter Two focuses primarily on the gap in literature exploring practitioner knowledge of early indicators of ASD and lactation, with a focus on the impact of atypical development on infant feeding behaviors and clarifies how this study will address this gap in literature. Chapter 3 describes the research design utilized in this study and the details of how this study was conducted. The final two chapters discuss the findings of the research. Chapter 4 provides the analysis results followed by interpretation and discussion of the findings in Chapter 5.
CHAPTER 2. LITERATURE REVIEW

Conceptual Foundations

Conceptual foundations provide essential guiding framework for every aspect of research, from the initial design stages to final analysis, summary, and dissemination. Mixed methods research places value on the importance of philosophical assumptions as the foundation upon which it is possible to establish what constitutes knowledge. Mixed methods research has yet to have an established consistent singular collection of assumptions about the nature of reality and knowledge, therefore, clear definitions are important to clarify the perspectives guiding the research. Similarly, theoretical frameworks provide a context from which research can build upon based on existent knowledge pertinent to a substantive field of study (Creswell & Plano Clark, 2011). This section will discuss the philosophical foundations that guide this mixed methods study, followed by the overarching theoretical framework, and concludes with a literature review of existing research that provides the empirical foundation for this study.

Philosophical Foundation

Researchers who utilize a mixed method approach can draw upon a diverse range of philosophical positions, across a variety of perspectives and worldviews, which can have opposing underlying belief systems (Creswell et al., 2011). Despite the potential for conflicting philosophical stances, mixed methods research allows researchers an opportunity to transform the opposing tensions into new knowledge and empirical evidence. The philosophical foundation of this study utilizes a pragmatic perspective to explore the research questions. A pragmatic philosophical stance allows the researcher to focus attention to the factors that have the most impact on the topic of research and the methods that will best meet those needs (Morgan, 2007). A pragmatic approach allows the use of theory and data in a back and forth manner, combining
both inductive and deductive processes, allowing theory to guide observations and inductive inferences while utilizing a deductive approach to predict future outcomes based on prior inductions. The pragmatic philosophical approach focuses on researcher intersubjectivity, combining both an objective and subjective approach to research allowing the researcher to account for aspects of conflict and consensus within differences in world views and perceptions of reality between individuals with an overarching goal of mutual understanding (Morgan, 2007). A final aspect of pragmatic philosophical foundation is the goal of transcending the duality between the concepts that knowledge is divided into two mutually exclusive groups: universal and generalized or context-dependent and specific to isolated population of interest or sample (Morgan, 2007). The goal is to examine the extent to which knowledge from one method, setting, and situation, can be further utilized in other circumstances blurring the lines between results being either context bound or generalizable (Morgan, 2007). A fundamental concept within the pragmatic stance is to focus on how empirical results and new knowledge can be utilized by people, as opposed to focusing solely on whether the findings are generalizable. The goal is to examine how this new knowledge can be applied in alternate circumstances while being mindful of the empirical justification for such claims.

**Theoretical Framework**

In this study, Bronfenbrenner’s bioecological theory of human development will provide the framework for explaining, understanding, and analyzing the research questions. The bioecological theory of human development provides a comprehensive framework for the study of children with disabilities, allowing researches to explore the complexity of their lives, genetically based potentials for effective psychological functioning, and the contexts that influence development (Bronfenbrenner & Ceci, 1994; Sontag, 1996). The bioecological model examines continuity and change over time, in both individuals and groups, while accounting for
the influence of biological characteristics on behaviors, thoughts, and feelings. Bioecological theory illuminates the contribution of the individual to the developmental process as a function of both environmental influences and individual genetic characteristics that occur over time. Bioecological theory views the child as an active agent in their own development, capable of influencing and contributing to the environmental context in a reciprocal nature (Bronfenbrenner, 1986; Bronfenbrenner & Morris, 2006; Lerner & Damon, 2006). Bioecological theory posits that specific measurable mechanisms can be examined to explore development within the environmental contexts that humans live. There are four principal components to the bioecological model: proximal processes, the biopsychological characteristics of the individual, immediate and remote environmental contexts, and time periods in which the proximal processes take place (Bronfenbrenner & Morris 2006).

A core concept in bioecological theory is that development occurs through processes of complex reciprocal interactions between a child and their environment on a regular basis over extended periods of time (Bronfenbrenner, 1994). There are four establishing principles and interactions that drive bioecological theory, the Process Person Context Time (PPCT) model within the bioecological framework highlights the importance of mutual, bidirectional interactions between an individual and aspects of their environment (Bronfenbrenner, 1994). Development occurs across the lifespan as the result of progressively more complex reciprocal interactions between an individual, whose biopsychological features evolve over time as well, and the immediate external environment. The frequency, consistency, and duration of interactions influence the efficacy of an interaction. Proximal processes encompass interactions between the individual and the environment, that occur on a regular basis, over an extended period of time. Proximal processes are bidirectional interactions that occur in the immediate
environment (Bronfenbrenner, 1994). These processes occur in the mother-infant dyad during early interactions between mother and infant, shaping social dynamic and behavior patterns over time, and can influence later development (Feldman et al., 1997; Wan et al, 2012). For children with ASD, the severity of symptoms directly affects how children interact with others, which in turn impacts the nature of relationships in their immediate and extended environments and the reciprocal interactions that occur over time.

While there is almost infinite variation among personal biopsychological characteristics, three specific characteristics have been identified as most influential in shaping development based on their capacity to impact the power and direction of proximal processes across the lifespan. Individual disposition, bioecological resources, and demand characteristics combine to account for interindividual differences as well as impact the direction and power of developmental effects of proximal processes (Bronfenbrenner & Morris, 2006). Individual disposition can impact both initiation and continuity of proximal processes over time. Biological resources vary across developmental stages and are defined as the individual’s abilities, experiences, knowledge and skills that are required for effective functioning of proximal processes. Demand characteristics invite or discourage reactions from the social environment ultimately fostering or disrupting the operation of proximal processes (Bronfenbrenner & Morris 2006). It is important to consider these personal characteristics at the microsystem level and the impact of individual variation on the interactions that occur with other people who interact with the developing person on a fairly regular basis over extended periods of time, including but not limited to parents, relatives, close friends, and teachers.

The ecological environment is defined as a set of nested structures or levels at the center of which is the developing individual (Bronfenbrenner, 1994). Intermediate and remote
environments include the environments within which the developing individual lives and socializes as well as the objects and symbols with which they interact. Variations in immediate environments can invite engagement in progressively complex interactions and activities or, conversely, inhibit interactions. Physical features of an environment can foster or interfere with the development of proximal processes.

The dimension of time is an essential component to the in the bioecological model and can be conceptualized across three successive levels: microtime, mesotime, and macrotime. Microtime refers to the continuity or discontinuity of proximal processes. Mesotime is the tendency of proximal process to occur across broader intervals of time. Macrot ime is conceptualized as the evolving events and expectations that occur within a society and at a broader context within and across generations that both influence and is influenced by individual changes over time across the lifespan.

Bronfenbrenner’s bioecological theory posits that human development occurs within a system divided into several nested levels. The individual exists at the center of the system of levels. The microsystem is comprised of the direct interactions that occur during activities and interactions with others. The exosystem is a level that consists of systems that influence the individual indirectly through the microsystem. The macrosystem encompasses the social ideologies, values, and norms of the culture in which the individual lives. A critical element of the bioecological model is the role of experience, including the features of an environment and the way that an individual personally experiences living in that environment.

From a bioecological perspective, the breastfeeding dyad exists within a larger family unit within the microsystem, directly being impacted by family relationships and interactions. Mothers form unique relationships with practitioners and community resource providers who fall
within the exosystem, directly impacting maternal perceptions of support and attempts to seek help. The ways in which mothers and practitioners interact can impact how mothers receive and relay information about their child (Casey & Whitt, 1980; Nelson et al., 2003; Schuster et al., 2000). Communication between practitioners and mothers plays a key role in the efficacy of the practitioners attempts to provide support, education, and guidance. All of these interactions are influenced at the macrosystem level by social and cultural norms, laws, and availability of resources.

The family is the principal context in which human development takes place, to better understand human development, it is essential to consider the entire bioecological system in which growth occurs (Bronfenbrenner, 1994). Bioecological theory will help provide a framework to interpret participant’s references to both formal and informal supports such as extended family, lactation consultants, pediatricians or other interventionists and the roles these interactions and relationships play in relation to practitioner knowledge, maternal experiences breastfeeding and their attempts to seek help (Bronfenbrenner, 1981). Bioecological theory conceptualizes distinct attributes of the infant, the reciprocal interactions with their mother, family systems in which mothers and infants later diagnosed with ASD interact, the practitioners that provide health care and support, and the additional multiple bioecological levels that impact their functioning as a breastfeeding dyad.
Figure 1. Theoretical and conceptual framework based on bioecological systems theory.

**Autism Spectrum Disorder**

The National Institutes of Health define developmental disabilities as disorders that are present at birth and can cause severe, long-term difficulties (Wicks-Nelson & Israel, 2013). Developmental disabilities negatively impact cognitive, physical, and emotional development or a combination of all three often affecting multiple activities of daily life (Saulnier & Ventola, 2012). The difficulties associated with developmental disabilities are persistent, life-long, and can disrupt an individual’s interactions with their environment across multiple ecological levels (Wicks-Nelson & Israel, 2013). Over the past decade, the prevalence rates of all developmental disabilities have increased. Of the individual developmental disorders, the rates of ASD have had significant and successive increases over time, making ASD the fastest-growing developmental disability. (Boyle et al, 2011). The number of children diagnosed with autism in U.S. has increased 15 percent in only two years, from 1 in 68 children having a diagnosis of ASD in 2016, to the current rate of 1 in 59 (Baio, 2018). There are currently more people diagnosed with ASD than at any other time.

ASD is a developmental disability, classified as 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 communication, social, and behavioral challenges (Saulnier & Ventola, 2012). ASD is considered a spectrum disorder due to the wide degree of variation in the severity and presentation of symptoms between individuals (Wicks- Nelson & Israel, 2013). There are no obvious outward physical differences associated with ASD, which contributes to the challenges of early diagnosis.

The symptoms of ASD include impairments in communication, such as delayed or total lack of the development of verbal speech (Saulnier & Ventola, 2012). Children diagnosed with ASD often have 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 with an 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, relationships, and developmental trajectories.

**Risk Factors and Characteristics**

Currently, an underlying explanation for the increase in ASD prevalence rates has yet to be determined. There is empirical evidence that has identified factors linked to increased risk of ASD. ASD tends to be more prevalent in families who already have one child diagnosed with ASD, parents who have one child with ASD have a 2%–18% chance of having a second child who also has ASD (Hallmayer et al, 2011). ASD is more common in twins, if one twin has ASD the other will be affected 36-95% of the time, with identical twins having the greatest risk (Hallmayer et al, 2011). In non-identical twins, if one twin has ASD, the other is affected up to 31% of the time (Hallmayer et al, 2011). Children born prematurely or with low birth weight are
at greater risk for ASD (Schendel & Bhasin, 2008). Parental age influences likelihood of having a child diagnosed with ASD, children born to older parents at increased risk (Durkin et al, 2008). Additionally, other developmental, psychiatric, neurologic, chromosomal, and genetic diagnoses can co-occur with ASD (Levy et al., 2010). These risk factors for ASD can help practitioners identify children who would benefit from increased monitoring and early assessment.

**Early Assessment**

Early assessment for ASD can be based on both practitioner assessments and caregiver observations to determine if an infant displays patterns of atypical development that would warrant further evaluation. There are specific infant behaviors and patterns of atypical development across multiple developmental domains that are indicators of later diagnosis of ASD. It is essential for caregivers and practitioners to be aware of the first signs of atypical infant development and have sufficient knowledge and ability to identify patterns of atypical behavior, as well as atypical physical, emotional, and social development during infancy associated with later diagnosis of ASD. Researchers have identified infant behaviors and patterns of atypical development that are indicators of later diagnosis of ASD. Valid and reliable assessments are available that can diagnose ASD as early as age two (Baio, 2014; Mandell et al, 2005). Parents of children with ASD often report observing atypical development and behaviors during infancy (Kozlowski et al, 2011; Talbott et al., 2015). When a school age child is screened for ASD, retrospective data regarding behaviors during the first years of life are utilized in the diagnostic process yet the majority of children do not receive a diagnosis until after age four.

In addition, parents of children with ASD frequently report a variety of feeding difficulties, food selectivity, and meal time behavior problems. Food selectivity includes, but is not limited to, eating behaviors that are restricted by food texture, by category, 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). Parental report has shown that, despite parental attempts and opportunities to provide a variety of food choices, children with ASD exhibit more frequent unusual mealtime behaviors when compared to typically developing children (Ahearn, 2001; Schrek et al., 2004). These behaviors can include requiring specific presentations of food and specific utensils, food texture preferences, and a narrow variety of preferred types of food (Ahearn, 2001; Schrek et al., 2004).

**Early Intervention**

The increasing rates of ASD highlight the importance of accurate diagnosis at an early age. The earlier assessment and diagnosis can occur, the sooner a child can begin to receive effective treatment and support. Early intervention during the first years of life can provide children, and their families, with necessary support to ensure the best possible future outcomes (Corsello, 2005; Green et al., 2015; Greenspan, 2007). Early intervention promotes healthy development during the first years of life when rapid brain development occurs and is linked to improved outcomes across multiple developmental domains (Clark et al., 2018). Unfortunately, ASD’s are typically not diagnosed or treated until a child enters school (Baio, 2018).

Researchers have found patterns of atypical development in children that are at risk for ASD. It is crucial for practitioners to have the skills to provide parents with opportunities for early assessment and intervention for their infant. Infants whose siblings are diagnosed with ASD are at greater risk and would benefit from being assessed across developmental domains on a frequent and regular basis. Early assessment and intervention is the key to helping lessen symptoms and improve outcomes for children who have ASD. Early symptoms may be apparent based on feeding behaviors related to atypical patterns of development.
Early Indicators of Autism Spectrum Disorders

Atypical Physical and Motor Development

Atypical physical and motor development is not currently included in ASD diagnostic criteria. Movement disturbances, however, often occur in children who are diagnosed with ASD. Several studies have linked specific patterns of physical and motor development during infancy to later diagnosis of ASD. Many of these behaviors are evident in the first few months of life (Green et al, 2009). In addition, the symptoms are often present at birth and could be used to screen infants who would benefit from closer developmental monitoring, especially if symptoms occur with other atypical patterns in other developmental domains (Teitelbaum, 1998).

Infants later diagnosed with ASD tend to have difficulty in multiple aspects of motor control such as uncoordinated movements, difficulty controlling head movement, low muscle tone in arms resulting in flopping, and difficulty sitting up unassisted. Infants later diagnosed with ASD are slower to learn how to sit and stand and are less likely to spontaneously change positions when compared to their typically developing peers (Nickel et al., 2013). Asymmetry of posture or movement, which can be assessed as young as 3 to 5 months of age, suggests potential for disrupted neural pathways that are linked to ASD (Esposito et al, 2009; Nickel et al, 2013; Teitelbaum, 1998). Symmetrical posture occurs when an infant’s arms and legs are positioned similarly relative to the corresponding limb, which can easily be assessed based on observation of the infant’s body. For example, symmetrical posture in typically developing infants can be observed in the lying position with both arms bent at the elbow up towards the head, as opposed to the left arm bent up and the right arm straight along the torso in infants later diagnosed with ASD (Esposito et al, 2009). Atypical physical and motor development such as uncoordinated movements and difficulty controlling head movements might disrupt breastfeeding. In order to breastfeed successfully, and infant must have control of head movements.
Infants may fail 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 or fail to gain the ability to roll over on their own (Teitelbaum, 1998). When unsteady in a specific position, infants may fall over more easily when compared to typically developing infants. These behaviors may indicate a lack protective reflexes when falling (Teitelbaum, 1998). A breastfed infant must maintain specific posture (in relation to the mother’s body) in order to feed effectively, asymmetrical posture and atypical reflexes may interfere with the positions in which an infant is held (Esposito et al, 2009; Teitelbaum, 1998). Researchers have highlighted atypical patterns of crawling, with infants exhibiting lack of symmetrical arm support, asymmetrical leg movements, 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 for the first 2 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. observed a characteristic shape of the mouth that can be seen the first few days after birth and may persist past infancy (1998). The lower lip is flat, but the upper lip is arched in a shape characteristic of Moebius Syndrome. Though there are currently no studies exploring the characteristic mouth shape observed by Teitelbaum et al. in relation to breastfeeding, the physical shape of an infant’s
mouth directly impacts breastfeeding. In order 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 lower gum line. If the infant has an atypical mouth shape, it might be challenging to form the proper mouth shape that allows for a complete seal around the mother’s nipple, causing feeding to be ineffective, and the mother may experience physical discomfort when breastfeeding due to compression of the nipple.

**Atypical Communication**

The ability to communicate effectively is a primary factor in developing relationships and is closely related to social skills and behaviors. Deficits and delays in receptive and expressive communication skills 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). Researchers have found that infants who are later diagnosed with ASD exhibit less frequent attempts to solicit attention from a care provider when compared to typically developing infants. They exhibit atypical signaling behavior when combining verbal communication with nonverbal gestures as well as atypical use of gestures for communication purposes such as reaching or pointing (Mitchell et al., 2006). These infants tend not to use complex gestures such as motioning to be picked up (Mitchell et al., 2006). Infants later diagnosed with ASD were found to be unable to generate reciprocal interactions and lacked purposeful attempts to communicate both through initiating and responding, such as pointing for a toy. Parents reported that they struggled to determine or understand what their baby wanted or needed (Mitchell et al., 2006). Many infants show limited production and understanding of simple verbal communication such as single words, understand significantly fewer phrases, and have limited overall use of gestures which may overlap with atypical physical or motor development (Mitchell et al., 2006).
Atypical Social Development

Researchers have observed several patterns of atypical social development during infancy. During the first year of life, typically developing infants show a preference for the faces, gaze, and voices of others but infants who are later diagnosed with ASD display poor social initiative and have difficulties 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 when compared to their typically developing peers (Jones & Klin, 2013; Osterling & Dawson, 1994; Shic et al., 2013). These patterns of interaction may cause infants to miss social cues that would help them understand emotional expressions and social interactions. When these infants hear talking in a social situation, they restrict their focus towards the sound, paying attention to only the speaker's mouth. The presence of speech might interrupt the attention of infants later diagnosed with ASD at a critical developmental point when other infants are acquiring language and learning about their social world and the emotional expressions of others (Shic et al., 2013). In addition, 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 Emotional Development

Several patterns of atypical emotional development have been associated with later diagnosis of ASD. Infants who are later diagnosed with ASD smile less often than those who do not have the disorder (Filliter et al., 2014; Zwaigenbaum et al., 2005). Retrospective data collected from parents who have a child with ASD reported that during infancy their children had a neutral or negative affect and were often passive or disengaged, especially in response to caregiver’s emotions (Cassel, 2007; Zwaigenbaum et al., 2005). Researchers have found that infants who are later diagnosed with ASD exhibit poor emotional modulation and tend to behave
in an extremely distressed manner to situations and environments that differ from the reactions of typically developing infants (Esposito et al., 2013; Maestro et al., 2005). These atypical emotional responses may be one of the first cues that parents may be aware and report to practitioners, warranting vigilant attention from health care providers.

**Feeding Issues and ASD**

Childhood is a period of rapid growth and development. However, along with these rapid changes, challenging behaviors can arise as children learn about the world in which they live. Many children have strong preferences and dislikes across a range of varied scenarios. Strong preferences can lead to challenging behaviors and cause parents stress, especially when the behaviors directly impact aspects of daily life. Parents often describe mealtime struggles when young children exhibit patterns of “picky eating”, a common occurrence when children begin to feed themselves. Picky eating tends to peak between the ages of 2 and 6 years old but then decreases for most children after entry to preschool (Suarez & Nelson, 2012). Food selectivity, though not consistently operationally defined in research, 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). These preferences are a normal part of development for typically developing children. However, for children with developmental disabilities, food selectivity is a common occurrence that can persist past the age at which feeding problems usually resolve for typically developing children and can be exacerbated by the symptoms of their disability (Cermak et al., 2010; Schreck et al., 2004).

The original diagnostic criteria for ASD included abnormal patterns of eating and behaviors problems associated with feeding (Ahearn, 2001). Researchers have relied on
caregiver report to understand feeding problems in children with ASD. Parents of children with ASD commonly report struggles associated with their child’s food selectivity behaviors, despite the behaviors not being included in the current criteria for diagnosis of ASD (Bandini et al., 2010; Beighley et al., 2013).

While the feeding issues that occur in typically developing children can be similar to those of children with ASD, current prevalence estimates suggest a substantial proportion, between 46-89%, of children with ASD exhibit abnormal feeding behaviors and problems (Allen et al., 2015; Sharp et al., 2013). Children with ASD are five times more likely to have both behavioral and skill-based feeding problems when compared to typically developing children. Feeding issues can be evident 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 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 age of the child, physiological dysfunction, and sensory sensitivities (Suarez & Nelson, 2012). Interest in food may decrease and children may exhibit protective behaviors to avoid or diminish discomfort associated with mealtime and eating when additional medical conditions are present in conjunction with a diagnosis of ASD (Suarez & Nelson, 2012). Biological disorders that cause discomfort including reflux, constipation, or food allergies may lead to food selectivity (Suarez & Nelson, 2012). Children with ASD are more likely to have gastrointestinal problems when compared to children who do not have a developmental disorder (Suarez & Nelson, 2012).
Sensory Processing and Feeding Issues

Researchers have found that sensory processing issues often occur in children who have ASD. Sensory processing issues are very common and cause a range of symptoms 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 sensations resulting in 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, when untreated or mismanaged, 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 can lead to chronic behavior patterns that can interfere with daily activities as well as create added stress for the family when untreated or mismanaged (Allen et al., 2015). Despite feeding difficulties, children with ASD tend to have comparable weight and height when compared with typically developing peers suggesting that the volume of food consumed is adequate to support growth. However, children with ASD are at greater risk of nutritional deficits based on decreased consumption of protein and calcium rich foods when compared to 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 during infancy that can be observed, assessed, and monitored to determine if intervention is needed. While there is individual variation in the amount consumed, 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 of typically developing infants occur frequently during the first year of life for multiple reasons such as acquisition of new developmental skills, periods of rapid growth, or illness (Dahl, 2015).

**Infant Nutrition**

Newborn human babies are relatively helpless when compared to other mammals when first born. Human newborns are unable to effectively move or protect themselves and rely on a caretaker for all aspects of survival. An essential part of survival is access to sufficient nourishment. While the method a mother chooses to feed her baby is considered a personal choice in the U.S., the need for infants to be fed is not debatable. For women who choose not to breastfeed, infant breast milk substitute (formula) is widely available and competitive companies conduct exhaustive research to generate advances in ingredients and formula components leading to ever expanding options for supplementation. However, there are numerous components within breast milk and benefits associated with the process of breastfeeding, for both mother and infant, that cannot be duplicated in a synthetic breast milk substitute.
Benefits of Breastfeeding

Breastfeeding has protective benefits for both mother and baby, providing infants with more than nutrition. Breastfeeding decreases maternal risk for multiple illnesses and breastmilk provides infants with essential nutrients and immunological benefits that are unable to be artificially reproduce (DHHS, 2011). Breastfeeding is associated with health benefits to women, including: decreased risk for type 2 diabetes, ovarian cancer, and breast cancer (Chung et al., 2007). Breastfeeding offers multiple benefits, in addition to providing a source of nutrition for infants, and is associated with decreased risk for many early-life diseases and medical conditions including: decreased rates of ear infections, respiratory tract infections, gastroenteritis, atopic dermatitis, type 2 diabetes, sudden infant death syndrome, and obesity (Chung et al., 2007).

Rates of Breastfeeding

The U.S. Surgeon General issued a Call to Action specifically focused on the importance of supporting breastfeeding mothers and their infants based on the numerous positive outcomes associated with breastfeeding across maternal and infant lifespans (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). Currently, 83.2% of mothers in the U.S. initiate breastfeeding after giving birth. However, despite the national initiative to encourage and support breastfeeding mothers, only 24.9% of babies are exclusively breastfed after six months (CDC, 2018). 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). Given so many factors contributing to early cessation, reaching a national breastfeeding goal may prove to be a challenge, but the biggest impact is at the individual level when 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 breast and nipple. The process of making milk begins approximately half way through pregnancy based on hormonal changes that occur within a woman’s body (Dahl, 2015; Wambach & Riordan, 2016). The combination of hormones and physical stimulation from a suckling infant continue and maintain the process after a woman gives birth. Milk production is often referred to as a “supply and demand process”, requiring frequent breastfeeding sessions and effective milk removal to establish a full breast milk supply that can support infant nutritional needs (Dahl, 2015; Wambach & Riordan, 2016).

During the newborn phase, mothers rely on infant feeding cues to know when their baby is hungry. Infants are born with several reflexes and behaviors that indicate hunger such as rooting (a reflex in which an infant will turn their face towards a stimulus when cheek or lip is touched, triggering innate sucking motions), moving their head from side to side, and licking lips (USDA, 2009). Crying is considered a late feeding cue occurring if initial feeding cues are unmet (USDA, 2009). When an infant misses a feeding, not only does the potential for hunger cues to escalate to fussiness or crying but the mother’s milk supply will be directly impacted, leading to the eventual decrease in milk volume (Dahl, 2015; Wambach & Riordan, 2016).

Early feeding problems can result in a diagnosis of failure to thrive, meaning an infant has insufficient weight gain (Keen, 2008). Similarly, poor oral motor skills, sensory
defensiveness, or disrupted physical coordination, can cause an infant to not breastfeed effectively lead to an inability to gain weight and the mother’s milk supply will in turn be compromised (Dahl, 2015; Wambach & Riordan, 2016). Early feeding behaviors include the process of self-regulation, sucking, swallowing and the ability to communicate both hunger and satiety, atypical development has the potential to negatively affect the breastfeeding process (Keen, 2008; Williams et al., 2000).

The breastfeeding process 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). 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). Abnormal biological and social responsiveness and early manifestations of impaired social communication are associated with diagnosis of failure to thrive during infancy (Keen, 2008). If an infant is having trouble communicating hunger, a mother may be unaware that she needs to feed her baby. Persistent and severe feeding problems during infancy, including failure to thrive, warrant developmental evaluation and monitoring for later diagnosis of ASD.

**Typical Infant Feeding and Hunger Cues**

Newborns communicate hunger through a variety of feeding cues and behaviors 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). Newborn infants have small stomachs that empty frequently, requiring frequent feedings. In addition, frequent feedings biologically protect against dehydration (Dahl, 2015; Wambach & Riordan, 2016). 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 infant weight gain, urine and bowel output,
and sufficient maternal milk supply (Dahl, 2015; Wambach & Riordan, 2016). When compared to breastfeeding patterns, 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 as their infant grows (USDA, 2009).

Infant feeding patterns naturally change as infants grow. Feeding behaviors 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 positioning their bodies in a feeding position and smiling, gazing at, or reaching for a caregiver (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, falling asleep, slow or decreased sucking, pushing away from the mother, and arching away from the breast or bottle. In addition to the 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. Currently there is no research examining patterns of atypical breastfeeding behaviors or practitioner knowledge of atypical breastfeeding behaviors that could indicate the need for further developmental assessment.

Practitioner Knowledge

Practitioner Knowledge of Autism

As the rates of ASD continue to climb, practitioner knowledge of early indicators of developmental disabilities is essential to identify children who would benefit from further evaluation. For families with young children, pediatricians are often the primary point of contact for information regarding behavior and development. Therefore, pediatricians are often the first practitioner to address parental concerns about development, perform initial screenings, and
recommend further developmental assessment (AAP, 2001). As rates of ASD increase, pediatricians are providing health care services and initial diagnostic screenings for an equally increasing proportion of their patients. Pediatricians play an essential role in early identification of developmental disabilities protect young children’s developmental trajectories and improve outcomes (Halfon et al., 2004).

The age at which diagnosis of ASD typically occurs may be related to a lack of practitioner knowledge and training (Rhoades, Scarpa, & Salley, 2007). Based on the early indicators of ASD previously discussed, practitioners need to be aware of some of the subtle variations in development associated with a later diagnosis of ASD. However, parents play a key role in the disclosure of relevant information pertinent to atypical development as a source of valid and reliable developmental information (Glascoe & Dworkin, 1995). Given the range and variation in the presentation of symptoms in children with ASD, pediatricians need to carefully balance a lack of consistent physical indicators associated with ASD, direct assessment, and parental concerns. While practitioners may be familiar with indicators of ASD that are present in older children, little is known about pediatrician’s knowledge of early indicators of ASD during infancy. A lack of knowledge and training specific to the identification of early indicators of ASD may undermine practitioners’ ability to identify infants who would benefit from further developmental evaluation (Atun-Einy & Ben-Sasson, 2018).

Accurate identification of ASD is essential to connect families to assessment and intervention services and it is essential for practitioners to have proper training to ensure timely and accurate identification processes. In order to target trainings and address practitioners’ knowledge deficits, it is essential to quantify ASD knowledge to be able to assess the need for practitioner training (Atun-Einy & Ben-Sasson, 2018). Researchers have found that practitioners
may still maintain outdated views and misconceptions including etiology, diagnostic criteria, common comorbid conditions, age of ASD onset during childhood, prognosis or developmental outcomes, and the importance of interventions (Atun-Einy & Ben-Sasson, 2018; Daley & Sigman, 2002; Eseigbe et al., 2015; Hartley-McAndrew et al., 2014; Heidgerken et al., 2005; Igwe et al., 2011; Rahbar, Ibrahim, & Assassi, 2011; Rhoades et al., 2007; Shah, 2001; Stone, 1987). Currently, there are over 40 ASD knowledge assessment measures from around the world that target educational, community and clinical settings (Atun-Einy & Ben-Sasson, 2018; Harrison et al., 2017). Despite the existence of numerous measures, there are multiple issues with existent measures ranging from outdated questions based on prior diagnostic criteria and issues with psychometric strength. Based on a systematic review of studies international measures, only a few existing measures have reliable and valid psychometric properties that include subdomains specifically addressing knowledge of early indicators of ASD (Atun-Einy & Ben-Sasson, 2018; Harrison et al., 2017).

For breastfed infants, atypical development associated with ASD may disrupt the breastfeeding process. Infants later diagnosed with ASD may exhibit dysregulated breastfeeding behaviors (Lucas & Cutler, 2015). An International Board Certified Lactation Consultant (IBCLC) is a certified healthcare professional who specializes in the clinical management of breastfeeding (Wambach & Riordan, 2016). Despite being trained professionals who focus on supporting breastfeeding dyads, access to lactation consultants varies based on location. Mothers may seek help form a lactation consultant to address specific feeding concerns related to early indicators of ASD. For families of infants with a sibling currently diagnosed with ASD, it is important for lactation consultants to understand the increased risk of ASD and that observations of dysregulated early feeding behaviors warrants further evaluation. However, little is known
about lactation consultant’s knowledge of early indicators of ASD that would impact feeding behaviors.

Multiple studies have explored the association between breastfeeding duration and later diagnosis of ASD, however, the studies did not explore infant feeding behaviors or maternal access to practitioner support. While the results of the comparison studies remain mixed as to whether later diagnosis of ASD is associated with changes in breastfeeding duration, the existing evidence related to early indicators of ASD during infancy describe a pattern of behaviors that may make feeding challenging for infants with ASD (Al-Farsi et al., 2012; Burd et al., 1988; Schultz et al., 2006; Shafai, Mustafa, Hild, Mulari, & Curtis, 2014; Tanoue & Oda, 1989). Knowledge of early indicators associated with ASD that could disrupt the feeding process is essential for practitioners, including both pediatricians and lactation consultants, who provide support to breastfeeding dyads.

**Practitioner Knowledge of Breastfeeding.**

Similar to the importance of sufficient knowledge related to early identification of ASD, practitioner knowledge of breastfeeding is essential to provide healthcare services, adequate support, and referrals for breastfed infants. Pediatricians are often the healthcare provider with most frequent contact for mothers who breastfeed, as breastfeeding directly impacts the growth and physical health of their infant. The pediatrician can play a key role in the support and success of breastfeeding. Despite the importance of their role as a healthcare provider, pediatricians often lack formal education specific to breastfeeding (Fernandez-Vegue & Orenaga, 2015). There have been several questionnaires developed to explore pediatrician knowledge of breastfeeding, however, they lacked psychometric validity as measures of breastfeeding knowledge (Fernandez-Vegue & Orenaga, 2015). In the absence of professional support from a lactation consultant, in order to provide evidence-based information pediatricians need to have a solid foundation of
breastfeeding knowledge or they risk jeopardizing the success and duration of breastfeeding. Little is known about the pediatrician’s knowledge of breastfeeding and whether they have the education or training necessary to provide lactation specific support to a breastfeeding dyad experiencing feeding difficulties.

**Summary**

Infants later diagnosed with ASD may exhibit disorganized feeding or atypical hunger cues, and the behaviors that indicate satiety may be disrupted due to atypical development associated with early indicators of ASD. The breastfeeding process may allow a unique opportunity to observe early indicators of ASD across multiple domains of development. However, practitioners need to have knowledge specific to both ASD and breastfeeding to differentiate between typical and atypical feeding issues. 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. Mother’s may in turn question whether they are making enough breast milk to feed their baby. During the early months, breastfed infants communicate hunger through feeding cues that may be disrupted if an infant is not looking at or attending to 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. Breastfeeding involves an array of sensory experiences for infants, for those with sensory over responsivity, such as tactile or
oral defensiveness, the process of breastfeeding may prove to be overwhelming. Additionally, breastfed infants are physically in close proximity to their mothers during the feeding process, which might trigger sensory over-responsivity. The rate of milk flow varies, both during a feeding and throughout the day, and can change in both consistency and flavor based on maternal diet which may trigger sensory issues (Dahl, 2015; Cermak et al., 2010; Suarez & Nelson, 2012). Behaviors associated with 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. A limited amount of research has explored maternal experiences and observations of breastfeeding behaviors of infants later diagnosed with ASD. The proposed study will additionally focus on mother’s attempts to access professional support. Similarly, little is known about the knowledge base of practitioners that would potentially provide support and services to families whose children have 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 increased duration of breastfeeding, improved developmental outcomes, and decreased risk of abuse and maltreatment. Exploring practitioner knowledge of ASD and breastfeeding within the context of maternal experiences feeding, caring for and seeking support for breastfeeding will provide an opportunity to identify barriers to support. 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.
CHAPTER 3. METHODOLOGY

Overview of Methodology

The purpose of this chapter is to introduce the research methodology for this multilevel mixed methods study exploring pediatricians’ and lactation consultants’ (IBCLC) knowledge of infant feeding behaviors and early indicators of autism within the context of maternal experiences. A multilevel concurrent mixed methods approach was utilized to examine the extent to which maternal experiences seeking help and receiving support from practitioners aligned with, diverged from, or contradicted practitioner self-report of ASD and lactation knowledge. Guided by Bronfenbrenner’s bioecological theory, this approach allowed for in-depth exploration of practitioner knowledge of both lactation and early indicators of ASD within the context of maternal experiences raising infants later diagnosed with ASD, providing insight into the needs of both practitioners and families. This chapter will provide a description of the applicability of utilizing a multilevel mixed methods approach and research plan including descriptions of participants, procedures, analysis methods, and ethical considerations.

Research Questions

This multilevel mixed methods study is both an analysis of practitioners’ knowledge of infant feeding behaviors and early indicators of ASD and an exploration of maternal experiences seeking help for infants later diagnosed with ASD. The following four research questions were examined:

1.) What knowledge do practitioners have related to lactation and early indicators of ASD?

2.) Are there differences between lactation consultants’ and pediatricians’ knowledge of lactation and early indicators of ASD?
3.) How do mothers experience receiving professional support caring for and feeding infants later diagnosed with ASD?
4.) To what extent do maternal experiences seeking and receiving support from practitioners align with or diverge from practitioner knowledge of ASD and lactation?

**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 and practitioner knowledge of both early indicators of ASD and lactation. Prior to data collection, a detailed outline of the research procedure outlining all processes needed to complete the research was provided to the Iowa State University Institutional Review Board (IRB). IRB approval ensures the study adheres to rigorous standards for the study of human participants including confidentiality and informed consent. After receiving IRB approval, quantitative and qualitative data were collected simultaneously (See Appendix A). Recruitment of participants, emailing surveys, and conducting direct interviews with participants followed the procedure outlined below.

**Rationale for Mixed Methods Approach**

Practitioner knowledge of lactation and ASD have been assessed independently; however, there have been no empirical comparisons made between these two practitioner groups. Additionally, the impact of practitioner knowledge of lactation and ASD within the context of maternal experiences breastfeeding and caring for infants later diagnosed with ASD has never been explored directly. Collecting data from practitioners through quantitative surveys, at the individual level through maternal interviews, and convergently integrating the results of both quantitative and qualitative findings will illuminate practices that support mother and infant, as
well as identify gaps in practitioner knowledge and practices that create barriers to successful breastfeeding and delay identification of ASD.

Mothers are often the primary caregiver for infants and can provide the best source of information regarding their child’s patterns of behavior and development, including atypical feeding behaviors or early indicators that might point to the need for developmental assessment. Qualitative data can be used to explore the unique lived experiences, obstacles, and challenges that occur during the child’s infancy. These experiences, when combined with quantitative survey results of practitioner knowledge, may help illuminate possibilities for early diagnosis as well as potential opportunities for better practitioner support and intervention. This study is designed to help readers understand if mothers felt breastfeeding was successful, if the process was inhibited by atypical behaviors associated with ASD, examine the ways in which mothers sought help while breastfeeding, and whether they received adequate and effective support from practitioners. The focus of the qualitative exploration within this study explored maternal experiences seeking professional support for early indicators of ASD through mothers’ reports of their experiences, observations, and perceptions. Results of the qualitative interviews were examined and analyzed from the mothers’ perspectives.

When exploring a phenomenon that intersects practitioner knowledge and maternal experiences in relation to atypical infant behavior, an exclusively qualitative or quantitative approach may not facilitate full exploration of the intricacies of the phenomenon to produce the depth of descriptive data necessary to address the study aims. Mixed methods research intentionally combines quantitative and qualitative data to expand, clarify, and exceed knowledge that can be discovered from one method of data collection and analysis in isolation (Creswell & Plano Clark, 2011). A mixed methods approach is appropriate when the goal of
research is to address identified gaps in knowledge that cannot be fully explored through quantitative or qualitative analysis alone. Quantitative differences between knowledge of lactation and ASD between practitioner groups were compared, qualitative data of maternal experiences were analyzed, and quantitative and qualitative results were integrated to explore the extent to which maternal experiences align with practitioner knowledge. Because the purpose of this study was to explore practitioner knowledge within the context of maternal experiences, a mixed methods approach is the best method to answer the research questions. In addition to the collection of qualitative and quantitative data, an essential component of mixed method approach is the inclusion of deliberate mixing of data through a process of integration to generate insights that would otherwise not be discovered by either strand of data collection independently.

**Multilevel Concurrent Mixed Method**

Mixed methods research incorporates quantitative and qualitative methods, in a single study, including a component of integration in either the design or analysis to address complex or multifaceted research questions comprehensively (Tariq & Woodman, 2013). A pragmatist orientation was utilized as a basis for the selection of the research design, given that the inquiry methods were considered secondary to the focus of answering the research questions (Creswell, 2003, Tashakkori & Teddlie, 2010). From a pragmatic orientation, research design and procedures serve the purpose of answering the research questions. A multilevel concurrent mixed methods approach was the appropriate method to best answer the research questions. A multilevel concurrent mixed methods approach allows the researcher to examine elements within a system and incorporate integration and analysis of data across multiple system levels (Plano Clark & Ivankova, 2016). A multilevel mixed methods design, a variant of mixed methods research is grounded in assumptions defined by theoretical systems frameworks. The goal of multilevel mixed methods design is to better understand elements within a system including but
not limited to the structure of a system, the components that evolve within a system, or interactions and functions between system levels.

This study is guided by the bioecological perspective that individuals interact and develop over time within a series of nested systems. Multilevel mixed methods design allows for exploration of the impact of directional mechanisms between levels (Tashakkori & Teddlie, 2010). For example, the influence of societal level mechanisms could be examined on the individual level, the impact of individual level mechanisms on society, or even reciprocal mechanisms resulting in transformation across multiple levels. Multilevel mixed methods designs are defined primarily by the purpose of the research, and research questions, including studies that aim to explore topics across multiple system levels. A high quality multilevel mixed methods design should include: a quantitative strand at one or multiple levels, a qualitative strand at one or multiple levels, a sampling and data collection strategy that involves more than one level or mechanism within a system of a system, quantitative and qualitative analysis techniques sufficient for generation of inferences across levels, and integration techniques (Headley, 2016). Integration techniques across levels must support meta-inferences that explain at least two of the following: the nature of the system, the nature of the levels, or the nature of the mechanisms (Headley, 2016).

A concurrent mixed methods design was utilized, consisting of independent and simultaneous collection and analysis of both quantitative and qualitative data followed by a final stage of analysis integrating the results of qualitative and quantitative analysis (Plano Clark & Ivankova, 2016). Qualitative inquiry provides an inherently flexible design, creating close interactions between the researcher and participants, leading to a deeper contextual and descriptive understanding of the phenomenon of interest. A descriptive phenomenological
approach was used to analyze the data collected from mothers of children with ASD to describe mothers’ experiences observing atypical infant behaviors and attempts to access help or support for their infant’s caretaking needs. Results of the qualitative analysis were integrated with quantitative results to identify practitioner gaps in knowledge and areas that can be improved to better provide families whose infants are at increased risk of ASD with access to support and services that promote healthy development. Additionally, the multilevel concurrent mixed methods design provides a unique contribution to the mixed methods research community. This study explores the phenomenon of interest at multiple ecological levels allowing for the complexity of human experiences, variations in development, and practitioner knowledge to be fully explored.

**Rationale for Descriptive Phenomenology**

In order to understand the meaning of the observations during caretaking, the experiences seeking help from practitioners, and interactions that occur between a mother and her infant, a descriptive phenomenological approach is best suited to meet the goals of the qualitative analysis within the current mixed methods 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.
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 experience it directly (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 bioecological theory, retrospective qualitative interviews were conducted to explore the breastfeeding experiences and observations of mothers with children later 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. 2009). 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 retrospective data collected in this study examined maternal recall of experiences seeking help from practitioners, breastfeeding, and observations of infant behaviors associated with breastfeeding as opposed to specific time frames or duration.
Participants

Sampling Strategy

Purposeful sampling was used to recruit participants. The sample included mothers of children currently diagnosed with ASD and two groups of practitioners: pediatricians and lactations consultants. A national sample of practitioners was recruited to quantify practitioner knowledge specific to early indicators of ASD and breastfeeding. Mothers of children diagnosed with ASD were recruited to provide information rich cases for the qualitative analysis to gain the most information about the phenomenon of interest (Merriam, 2002). According to Giorgi (2009), there is no specific requirement for sample size when using a descriptive phenomenological approach. However, a minimum of at least three participants is recommended.

Mothers of children with ASD

A total of eight mothers who breastfed infants later diagnosed with ASD participated in this study. The mothers ranged in age from 26 to 39 and all resided in Iowa. Education levels ranged from high school diploma to master’s degree. All the mothers breastfed their child with ASD for at least 2 months after giving birth. Half the participants were married, two were divorced, one was separated, and one was not married at the time the study was conducted. One of the eight mothers had a cesarean section delivery, one reported having inverted nipples, and no other medical diagnoses were reported. Half the mothers reported their infants were fed formula while in the hospital but did not supplement with additional formula until cessation of breastfeeding if their child was under one year of age. Table 1 outlines additional demographic characteristics. Two of the participants only had one child. Only one of the participant’s child with ASD was not a first-born child. Two participants had two children diagnosed with ASD, one of which only had two children whereas the other had a total of four children. However, of her four children, the children with ASD were first and second in birth order.
Table 1  
*Mother’s Demographics*

<table>
<thead>
<tr>
<th>N= 8</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not Married</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Married</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Separated</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Divorced</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Educational Attainment</th>
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</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
</tr>
<tr>
<td>High School</td>
<td>2</td>
</tr>
<tr>
<td>Some College</td>
<td>1</td>
</tr>
<tr>
<td>Associates Degree</td>
<td>1</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>3</td>
</tr>
<tr>
<td>Graduate Degree</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of Children</th>
<th>Mean</th>
<th>2.25</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Min</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Max</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Breastfeeding Duration of Child with ASD (months)</th>
<th>Mean</th>
<th>16.8</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Min</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Max</td>
<td>48</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th>Mean</th>
<th>33.5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median</td>
<td>33.5</td>
</tr>
<tr>
<td></td>
<td>Min</td>
<td>26</td>
</tr>
<tr>
<td></td>
<td>Max</td>
<td>39</td>
</tr>
</tbody>
</table>

| Ethnicity | White | 8 | 100% |

A total of 18 children were represented in this study, and ten had a diagnosis of ASD. The children of participants in this study ranged in age from two to 12 years old. The mean age of the children diagnosed with ASD was 7.55 years old, with a median age of 6.25 years old. The siblings of the children diagnosed with ASD ranged in age from two to ten years old, with a mean age of six years old and a median age of seven years old. Three of the children with ASD were also diagnosed with sensory processing disorder. Additionally, two of the children with
ASD were nonverbal and two other children had diagnosed language disorders: apraxia of speech and expressive language disorder. Table 2 outlines additional demographic characteristics for the children represented in this study.

Table 2
Children’s Characteristics

<table>
<thead>
<tr>
<th></th>
<th>Children with ASD N= 10</th>
<th>Siblings N= 8</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Female</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>ASD Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autism</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Child age in years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>7.55</td>
<td>6</td>
</tr>
<tr>
<td>Median</td>
<td>6.25</td>
<td>7</td>
</tr>
<tr>
<td>Min</td>
<td>4.5</td>
<td>2</td>
</tr>
<tr>
<td>Max</td>
<td>12</td>
<td>10</td>
</tr>
<tr>
<td>Age of Autism Diagnosis (Months)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>36.9</td>
<td></td>
</tr>
<tr>
<td>Median</td>
<td>33</td>
<td></td>
</tr>
<tr>
<td>Min</td>
<td>18</td>
<td></td>
</tr>
<tr>
<td>Max</td>
<td>60</td>
<td></td>
</tr>
</tbody>
</table>

Practitioners
A national sample of 71 practitioners, pediatricians and IBCLCs, were recruited to assess practitioner knowledge through online surveys. Between two groups of practitioners, 23 licensed pediatricians and 47 IBCLCs completed the online surveys. A subset of ten pediatricians and five IBCLCs from Iowa were purposively sampled to be used in the mixed methods analysis and integration of results from practitioners and mothers to explore practitioner knowledge within the context of maternal experiences.
Pediatricians

A total of 23 licensed pediatricians from across the United States participated in this study. The majority of pediatricians in this sample were general pediatricians, five were academic general pediatricians, and one was a pediatric hospitalist. Seven male and sixteen female pediatricians participated in the study. Pediatricians’ ages ranged from 30 to 60 years old or older with the majority of pediatricians’ ages ranging between 40 and 49 years old. A total of 12 pediatricians had personal breastfeeding experience and five reported that their partner had breastfeeding experience. Two participants reported personal breastfeeding experience but did not report the duration of breastfeeding, and four participants had no personal or partner breastfeeding experience. Five participants reported not having any children. Table 3 outlines additional demographic characteristics for pediatricians.

Table 3
Pediatrician Demographics

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>African American/Black</td>
<td>3</td>
<td>13%</td>
</tr>
<tr>
<td>Middle Eastern</td>
<td>1</td>
<td>4.3%</td>
</tr>
<tr>
<td>Multiracial</td>
<td>1</td>
<td>4.3%</td>
</tr>
<tr>
<td>White or Caucasian</td>
<td>18</td>
<td>78.3%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>7</td>
<td>30.4%</td>
</tr>
<tr>
<td>Female</td>
<td>16</td>
<td>69.6%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Pediatric practice</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community general pediatrician</td>
<td>17</td>
<td>73.9%</td>
</tr>
<tr>
<td>Academic general pediatrician</td>
<td>5</td>
<td>21.7%</td>
</tr>
<tr>
<td>Pediatric hospitalist</td>
<td>1</td>
<td>4.3%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age:</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>30-39</td>
<td>6</td>
<td>26.1%</td>
</tr>
<tr>
<td>40-49</td>
<td>8</td>
<td>34.8%</td>
</tr>
<tr>
<td>50-59</td>
<td>6</td>
<td>26.1%</td>
</tr>
<tr>
<td>60 or older</td>
<td>3</td>
<td>13%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of Children</th>
<th>Mean</th>
<th>2.39</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Min</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Max</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Experience in practice (Years)</th>
<th>Mean</th>
<th>14.37</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Min</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Max</td>
<td>34</td>
</tr>
</tbody>
</table>
The state with the greatest number of participants in this study reported practicing in Iowa, due to purposive sampling; this subset of eight pediatricians was utilized to support the integrated analysis of pediatrician knowledge within the context of maternal experiences given the mothers in this study were all from Iowa. The remaining participants were from ten other states across the United States (see Figure 2).

![Pediatrician location of practice by state.](image)

**International Board Certified Lactation Consultants**

A total of 47 IBCLCs, all female, participated in this study. The majority of participants had children, four IBCLCs reported they had children but did not report the number and only four IBCLCs reported not having children. Similarly, four of the IBCLC participants did not have any personal breastfeeding experience, the remaining IBCLCs had between six and 137 months of cumulative personal breastfeeding experience. Table 4 outlines additional demographic characteristics.
Table 4  
**IBCLC Demographics**

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hispanic or Latino</td>
<td>2</td>
<td>4.2%</td>
</tr>
<tr>
<td>Middle Eastern</td>
<td>1</td>
<td>2.1%</td>
</tr>
<tr>
<td>Native American/ American Indian/ Alaska Native</td>
<td>1</td>
<td>2.1%</td>
</tr>
<tr>
<td>White or Caucasian</td>
<td>43</td>
<td>91.5%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age:</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-29</td>
<td>2</td>
<td>4.3%</td>
</tr>
<tr>
<td>30-39</td>
<td>16</td>
<td>34%</td>
</tr>
<tr>
<td>40-49</td>
<td>14</td>
<td>29.8%</td>
</tr>
<tr>
<td>50-59</td>
<td>6</td>
<td>12.8%</td>
</tr>
<tr>
<td>60 or older</td>
<td>9</td>
<td>19.1%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education Attainment</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>High School</td>
<td>2</td>
<td>42.9%</td>
</tr>
<tr>
<td>Some College</td>
<td>1</td>
<td>2.1%</td>
</tr>
<tr>
<td>Associates Degree</td>
<td>7</td>
<td>14.9%</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>21</td>
<td>44.7%</td>
</tr>
<tr>
<td>Master's Degree</td>
<td>14</td>
<td>14%</td>
</tr>
<tr>
<td>Doctorate Degree</td>
<td>2</td>
<td>4.3%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of Children</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>2.53</td>
<td></td>
</tr>
<tr>
<td>Min</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Max</td>
<td>8</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Experience in practice (Years)</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>10.02</td>
<td></td>
</tr>
<tr>
<td>Min</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Max</td>
<td>46</td>
<td></td>
</tr>
</tbody>
</table>

The highest number of IBCLCs in the study reported practicing in Pennsylvania, with seven total IBCLCs completing the online surveys, followed by Iowa and Illinois with five IBCLCs from each state. The subset of five IBCLCs from Iowa was utilized to conduct the integrated analysis of IBCLC knowledge within the context of maternal experiences. The remaining participants were from 22 other states across the United States (see Figure 3).
Data Collection

Recruitment Process

All participants signed informed consent documents before data collection began. A research summary was available for potential participants to learn more about the study prior to consent to participate (Appendix D). The procedures outlined below will clarify the processes used to recruit participants from each group.

Recruitment emails with a direct hyperlink to an Internet-based survey using Qualtrics software were sent to practitioners (See Appendix B). Two medical marketing companies were utilized to distribute recruitment emails to members of the American Academy of Pediatrics and IBCLCs in the United States who were members of the International Lactation Consultant Association. The recruitment emails contained a brief description of the study and a direct link to the survey website. When participants followed the survey hyperlink, they were directed to the consent form and explicitly asked if they were interested and willing to participate in the study. Participants were given the option to choose “yes” or “no.” Selecting “yes” confirmed their
consent to participate in the survey. If they chose “no” they were directed to a webpage that thanked them for their time and consideration. After providing consent, participants were asked to complete the surveys. Upon completion of the surveys, practitioner participants were offered the option to be entered into a drawing for a $125 Amazon.com gift card.

**Pediatrician Recruitment**

MMS Lists—Medical Marketing Service Inc was utilized to deliver pediatrician recruitment emails. A total of 6,371 emails were sent to pediatricians in two waves of disbursement (See Table 5). In December 2018, 3,384 total recruitment emails were sent to 511 pediatricians in Iowa and an additional 2,873 pediatricians across the United States. The subject line for Wave 1 emails was “Breastfeeding and Early Indicators of Autism Research Opportunity” In January 2019, a second wave of 2,987 total recruitment emails were sent to 468 pediatricians in Iowa and an additional 2,519 pediatricians across the United States. The subject line for Wave 2 emails was “Receive Amazon Gift Card for Autism Research Opportunity.” Additionally, the survey link and recruitment fliers were shared on social media, including Facebook and LinkedIn. Inclusion for pediatricians was limited to pediatricians who were either Doctor of Medicine (M.D.) or Doctor of Osteopathic Medicine (D.O.), American Board of Pediatrics certified, and provided health care services to infants and toddlers.

Table 5

<table>
<thead>
<tr>
<th>Pediatrician Email Analytics</th>
<th>Wave 1 Email N= 3,384</th>
<th>Wave 2 Email N= 2,987</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Region:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Iowa</td>
<td>511</td>
<td>468</td>
</tr>
<tr>
<td>United States</td>
<td>2873</td>
<td>2529</td>
</tr>
<tr>
<td><strong>Emails Opened:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Iowa</td>
<td>12.33% (N=63)</td>
<td>5.98% (N=28)</td>
</tr>
<tr>
<td>United States</td>
<td>18.1% (N=520)</td>
<td>7.78 % (N=196)</td>
</tr>
</tbody>
</table>
Table 5 continued

<table>
<thead>
<tr>
<th></th>
<th>Wave 1 Email N= 3,384</th>
<th>Wave 2 Email N= 2,987</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Viewing Engagement (Iowa)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Read</td>
<td>58% (N=37)</td>
<td>73.33% (N=)</td>
</tr>
<tr>
<td>Skimmed</td>
<td>29% (N=18)</td>
<td>26.67% (N=)</td>
</tr>
<tr>
<td>Glanced</td>
<td>13% (N=8)</td>
<td>0% (N=0)</td>
</tr>
<tr>
<td><strong>Viewing Engagement (United States)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Read</td>
<td>69% (N=359)</td>
<td>79.84% (N=)</td>
</tr>
<tr>
<td>Skimmed</td>
<td>20% (N=104)</td>
<td>12.10% (N=)</td>
</tr>
<tr>
<td>Glanced</td>
<td>11% (N=57)</td>
<td>8.06% (N=)</td>
</tr>
</tbody>
</table>

**Lactation Consultant Recruitment**

Marketing General Incorporated was utilized to deliver IBCLC recruitment emails. A single disbursement of 976 total emails was sent to IBCLCs who were members of the International Lactation Consultant Association. (See Table 6). Of the 976, 896 were successfully delivered with a 19.1% open rate and 5.5% following the survey link. Additionally, the survey link and recruitment fliers were shared on social media, including Facebook and LinkedIn.

Inclusion criteria for IBCLCs were as follows: International Board of Lactation Consultant Examiners certified; provided lactation support services to mothers and infants after being discharged from the hospital; areas of practice included clinic/birthing center/wards, community/public health/WIC clinics, government/military, home visits, hospital, physician's office, private practice, and volunteer support.

Table 6

*Lactation Consultant Email Analytics*

<table>
<thead>
<tr>
<th></th>
<th>IBCLC Email N= 976</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delivered</td>
<td>95.7% (N= 896)</td>
</tr>
<tr>
<td>Emails Opened:</td>
<td>19.1% (N= 171)</td>
</tr>
<tr>
<td>Undeliverable</td>
<td>4.3% (N=40)</td>
</tr>
<tr>
<td>Soft bounced</td>
<td>3.7% (N=35)</td>
</tr>
<tr>
<td>Hard bounced</td>
<td>0.53% (N=5)</td>
</tr>
<tr>
<td>Survey link clicked</td>
<td>5.5% (N=49)</td>
</tr>
<tr>
<td>Survey link not clicked</td>
<td>94.5% (N= 847)</td>
</tr>
</tbody>
</table>
Recruitment of Mothers of Children with ASD

The recruitment process for mothers of children with ASD included contacting ASD support group leaders, Area Education Agency (AEA) providers, and early interventionists via phone and email. A summary of the research process was discussed, and recruitment flyer, research summary, and a copy of the informed consent document was emailed to all contact persons who were willing to help recruit participants. Flyers were shared on Facebook support group pages, in person at early intervention agencies, and at local libraries. Based on prior data collection, this process increased the ability to find participants that fit the inclusion criteria for the qualitative data collection for this study (Dooley, 2017). A research summary was available for both a contact person and a potential participant to learn more about the study prior to consenting to participate or to sharing recruitment flyers. Semi-structured face to face interviews were conducted with mothers of children currently diagnosed with ASD.

The inclusion criteria for mothers to participate in this study included the following:
- Mother who had a child less than thirteen years of age who currently has a diagnosis of ASD, Asperger’s Syndrome, or Pervasive Developmental Disorder
- Breastfed their child for at least four weeks
- Sought help from a lactation consultant at least once while breastfeeding
- Had a pediatrician as the primary health care provider for their child with ASD
- Had a child with ASD who was born after 39 weeks gestational age and did not have other medical conditions that may have impacted feeding

Including participants who breastfed for at least four weeks allowed the study to capture the breastfeeding experience after a full milk supply was established but before most women returned to the workforce, to ensure that external factors were not influencing the breastfeeding relationship between mother and infant. Participants were required to be the primary caregiver of the child with ASD to best explore maternal experiences receiving professional support caring
for and feeding an infant who was 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 will provide an accurate portrayal of the breastfeeding behaviors of infants who are later diagnosed with ASD. Participants whose child was less than thirteen years of age will allow for recall of experiences from their child’s infancy to be more salient.

**Procedure**

Data collection from both mothers and practitioners occurred simultaneously. Recruitment emails and online fliers were sent to practitioners while recruitment fliers for mothers were dispersed in person, online, and to area agencies that provide autism support. Practitioners were able to immediately consent to participate and access the online surveys by following a link that was shared directly in the recruitment emails and listed on the fliers. Upon following the link, practitioners were provided informed consent information and required to acknowledge consent before being able to access the survey (See Appendix C).

**Mothers’ interview process**

Mothers who were interested in participating contacted the researcher via email or phone. Mothers were then sent individual emails describing the purpose of the study, inclusion criteria, 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. Before commencement of the interview, all participants signed the informed consent document. Semi-structured in-person interviews were conducted with mothers to collect detailed descriptive accounts of their lived experiences. The interviews took place between December 2018 and January 2019. Semi-
structured interviews were individually conducted with eight mothers in face-to-face environments such as a participant’s home, public school meeting room, or private meeting rooms at a public library. Before each interview began, 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 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 beginning the interview. After the informed consent document was read and any questions were answered, the participant was asked to sign the informed consent document.

Interviews began with demographic and health related questions, followed by a semi-structured interview (Appendix E). The interviews were 90 to 120 minutes in duration. The following is an example of interview questions in relation to the theoretical framework of this study and Research Question three that focused on maternal experiences seeking support (See Table 7).

<table>
<thead>
<tr>
<th>Related RQ or Framework</th>
<th>Example of Interview Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research Question 3</td>
<td>1. Did you seek assistance for breastfeeding? If so, who helped and what were the suggestions?</td>
</tr>
<tr>
<td></td>
<td>2. Tell me about the kind of support that you wanted and whether it was accessible.</td>
</tr>
<tr>
<td></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 you received.</td>
</tr>
</tbody>
</table>
Observational field notes were collected by the researcher during each interview to document each participant’s nonverbal responses, highlight important details, and connect participant responses to research questions (See Appendix H). All interviews were audio recorded for later transcription and analysis. A digital voice recorder was used to record each participant interview. Each interview was transcribed by a professional transcription service.

**Ethical considerations**

It is for researchers to make deliberate and intentional ethical decisions to protect participants when conducting research with human subjects. Ethical research practices require informed consent and careful planning to maintain and protect participant confidentiality during and after the research process. Participation in this research study was completely voluntary; therefore, it was essential to provide potential participants with information about the purpose of the study prior to data collection and respond to questions at any point during or after interviews were conducted. Once interviews were completed, multiple measures were taken to ensure the collected information was treated in a manner that ensured the rights and confidentiality of all participants were safeguarded.

**Informed consent**

Informed consent was a priority at all points of the research process. All quantitative data were collected from anonymous survey links. Practitioners who chose to be entered into the gift card drawing upon completion of the survey were redirected to a separate survey that did not link participant survey responses to contact information. To maintain transparency, all potential participants for the qualitative data collection received an emailed copy of the informed consent document as a part of the initial email contact. 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 were altered to maintain and protect participants’ confidentiality. All data were stored on password protected-devices and in separate locations to prevent unauthorized access to the data.

**Data Sources**

This study collected data from both mothers and practitioners; to best answer the research questions both qualitative and quantitative data were collected. This process entailed two distinct data sources and collection processes, one for the qualitative data strand and a different process for the quantitative data strand. Despite the different data sources and collection processes, both strands of data were collected simultaneously. Data collection took place over several months, with qualitative data reaching a point of saturation and finalization before quantitative data collection ceased. The order of data collection did not impact or inform data analysis. Qualitative data coding began before quantitative analysis was conducted, preventing the quantitative results from influencing qualitative analysis.

**Qualitative data**

A qualitative approach was utilized to examine mothers’ retrospective perceptions of their experiences. In-person interviews were utilized to collect detailed descriptive accounts of lived experiences. Additionally, in-person interviews provide an opportunity to clarify concepts, address information that needs further explanation, and delve deeper into the topics of interest. Interviews provide 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 (Creswell, 2013). Interviews provide researchers an opportunity learn about what cannot be obtained directly through survey results or observation
alone while providing participants an opportunity to explain their lived experiences (Glesne, 2011).

**Semi-structured maternal interviews**

Qualitative data were collected through in person semi-structured interviews with mothers who met all inclusion criteria. The semi-structured interviews examined mother’s experiences breastfeeding and raising infants later diagnosed with ASD, their experiences seeking help for their infants, receiving professional support, and demographic information (see Appendix E). The semi-structured interview allowed for flexibility to further explore topics of interest based on individual participant experiences. Each mother who participated received a $50 Walmart gift card.

Demographic information collected from mothers that included age, education, and marital status, as well as maternal medical history including but not limited to: length of pregnancy, maternal medical conditions associated with increased risk of giving birth to a child with ASD, number of pregnancies and births, breastfeeding experiences with other children, and medical conditions that may have impacted lactation. Mothers were asked if they experienced or were diagnosed with any of the following conditions: breast surgery, history of Cesarean section (C-section), flat or inverted nipples, absence of breast changes during pregnancy, and diagnosis of any hormonal disorder. Additionally, mothers were asked to report whether their child received any formula supplementation while in the hospital after birth, if there were any additional diagnosed medical disorders, and confirmation that their child was born after 39 weeks gestation.

**Quantitative data**

For the quantitative component of this study, practitioners were asked to complete an online survey consisting of three quantitative measures to assess knowledge of lactation and
early indicators of ASD, as well as a demographic questionnaire (See Appendix F). Participants completed the Breastfeeding Knowledge Survey (Freed et al., 1995), the Questionnaire about Breastfeeding Knowledge (Fernandez-Vegue & Orenga, 2015), and two sections from the Autism Knowledge, Beliefs, and Self-Efficacy Questionnaire (i.e. Knowledge about Early Autism Signs and Clinical Competence and Self Efficacy in the field of Autism; Atun-Einy & Ben-Sasson, 2014). In order to best answer the research questions while creating a manageable overall number of survey questions for practitioners, only two of the four parts of the Autism Knowledge, Beliefs, and Self-Efficacy Questionnaire were utilized.

**Demographic Questionnaire**

The demographic questionnaire for practitioners included questions regarding personal characteristics such as age, gender, ethnicity, and educational attainment. Each participant was asked to report their current job title, professional certifications, employment status, and years of practice. Pediatricians were asked to describe their practice style, choosing from community general pediatrician, academic general pediatrician, or pediatric hospitalist. IBCLCs reported the department in which they currently spend the most time. Each participant was asked to report whether they have children and any personal (or partner) breastfeeding experience.

**Breastfeeding Knowledge Survey**

To assess pediatricians’ training, personal views, experience, and knowledge of breastfeeding, the Breastfeeding Knowledge Survey was completed by pediatricians (Freed et al., 1995). This 22-item questionnaire measures breastfeeding knowledge, attitudes training, and experience. Five-point Likert scales were used for questions that addressed attitudes and beliefs allowing for a neutral response. Additional questions focused on breastfeeding guidance, intervention, and treatment of breastfeeding issues. For the breastfeeding treatment questions, a clinical vignette was utilized followed by treatment choices. The survey collects additional
retrospective information to report breastfeeding training including years of training, and personal (or partner) breastfeeding experience. Completion time for this survey is less than 15 minutes. This questionnaire explored pediatrician knowledge of breastfeeding, lactation specific training experiences, and attitudes specific to breastfeeding.

**Questionnaire about Breastfeeding Knowledge**

Additional data were obtained from both practitioner groups to assess knowledge and clinical skills related to providing care to breastfeeding mothers and infants. The Questionnaire about Breastfeeding Knowledge was developed to quantify practitioner breastfeeding knowledge and skills (Fernandez-Vegue & Orenga, 2015). It was not designed to encompass the entire range of breastfeeding knowledge, rather to quantify whether practitioners had basic knowledge required to support breastfeeding mothers. The survey consisted of 22 items including questions focused on education, knowledge, and experience (KR-20 = .87). The measure used dichotomous, multiple choice, and open-ended item responses. A maximum score of 26 points was possible. There were 14 dichotomous (true or false) items in this measure. Six of the items were multiple choice with an additional multiple-choice question that included an open-ended response option specific to reporting resources practitioners could use to look up medication compatibility during lactation and breastfeeding. The open-ended multiple-choice question was designed to measure a practitioner’s ability to obtain quick and reliable evidence-based information about drug and medication compatibility with breastfeeding. The remaining item was an open-ended question that asked for five characteristics of effective latching that could be used to evaluate successful breastfeeding; this item was scored based on the specificity of the response as well as accuracy. Correct responses on this item were scored based on the WHO breastfeeding observation form (WHO, 1993). Completion time for this measure was between 15 and 20 minutes. This questionnaire explored practitioner knowledge of breastfeeding.
Given that all items in this measure are dichotomous, either correct or incorrect, the Kuder-Richardson formula was utilized to determine the degree to which the individual items are related to each other and whether a global score is appropriate. Kuder-Richardson is an appropriate measure of internal consistency for a measure with binary variables, a KR-20 score above .7 is considered acceptable (Salkind, 2010; Streiner, 2010).

**Autism Knowledge, Beliefs, and Self-Efficacy Questionnaire**

To assess knowledge of early ASD signs and clinical skills related to ASD, the Autism Knowledge, Beliefs, and Self-Efficacy Questionnaire was completed by both practitioner groups (Atun-Einy & Ben-Sasson, 2014). This measure assessed practitioner knowledge of ASD and self-efficacy as a function of ASD experience. The survey covered the following four topic areas: (1) Knowledge and Beliefs about ASD; (2) Knowledge about Early Autism Signs; (3) Advanced Knowledge of Diagnostic Criteria For ASD; (4) Clinical Competence and Self-Efficacy in the field of Autism. Two of the four measures were utilized in this study: Knowledge about Early Autism Signs ($\alpha = 0.53$) and Clinical Competence and Self-Efficacy in the field of Autism ($\alpha = 0.69$).

**Knowledge about Early Autism Signs**

To assess pediatrician knowledge of early signs of ASD both practitioners completed this nine-item subscale. Agreement with each statement was rated on a 6-point Likert-type scale that ranged from one (strongly agree) to six (strongly disagree). Each item had an additional option to select the response “I have no specific knowledge.” The average score on this subscale reflected the respondent’s knowledge of early autism signs. Higher scores demonstrated greater knowledge of early indicators of ASD. In addition to the total score for this measure, a total score of items marked as “I have no specific knowledge” was calculated.
Clinical Competence and Self-Efficacy in the field of Autism

Both practitioner groups were asked to self-report their confidence regarding self-efficacy in clinical ASD skills. This subscale consisted of 14 items describing participants’ confidence in their ability to perform ASD screening, diagnose, consult with families, and provide intervention, and included items regarding awareness of community resources and need for increased training specific to ASD. Agreement with each statement was rated on a 4-point Likert-type scale that ranged from one (strongly agree) to four (strongly disagree). Higher scores reflected higher self-efficacy, eleven items were reverse scored to ensure the total score accurately represented self-efficacy.

Table 8

Summary of quantitative measurement tools

<table>
<thead>
<tr>
<th>Measurement tool</th>
<th>Breastfeeding</th>
<th>ASD</th>
<th>IBCLC</th>
<th>Pediatric</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breastfeeding Knowledge Survey</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Questionnaire about Breastfeeding Knowledge</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowledge about Early Autism Signs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical Competence and Self-efficacy in the field of Autism</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Data Analysis

This mixed methods research study used qualitative analytic processes concurrently with practitioner data collection. Data analyses included qualitative analysis using a descriptive phenomenological approach, quantitative analysis of practitioner surveys, and an integrated analysis of qualitative and quantitative data. Quantitative and integrated analytic processes began after practitioner data collection was completed. The multilevel concurrent mixed methods
research design allowed for multiple strands of simultaneous data collection and analysis creating a unique opportunity for a high degree of integration during analysis.

Although data were collected and analyzed concurrently, the detailed description of the analysis methods will be presented linearly. Qualitative data were collected, transcribed, and analyzed while online survey data were being collected. Qualitative analysis was completed in isolation of quantitative results. Quantitative data were downloaded from the online surveys and analyzed after 30 consecutive days with no additional new respondents to the survey. Neither strand of data collection nor analysis were prioritized; however, quantitative analysis was completed after qualitative themes were constructed to prevent the quantitative results from influencing the qualitative analytic process, followed by integrated analysis of both strands. Thorough exploration of the research questions required completion of data collection and analysis of each strand prior to data integration to ensure the integrity of the integrated analysis. The completed individual analysis of each strand helped to inform the integrated analysis through an iterative process of exploring both strands of data and results from individual strand analysis to explore the extent to which results converge or diverge. Figure 4 delineates the data collection and analytic process in relation to each research question.
Figure 4. Data collection and analytic process in relation to research questions.
Quantitative analysis

The focus of the quantitative data analysis was to address the two overarching quantitative research questions: 1.) What knowledge do practitioners have specific to lactation and early indicators of ASD? and 2.) Are there differences between IBCLC and pediatrician knowledge of lactation and early indicators of ASD? A main purpose of this exploratory study was to quantify practitioner knowledge; the quantitative analysis was intended to be descriptive as well as comparative between practitioner groups. Given that the measures used to answer these questions were primarily focused on knowledge assessment, a large portion of the quantitative analysis focused on describing the sample in addition to between group comparison of survey results.

To address the first and second research questions, total scores of the knowledge assessment measures were calculated for each group of practitioners. Independent group $t$ test and Mann-Whitney U test were utilized to determine if there were differences in scores of both knowledge of early indicators of ASD and breastfeeding between pediatricians and lactation consultants. The analysis explored practitioner knowledge by highlighting the similarities and differences between groups in relation to both topics.

Scoring and analysis of the Questionnaire about Breastfeeding Knowledge was based on a 20-item sub-scale specific to knowledge of breastfeeding including 14 true/false options and six multiple choice questions. Items 18 and 21 (see below) are open-ended questions and were analyzed separately for content and accuracy. The remaining items on the survey are specific to practitioner training, beliefs about breastfeeding, and confidence in providing care for breastfeeding mothers and infants. Based on prior analysis by author of the measure, scoring was classified into the following categories for interpretation: <55% very insufficient, 55-70%
insufficient, 70-85% good, and >85% excellent (Fernandez-Vegue & Orenga, 2015). The responses to the two open ended questions below were scored for accuracy:

Item 18: List 5 features of a correct latch you could use to assess a breastfeed

Item 21: A nursing mother asks you because she is going to begin treatment with adalimumab for Crohn’s disease. Her gastroenterologist has told her she should wean her 8-month-old baby because the treatment is important. Where could you look up if the drug is compatible or not with breastfeeding?

For item 18, broad or ambiguous responses, e.g. “lips” or “mouth posture” were not accepted. Participants were asked to be specific in just 2 or 3 words. A total of 5 points was possible for this item. Item 21 had a 5-item response option and included one open ended option that was scored for evidence-based, trustworthy websites that could be quickly accessed at a patient’s bedside, including Toxnet, LactMed, and Infant Risk Center cell phone applications.

The Knowledge about Early Autism Signs survey included nine items related to early ASD indicators. Scoring was based on participant agreement with each of the nine items and the measure had two additional open-ended questions. The nine items were rated on a 6-point Likert-type scale ranging from 1 (strongly agree) to 6 (strongly disagree) with an additional option for “I don’t have specific knowledge about this topic.” The average score reflected respondent’s knowledge. A score counting the number of times “I don’t have specific knowledge about this topic” was created.

Conventional content analysis was used to explore responses to the two open-ended questions below:

Item 10: What early signs in a baby under your care raise your concern for autism?

Item 11: In your opinion, which babies are at increased risk for autism?
Conventional content analysis is a qualitative analysis method used to analyze text data with a focus on the content or contextual meaning of the text to provide knowledge and understanding of a phenomenon of interest (Hsieh & Shannon, 2005). Data are systematically coded through a classification process to identify themes and patterns. Practitioner responses to each question were coded into labels based on key words or phrases. Once all responses were coded, codes were examined and organized into categories, and the final step was development of emergent themes based on how codes and categories were related and linked. In addition to development of themes, the codes were statistically analyzed to examine response rate frequency and allow for comparison between practitioner groups.

The Clinical Competence and Self-efficacy in the Field of Autism survey included 14 items describing the participant’s confidence in performing ASD screening, consulting with families, providing intervention, and the participant’s opinion of their own need for training and awareness of community resources for ASD. Items were rated from 1 (strongly agree) to 4 (strongly disagree). This measure included 11 reverse coded items to ensure that higher total scores meant higher self-efficacy.

Quantitative analysis was conducted using IBM SPSS Statistics 24. Before beginning analysis, data were cleaned, and items were reverse coded as necessary. To summarize the sample, descriptive statistics were generated. A summary score was calculated for each survey provided to both groups of practitioners, with the exclusion of the breastfeeding knowledge questionnaire (Freed et al., 1995) that only pediatricians answered. Data distribution and measures of central tendency were reviewed and revealed that only the summary score for the Knowledge about Early Autism Signs survey from the pediatrician group followed a normal distribution. Similarly, only the summary scores for Clinical Competence and Self-Efficacy in
the field of Autism had homogeneity of variance between groups. Therefore, to test if the distribution of summary scores, across all measures of practitioner knowledge, differed between groups of practitioners an Independent groups $t$ test with bootstrapping was utilized. The bootstrap distribution was corrected for bias (i.e. skew) and acceleration (i.e., lack of homogeneity of variance) using the Bias-Corrected and Accelerated Interval Methods (BCa).

**Missing data**

Before analyzing the quantitative survey data, an analysis of missing value patterns was conducted for each group of practitioners and each survey. Pediatricians had a 100% response rate for the Breastfeeding Knowledge and Skills Questionnaire whereas there was a single missing item response in the IBCLC group. During content analysis of open-ended questions in the Knowledge about Early Autism Signs measure, missing data were counted and compared with the total number of “no specific knowledge” responses to the remaining survey items. Two separate codes were created to distinguish missing data from participant responses indicating a lack of knowledge specific to the question. Two pediatricians did not complete the Clinical Competence and Self-efficacy in the field of Autism; they were excluded from analysis of that measure.

**Qualitative analysis**

The third research question was addressed using a descriptive phenomenology approach to qualitative analysis. The analytic process began upon completion of qualitative data collection. Interviews with participants were audio recorded and analyzed in conjunction with analytic memos and observational field notes. First, an external transcription service was utilized to transcribe each interview. Specific steps were taken to maintain participant anonymity and protect the confidentiality of each participant. The transcription service signed a nondisclosure agreement to protect the anonymity of participants. 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, to maintain the privacy of the participants, all discussion of locations, agencies, colleges or other places that could reveal a participant’s identity were replaced with pseudonyms or other fictitious representations. These modifications were applied before analysis began.

Based on the theoretical framework, transcriptions and field notes were analyzed to describe mothers’ lived experiences. Data were analyzed for emergent significant statements, recurring patterns, and themes. Using a descriptive phenomenological approach grounded in the research questions, conceptual codes of meaning units were developed, transformed into emergent descriptive statements, culminating in 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 5). 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).

The goal of descriptive phenomenology is to explore participants’ reports of their lived experiences utilizing phenomenological scientific reduction to reveal essential descriptions of a phenomenon (Giorgi, 2009). Phenomenological scientific reduction involves synthesizing the participants’ experiences to illuminate the lived reality of the phenomenon (Giorgi, 2009). The
main emphasis of descriptive phenomenology is on description, differing from other interpretative perspectives.

Before beginning analysis, transcripts were read in their entirety to ensure emerging codes and themes represented accurate descriptions. Each transcript was coded into meaning units using MAXQDA 2018 through a process of free imaginative variation. Coding using imaginative variation involves using varying frames of reference to approach a phenomenon from different perspectives resulting in the emergence of the essential structures of a phenomenon (Giorgi, 2009). Each meaning unit is considered a specific instance or example that is crucial to accurately describe the phenomenon of interest. Meaning units allow the data to be broken down into smaller manageable elements 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 sleeping habits and the following sentence may be discussing her family’s inability to have a care provider help during nap time 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 (see Figure 5).
Figure 5. Graphic representation of data analysis steps used to interpret results as detailed in the analysis description based on the descriptive phenomenology method.

Meaning units were then further analyzed into themes that provided a detailed descriptive summary to represent aspects of lived experiences essential to the general structure of the
phenomenon. This process was repeated across all transcripts; meaning units and themes were analyzed repeatedly 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 on Table 9.

Table 9
Summary of qualitative 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>“For the things that were behind, the doctor seemed encouraging like, “He'll catch up,” or “We'll see down the road.” It never was a, “Well, we need to watch that.” Which, I kind of wish it was, because then I think I would have picked up on the things a little bit sooner.</td>
<td>Doctor expressed belief that the developmental milestones would eventually be met, in an encouraging way and waiting for delayed milestones was appropriate. Developmental delays were not expressed as a concern. Mother felt that she would have noticed developmental delays sooner if she would have known what to look for.</td>
<td>Wait and See</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>Unaware of developmental differences</td>
</tr>
<tr>
<td>“I remember the doctor saying “Well, he's happy, and he's healthy, and you're doing a good job.”</td>
<td>Doctor reported that her child was in good health and happy. Doctor provided positive affirmations about mother’s parenting.</td>
<td>Practitioners primarily provide medical support</td>
</tr>
</tbody>
</table>
**Integrated analysis**

Integration during data analysis is one of several key components of mixed methods research, though integration can occur at other points in the research process such as at the design level, the methods level, and at the interpretation and reporting level (Fetters, Curry, & Creswell, 2013). Multilevel concurrent mixed methods design provides opportunities for a high degree of integration. For example, qualitative results and themes may suggest potentially unrealized exploratory analysis of quantitative data. Similarly, quantitative results may help frame a lens from within which to explore qualitative data to illuminate a deeper understanding of emergent themes. After conducting the individual analysis of each strand of data, a final mixed method integrated analysis was conducted. Several approaches to integration were utilized given that each source of quantitative data assessed unique aspects of practitioner knowledge.

The final research question was answered through integration of quantitative and qualitative data results, including item level analysis of practitioner knowledge to explore the impact of specific knowledge gaps on maternal experiences. Results of the content analysis from the quantitative measures were included in the integration across quantitative and qualitative data. Quantitative and qualitative data results were analyzed both separately and together for the integrated analysis. Upon completion of separate analysis of qualitative and quantitative data, the data were converged through comparison and contrast of the results. The qualitative data were examined to determine the degree to which the quantitative findings corroborate, expand on, or contradict results of the quantitative measures.

Results of the integration are disseminated using a narrative approach to describe the findings, an integrated data matrix, and joint displays to clarify the integration of results. Integrated analyses involved an iterative process that included reexamination of qualitative data
and themes with the quantitative results as a point of comparison, and similarly exploring quantitative results based on qualitative findings.

Categorical themes of items from quantitative surveys were developed based on topics, concepts, and content of survey items from the Knowledge about Early Autism Signs and Breastfeeding Knowledge and Skills Questionnaire (See table 10). Self-efficacy factors were used, in addition to the categories of breastfeeding knowledge and early ASD signs, for the integrative comparison between strands. Factors based on the psychometric evaluation of the Clinical Competence and Self-Efficacy in the Field of Autism survey were used as categorical themes for the integrated analysis. Factor results are presented below (Atun-Einy & Ben-Sasson, 2018).

1. Self-efficacy in ASD clinical skills (0.56–0.80; α=0.81), reflecting respondents’ confidence in performing ASD screening, diagnosis, and intervention.

2. Available resources (0.61–0.75; α=0.67), reflecting the respondents’ awareness of community resources for ASD.

3. Need for ASD training (0.62–0.87; r=0.36, p < .001), reflecting the respondents’ need for training.

4. Communicating with parents about their ASD concerns (0.73; r =0.14, p=.03), reflecting respondents’ confidence in performing family consultation.

Table 10:
Excerpts from categorical themes developed from quantitative surveys items and factors

<table>
<thead>
<tr>
<th>Categorical Theme</th>
<th>Measure</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breastfeeding Physiology</td>
<td>Questionnaire About Breastfeeding Knowledge</td>
<td>Breastfeeding in normal conditions, prematurity, extended breastfeeding</td>
</tr>
<tr>
<td>Breastfeeding Public Health</td>
<td>Questionnaire About Breastfeeding Knowledge</td>
<td>Official recommendations, risks of artificial feeding</td>
</tr>
<tr>
<td>Family History of ASD</td>
<td>Knowledge about Early Autism Signs</td>
<td>Family history of ASD, Parents with ASD, Siblings with ASD</td>
</tr>
<tr>
<td>Communicating with parents about their ASD concerns</td>
<td>Clinical Competence and Self-Efficacy in the Field of Autism</td>
<td>Respondents’ confidence in performing family consultation.</td>
</tr>
</tbody>
</table>

Table 10.
Integrated results were constructed from the convergence of qualitative data describing mothers’ experiences, practitioner survey responses, and themes from the content analysis, with associated categorical themes developed from the knowledge assessments. Convergence labels were used to explore the qualitative findings in relation to practitioner knowledge scores, themes from open ended question results, and self-efficacy factors. Convergence labels describe the relationship between the data collected from each strand. Convergence labels were used to explore and classify the alignment of qualitative and quantitative results (See Table 11).

Table 11. *Data convergence labels describing relationship between qualitative findings and quantitative results*

<table>
<thead>
<tr>
<th>Label</th>
<th>Definition</th>
</tr>
</thead>
</table>
| Confirm     | Positive alignment between results of each strand  
Both forms of data reveal the same information                                                                                  |
| Enhance     | Results from each strand of data do not confirm or contradict  
Provide different perspectives  
Reveal an improved general understanding of the phenomenon                                                                   |
| Mixed       | Results are neither contradicting nor confirming between strands  
Participants responses vary in respect to a given phenomenon                                                                     |
| Contradict  | Lack of agreement between results of both strands                                                                                     |
| Insufficient| Qualitative data were not available because participants did not have the opportunity to interact with practitioners in relation to a specific categorical theme |

Assigning of convergence labels began with development of a data matrix listing quantitative survey categories, qualitative codes, and convergence labels. The data matrix includes quantitative results for survey items that make up a topical survey category, including themes from the content analysis of practitioner responses to the open-ended survey questions. Upon completion of the organization of quantitative categorical themes within the matrix, transcripts from maternal interviews were analyzed to look for data that addressed the same topic. Qualitative data interview quotes, codes, and themes were identified and coded based on associated quantitative categorical themes. (See Table 12).
Table 12. *Excerpt from full data matrix*

Research Question 4: To what extent do maternal experiences seeking and receiving support from practitioners align with or diverge from practitioner knowledge of ASD and lactation?

<table>
<thead>
<tr>
<th>Associated Categorical Theme</th>
<th>Quantitative Data</th>
<th>Qualitative Data</th>
<th>Associated Qualitative Code Data</th>
<th>Convergence Label</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communicating with parents about their ASD concerns</td>
<td>Factor scores: Pediatrician (M = 3.29, SD = 0.57)</td>
<td>“I felt reassured, the doctor said “Oh, she's fine. She's growing just fine. She's learning other skills.” I get back home, and it was like but she's not fine. Look at her.”</td>
<td>Maternal knowledge of development: suspecting ASD</td>
<td>Contradict</td>
</tr>
<tr>
<td>Need for ASD training</td>
<td>Factor scores: Pediatrician (M = 2.54, SD = 0.33)</td>
<td>“I think the doctor was just more focused on the fact that her growth was great, and she was walking and sitting up and doing normal physical stuff not the delayed milestones.”</td>
<td>Atypical infant behavior: speech delay/ regression</td>
<td>Confirm</td>
</tr>
<tr>
<td>Breastfeeding Physiology</td>
<td>Babies should breastfeed every 2-3 hours for 15 minutes on each breast. Pediatrician: 22% correct (n = 5) IBCLC: 81% correct (n = 38)</td>
<td>“When we went to the lactation consultant the first time, it was supposed to be 15 minutes per side as both of us could tolerate.”</td>
<td>IBCLC: For health issues</td>
<td>Contradict</td>
</tr>
</tbody>
</table>

Upon completion of the data matrix, mixed methods coding was utilized to explore relationships between the quantitative and qualitative data. Each quantitative categorical theme was coded with a convergence label to describe the relation between and the associated qualitative and quantitative data at each point of convergence. The process of mixed methods coding was repeated across all categorical themes. The data convergence labels allowed for a
succinct summary of the extent to which maternal experiences seeking and receiving support from practitioners aligned with practitioner knowledge, confidence, and self-efficacy.

**Summary**

This chapter described the multilevel concurrent mixed methods research design and process utilized in this study. The goal of this study was to provide a deeper understanding of pediatricians’ and IBCLCs’ knowledge of infant feeding behaviors and early indicators of autism within the context of maternal experiences. The concurrent design allowed for data collection to occur expeditiously while still allowing for collection of rich data. The multilevel approach allowed for a novel exploration across ecological levels to identify practitioner strengths and knowledge gaps while illuminating the lived experiences of mothers seeking services for children with ASD. The sample included mothers of children with ASD and two practitioner groups, pediatricians and IBCLCs. The quantitative strand assessed practitioner knowledge of breastfeeding and early ASD signs as well as a self-efficacy measure related to clinical skills in the field of ASD. The qualitative strand described the lived experiences of mothers who breastfed infants later diagnosed with ASD and the events that occurred while seeking services for their children. The integration of both strands using merged data techniques that allowed for new insights through the convergence of both sources of data.
CHAPTER 4. FINDINGS

Overview

The purpose of this multi-level mixed methods study was to explore practitioner knowledge of ASD and lactation within the context of maternal experiences. This chapter presents key findings. The following results are presented in order of research questions, starting with results of the quantitative analyses used to answer Research Questions 1 and 2, followed by results of qualitative analysis used to answer Research Question 3, and the chapter ends with the integrated results addressing Research Question 4. Despite quantitative results being presented first, there is no priority given over qualitative results.

For this study, the distinction between practitioner groups was critical given that each practitioner played a unique role when providing services to mothers and infants. Pediatricians often have long term relationships with families with multiple visits occurring over time. However, IBCLCs may only meet with a breastfeeding dyad a single time, sometimes only providing services via phone. Unlike regularly scheduled health checks that occur during infancy, there is not a consistent protocol for regularly scheduled visits during the duration of breastfeeding nor is there a limit to the number of consultation visits a breastfeeding dyad can receive. Given the difference in practitioner interactions with a breastfeeding dyad, it is important to consider results from this study’s research aims. Despite the difference in time spent with breastfeeding dyads, each practitioner group has the potential to identify atypical patterns of behavior and connect families to resources. The quantitative data in this study described practitioner knowledge specific to both lactation and early indicators of ASD. Results of quantitative data will be delineated for each practitioner group for Research Questions 1 and 2.
Quantitative Results

The quantitative strand of this research was designed to assess and compare knowledge of lactation and early indicators of ASD between pediatricians and IBCLCs. Additionally, a measure of clinical self-efficacy was utilized to explore and compare practitioners’ confidence in performing ASD screening, diagnosis, family consultation, and intervention, as well as participants’ personal perspectives regarding their awareness of community resources for ASD and personal need for training. This section begins with a description of results of the survey data and results of tests of normality, followed by comparative analysis between practitioner groups.

Descriptive statistics

A total of 70 practitioners participated in this study. Only participants with complete data were included in the analysis. A total of 34 pediatricians began the online survey, with 23 pediatricians fully completing the survey. A total of 63 IBCLCs began the online survey, with 47 IBCLCs fully completing the survey. Pediatricians reported an average of 14.37 years ($SD = 9.96$) experience in practice, ranging from 1 to 34 years. IBCLCs reported an average of 10.20 years ($SD = 9.10$) experience in practice, ranging from 1 to 46 years (see Appendix I). IBCLCs reported a higher rate of personal breastfeeding experience, with 91.5% of IBCLCs having personal breastfeeding experience compared to only 60.9% of pediatricians. Only two of the IBCLCs reported they were part of a medical team that diagnoses children with ASD, whereas 70% of pediatricians reported being a part of a medical team that diagnoses children with ASD ($N = 16$).

Pediatrician experience

Pediatricians were asked to rate their beliefs regarding whether breastfeeding promotion is an important use of pediatrician time, using a four-point scale ranging from not important to very important. Almost half the pediatricians felt that breastfeeding promotion is a very
important use of pediatrician time (N = 11), nine pediatricians felt that breastfeeding promotion is an important use of time and three reported that breastfeeding promotion is only somewhat important. No pediatricians reported breastfeeding promotion was not important (See Table 13).

Table 13. Pediatrician attitudes regarding breastfeeding promotion (Percent agreement with statement)

<table>
<thead>
<tr>
<th>Pediatrics N= 23</th>
<th>Strongly disagree</th>
<th>Somewhat disagree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>It is the role of pediatricians to:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recommend breastfeeding to expectant mothers</td>
<td>4.3%</td>
<td>0</td>
<td>0</td>
<td>21.7%</td>
<td>73.9%</td>
</tr>
<tr>
<td>Assist breastfeeding mothers in the hospital</td>
<td>4.3%</td>
<td>4.3%</td>
<td>8.7%</td>
<td>56.5%</td>
<td>26.1%</td>
</tr>
<tr>
<td>Follow up breastfeeding issues after discharge</td>
<td>4.3%</td>
<td>0</td>
<td>4.3%</td>
<td>17.4%</td>
<td>73.9%</td>
</tr>
</tbody>
</table>

When asked to rate confidence in assisting post-partum women initiate breastfeeding on a four-point scale ranging from not confident to very confident, the largest number of pediatricians reported feeling somewhat confident (n=8) and seven reported feeling confident of their ability to effectively assist post-partum women initiate breastfeeding. Three pediatricians reported not feeling confident in their ability to assist post-partum women initiate breastfeeding, whereas only five pediatricians reported feeling very confident in their ability to effectively assist post-partum women in initiating breastfeeding.

Pediatricians were asked to rate how well their residency program prepared them to support breastfeeding mothers on a five-point scale ranging from no preparation to excellent preparation. Over half the pediatricians reported they received less than adequate preparation to support breastfeeding mothers (n=12) and three reported having no preparation during their residency. Four pediatricians reported having adequate preparation, two pediatricians felt they
had good preparation, and two reported feeling their residency provided excellent preparation for supporting breastfeeding mothers.

Pediatricians were asked to reflect on their experiences specific to breastfeeding and providing support to mothers in the past year (See Table 14). The majority of pediatricians reported counseling an expectant or newly delivered mothers about infant feeding choices five or more times in the past year. Regarding providing direct breastfeeding support, 73.9% of pediatricians reported observing a mother breastfeeding in a hospital or office setting five or more times in the past year. Almost half of the pediatricians reported teaching mothers a new breastfeeding technique in the past year (e.g. latching on or infant placement at the breast while feeding), and 60.9% reported counseling a mother about lactation problems. The majority of pediatricians reported they had not taught a mother how to use a breast pump.

Table 14.

<table>
<thead>
<tr>
<th>Pediatrician experiences providing support to breastfeeding mothers in the past year</th>
<th>Never</th>
<th>Once or Twice</th>
<th>Three or four times</th>
<th>Five or more times</th>
</tr>
</thead>
<tbody>
<tr>
<td>N= 23</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Observed a patient breastfeeding in a hospital or office setting</td>
<td>0</td>
<td>8.7%</td>
<td>17.4%</td>
<td>73.9%</td>
</tr>
<tr>
<td>Counseled an expectant or newly delivered mother about infant feeding choices</td>
<td>0</td>
<td>17.4%</td>
<td>8.7%</td>
<td>73.9%</td>
</tr>
<tr>
<td>Taught a new mother breastfeeding technique (e.g. latching on, infant placement)</td>
<td>13%</td>
<td>21.7%</td>
<td>17.4%</td>
<td>47.8%</td>
</tr>
<tr>
<td>Taught a breastfeeding mother how to use a breast pump</td>
<td>39.1%</td>
<td>13%</td>
<td>21.7%</td>
<td>26.1%</td>
</tr>
<tr>
<td>Counseled a breastfeeding mother about lactation problems (e.g. mastitis, cracked nipples)</td>
<td>0</td>
<td>21.7%</td>
<td>17.4%</td>
<td>60.9%</td>
</tr>
</tbody>
</table>
Research Question 1

To answer Research Question 1 examining practitioner knowledge of lactation and early indicators of ASD, total scores for each knowledge assessment were calculated with higher scores reflecting greater knowledge. Additionally, a score for the self-efficacy measure was calculated to explore practitioners’ confidence in ASD screening, diagnosis, family consultation, and intervention. Similar to the knowledge assessments, higher scores on the measure of self-efficacy reflect higher self-efficacy. A mean score was created for both ASD measures based on participant responses. Means, standard deviations, and minimum and maximum scores for each of the measures are provided on Table 15.

Table 15.
Scores on quantitative measures used in this study

<table>
<thead>
<tr>
<th>Measure</th>
<th>Pediatricians</th>
<th>IBCLCs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N= 23</td>
<td>N=47</td>
</tr>
<tr>
<td>Breastfeeding Knowledge</td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td></td>
<td>17</td>
<td>4.71</td>
</tr>
<tr>
<td>Knowledge of Early Autism Signs</td>
<td>4.19</td>
<td>0.73</td>
</tr>
<tr>
<td>Clinical Self-efficacy in ASD</td>
<td>3.08</td>
<td>0.39</td>
</tr>
</tbody>
</table>

Breastfeeding knowledge

The Questionnaire about Breastfeeding Knowledge was used to assess practitioner knowledge and skills specific to breastfeeding. Both groups of practitioners completed the online survey. Total scores of breastfeeding knowledge were calculated based on correct answers to the questionnaire, with a maximum score of 26 possible points. The purpose of the questionnaire was to quantify whether practitioners had basic knowledge required to support breastfeeding mothers. A total score was created based on participant responses to quantify practitioner knowledge and basic skills specific to supporting breastfeeding mothers. Higher scores represent
greater knowledge and skills specific to breastfeeding and providing support to breastfeeding dyads.

None of the pediatricians in this sample scored the maximum possible for breastfeeding knowledge, however, two IBCLCs scored the maximum total points possible. IBCLCs had an average total score of 23.43 on breastfeeding knowledge ($SD = 1.77$) whereas the pediatricians’ average breastfeeding knowledge total score was 17 ($SD = 4.71$) (See Figure 6).

![Figure 6. Breastfeeding knowledge total scores by practitioner group.](image)

Scoring for breastfeeding knowledge was further classified into four categories for easier interpretation: <55% very insufficient, 55-70% insufficient, 70-85% sufficient, $\geq$85% excellent (Fernández-Vegue & Orenga, 2015). The majority of IBCLCs scored excellent knowledge of breastfeeding, with 87.2% ($n=41$) of IBCLCs having a total score of 85% or greater. The remaining six IBCLCs total scores ranged between 70-85% demonstrating sufficient breastfeeding knowledge and one scored in the 55-70% insufficient range. In this sample, slightly more than half the pediatricians had sufficient breastfeeding knowledge ($n=12$). Only
three pediatricians had scores high enough to represent excellent knowledge of breastfeeding. Nine pediatricians had scores between 70-85%, representing sufficient knowledge. Two pediatricians had scores between 55-70% representing insufficient knowledge and nine had scores that were 55% or less representing insufficient breastfeeding knowledge (See Figure 7).

**Figure 7.** Breastfeeding knowledge scores shown as knowledge classifications

The majority of pediatricians in this study were community general pediatricians (n=17); there were five academic general pediatricians and one pediatric hospitalist. In the sample of community general pediatricians, 41% (n = 7) had scores representing sufficient breastfeeding knowledge. Only two community general pediatricians had excellent breastfeeding knowledge. Two community general pediatricians had scores between 55-70% representing insufficient knowledge. The remaining six pediatricians had scores that were 55% or less representing very insufficient breastfeeding knowledge. There were five academic general pediatricians who participated in this study, 40% (n=2) had scores representing sufficient breastfeeding knowledge.
Only one academic general pediatrician scored above 85% representing excellent breastfeeding knowledge. Two academic general pediatricians had scores between 55-70% representing insufficient knowledge. There was only one pediatric hospitalist in this study with a score less than 55% representing very insufficient breastfeeding knowledge (See Figure 8).

![Breastfeeding knowledge scores shown as knowledge classifications based on pediatric practice style](image)

*Figure 8.* Breastfeeding knowledge scores shown as knowledge classifications based on pediatric practice style

**Knowledge about Early Autism Signs**

Practitioner knowledge specific to early indicators of ASD and early risk factors was assessed using the Knowledge about Early Autism Signs measure. Mean scores were calculated for both groups of practitioners, with a maximum score of six. Pediatricians’ total mean knowledge score of early indicators of ASD was 3.39 ($SD = 0.18$) and IBCLCs total mean score was 2.99 ($SD = 1.59$) (See Figure 9).
In the pediatrician group, items “Autism can be diagnosed as early as 24 months” \((M = 5.13, SD = 1.12)\), “The need for sameness and difficulty coping with transitions between activities are one of the early behavioral features of autism” \((M = 5.13, SD = 0.87)\), and “Delays in attaining motor milestones such as sitting and walking are not a necessary sign for autism” \((M = 5, SD = 0.853)\), had the highest mean score. The items “Increased head circumference relative to age is an early sign for autism” \((M=2.52, SD = 1.83)\), “Premature babies have higher risk of autism” \((M = 3.57, SD = 1.754)\), and “Most children with autism under the age of four can draw their parent’s attention to an interesting event such as a street clown” \((M = 3.57, SD = 1.59)\) had the lowest mean score.

In the IBCLC group, items “The need for sameness and difficulty coping with transitions between activities are one of the early behavioral features of autism” \((M = 4.13, SD = 2.16)\), “Delays in attaining motor milestones such as sitting and walking are not necessary sign for autism” \((M = 3.72, SD = 2.26)\), and “Some children with autism show typical global development until the age of one and a half \((M = 3.68, SD = 2.18)\) had the highest mean scores. Similar to the pediatrician group, the lowest scoring items for IBCLCs were as follows:
“Increased head circumference relative to age is an early sign for autism” (M = 1.17, SD = 1.71),
“Most children with autism under the age of four can draw their parent’s attention to an
interesting event such as a street clown” (M = 2.28, SD = 2.01) and “Premature babies have
higher risk of autism” (M = 2.49, SD = 2.44).

There were only three items about which pediatricians reported “having no specific
knowledge,” though all three had a fairly low response percentage: “Increased head
circumference relative to age is an early sign for autism” (17.4%), “Early developmental
regression autism can occur up to the age of three years” (13%), and “Premature babies have
higher risk of autism” (8.7%). In the IBCLC group, each item had at least nine participants
reporting they had “no specific knowledge,” The same three items from the pediatrician group
were most frequently reported as “having no specific knowledge”, though at a higher response
frequency. “Increased head circumference relative to age is an early sign for autism” had the
most frequent “no specific knowledge” response (61.7%). The second most common item for
which IBCLCs reported “having no specific knowledge” was “Early developmental regression
autism can occur up to the age of three years” (44.7%), followed by “Premature babies have
higher risk of autism” (42.6%).

**Clinical Competence and Self-Efficacy in the field of Autism**

Practitioner confidence in their ability to screen for ASD, provide diagnosis, family
consultation and treatment was rated through self-report using the Clinical Competence and Self-
Efficacy in the field of Autism measure. Participants were asked to rate how each item described
their confidence in performing clinical tasks related to ASD screening, intervention and
consultation. Items were rated on a four-point scale ranging from *strongly agree* to *strongly
disagree*. Higher scores represented higher confidence. Two pediatricians did not respond to any
questions on the self-efficacy scale; therefore, the sample size for pediatricians for this measure
was 21 and 47 IBCLCs. Mean self-efficacy for pediatricians was 3.08 (SD = 0.39) and 2.08 (SD = 0.57) for IBCLCs (See Figure 10.)

![IBCLC and Pediatrician Self-Efficacy Scores](image)

**Figure 10.** Frequency of total mean clinical self-efficacy in autism scores by practitioner group.

A factor analysis was conducted using pediatricians and IBCLCs responses independently to determine underlying factors within the self-efficacy measure. Several variables in each group had a correlation coefficient less than 0.3, indicating the data from this sample was not likely to be factorizable. A principal factor analysis failed to reveal components similar to the author’s factor solution for the original measure, likely due to the small sample size. Despite this limitation, factor scores were created based on the scale authors’ recommendations (Atun-Einy & Ben-Sasson, 2018). Mean factor scores were created for each practitioner group based on the following four factors: 1) Self-efficacy in ASD clinical skills, 2) Available resources, 3) Need for ASD training, and 4) Communicating with parents about their ASD concerns (See Table 16). Pediatricians’ highest mean score was for the self-efficacy in ASD clinical skills factor at 3.30 out of four (SD=0.70) and the lowest mean factor score was in the need for ASD training factor (M=2.54, SD=0.33). IBCLCs highest mean score was for the knowledge of available resources factor at 2.46 out of four (SD=0.70) and, similar to the pediatrician group, the lowest mean score
was in the need for ASD training factor (M=1.70, SD=0.56). The majority of IBCLCs reported they could benefit from training in the area of ASD (34%) whereas only 6% of pediatricians reported the need for additional training. Over half of pediatricians (53.4%) reported feeling comfortable and confident discussing early warning signs of ASD with parents. However, only 10.6% of IBCLCs reported feeling comfortable and confident discussing early warning signs of ASD with parents and 46.8% reported they were not comfortable or confident discussing early warning signs of ASD with parents.

Table 16.  
*Mean Factor scores for Clinical Self-efficacy in ASD*

<table>
<thead>
<tr>
<th></th>
<th>Pediatricians</th>
<th>IBCLCs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N= 21</td>
<td>N=47</td>
</tr>
<tr>
<td></td>
<td>M    SD    Min  Max</td>
<td>M    SD    Min  Max</td>
</tr>
<tr>
<td>Self-efficacy in ASD clinical skills</td>
<td>3.27 0.62 1.60 4</td>
<td>1.98 0.82 0.75 4</td>
</tr>
<tr>
<td>Available resources</td>
<td>3.06 0.52 2  4</td>
<td>2.46 0.70 1  4</td>
</tr>
<tr>
<td>Need for ASD training</td>
<td>2.23 0.30 1.50 2.5</td>
<td>1.70 0.56 1  3</td>
</tr>
<tr>
<td>Communicating with parents about their ASD concerns</td>
<td>3.29 0.57 1.75 4</td>
<td>2.18 0.70 1  4</td>
</tr>
</tbody>
</table>

**Research Question 2**

To answer Research Question 2, exploring differences between IBCLC and pediatrician knowledge of lactation and early indicators of ASD, independent-samples *t* test and Mann-Whitney U test were used to compare between groups scores from assessment measures.

**Tests of normality**

To compare knowledge between practitioner groups, the initial step of analysis involved testing for normality of data for each group and across all three knowledge assessment measures. An additional test of normality was conducted for the total score of participants “I don’t have specific knowledge about this topic” responses to the *Knowledge about Early Autism Signs*
survey. Skewness is a measure of the asymmetry of the distribution of a variable, an absolute skew value of >2.1 represents a substantial departure from normality (Kim, 2013). Kurtosis measures the distribution peakedness of data within a sample, an absolute kurtosis value of >7.1 represents a substantial departure from normality (Kim, 2013). However, sample size impacts the accuracy of interpretation; therefore, interpretation of tests of normality differ according to sample size. When using skewness and kurtosis to test for normality within a small sample, a z-test is applied. Z scores are created by dividing the skew and kurtosis values by their standard errors. For small samples (n < 50), if absolute z-scores for either skewness or kurtosis are larger than 1.96 (α = 0.05), the distribution of the sample is considered non-normal.

Breastfeeding knowledge scores from pediatricians were normally distributed with a skewness of -0.16 (SE = 0.48) and kurtosis of -1.574(SE = 0.96). However, the breastfeeding knowledge scores from IBCLCs were not normally distributed with a skewness of -1.16 (SE= 0.35) and kurtosis of 1.33(SE = 0.69). Breastfeeding knowledge scores were not normally distributed for either group of practitioners, as assessed by Shapiro-Wilk's test (p < .05).

Knowledge of early indicators of autism signs mean scores were normally distributed for pediatricians with a skewness of -1 (SE = 0.29) and kurtosis of 0.35 (SE = 0.57) and for IBCLCs with a skewness of -0.65 (SE = .35) and kurtosis of -0.57(SE = -0.68). Early indicators of autism signs knowledge scores were normally distributed for pediatricians but not for IBCLCs, as assessed by Shapiro-Wilk’s test (p < .05).

Clinical self-efficacy in ASD scores from pediatricians were not normally distributed with a skewness of -0.68 (SE= 0.50) and kurtosis of 0.1 (SE = 0.97). The self-efficacy scores from IBCLCs were not normally distributed with a skewness of 1.040 (SE= 0.35) and kurtosis of
0.25 ($SE = 0.68$). Clinical self-efficacy in ASD scores were not normally distributed for either group of practitioners, as assessed by Shapiro-Wilk's test ($p < .05$).

The total number of participants “I don’t have specific knowledge about this topic” responses to the *Knowledge about Early Autism Signs* survey scores from pediatricians were not normally distributed with a skewness of 2.26 ($SE = 0.48$) and kurtosis of 5.131 ($SE = 0.94$). Self-efficacy scores from IBCLCs were normally distributed with a skewness of 0.848 ($SE = 0.35$) and kurtosis of -0.545 ($SE = 0.68$). The total scores of participants “I don’t have specific knowledge about this topic” responses to the *Knowledge about Early Autism Signs* survey were not normally distributed for either group of practitioners, assessed by Shapiro-Wilk's test ($p < .05$).

There were four outliers, in the IBCLC group, whose scores were higher than the majority of other scores and one extreme outlier below the other scores in the pediatrician group for the *Competence and Self-Efficacy in the field of Autism* measure. Similarly, there was one outlier and one extreme outlier in the total amount of “no specific knowledge” responses for the pediatrician group. Additionally, there were two outliers in the IBCLC group that scored lower than the majority of others on the breastfeeding knowledge measure. A comparative analysis was run with and without outliers included in the datasets resulting in statistically significant results for both analyses, therefore outliers were not removed from the dataset.

**Between-group comparisons**

The independent-samples $t$ test is used to determine if a statistically significant difference exists between the means of two independent groups (Kim, 2015). Independent $t$ tests are utilized when two groups being compared are independent of each other (Kim, 2015). An essential requirement for independent $t$ tests is no relationship between groups. Given that participants were only allowed to be in one group or the other, the groups remained completely independent. There were no IBCLCs who were also pediatricians and, similarly, there were no pediatricians
who were also IBCLCs. An independent samples $t$ test was run to compare scores on all measures between pediatricians and IBCLCs. There were 23 pediatricians and 47 IBCLCs in the sample, however, only 21 completed the Competence and Self-Efficacy in the field of Autism measure.

The Mann-Whitney U test is a rank-based test used to determine differences between two groups that is often used as the nonparametric alternative to the independent samples $t$ test (McKnight & Najab, 2010; Ruxton, 2006). However, the Mann-Whitney U test is not equivalent to the independent samples $t$ test but rather a test that can explore differences in the distributions or medians of two groups. The Mann Whitney U test ranks each participant score, irrespective of the group, according to size and creates a matching rank order from smallest to largest value, with the smallest value being assigned the smallest rank continuing across all scores. The distribution scores of both independent variables determines whether differences in distributions or medians are being measured. Based on results of normality testing and distribution of the data in each practitioner group, independent group $t$ test to compare mean scores and Mann-Whitney U tests to determine differences in distributions were utilized.

**Questionnaire about Breastfeeding Knowledge**

An independent samples $t$ test was conducted to compare total scores of the Questionnaire about Breastfeeding Knowledge between practitioner groups even though the assumption of homogeneity of variances was not met for total scores of breastfeeding knowledge, as assessed by Levene’s test for equality of variances ($F(68)= 69.56, p<.001$). There was a significant mean difference in the scores between IBCLCs and pediatricians, $t(25.08)= 6.33, (p<.001), d=2.12$ (See table 17). IBCLCs had higher breastfeeding knowledge total scores compared to pediatrician total scores.
Table 17.  
**Comparison of breastfeeding knowledge assessment scores between practitioner groups**

<table>
<thead>
<tr>
<th>Measure</th>
<th>Mean (SD) Pediatrics N=23</th>
<th>Mean (SD) IBCLCs N=47</th>
<th>Mean difference (95% CI)</th>
<th>T (df)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breastfeeding Knowledge</td>
<td>17 (4.71)</td>
<td>23.43 (1.77)</td>
<td>6.43 (4.3, 8.52)</td>
<td>6.33</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

*Note. Higher total scores represent greater breastfeeding knowledge.*

A Mann-Whitney U test was run to determine if there were differences in total scores of breastfeeding knowledge between pediatricians and IBCLCs. Distributions of the mean scores of breastfeeding knowledge for pediatricians and IBCLCs were not similar as assessed by visual inspection. Total scores of breastfeeding knowledge for IBCLCs (mean rank = 45.67) were statistically significantly higher than for pediatricians (mean rank = 14.72), $U = 62.5$, $z = -6.022$, $p<.001$. (See Figure 11)

![Figure 11](image)

*Figure 11. Population pyramid of practitioner score distributions for breastfeeding knowledge.*

**Knowledge about Early Autism Signs**

An independent samples $t$ test was conducted to compare mean scores of the Knowledge about Early Autism Signs measure between practitioner groups. Levene’s test indicated unequal variances ($F (68) = 13.54$, $p<.001$). There was a statistically significant difference in the scores
between pediatricians and IBCLCs, *t*(67.85) = 4.3, (*p* < .001). Pediatricians’ mean knowledge scores of early autism signs were higher than the IBCLCs’ mean knowledge scores of early autism signs (See Table 18).

Total scores of participants “I don’t have specific knowledge about this topic” responses to the Knowledge about Early Autism Signs were calculated. The assumption of homogeneity of variances was not met for not having “specific knowledge” of early ASD signs responses, as assessed by Levene’s test for equality of variances (*p* < .001). IBCLCs were more likely to report lack of knowledge of early autism signs (*M* = 2.98, *SD* = 3.12) compared to pediatricians (*M* = 0.39, *SD* = 0.78). There was a significant difference in the response rate between pediatricians and IBCLCs *t*(56.65) = 5.36, (*p* < .001), *d* = 1.01. IBCLCs had a higher number of total “no specific knowledge” responses compared to the total number of responses from pediatricians (see Table 18).

### Table 18.
Comparison of knowledge of early ASD signs mean scores between practitioner groups

<table>
<thead>
<tr>
<th>Measure</th>
<th>Mean (SD)</th>
<th>Mean difference (95% CI)</th>
<th><em>T</em> (df)</th>
<th><em>p</em></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pediatricians N=23</td>
<td>IBCLCs N=47</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowledge of Early ASD Signs</td>
<td>4.19 (0.73)</td>
<td>2.99 (1.59)</td>
<td>1.15 (0.5, 1.70)</td>
<td>4.16 (67.75)</td>
</tr>
<tr>
<td>“No knowledge” response total</td>
<td>0.39 (0.78)</td>
<td>2.98 (3.12)</td>
<td>2.59 (1.62, 3.56)</td>
<td>5.36 (56.65)</td>
</tr>
</tbody>
</table>

*Note. Higher mean scores of Early ASD Signs represents greater knowledge of early ASD signs.*

A Mann-Whitney U test was run to determine if there were differences in mean scores of knowledge of early ASD signs between pediatricians and IBCLCs. Distributions of the mean knowledge of early ASD signs for pediatricians and IBCLCs were not similar as assessed by visual inspection. Mean scores of knowledge of early ASD signs for pediatricians (mean rank =
45.85) were statistically significantly higher than for IBCLCs (mean rank = 30.44), $U = 778.5$, $z = 2.979$, $p < .001$ (See Figure 12).

![Figure 12. Population pyramid of practitioner score distributions for Knowledge of Early ASD Signs](image)

An important aspect of the Knowledge of early ASD signs measure is to calculate the total number responses that participants selected having “no specific knowledge”. A Mann-Whitney U test was run to determine if there were differences in mean scores of the total number of items for which participants reported having “no specific knowledge” of early ASD signs between practitioner groups. Distributions of the total number of items that participants reported having “no specific knowledge” of early ASD signs for pediatrics and IBCLCs were not similar based on visual inspection. Total number of items that participants reported having “no specific knowledge” of early ASD signs for pediatrics (mean rank = 22.76) were statistically significantly lower than for IBCLCs (mean rank = 41.73), $U = 247.5$, $z = -3.862$, $p < .001$ (see Figure 13).
Clinical Competence and Self-Efficacy in ASD

An independent samples \( t \) test was conducted to compare mean scores of the Clinical Competence and Self-Efficacy in the field of Autism measure between practitioner groups. There was homogeneity of variances for mean scores between groups, as assessed by Levene’s test for equality of variances \((p=.14)\). Pediatricians mean scores \((M=3.08, SD=0.39)\) were higher compared to IBCLCs \((M=2.08, SD=0.56)\). There was a significant difference in the mean scores between pediatricians and IBCLCs, \(t(66) = 7.33, (p<.001), d = 1.97\) (See Table 19).

Table 19.
Comparison of self-efficacy mean scores between practitioner groups

<table>
<thead>
<tr>
<th>Measure</th>
<th>Mean (SD)</th>
<th>Mean difference (95% CI)</th>
<th>( t ) (df)</th>
<th>( p )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatricians N=21</td>
<td>IBCLCs N=47</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical Self-efficacy in ASD</td>
<td>3.08 (0.39)</td>
<td>2.08 (0.56)</td>
<td>1.00 (0.72, 1.27)</td>
<td>7.33 (66)</td>
</tr>
</tbody>
</table>

Note. Higher mean scores represent higher self-report of self-efficacy in the field of ASD

A Mann-Whitney U test was run to determine if there were differences in mean scores on clinical self-efficacy in ASD between pediatricians and IBCLCs. Distributions of the mean scores of clinical self-efficacy for pediatricians and IBCLCs were not similar as assessed by

**Figure 13.** Population pyramid of practitioner score distributions for number of items participants reported having “no specific knowledge” of early ASD signs.
visual inspection. Mean scores of clinical self-efficacy for pediatricians (mean rank = 53.50) were statistically significantly higher than for IBCLCs (mean rank = 26.01), $U = 892.50$, $z = 5.30$, $p < .001$ (See Figure 14).

![Figure 14. Population pyramid of practitioner mean score distributions for Clinical Competence and Self-Efficacy in the field of Autism](image)

**Qualitative Results**

This section provides key findings from the qualitative analyses conducted in this study. Two sets of qualitative data were collected: data from face to face interviews with mothers and data collected from open ended online practitioner survey questions. Each data set was analyzed separately. Maternal data were coded using a descriptive phenomenological approach and practitioner data were coded using conventional content analysis.

**Maternal interviews**

Guided by bioecological theory, categories and themes were developed to describe the general structure of mother’s experiences. The qualitative analytic process involved refining meaning units into descriptions; therefore, the emergent themes were not a summary of unique experiences of each participant but rather a descriptive representation of experiences receiving professional support caring for and feeding infants later diagnosed with ASD. The participants did not have a singular unified experience that can be directly translated into a summary. The
manifestation of ASD symptoms can vary greatly among individuals, leading to a wide variety of unique experiences mothers face when attempting to receive professional support caring for and feeding infants 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. Four themes emerged from the data analysis to form the general structure of mothers’ experiences breastfeeding an infant later diagnosed with ASD (see Table 20):

1. **Breastfeeding as an Intervention:** Breastfeeding was used to manage atypical or challenging behaviors to calm, comfort, and soothe their infant.

2. **Unaware of developmental differences:** Participants were unaware that certain feeding and other behaviors occurring during their child’s infancy were atypical.

3. **Wait and see practitioner approach:** Participants reported that practitioners waited for atypical behaviors or developmental delays to resolve over time before suggesting a referral for further developmental assessment.

4. **Practitioners primarily provide medical support:** Participants primarily sought services from practitioners for medical or health-related issues, as opposed to seeking advice specific to observed atypical feeding or other behaviors.
Table 20
Four themes of mother’s experiences receiving professional support caring for and feeding infants later diagnosed with ASD.

<table>
<thead>
<tr>
<th>Breastfeeding as Intervention</th>
<th>Unaware of developmental differences</th>
<th>Wait and see practitioner approach</th>
<th>Practitioners primarily provide medical support</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Soothe, calm, and comfort</td>
<td>• Not aware of atypical feeding behaviors</td>
<td>• Delays in addressing developmental delays or concerns</td>
<td>• Practitioners focus on growth and weight gain</td>
</tr>
<tr>
<td>• Manage challenging infant behaviors</td>
<td>• Atypical behaviors were not reported to practitioners during infancy</td>
<td>• Hesitant to make referrals for development</td>
<td>• Mothers seek healthcare for medical/health issues</td>
</tr>
<tr>
<td>• Consistently effective strategy</td>
<td>• More than solely a source of nutrition</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Theme 1: Breastfeeding as an Intervention

The relationships between mother and infant, in the context of the breastfeeding relationship, are complex and multifaceted. Atypical infant behaviors can impact multiple aspects of infant feeding. It is essential to understand the complexity of the breastfeeding relationship within the context of family and social support networks. This theme was explored from the unique perspective of the breastfeeding dyad. Similar to findings from prior exploration of the experiences of mothers who breastfed infants later diagnosed, the majority of participants reported that breastfeeding was used to manage atypical or challenging behaviors to calm, comfort, and soothe their infant (Dooley, 2017). When breastfeeding was used as an intervention to manage challenging atypical behaviors during infancy, the frequency of feedings tended to increase. One participant said: “He actually nursed really well. It was very soothing to him. It kind of felt like ‘homework’ because he was a very colicky kid, it was hard to soothe him unless he was breastfeeding. Breastfeeding and baby wearing were the things that really, really, really soothed him. So, we leaned heavily on breastfeeding… we relied on breastfeeding to soothe him.”
Of the eight participants, all but one of the mothers specifically described how quickly breastfeeding would calm their infants, when they were not necessarily hungry. Most indicated that breastfeeding was the fastest and most consistent way to calm their infant: “He would be upset, and breastfeeding would calm him down instantly.”

Several mothers equated frequent feeding to hunger or insufficient milk supply. However, they reported their perceptions of hunger were trivial when compared to the importance of being able to calm and comfort their infant by breastfeeding. Six mothers reported they were not aware of whether their infant was crying due to hunger, and four reported wondering if their child’s crying or fussiness was due to insufficient milk supply. The mothers would breastfeed in response to their infant crying as the only option to settle fussiness. One subject shared, “Maybe it was that she was crying so much that I felt like I was putting her on my breast like every half hour.”

While three of the mothers reported that they felt comfortable with the frequency of feeding and believed breastfeeding was a soothing intervention for their infants, the other five mothers expressed exasperation at not knowing how to meet their infant’s needs, and frustration that breastfeeding was the only resource they had to comfort their infant. However, during their children’s infancy, none of the mothers recall making a connection between using breastfeeding as a strategy to manage atypical behaviors. Instead, the focus was on the benefit of having at least one caregiving strategy that was consistently available and met their child’s need. The mothers reported that breastfeeding was their most often used soothing strategy and that they would respond to their infant regardless of the frequency at which they were breastfeeding. One mother said, “It felt like we didn't know what we were doing. We can't make her happy. Breastfeeding was all we had but it was all the time.”
Frequent feeding often resulted in exceptional infant growth and weight gain, with the majority of infants in this study being above the 90\textsuperscript{th} percentile for height and weight during their infancy. The rapid growth and weight gain were often viewed positively by practitioners and used to reassure mothers that their child was healthy while dismissing developmental concerns.

Despite atypical feeding behaviors, the majority of participants commented on how they perceived their child to enjoy breastfeeding and that they genuinely cherished the process as well. Participants shared that they felt breastfeeding, though challenging, was one of their favorite memories of their children’s infancy. Participants all discussed being glad to have made the decision to breastfeed, not only because it helped them have a strategy to manage atypical behaviors, but because they genuinely valued the interactions and experience. One mother recalled: “She was literally happy just feeding and nobody messing with her… it was joyful. I mean I enjoyed it. I definitely enjoyed breastfeeding her.”

The majority of the participants held strong beliefs and desires to breastfeed prior to giving birth, as well as having family members and friends who breastfed. Another mother remembered: “I just knew that's what I was going to do. I guess there were some women in my life that were pregnant before me and breastfed and that just seemed like the thing to do … my plan was always to breastfeed at least a year.”

The mothers were exceptionally resilient, overcoming the challenges they faced caring for their infants by finding strategies, seeking solutions, and ultimately persevering often without the guidance of any trained professional. They all recalled fond memories of the experience of breastfeeding, despite the struggle and challenges that occurred. One mother stated: “It was wonderful and loving and it was like a warm hug. You know what I mean? Like putting on your favorite comfortable clothes.”
When recalling their experiences during their children’s infancy, all participants reflected a loving devotion driven by the desire to meet their child’s needs and their comments revealed a nuanced view of their experiences. Though they all faced challenges, and some struggled with their own physical discomfort and physiological challenges while breastfeeding, overarching themes of determination and positivity emerged. The mothers described breastfeeding challenges in detail, yet all reflected on their overall breastfeeding experience with fondness. Participants were asked to reflect on their experiences breastfeeding and raising their infant, summarizing the experience into three words, or a short phrase. One mother commented that her experiences of breastfeeding were “Difficult.” She then continued to reflect on her experiences and described her desire to report her breastfeeding experience from a positive perspective, highlighting her resilience: “I’m trying to think of the right positive words. I know a lot of it was negative, and I’m like, ‘I want to also say something positive. What positive word do I want to use?’ Because there were parts of it that were ‘beautiful’, there were parts that were good.”

Despite the intensity of the challenges, all the mothers connected at least one positive word to their experience. A word cloud was created using MaxQDA 2018 based on (Figure 15). The word cloud is a random arrangement of words using font size to indicate words that occurred at a higher frequency. Figure 15 shows the range of positive and negative views of their experiences. Some mothers had all positive descriptors, while others had a combination of both positive and negative descriptors. However, mothers who shared negative descriptors followed with a positive statement, highlighting their resilience and drive to overcome adversity.
Figure 15. Single word descriptors mothers reported about their experience breastfeeding and raising an infant later diagnosed with ASD.

Theme 2: Unaware of developmental differences

Participants were unaware that certain feeding and other behaviors occurring during their child’s infancy were atypical. While developmental differences became apparent as the children failed to meet developmental milestones, the behaviors that were observed during infancy were not recognized as atypical. Given that the mothers were unaware of the differences in their infant, they were unable to report concerns to practitioners. The most commonly reported observation was fussiness and an inability to soothe their infant. Upon reflection, however, many mothers recalled the process of “putting the pieces together” after their child received an ASD diagnosis. One mother recalled, “On the videos, you can see the progression of like how could I not notice, which is like really sad. In all the videos, she is not smiling anymore. She's like a really serious and sad baby. She's a very happy baby but she just was not smiling. Some of her favorite activities were just putting stuff in containers and then dumping them out for like hours.”
Seven of the mothers reported observations of infant behaviors that were atypical, yet they did not have the knowledge to accurately report information to practitioners. In attempts to meet the needs of their infants, mothers found creative strategies to manage atypical behaviors, though the focus at the time was on successfully figuring out how to meet the challenges they were facing. Five of the mothers reported being unable to put their infant down in a crib, several turned to baby wearing combined with constant walking. Six mothers reported that their infant would only be calm in an infant swing turned to maximum speed.

Four mothers described subtle feeding behaviors, though at the time they were unaware the behaviors were atypical. Seven of the mothers reported their infant had postural preferences while breastfeeding. They reported that the positional preferences were driven by the infant’s behavior, rather than their own discomfort or preference. One mother shared, “I will say he was really picky about (breastfeeding) posture and positions. I always had to lay down with him. I had a nursing pillow and I could get him to latch that way, but before he even got on the nursing pillow for a long time, I would just lay down like that. Sometimes he didn’t even want to be held. He would want to be propped up on me.”

Four of the mothers reported atypical rigidity and back arching during infancy. The mothers reported their infant always felt tense and that their bodies never appeared able to relax, even during breastfeeding which is typically a relaxing experience for infants. One mother described her infant: “She was always very physically rigid, and I think that that was more so the case a lot of the time when she was feeding. I guess I would notice it too when I’m actually holding and trying to get her comfortable, but her body was always physically rigid and tense.”

Another mother shared, “I’ll be breastfeeding her and she always had her eyes open. She would be like breastfeeding and would have her hand out, and would just watch her fingers, just
always so close to her face. I was like, ‘Okay, so she thinks her hands are cool.’ It really was like a stimulation type of behavior; I didn't really make any connections at that point. She always had her hands close to her face while breastfeeding.”

Everyday caregiving tasks were often difficult during infancy such as bathing, dressing their child, or trying to leave the house. One mother reflected on bathing as being particularly challenging, often triggering hours of prolonged fussiness and distress in her infant. She reflected, “Baths were supposed to be relaxing to newborns … Well he would immediately start just shrieking, he was a very loud crier and so I at first tried to work him gently into the bath. I'd always keep my hands on him and tried to help soothe. After that failed, I started to just get him in and out as quick as possible. But after the bath was over and he was redressed and everything, he would continue to be stressed and cry for hours afterward.”

Sleeping issues were pervasive in the sample of children during their infancy, that persisted into childhood. While there is variation in infant sleep patterns, and it is not biologically normal for young infants to sleep for extended periods of time, six mothers reported a combination of fussiness, being unable to put their infant down in a crib, and a lack of extended stretch of sleep in a 24 hour period. One mother recalled, “He would just be awake. I remember being at my mom's house and having him just cry, and me crying. It was just awful.”

The mothers shared that the intensity of these clusters of behaviors, combined with their own sleep deprivation, was incredibly difficult to endure. Mothers reported the infant behaviors persisted longer than what may be considered typical for newborn behaviors. The mothers were hypervigilant, constantly trying to predict behaviors and at the same time find a solution.
“We got so good at reading him. We had a PhD in our baby”, was the way that one mother phrased the intensity of which she devoted her attention to predicting and understanding her infant’s needs.

Isolation and exhaustion were common themes as mothers tried to navigate the complexity of the unexplained challenges, they faced providing care for their infants. In the absence of understanding that their experiences were atypical at the time, the mothers worked tirelessly to meet their infants’ needs, often focusing on which strategy to try next when breastfeeding was the only reliable strategy. One mother shared, “Most of the time, I felt like I was just sitting there breastfeeding because I was tired. At the time, I just felt exhausted. I’d wonder: ‘What do you want from me?’ It's a very isolating thing. We really ended up isolating quite a bit and staying at home.”

**Theme 3: Wait and see practitioner approach**

Participants reported that practitioners waited for atypical behaviors or developmental delays to resolve over time before suggesting a referral for further developmental assessment. In this sample, the majority of the children diagnosed with ASD were first born children. Though not a requirement in the inclusion criteria, it posed several additional challenges for mothers who had no means of comparison to base their observations and experiences, ultimately adding to the challenges mothers had communicating their concerns to practitioners. The majority of mothers did not report observing atypical behaviors, to their pediatrician, until the children were well over one year old based on their lack of knowledge of differences during their children’s infancy.

Despite attempts to inquire about developmental concerns, the majority of participants reported that pediatricians often told them that there was no need to worry and that the delays would eventually disappear leading to a normal developmental trajectory. One mother
commented, “For the (developmental) things that were behind, the doctor seemed encouraging like, ‘He'll catch up,’ or ‘We'll see down the road.’”

Seven mothers reported their doctors mentioned arbitrary guidelines used to make decisions about further evaluations for developmental concerns such as waiting for developmental regression or stating that if the child wasn’t exhibiting certain ASD signs or behaviors, such as a lack of eye contact, that there was no need for concern. One mother reported, “She had already been head banging and we asked for a referral for early intervention services, or some type of help. The doctor wouldn’t recommend it until she regressed. The doctor told us that she couldn’t be autistic because she makes eye contact.”

Six of the mothers reported that pediatricians told them that developmental delays could be normal or justified. Mothers’ inability to clearly describe the experiences and behaviors that had been happening since infancy limited pediatricians understanding of the scope and duration of atypical behaviors. For example, one mother shared: “I went to the pediatrician because she wasn’t using very many words, and the doctor said, ‘Well, sometimes when babies start new skills, they kind of back off with other ones’ because she was honing in on her walking. We talked about her being fussy, but we never said autism. We never said sensory disorder. The only words we had were she’s kind of awake and picky.”

One mother remembered being concerned that her son was delayed in crawling. While the response was very reassuring for the mother to hear at the time, the doctor did not follow up with further questions that might have illuminated other atypical behaviors happening at the same time. The mother commented that “the doctor said it's becoming more common for babies not to crawl because we don't put them on their tummies to sleep anymore and so they're not
getting the tummy time, so we're seeing statistically just more babies aren't crawling because they're not building up the muscles in the same way.”

Six of the mothers reported that they felt their concerns were being dismissed. Mothers reported that the statements from pediatricians encouraging mothers to postpone seeking developmental assessment or intervention made them feel temporarily reassured in the doctor’s office. However, upon returning home the doctors’ comments only added to their confusion about the atypical behaviors they were seeing. One mother recalled, “The doctor would come in and sit down with the pen, run through the milestone checklist. Then she would say, ‘Well, according to this, he's doing great.’"

In the absence of practitioner guidance, mothers resorted to researching concerns on their own. Seven mothers reported taking their own initiative, turning to friends, family members or internet searches to gain a better understanding of development. One mother shared, “I Googled way too much. And then I was just like, ‘He has autism.’ I wasn't even like, ‘We have to find out.’ I was like, ‘He does. I know he does.’ And so then I went to his pediatrician, and I remember they gave us the list, and the doctor was still like, ‘Maybe.’

**Theme 4: Practitioners primarily provide medical support**

Participants primarily sought services from practitioners for medical or health-related issues, as opposed to seeking advice specific to observed atypical feeding or other behaviors. Given the majority of mothers in this sample were unaware that feeding behaviors were atypical, none were able to mention any specific feeding concerns. When developmental concerns were dismissed, pediatricians often followed up with an explanation tied to health, shifting the focus away from atypical behaviors or delays. For example: “The doctor was just more focused on the fact that her growth was great, and she was walking and sitting up.”
Given that the majority of children in this study were not having any issues with growth or weight gain, doctors focused on positive aspects of health and a lack of medical concerns, often reassuring mothers that they were doing a good job parenting. One mother commented that “the doctor was very encouraging. He was always like, “You're doing such a good job.” And, he told me my son was growing well and that kind of thing”

Six mothers in this study reported that after developmental concerns were dismissed, they primarily turned to the pediatrician when their child was physically ill or needed medical care. Some of the mothers expressed frustration with not having access to assessment services and intervention sooner and tended to believe that part of the practitioner role is to reassure mothers. One mother explained, “It never was a, ‘Well, we need to watch that.’ Which, I kind of wish it was, because then I think I would have picked up on the things a little bit sooner. I'm sure they have a lot of mothers coming in with a million concerns and part of a doctor's job is probably reassuring that things are normal.”

An inclusion requirement for this study was that mothers had to have sought services from a lactation consultant after returning home from the hospital. None of the participants sought services specific to atypical infant feeding behaviors or atypical developmental behaviors. Each one sought services from an IBCLC for a health-related issue, such as mastitis or nipple pain. Similarly, none of the participants sought breastfeeding advice from their pediatrician.

**Practitioner data**

The final step of the qualitative analyses involved a content analysis of the open-ended questions from the Knowledge of Early ASD Signs measure listed below:

Item 10: What early signs in a baby under your care raise your concern for autism?

Item 11: In your opinion, which babies are at increased risk for autism?
Content analysis is a qualitative analytic approach used to interpret meaning from the content of text data (Hsieh & Shannon, 2005). Practitioner responses were analyzed and their descriptions of early signs of ASD and the indicators that cause them concern about an infant in their care were extracted and brought together into one document (Graneheim & Lundman, 2004). Responses were divided into meaning units and labelled with a descriptive code (Graneheim & Lundman, 2004). Codes were compared and sorted into overarching themes. Data analysis of practitioner responses yielded five themes for Question 10 and six themes for Question 11 (See Table 21 and Table 22).

A total of 140 coded meaning units were identified from the individual responses that describe early ASD signs that practitioner watch for when providing health care to infants. The pediatrician group had 86 meaning units identified within the responses and the IBCLC group had 169 meaning units identified. Three pediatricians and 12 IBCLCs did not respond to this question. From the IBCLC group 13% (N=6) responded that they had a lack of knowledge regarding early ASD signs. No pediatricians explicitly stated they were unsure of early ASD signs. Participants responses to Question 10 ranged from two-word answers to 66-word responses. Analysis of the 140 meaning units revealed five organizing themes that emerged from the responses (See Table 21).

The most common early ASD sign reported by pediatricians was atypical patterns or a lack of eye contact (N= 11), followed by lack of joint attention or atypical social behaviors (N=10). Similarly, the most frequently reported early sign of ASD from the IBCLC group was a lack of or atypical patterns of eye contact. A lack of response was the second most frequent response from IBCLCs. However, lack of joint attention or atypical social behaviors (N=7) was the third most frequently reported early ASD sign. Only one practitioner, from the IBCLC group,
noted parental concerns as an indicator of an early sign of ASD. While the other practitioner responses were able to be coded into one of the remaining four themes, the detailed description of the importance of exploring parental concerns was connected to the breastfeeding dyad, development, and practice. The unique contribution of the response warranted the creation of a theme describing a process that practitioners may use when identifying an infant in their care that causes concern for potential ASD.

Table 21

*Themes of open-ended practitioner responses describing early signs of ASD*

| Item 10: What early signs in a baby under your care raise your concern for autism? |
|--------------------------------|---------------------------------|----------------|----------------|-----------------|----------------|
| Lack of knowledge            | Known diagnostic criteria for ASD | Developmental indicators | Infant behaviors | Parent concerns |
| Unsure of early indicators    | Repetitive behaviors             | Developmental delays/regression | Sleep difficulties | Concerns about child’s development |
| Not yet observed in practice | Difficulty with transitions      | Atypical social interaction | Feeding issues    | Concerns about social emotional development |
| No response                  | Rigidity in preferences          | Lack of eye contact and smiling | Atypical crying/fussiness | |
|                              | Sensory issues                   | Atypical language          |                  |                  |

Below are examples of excerpts from IBCLCs descriptions of early ASD signs:

“At this time, I have not been looking for autism in babies. I would be interested in learning. IBCLCs spend a long amount of time with babies and often we pick up on medical conditions that doctors have not yet noticed. I would like to be able to spot autism early as well so that I can help babies obtain care as early as possible.”

“I am concerned when a baby is initial very colicky (for a non-identifiable issue), or is a 'quiet' baby that lays in their crib staring at the mobile or ceiling and doesn't cry or attempt to communicate well. Then as the infant gets older, I am concerned again about these polar displays, either hyperactive and difficult to calm down (easily reactive)”
A total of 115 coded meaning units were identified from the individual responses that describe the indicators practitioners look for to identify infants at increased risk for ASD. The pediatrician group had 40 meaning units identified within responses and the IBCLC group had 75 meaning units identified. Three pediatricians and 11 IBCLCs did not provide a response to the question. From the IBCLC group, 28% \((n=13)\) as well as 9% \((n=3)\) of pediatricians reported a lack of knowledge regarding identification of infants who have an increased risk of ASD. Participants’ responses ranged from one-word answers to 33 word responses. Responses to the question regarding children at increased risk for ASD were coded into six themes (See Table 22).

The most commonly coded meaning unit from the pediatrician group was a family history \((n=8)\) of ASD followed by premature infants \((n=6)\) as being at increased risk of ASD. For IBCLCs, the most frequently reported response was a lack of knowledge about factors that increase an infant’s risk of ASD \((n=13)\). The next most common meaning units were similar to those from pediatricians. Of the participants that were able to describe indicators in the IBCLC group, prematurity was the most frequently reported cause for concern regarding an increased risk of ASD \((n=12)\) with family history being the second most reported \((n=5)\).

Table 22
Themes of open-ended practitioner responses describing babies at increased risk of ASD

<table>
<thead>
<tr>
<th>Item 10: What early signs in a baby under your care raise your concern for autism?</th>
<th>Family history of ASD</th>
<th>Parental health</th>
<th>Infant health &amp; development</th>
<th>Environmental factors</th>
<th>Random or multiple factors</th>
<th>Lack of knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Parents with ASD</td>
<td>• Parental age (older)</td>
<td>• Developmental delay</td>
<td>• Low income</td>
<td>• All babies are at risk of ASD</td>
<td>• No known causes of increased risk</td>
<td></td>
</tr>
<tr>
<td>• Siblings with ASD</td>
<td>• Maternal stress</td>
<td>• Fussiness</td>
<td>• Poor parental interaction</td>
<td>• Poor feeding</td>
<td>• Unsure</td>
<td></td>
</tr>
<tr>
<td>• Genetic predisposition</td>
<td>• Pregnancy complications</td>
<td>• Poor feeding</td>
<td>• Not receiving early access</td>
<td>• Maternal health (PCOS, diabetes)</td>
<td>• No response</td>
<td></td>
</tr>
<tr>
<td>• Family members with comorbidities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Below are excerpts from pediatrician responses to indicators of increased risk:

“All kids, moms who have had an infection during pregnancy, older moms, preemies, infants with infections after birth, others”

“All low income. Maternal stress and medication during pregnancy.”

**Integrated Results**

**Data Integration**

This study explores a complex and multifaceted topic, across ecological levels, between practitioners and people who receive their services. As such, an important aspect of this research is to illuminate and highlight issues for practitioners to consider. Exploring the ways survey results and data from maternal interviews align with one another is best approached through a mixed methods convergence analysis (Creswell & Plano Clark, 2007). Mixed methods results were compiled through exploration of the alignment of the qualitative and quantitative results. To answer Research Question 4 and explore the extent to which maternal experiences seeking and receiving support from practitioners align with or diverge from practitioner knowledge of ASD and lactation a convergence data matrix was created (See table 24). The purpose of the data matrix is to array quantitative and qualitative data in a side by side display.

Mixed methods results were compiled through the alignment of qualitative and quantitative data. The first step in the mixed methods analysis involved the identification of categorical themes based on items within quantitative measures and developing data convergence label definitions. Convergence labels were used to explore and classify the alignment of qualitative and quantitative results (See Table 23).
Table 23.

Data convergence labels describing the relationship between qualitative findings and quantitative results

<table>
<thead>
<tr>
<th>Label</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confirm</td>
<td>Positive alignment between results of each strand Both forms of data reveal the same information</td>
</tr>
<tr>
<td>Enhance</td>
<td>Results from each strand of data do not confirm or contradict Provide different perspectives Reveal an improved general understanding of the phenomenon</td>
</tr>
<tr>
<td>Mixed</td>
<td>Results are neither contradicting nor confirming between strands Participants responses vary in respect to a given phenomenon</td>
</tr>
<tr>
<td>Contradict</td>
<td>Lack of agreement between results of both strands</td>
</tr>
<tr>
<td>Insufficient</td>
<td>Qualitative data were not available because participants did not have interactions with practitioners in relation to a specific categorical theme</td>
</tr>
</tbody>
</table>

The confirm and contradict convergence labels are straightforward in that the comparison of findings across strands either support or offer opposing discrepancies. A positive, confirmed, alignment across strands shows strengths in practitioner skills that matched mothers’ experiences. Alternately, it is possible for practitioner knowledge or skill deficits to align with mothers’ experiences, thus confirming the results across strands. Contradicting results allow opportunities for both explanations and further understanding of maternal experiences seeking help for infants later diagnosed with ASD while creating a roadmap for professional development and can address gaps in service by illuminating a lack of agreement between strands. The mixed convergence label allows for ambiguous alignment across strands, when there may be variation in practitioners’ scores or mothers’ experiences that can neither consistently confirm or contradict each other across strands. Mixed alignment suggests that further examination of the issue might be warranted to completely understand the phenomenon.

The enhance convergence label allows for results from each strand to bring to light differing experiences addressing the same phenomenon that neither confirm nor contradict each other but rather create a deeper understanding. This label allows for polarizing results that
enhance the understanding of the complexities that exist in the intersection between practitioner knowledge and skill and maternal experiences seeking support.

Quantitative categorical themes were identified from each of the quantitative survey measures and factor-based scores were created for practitioners (See Appendix K). To better ascertain the relationship between data strands, three categorical themes were identified from the Knowledge of Early ASD Signs: behaviors, diagnostic risk, and developmental delay. Factor analysis using a Varimax rotation of the 14 items from the Clinical Self Efficacy in ASD Survey yields a four-factor solution (Atun-Einy & Ben-Sasson, 2018). The four factors from the Clinical self-efficacy in ASD survey are: Self-efficacy in ASD clinical skills, Available resources, Need for ASD training, and Communicating with parents about their ASD concerns. Five categorical themes were identified from the Questionnaire about Breastfeeding Knowledge survey: Physiology, Public health, Issues during the first days, Late issues, and Assessment of feeding.

The second step of the integrated analysis was the examination of the alignment of strands based on convergence labels. The data convergence matrix explored the alignment between results from both data strands (See Table 24). The integrated analysis revealed three instances where quantitative and qualitative results align to address the same phenomenon and confirmed one another, seven instances where the results from each strand contradicted one another, one instance where the data provided a mixed convergence of results between strands, one instance where the results enhanced the general understanding of the phenomenon, and 13 instances where there were insufficient maternal experiences to accurately identify alignment.

The integrated results suggest that pediatricians self-report moderate to sufficient knowledge related to early ASD signs, diagnostic risk and knowledge of development; however, mothers’ experiences seeking help for their children did not reflect that knowledge translated to
practice (See table 24). Similarly, pediatricians reported moderate confidence in their diagnostic abilities and knowledge of ASD resources and did not feel they needed additional training for ASD yet maternal experiences reflected contradictory information. IBCLCs’ low knowledge scores specific to early ASD signs revealed insufficient experiences with mothers, given that mothers did not seek consultation with IBCLCs to assess, screen, or identify developmental differences. In this sample, mothers did not turn to IBCLCs for questions about atypical feeding behaviors due to a combination of factors including but not limited to the lack of awareness that behaviors were atypical and a lack of knowledge that an IBCLC could help with older infants feeding challenges.

IBCLCs self-reported knowledge of breastfeeding was excellent across the categorical themes related to the assessment of feeding, physiology, and breastfeeding issues in the first days and was confirmed by maternal experiences. Despite having excellent scores related to public health, mothers experienced a variety of recommendations specific to supplementation including supplementation with formula, that was not indicated by infant health need, resulting in mixed alignment. Based on the Academy of Breastfeeding Medicine Clinical Protocol #3: Supplementary Feedings in the Healthy Term Neonate, expressed breast milk is the first choice for extra feeding of a breastfed infant, followed by donor human milk, and synthetic formulas are recommended as the final option for the health of the infant and to protect he mothers milk supply (Kellams et al., 2017). The mixed alignment label suggests that further examination of the frequency at which mothers were recommended to supplement with formula over other options that are associated with better lactation related outcomes may be warranted.

IBCLCs had excellent knowledge of late breastfeeding issues based on assessment results. However, given that none of the mothers sought consultation with an IBCLC past the
newborn phase, there were insufficient experiences to determine alignment. Pediatricians self-report scores specific to the knowledge of breastfeeding ranged from below-average to insufficient across all categorical themes. None of the mothers in this sample consulted with pediatricians regarding their infants’ atypical feeding behaviors or challenges breastfeeding resulting in insufficient experiences to assess alignment in that category as well.

The contradictions between practitioner knowledge and maternal experiences, combined with insufficient experiences across certain categorical themes, indicates an opportunity for further understanding of the phenomenon. The enhance label specific to the knowledge of resources reflects mother's desire to have easier access to more information and resources specific to ASD and illuminated mothers’ constant attempts to balance being care provider, advocate, and interventionist both before and after diagnosis. Pediatricians’ moderate scores relating to knowledge of resources specific to ASD in their respective communities was confirmed by mothers. However, pediatrician knowledge of available resources was not typically the reason mothers were successful in securing an ASD diagnosis and services for their children. In this sample, it was the mother's tenacity and drive to ascertain diagnosis and services they needed to care for their children that brought about connection to resources. While knowledge of services can be challenging for practitioners to maintain over time, mothers reported it was through persistence on their part that they were eventually connected to services. The qualitative findings enhance the understanding of the complexity of the challenges related to translating knowledge to practice in regards to practitioner knowledge of available services.
### Table 24
Condensed Data Convergence Matrix for Research Question 1

<table>
<thead>
<tr>
<th>Quantitative Categorical Theme</th>
<th>Qualitative Code</th>
<th>Convergence Label</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What knowledge do practitioners have?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pediatrician knowledge of early ASD signs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infant/Child Behaviors</td>
<td>Wait and see practitioner approach; Challenging infant behaviors; Infant/child sleep issues; Infant development\Hard to soothe/fussy/crying; Atypical infant behaviors; Maternal knowledge of development</td>
<td>Contradict</td>
</tr>
<tr>
<td>Diagnostic risk</td>
<td>Delay in diagnosis; Pediatrician\Wait for referral; Wait and see practitioner approach</td>
<td>Contradict</td>
</tr>
<tr>
<td>Developmental delay</td>
<td>Infant Development \Atypical infant behavior; Wait and see practitioner approach; Maternal knowledge of development</td>
<td>Contradict</td>
</tr>
<tr>
<td><strong>Pediatrician knowledge of lactation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physiology</td>
<td></td>
<td>Insufficient</td>
</tr>
<tr>
<td>Public health</td>
<td></td>
<td>Insufficient</td>
</tr>
<tr>
<td>Breastfeeding issues during the first days after birth</td>
<td></td>
<td>Insufficient</td>
</tr>
<tr>
<td>Late breastfeeding issues</td>
<td></td>
<td>Insufficient</td>
</tr>
<tr>
<td>Assessment of feeding</td>
<td></td>
<td>Insufficient</td>
</tr>
<tr>
<td><strong>IBCLC knowledge of early ASD signs</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infant/Child Behaviors</td>
<td></td>
<td>Insufficient</td>
</tr>
<tr>
<td>Diagnostic risk</td>
<td></td>
<td>Insufficient</td>
</tr>
<tr>
<td>Developmental delay</td>
<td></td>
<td>Insufficient</td>
</tr>
<tr>
<td><strong>IBCLC knowledge of lactation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physiology</td>
<td>IBCLC support\For health issues</td>
<td>Confirm</td>
</tr>
<tr>
<td>Public health</td>
<td>IBCLC support\For health issues; IBCLC\Positive experience; IBCLC\Negative experience\Uncomfortable</td>
<td>Mixed</td>
</tr>
<tr>
<td>Breastfeeding issues during the first days after birth</td>
<td>IBCLC support\For health issues; IBCLC\Positive experience; IBCLC\Mastitis</td>
<td>Confirm</td>
</tr>
<tr>
<td>Late breastfeeding issues</td>
<td></td>
<td>Insufficient</td>
</tr>
<tr>
<td>Assessment of feeding</td>
<td>IBCLC support\For health issues;</td>
<td>Confirm</td>
</tr>
<tr>
<td>Quantitative Categorical Theme</td>
<td>Qualitative Code</td>
<td>Convergence Label</td>
</tr>
<tr>
<td>-----------------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>How do mothers experience professional support for ASD?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pediatrician Clinical self-efficacy in ASD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-efficacy in ASD clinical skills</td>
<td>Pediatrician\Recommendations; Pediatrician\Wait for referral; Pediatrician\Can’t be autistic; Pediatrician\Recommendations; Maternal Knowledge of Development</td>
<td>Contradict</td>
</tr>
<tr>
<td>Knowledge of available resources</td>
<td>Pediatrician\Recommendations; Pediatrician concerned about alarming or offending parents; Parental concerns</td>
<td>Enhance</td>
</tr>
<tr>
<td>Need for ASD training</td>
<td>Pediatrician dismissive; Practitioner for medical not developmental; Pediatrician as source of reassurance; Power dynamic</td>
<td>Contradict</td>
</tr>
<tr>
<td>Communicating with parents about their ASD concerns</td>
<td>Pediatrician concerned about alarming or offending parents; Pediatrician\Recommendations; Pediatrician dismissive; Atypical infant behavior; Practitioner for medical not developmental</td>
<td>Contradict</td>
</tr>
<tr>
<td>IBCLC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical self-efficacy in ASD</td>
<td></td>
<td>Insufficient</td>
</tr>
<tr>
<td>Knowledge of available resources</td>
<td></td>
<td>Insufficient</td>
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<tr>
<td>Need for ASD training</td>
<td></td>
<td>Insufficient</td>
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<tr>
<td>Communicating with parents about their ASD concerns</td>
<td></td>
<td>Insufficient</td>
</tr>
</tbody>
</table>
Summary

This chapter describes results from the quantitative strand, the qualitative strand, and the mixed methods integration. $T$ test and Mann Whitney U tests were utilized to assess differences in knowledge of early ASD signs and breastfeeding between practitioner groups. Results suggest there are differences in knowledge across both topics between practitioner groups. IBCLCs scored higher on assessment of breastfeeding knowledge and pediatricians scored higher on knowledge of early ASD signs. IBCLCs also had a statistically significantly higher total number of responses indicating they lacked knowledge about the topic addressed within an item on the assessment for knowledge of early ASD signs. Self-efficacy scores in the field of ASD revealed that IBCLCs have statistically significantly lower self-efficacy scores in the field of ASD than do pediatricians.

Qualitative analyses were used to explore practitioner responses to open-ended questions on the early signs of ASD survey and to analyze data collected from mothers of children diagnosed with ASD. Results of the open-ended questions show that both practitioner groups identify atypical social interactions and atypical patterns of eye contact as a cause for concern in infants. Family history of ASD was the most frequently reported indicator of increased risk in infants in the pediatrician group, whereas, IBCLCs reported infants who are born prematurely as the second most frequent indicator of increased risk. However, it is important to note that the IBCLC group’s most frequent response to the identification of infants at increased risk of ASD was that they were unsure or lacked knowledge on the topic.

Qualitative analysis of maternal experiences seeking and receiving professional support caring for and feeding their infant later diagnosed with ASD revealed the following four themes: Breastfeeding as an Intervention, Unaware of Developmental Differences, Wait and See Practitioner Approach, and Practitioners Primarily Provide Medical Support.
Breastfeeding was used to manage atypical or challenging behaviors to calm, comfort, and soothe infants represented in this sample. Participants were unaware that certain feeding and other behaviors occurring during their child’s infancy were atypical. The majority of participants were able to reflect back on atypical behaviors after their child received a diagnosis but were unaware during their child's first years that atypical behaviors were associated with ASD.

Participants reported that upon attempting to get more information about their infants' atypical behaviors, practitioners often recommend waiting to see if atypical behaviors or developmental delays would resolve over time before making a referral for further developmental assessment. In response to being told to wait for developmental assessments and developmental concerns being dismissed, participants primarily sought services from practitioners for medical or health-related issues, as opposed to seeking advice specific to observed atypical feeding or other behaviors. None of the participants in this sample sought help from an IBCLC for atypical feeding behaviors past the newborn phase and solely sought consultation to address medical concerns related to their own health associated with breastfeeding.

The mixed methods result highlighted several areas where professional knowledge was not directly translating to practice in the pediatrician group. There were multiple categorical themes that could not be analyzed for alignment due to insufficient experiences between mothers and practitioner, highlighting a gap in services. IBCLCs had low scores on knowledge of early ASD signs, similarly, mothers did not know that behaviors occurring during infancy were atypical leading them to not seek an assessment from an IBCLC. Similarly, the feeding problems that did arise were not brought to the attention of a pediatrician either. Given that pediatricians scored very low on assessments of breastfeeding and mothers did not report feeding difficulties to pediatricians, there were insufficient experiences to assess alignment related to breastfeeding.
CHAPTER 5. DISCUSSION AND INTERPRETATION

This multilevel mixed methods study explored pediatricians’ and lactation consultants’ (IBCLC) knowledge early indicators of autism and breastfeeding within the context of maternal experiences. Guided by bioecological theory, a multilevel concurrent mixed methods approach was utilized to examine the extent to which maternal experiences seeking help and receiving support from practitioners aligned with practitioners’ self-report of ASD and lactation knowledge. Guided by Bronfenbrenner’s bioecological theory, this approach allowed for an in-depth exploration of practitioner knowledge of both lactation and early indicators of ASD within the context of maternal experiences raising infants later diagnosed with ASD, providing insight into the needs of both practitioners and families. The findings from this study address four areas: 1.) practitioners’ knowledge related to lactation and early indicators of ASD, 2.) the differences between lactation consultants’ and pediatricians’ knowledge of lactation and early indicators of ASD, 3.) how mothers experienced receiving professional support caring for and feeding infants later diagnosed with ASD, and 4.) the extent to which maternal experiences seeking and receiving support from practitioners align with or diverge from practitioner knowledge of ASD and lactation. This chapter describes the major findings and conclusions in relation to current research, followed by limitations, and implications for future research and practice.

Interpretation

Quantitative inferences: Practitioner knowledge of lactation and ASD

This study assessed practitioner knowledge of ASD and breastfeeding. Each practitioner group is highly specialized in their respective healthcare fields. Pediatricians specialize in the medical care of infants and children, whereas, IBCLCs are healthcare professionals with the highest level of certification for clinical management of breastfeeding. This study did not explore
the breadth of knowledge each practitioner group had across the range of skills within their scope, but rather focused in on practitioner knowledge of unique identifiers of atypical development and breastfeeding that are relevant to both groups’ practice with families.

Pediatricians’ knowledge assessment scores related to early signs of ASD revealed that they have moderate knowledge of early indicators associated with diagnosis of ASD. Given that pediatricians monitor infants’ growth and development over time through well baby visits, they have unique opportunities to screen for atypical development. IBCLCs’ knowledge scores were insufficient to be able to identify infants exhibiting early signs of ASD. Given that IBCLCs work closely with mothers and infants, knowledge of atypical development is crucial to determine when further assessment is warranted. However, there are not currently protocols that fall within the IBCLC scope of practice that would allow for developmental screening to occur when an infant is exhibiting atypical behaviors. Given the scores of the IBCLC knowledge assessment for ASD, it is unclear whether an IBCLC would have sufficient knowledge to make a referral for further developmental assessment.

When answering open ended questions regarding indicators of ASD that warrant concern in an infant or young child, practitioners reported symptoms of ASD that are commonly looked for in older toddlers or children. This topic poses particular challenges with infants, given that infants communicate through gaze, often averting their eyes when they are disinterested or want to disengage from an interaction (Akhtar & Gernsbacher, 2008; Csibra, 2010; Grossman et al., 2008). The blanket statement of atypical eye contact and atypical social interaction may be harder to define during infancy. However, researchers have found that some of these indicators are present during infancy (Bedford et al., 2012; Dawson et al., 2004). It is unclear if practitioners are aware of the subtle differences in how to ascertain atypical social behaviors or
eye contact in an infant given that their responses did not provide enough detail. Assessing a breastfeeding dyad during a feeding session may provide practitioners with a unique opportunity to observe atypical behaviors during infancy.

IBCLCs had excellent scores on assessment of breastfeeding knowledge, reflecting the specialized knowledge required by the certification. Pediatricians, however, did not have sufficient knowledge and skills related to breastfeeding. When asked where to access evidence-based information about medication use while breastfeeding, pediatricians struggled to provide adequate answers. Only four out of the 23 pediatricians provided sufficient answers about and connections to resources. In the absence of knowledge regarding where to seek evidence-based information, a pediatrician may not be able to make informed decisions for a breastfeeding dyad potentially leading to an inaccurate recommendation for breastfeeding cessation.

Pediatricians outnumber IBCLCs in practice and are spread more broadly across the U.S. (See Figure 16). Despite the number of pediatricians in the U.S., the American Academy of Pediatrics (AAP) has concluded the current distribution of primary care pediatricians, especially in rural and other underserved areas, is inadequate (Basco & Rimsza, 2013). The number of pediatric physicians who work part time has increased from 15% in 2000 to 23% in 2006 resulting in the need for greater numbers of pediatricians needed to provide clinical care (Basco & Rimsza, 2013). As the rates of ASD continue to climb, access to trained physicians that can identify atypical development is essential. A shortage of pediatricians might increase the likelihood that a breastfeeding dyad, with an infant at increased risk for later diagnosis of ASD, would be receiving health care from a practitioner that does not have a specialization in the healthcare needs of infants, knowledge of early ASD signs, nor lactation. The AAP also states that the role of the pediatrician has changed over time. Pediatricians are spending increasing
amounts of time on coordination of care services, providing counseling to families, advocacy roles within communities, management of paperwork and insurance barriers, combined with increasingly complex pediatric patients requiring greater time commitment and resources (Basco & Rimsza, 2013).

Figure 16. Number of Children per general pediatrician in the United States of America, based on 2010 Census data. Retrieved from: https://www.aap.org/en-us/professional-resources/Research/research-resources/Pages/National-Data-of-Mapping-Health-Care-Delivery-for-Americas-Children.aspx

Information regarding insufficient knowledge about breastfeeding and a lack of training to support the needs of breastfeeding dyads among pediatricians has been prevalent in the literature for years (Freed et al., 1995; Guise & Freed, 2000; Pound et. al, 2014; Schanler, O’Connor & Lawrence, 1999). Researchers have found several areas of potential deficits specific
to breastfeeding knowledge. Results of this study revealed a pattern similar to that found in prior research. It may be unrealistic to assume that all pediatricians, who are already overburdened within their roles as healthcare providers, will have the ability to gain sufficient knowledge to support families with the same level of expertise as an IBCLC. However, as breastfeeding rates increase, it is essential for pediatricians to be able to provide evidence-based information to families in their care or have the knowledge to connect families to a specialist, such as an IBCLC that can provide necessary evidence-based healthcare services.

Alternately, given that IBCLCs demonstrated excellent knowledge specific to breastfeeding, pediatricians could benefit from being aware of IBCLCs in their area so they could refer families and connect them to adequate lactation support. Researchers have found that access to IBCLCs during the newborn phase is associated with longer durations of breastfeeding (Brent et al., 1995; Lukac, Riley, & Humphrey, 2006). Access to an IBCLC can address the need for lactation support while at the same time reducing the time pediatricians spend providing lactation support, often in the absence of specialized training (Witt et al., 2012). Referrals to IBCLCs would also cut down on additional clinical time spent finding resources, counseling, and providing support to breastfeeding dyads. The downside to referring to an IBCLC is that there are still widespread areas across the country without access to an IBCLC outside of a hospital setting (See Figure 17). Mothers are limited by other factors such as lack of knowledge of IBCLCs as a profession; if a mother is not aware that an IBCLC is available in her area she will be unable to seek assistance. Additionally, the cost of consultation services can be prohibitive if not covered by medical insurance. Pediatricians can connect mothers to lactation services; however, it is essential for pediatricians to inquire about breastfeeding challenges to know when to make a referral.
Based on knowledge scores specific to breastfeeding, IBCLCs have more than sufficient knowledge to provide lactation support to mothers who are struggling with common breastfeeding difficulties. The results of the assessment of early ASD signs reveal a significant knowledge gap that would make it difficult for IBCLCs to identify or provide support to breastfeeding dyads that are struggling to breastfeed due to developmental differences potentially associated with ASD. The early signs of ASD survey allowed respondents to identify whether they had no knowledge of the topic being asked; 13% of IBCLCs reported they did not have sufficient knowledge to answer any of the nine questions on the survey. The insufficient knowledge scores specific to early signs of ASD, in the IBCLC group, highlights the need for further training. IBCLCs might be able to observe and identify atypical development in the infants to whom IBCLCs provide services but a solid knowledge foundation is required to translate into effective practice.
Quantitative inferences: Practitioner group knowledge differences.

One objective of this study was to compare knowledge of early ASD signs and breastfeeding between practitioner groups. Knowledge scores in this study were influenced by specialty (IBCLC or pediatrician). Pediatricians had higher knowledge scores of early ASD signs, whereas IBCLCs had higher knowledge scores specific to breastfeeding. Higher knowledge of early ASD signs was correlated with higher rating of self confidence in ASD clinical skills among both practitioner groups. Both practitioner groups may encounter families with questions about breastfeeding and ASD as public awareness campaigns continue to separately promote breastfeeding and the early identification of ASD.

The majority of pediatricians felt confident in their clinical abilities and have enough time within their clinical practice to screen for, diagnose, and provide intervention for ASD. In the pediatrician group, 33% agreed with the statement that they were comfortable diagnosing or identifying a child with ASD, only seven pediatricians strongly agreed. In contrast, 51% of IBCLCs strongly disagreed with feeling comfortable diagnosing or identifying a child with ASD, and only three strongly agreed with the statement. IBCLCs’ knowledge scores of early signs of ASD were significantly lower than pediatricians’ scores, suggesting a lack of knowledge that directly connects to their confidence in their clinical skills related to ASD.

Only two of the IBCLCs in this sample reported being part of a team that screens and diagnoses children with ASD. In comparison, the majority of pediatricians ($n=16$) reported being a part of team that diagnoses children with ASD. IBCLCs in this sample may have limited experiences working with children who have ASD given that their specialty typically focuses on working with infants. Those who are not members of a team that diagnoses ASD, would have limited resources to learn about screening and early signs of ASD given those topics are outside their scope of practice.
Results of this study are intended not to imply that IBCLCs should be responsible for diagnosing ASD, rather highlighting the need for training that would allow them to identify infants exhibiting atypical behaviors associated with later diagnosis of ASD and encourage communication of concerns with pediatricians when referrals are necessary. As the rates of ASD continue to climb, IBCLCs helping assess feeding difficulties may be one of the first practitioners to observe atypical behaviors while working to support breastfeeding. Future research is needed to focus on the identification of indicators that may be present during feeding that would allow IBCLCs to make referrals when necessary.

The AAP recommendations to promote and support breastfeeding is based on data that has found a strong correlation between breastfeeding and positive child outcomes across multiple domains. While participants in this study self-report recommending breastfeeding, the practitioner groups differ in their knowledge of breastfeeding and clinical skills to support breastfeeding mothers. Breastfeeding knowledge among pediatricians, without additional lactation specific certifications, was lower than scores from the IBCLC group. The difference in knowledge between practitioner groups was not unexpected, given that prior studies have found pediatrician training specific to lactation and breastfeeding to be inadequate and participant responses in this study corroborated those findings (Freed et al., 1995; Guise & Freed, 2000; Pound et. al, 2014; Schanler, O’Connor & Lawrence, 1999).

Topics addressed within the breastfeeding knowledge questionnaire are considered important for practitioners who provide healthcare to infants to provide adequate care to breastfeeding dyads. However, the knowledge scores of pediatricians reflect clear deficiencies. When asked to rate how well they felt their residency prepared them to support breastfeeding mothers, 52% of pediatricians reported their residency provided less than adequate preparation to
support breastfeeding mothers with 48% reporting that they counsel mothers more often than anticipated. Pediatricians’ scores and responses highlight the need for further training given the importance of their role as often the primary healthcare provider for infants.

Years in practice did not impact pediatricians’ or IBCLCs’ breastfeeding knowledge in this sample. Given that all but one of the IBCLCs scores were at least 70-80% correct on the breastfeeding knowledge assessment, years in practice had no statistical impact on scores. However, several of the pediatricians with the least years in practice had very insufficient breastfeeding knowledge scores. In contrast, the pediatrician who had been in practice the longest scored in the very insufficient range. All but one participant with personal breastfeeding experience (N= 12) had knowledge scores between 70-85% representing good knowledge to support breastfeeding dyads. Similar to prior studies, personal breastfeeding experience may help pediatricians have a better understanding of how to meet the needs of breastfeeding dyads but it is not equivalent to evidence based training (Schanler, O’Connor & Lawrence, 1999).

Additionally, all but one of the male pediatricians in the sample scored less than 55% demonstrating very insufficient knowledge. Further exploration of gender differences among pediatricians related to knowledge of breastfeeding may help to identify potential impacts of gender on knowledge or comfort in seeking further lactation specific training and education.

While differences between practitioner group knowledge were not surprising, the results identified knowledge gaps noted by other researchers specific to breastfeeding and expanded the evidence base with novel identification of knowledge gaps related to early signs of ASD. The knowledge gaps in each group demonstrate significant needs to strengthen educational preparation across practitioner groups. There are areas of overlap in education requirements
between groups; however, results of the knowledge assessments show knowledge deficits in each group and across both topics.

**Qualitative inferences: Maternal experiences**

The first major finding from the qualitative analysis was that the majority of mothers used breastfeeding as a strategy to calm, comfort and soothe their infant. These results are similar to prior study exploring breastfeeding behaviors of infants later diagnosed with ASD (Dooley, 2017). These results affirm the importance of educating mothers on the nonnutritive benefits of breastfeeding to avoid misinterpretation of behaviors as signals of low milk supply after other physiological concerns have been ruled out. These behaviors are also a potentially easy pattern for pediatricians or IBCLCs to inquire about when learning about infants’ breastfeeding behaviors. An important concept to note is that there are biological variations in maternal milk capacity, the amount of milk a mother produces for each feeding, as well as the age of the infant, that can influence the frequency with which infants feed. Frequent feeding alone may not warrant concern; however, clusters of behaviors indicating the infant cannot be soothed in ways other than breastfeeding warrant further developmental observation and screening.

The second finding from the qualitative analysis was that mothers were not aware of developmental differences during their first-born child’s infancy. Participants whose older children were diagnosed with ASD tended to be aware of developmental differences earlier in their child, and similarly, there was one participant who had several typically developing children before giving birth to her child with ASD. Birth order seems to play an important role in a mother’s ability to identify atypical behaviors during infancy and the persistence with which they sought help for challenging behaviors. Similar to the findings from a prior study exploring maternal experiences breastfeeding infants later diagnosed with ASD, mother’s whose first-born
children were diagnosed with ASD can have difficulty determining what is “normal” infant behavior (Dooley, 2017).

After diagnosis occurred, all mothers reported looking retrospectively at behaviors that occurred prior to diagnosis and were able to identify atypical behaviors. However, pediatricians’ dismissal of maternal concerns and reports of challenging behaviors during infancy reinforced a lack of awareness that the behaviors their child was exhibiting were in fact atypical. When breastfeeding is used to manage challenging behaviors, it may be even more difficult for mothers to articulate developmental differences. First time mothers with no breastfeeding experience or means to compare infant behaviors will potentially face greater challenges than those who have prior experience breastfeeding and raising an infant.

The third finding from the qualitative analysis described a “wait and see” practitioner approach. Currently there are adequate screening tests that can detect ASD as early as 18 months of age, and the AAP recommends universal screening for ASD in all children between the ages of 18 and 24 months in conjunction with developmental screening. Routine developmental monitoring is recommended with follow-up screenings if developmental concerns arise (Siu et al., 2016). All but one child in this study received consistent healthcare from a pediatrician including well child visits during their infancy and toddler years. All mothers reported filling out developmental screenings, though they were unsure of the name of the assessments.

A consistent theme that emerged was that regardless of whether delays were identified through developmental screening or maternal report, the most common initial response from all pediatricians was to wait and see if the child would “outgrow” the differences or delays at the next well child visit similar to other studies exploring parental report of pediatrician responses to initial inquiries about atypical development (Johnson, 2008; Sansosti, Lavik, & Sansosti, 2012).
Well child visits decrease in frequency as children age starting with the first visit occurring between 3-5 days, followed by a one month and two month visits, between two and six months visits are spaced two months apart, followed by every three months between six and 18 months, followed by every six months until a child is three years old, then yearly until the age of 21. Depending on the age of a child, waiting until the next appointment could be six months to a year of time delaying access to service and intervention during crucial formative years.

There are several screening options pediatricians can use when assessing development. The Modified Checklist for Autism in Toddlers, Revised With Follow-up (MCHAT-R/F) is a screening tool used by pediatricians to identify toddlers at risk for ASD. A question on the MCHAT-R/F deals specifically with atypical hand movements: “Does your child make unusual finger movements near his or her eye?” One participant reported observing her infant demonstrating atypical hand movements close to the eye while breastfeeding; given that the behavior occurred during infancy before 18 months of age, this is a novel finding. The mother was unaware that this was atypical behavior and did not report it at the time, nor was there currently a validated measure for such behaviors during infancy. However, there may be other opportunities for identification of infants that warrant closer monitoring based on infant behaviors during feeding. Future research can explore measures to help practitioners identify infants and develop interventions, as long as practitioners follow through with referrals for further assessments.

The final theme that emerged from the qualitative analysis was a complex description of how practitioner responses to maternal concerns altered the nature of the reasons mothers sought help from practitioners. Results of prior studies have found that mothers reported practitioners provided inconsistent education, support, and information specific to breastfeeding prenatally
through their child’s first year (Cross-Barnet et al., 2012). This study revealed a similar pattern with regard to both breastfeeding and development, specifically early ASD signs. Mothers reported that with each dismissive response, they felt conflicted and frustrated. The mothers described a process of repeated attempts, some over the course of years, to describe atypical behaviors only to have pediatricians recommend waiting, switching focus to health, or at times implying the mother was somehow the cause of infant behaviors. Though not explicitly stated, each mother described a process of slowly changing the information they shared with their pediatrician over time, after each failed attempt, until they viewed the pediatrician solely as a source of medical information. While some were reassured in the pediatrician’s office, the reassurance did little to help the mothers manage the challenges they faced at home without the benefit of guidance from a trained interventionist. One mother became so disenfranchised with her pediatrician’s response to her concerns that she stopped taking her young infant for well child visits and only sought medical care for acute illnesses.

The mothers shared a similar view in regard to seeing IBCLCs. None of the mothers sought help for atypical breastfeeding behaviors; they sought lactation consultation solely for physiological issues such as mastitis. This aspect of the findings is complicated by the fact that mothers in this sample were unaware that the breastfeeding behaviors their infants were exhibiting were atypical. Instead they all seemed to focus on the success of finding a way to manage challenging behaviors and have one consistent parenting option to calm, comfort, and soothe their babies. Similarly, it did not occur to mothers in this sample to seek breastfeeding advice from a pediatrician. The relationship between a breastfeeding mother and infant can vary greatly just as the symptoms of ASD vary among individuals. Though there are common physiological and developmental processes that remain consistent within a range of normal,
future research can further explore the complexities of the experiences that occur during the infancy of children diagnosed with ASD.

**Mixed methods inferences: Alignment between strands.**

The mixed methods inferences from this study explore the extent to which practitioner knowledge aligns with maternal experiences seeking and receiving support for their infant later diagnosed with ASD. Maternal experiences in relation to pediatrician knowledge of available resources enhanced each other with mothers reporting they felt, once the diagnostic process had begun, they were connected to resources based on receiving a diagnosis of ASD for their child. Pediatricians’ self-report of being aware of available resources was moderate; however, the integrated analysis revealed that the mothers all had recommendations of ways that access to resources could be improved for care providers including but not limited to streamlined online resources that connect families to area specific resources or online sources of detailed infant development and early ASD signs. Pediatricians’ self-report combined with mothers’ suggestion of beneficial additional resources helped to enhance the understanding that ease of access to information and streamlined processes for helping families be aware of available resources would be beneficial for families of children with ASD.

Maternal experiences varied in regard to topics related to public health when receiving services from IBCLCs. While IBCLCs had excellent scores in knowledge of public health issues, mothers reported a variety of experiences resulting in a mixed alignment between the results of IBCLC knowledge scores and maternal experiences. The public health category encompasses the risks of artificial feeding and supplementation with formula. Several mothers reported they were offered formula at least once in the hospital setting; however, upon seeking healthcare from an IBCLC at later times their experiences matched IBCLC knowledge. The variety in maternal
experiences specific to recommendations for supplementation resulted in a mixed alignment when comparing results.

Maternal experiences seeking and receiving breastfeeding support from IBCLCs confirmed IBCLC knowledge of breastfeeding physiology, breastfeeding issues during the first days, and assessment of feedings. Given that the IBCLCs had such high results of breastfeeding knowledge, the confirmation that their knowledge translates to practices helps add credibility to the credential and show the benefit of helping connect mothers to IBCLCs as a resource for breastfeeding challenges.

The majority of mothers’ experiences contradicted practitioner knowledge and self-efficacy related to ASD. Maternal experiences with the ASD screening and diagnostic process contradicted pediatricians’ self-report of their confidence in ASD clinical skills, knowledge of behaviors associated with early signs, diagnostic risk, and developmental delays. All mothers reported having at least one experience where a doctor did not follow through on maternal report combined with results of screening indicating a developmental delay that warranted further assessment. Several mothers waited years for their pediatrician to make a formal referral despite multiple indicators being present, often coinciding with enrollment in public school. Only one of the mothers had a negative relationship with the pediatrician, leading to her not following up with well child visits; the other mothers even reported liking their pediatrician’s personality despite the delays in access to services for their child. While they spoke of frustration in the process, they did not seem to have overall negative views of the pediatricians as practitioners. Many attempted to justify the pediatrician’s wait and see approach or lack of clear communication as part of trying to not alarm parents, attempts at reassurance, or having to deal with stressed new parents who worry excessively. Pediatricians rated themselves as not needing
training for ASD and that they were confident in their communication skills with parents.

Mothers’ experiences directly contradicted these results in common themes of dismissal of maternal concerns and direct assessments of delays that did not improve over time. Meanwhile, the families were left struggling to manage challenging behaviors, questioning their own parenting abilities, and frustrated that they didn’t understand how to provide the care necessary to keep their infants content.

One of the most important findings from the integrated analysis was the result of insufficient maternal experiences to properly identify alignment between maternal experiences and practitioner knowledge. The two main areas of insufficient maternal experiences were in relation to pediatrician knowledge of lactation and IBCLC knowledge of late breastfeeding issues and early ASD signs. Data from these two categories could not be compared for alignment because mothers were unaware of the practitioners as being resources specific to each topic and did not seek services.

None of the mothers in this sample turned to pediatricians for breastfeeding information or support after their infant was born, though they all sought help at least once after being discharged from the hospital from an IBCLC to address breastfeeding concerns. The mothers never brought up the frequency of feedings to their pediatricians or the use of breastfeeding to manage challenging behaviors. The absence of inquiry from the pediatrician combined with, as reported previously, mothers’ reluctance to consult with pediatricians for topics outside of health-related issues influenced the lack of maternal experiences seeking help from a pediatrician for breastfeeding issues. Pediatricians may need further training to know how to address breastfeeding within a well child visit to become familiar with questions to ask to ensure a mother is not in need of a referral. Results from a prior study found that when mothers of infants
later diagnosed with ASD were asked questions about their infants breastfeeding behaviors, they were unaware that their infant’s behaviors were atypical because they misinterpreted certain commonly used phrases such as “feed your baby every time they are hungry” to mean that their inability to calm their infant without breastfeeding was “normal” (Dooley, 2017). Thus, clear wording and explanations are crucial to make sure mother and practitioner understand each other. Another important finding from the integrated results is that mothers did not assume a pediatrician could help them with breastfeeding, they viewed breastfeeding as a part of maternal health, and had not thought about asking their pediatrician for advice. Based on pediatricians’ knowledge results, further studies could duplicate the integrated approach in this study to explore what conditions cause mothers to seek breastfeeding help from pediatricians and how they experience receiving breastfeeding support from pediatricians.

Similar to the lack of maternal experiences seeking help from pediatricians for breastfeeding and following the same thought processes, mothers did not seek services from IBCLCs for atypical infant behaviors resulting in insufficient experiences from which to compare results of knowledge assessments. There were multiple reasons the mothers did not seek further assistance from IBCLCs; one of the most prominent was that despite the challenges of relying on breastfeeding as a strategy, the mother’s all ultimately viewed breastfeeding as a success. Several mothers, even those with other typically developing children, were unaware of the atypical breastfeeding behaviors their infants were exhibiting such as lack of eye contact, hand movements near the eye, posture preferences, and physical rigidity while feeding.

Additionally, the mothers viewed breastfeeding as a part of their health, not their infant’s development, and while the majority accessed lactation services in the hospital to help initiate breastfeeding, they only sought help from an IBCLC to treat their own health concerns related to
breastfeeding. Similar to the breastfeeding knowledge scores of pediatricians, the lack of maternal experiences seeking help from an IBCLC for atypical feeding behaviors caused by developmental differences resulted in an inability to compare across results. Results of a prior study exploring mothers’ experiences revealed that when faced with atypical developmental behaviors, IBCLCs may be unprepared to find a solution or know where to refer mothers and infants for further assessment (Dooley, 2017). The low knowledge scores of early ASD signs in the IBCLC group warrant further investigation and a larger scale replication of mothers of infants later diagnosed with ASD might further illuminate the scope of IBCLC knowledge and the experiences mothers have when challenges arise from atypical behaviors in infants later diagnosed with ASD.

Mothers’ perceptions of practitioner’s roles are crucial, and if they are unaware of the scope of services provided by a practitioner, they will be unable to seek assistance when needed. The insufficient alignment categories in this study illuminated a previously unknown gap in relation to reasons why and how mothers choose to seek care from practitioners. The integrated results revealed the importance of making sure mothers were aware of the range of services a practitioner offered. Practitioners who shared the extent of their services would help mothers make informed decisions and understand there were options to ask for assistance.

**Limitations**

One limitation of this study was small and unequal practitioner sample sizes; however, equal sample sizes are not a requirement when comparing between groups. Similarly, the sample of mothers was small and restricted to one Midwest state. While small sample sizes for qualitative studies are acceptable, a broader range of maternal experience will promote full understanding of the phenomenon. Additionally, this study did not link mothers to their own practitioners; the reason behind that decision was the limited number of IBCLCs and the
constraints of data collection of maternal experiences would create challenges protecting the anonymity of participants. Another limitation was that the surveys were completed online, meaning that practitioners could use resources to answer knowledge questions and get a falsely elevated score.

An additional limitation of this study is that health care consumers seldom know the exact certifications a practitioner holds; therefore, it is difficult to know if the mothers in this sample actually received services from IBCLCs. There is currently a wide range of entry level lactation specific certifications, all with a variety of names that sound similar when abbreviated. In addition, some hospitals and clinics have staff that lack any lactation specific credentials yet provide breastfeeding support and advice to mothers. While being an IBCLC was a requirement to participate in the practitioner online survey, a limitation of this study is that mothers may not have been aware that they were consulting with a nurse without lactation specific credentials as opposed to an IBCLC.

**Implications for Future Research**

This multilevel mixed methods approach allowed for an in-depth exploration of practitioner knowledge of breastfeeding and early signs of ASD within the context of maternal experiences. This exploratory study highlighted several complex issues that warrant further examination at the practitioner, maternal, infant, and breastfeeding dyad levels.

Results of this study highlight the important contribution of including exploration of care providers experiences by illuminating otherwise unknown factors impacting families of children with ASD as well as highlighting unmet needs related to barriers that exist to accessing assessment, diagnosis, and intervention services for children with ASD. Future studies can further explore experiences of mothers who sought help from an IBCLC specifically for infant feeding behaviors. Future research can further explore early indicators of ASD based on infant
feeding behaviors and expand additional exploratory studies across diverse groups to examine whether there are between group differences in observations of infant behaviors.

Early access to intervention is associated with improved developmental and family outcomes; future studies can explore the ways infant feeding might be used to assess atypical development (Corsello, 2005; Green et al., 2015; Greenspan, 2007). While most studies focus on rates and duration of breastfeeding and as infants grow breastfeeding tends to become easier, future studies can explore the ages of infants that are typically receiving services from an IBCLC and explore patterns among behaviors that occur in older infants resulting in mothers seeking breastfeeding help past the newborn phase. A further complication specific to IBCLCs is that while IBCLCs have adequate training to provide services to infants of all ages for the duration of breastfeeding, mothers may be unaware that they can seek services from an IBCLC after the newborn period making it difficult to address the scope of late feeding issues. Similarly, future studies could explore the experiences of women who stop breastfeeding based on infant behaviors and switch to bottle feeding, it is essential to extend future studies to explore atypical patterns of bottle-fed infants as well.

**Final Thoughts**

This multilevel mixed methods study explored a complex topic across ecological levels. While several of the results raised further questions and the process of conducting a study across ecological levels was challenging, the results brought to light several previously unknown findings. The goal of this study was not to imply practitioners are not able to meet the requirements of this vocation, but rather to see where unmet needs still linger. While maternal report of a situation, when compared to a practitioners’ experience of the same situation may not align, it is essential to understand that the lived experiences of participants in any research will
always be filtered through their own perceptions and in the end, it is the experiences that make their reality.

The women who participated in this study described heroic, exhausting, often sleep depriving efforts to meet the needs of their infants. It is no doubt that in those times, information gets lost or forgotten. This is where the practitioner holds a powerful role in helping to find ways to ensure communication occurs effectively, checking in with caregivers to see what their unmet needs are and employing effective counseling strategies will not only ensure the best outcomes for the children but also may bring to light a missing piece of information that ultimately leads a practitioner to follow up with further assessment or intervention. Practitioners’ time is limited, pediatricians are spread thin, and IBCLCs are scarce but there may be opportunities to disperse the healthcare roles through stronger referral processes and open lines of communication.
REFERENCES


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.

- **Inform the IRB if the Principal Investigator and/or Supervising Investigator end their role or involvement with the project** with sufficient time to allow an alternate PI/Supervising Investigator to assume oversight responsibility. Projects must have an eligible PI to remain open.

- **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 human subjects research activity if IRB approval lapses, unless continuation is necessary to prevent harm to research participants. Human subjects research activity can resume once IRB approval is re-established.

• Submit an application for Continuing Review 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 date 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.

• Please be advised that your research study may be subject to post-approval monitoring by Iowa State University’s Office for Responsible Research. In some cases, it may also be subject to formal audit or inspection by federal agencies and study sponsors.

• Upon completion of the project, transfer of IRB oversight to another IRB, or departure of the PI and/or Supervising Investigator, please initiate a Project Closure to officially close the project. For information on instances when a study may be closed, please refer to the IRB Study Closure Policy.

Please don’t hesitate to contact us if you have questions or concerns at 515-294-4566 or IRB@iastate.edu
APPENDIX B. RECRUITMENT SCRIPTS

Recruitment Email (Pediatrician)

Hello!

You are invited to participate in a research study exploring pediatricians’ and lactation consultants’ knowledge of breastfeeding and early indicators of autism. The purpose of this study is to learn more about how practitioner knowledge of breastfeeding and early indicators of autism impacts their ability to help mothers and infants in an effort to improve family’s access to services and support. Additionally, this study will explore the experiences mothers of children with autism had seeking help from practitioners during their child’s first years of life, including descriptions of experiences breastfeeding and observations of infant behaviors. Descriptions of mother’s observations of infant behavior will help to identify infants who could benefit from further assessment. The Iowa State University Institutional Review Board approved this study.

You are eligible to participate in this study because you are pediatrician.

I am looking for pediatricians who are:
- Doctor of Medicine (M.D.) or Doctor of Osteopathic Medicine (D.O.)
- American Board of Pediatrics certified
- Provide health care services to infants and toddlers

I am Leslie Dooley, an International Board Certified Lactation Counselor and PhD student in the Department of Human Development and Family Studies at Iowa State University. I am conducting this research study to complete my dissertation and have chosen this topic based on my experiences providing breastfeeding support to mothers and infants who struggled to breastfeed successfully based on an undiagnosed developmental disability. I hope you will be interested in participating.

Your participation in this study is completely voluntary. The results of the study may be used in reports, presentations, and publications but your identity will not be known. These data will not be linked back to you as an individual during reporting.

If you agree to participate in this study, you will complete a brief online survey. Upon completion of the survey, you will be entered into a drawing for a chance to receive one of five $125.00 Amazon.com gift cards to thank you for your participation.

To participate in this research please follow the link below to begin the survey:
https://iastate.qualtrics.com/jfe/form/SV_cvl5VEiQPXela2N

If you have any questions or would like more information please contact me at:

Leslie Dooley (researcher) by phone (XXX-XXX-XXXX) or by e-mail at ljdooley@iastate.edu

Sincerely,

Leslie Dooley, PhD Student and Carla Peterson, PhD.
Recruitment Email (Lactation Consultants)

Hello!

You are invited to participate in a research study exploring pediatrician and lactation consultant’s knowledge of breastfeeding and early indicators of autism. The purpose of this study is to learn more about how practitioner knowledge of breastfeeding and early indicators of autism impacts their ability to help mothers and infants in an effort to improve families’ access to services and support. Additionally, this study will explore the experiences mothers of children with autism had seeking help from practitioners during their child’s first years of life, including descriptions of experiences breastfeeding and observations of infant behaviors. Descriptions of mothers’ observations of infant behavior will help to identify infants who could benefit from further assessment. The Iowa State University Institutional Review Board approved this study.

You are eligible to participate in this study because you are an International Board Certified Lactation Consultant (IBCLC).

I am looking for IBCLCs who are:

International Board of Lactation Consultant Examiners certified

Provide lactation support services to mothers and infants after being discharged from the hospital

Areas of Practice include:

- Clinic/Birthing Center/Wards
- Community/Public Health/WIC
- Government/Military
- Home
- Visits
- Hospital
- Physician's Office
- Private Practice
- Volunteer Support

I am Leslie Dooley, an International Board Certified Lactation Counselor and PhD student in the Department of Human Development and Family Studies at Iowa State University. I am conducting this research study to complete my dissertation and have chosen this topic based on my experiences providing breastfeeding support to mothers and infants who struggled to breastfeed successfully based on an undiagnosed developmental disability. I hope you will be interested in participating.
Your participation in this study is completely voluntary. The results of the study may be used in reports, presentations, and publications but your identity will not be known. These data will not be linked back to you as an individual during reporting.

If you agree to participate in this study, you will complete a brief online survey. Upon completion of the survey, you will be entered into a drawing for a chance to receive one of five $125.00 Amazon.com gift cards to thank you for your participation.

To participate in this research please follow the link below to begin the survey: https://iastate.qualtrics.com/jfe/form/SV_3JZbGCGBbpKTSaF

If you have any questions or would like more information please contact me at:

Leslie Dooley (researcher) by phone (XXX-XXX-XXXX) or by e-mail at ljdooley@iastate.edu

Sincerely,

Leslie Dooley, PhD Student and Carla Peterson, PhD.
Iowa State University
Department of Human Development and Family Studies
Ames, IA 50011
Recruitment Email (Mothers)

Hello!

My name is Leslie Dooley. I am a Certified Lactation Counselor and PhD student in the department of Human Development and Family Studies at Iowa State University. I am contacting you today regarding an opportunity for mothers of children diagnosed with autism to participate in a research study.

**You are invited** to participate in a research study exploring pediatrician’s and lactation consultant’s knowledge of breastfeeding and early indicators of autism. In order to improve family’s access to services and support, it is important to understand mother’s experiences seeking help from pediatricians and lactation consultants. This study will include mother’s memories of experiences during the first years of their child’s life, including breastfeeding and other behaviors. The purpose of this study is to learn more about how practitioner knowledge of breastfeeding and early indicators of autism impact their ability to help mothers and infants. Additionally, descriptions of mother’s experiences seeking help and observations of infant behavior will help to identify infants who could benefit from further assessment. The Iowa State University Institutional Review Board approved this study.

I am looking for mothers who are:

- Over the age of 18
- Breastfed for at least 6 weeks without formula or solid food supplementation
- Sought help from a lactation consultant at least once after leaving the hospital

Whose child is:

- 10 years of age or younger
- Born at full term (after 39 weeks of pregnancy)
- Primary care doctor during infancy was a pediatrician
- 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 **$50.00 gift card** to thank you for your participation.

Your participation in this study is 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.
Recruitment Phone Script (Mothers)

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 and. I am looking for mothers who are:

• Over the age of 18
• Breastfed for at least 4 weeks without formula or solid food supplementation
• Sought help from a lactation consultant at least once after leaving the hospital

Whose child is:

• 13 years of age or younger
• Born at full term (after 39 weeks of pregnancy)
• Primary care doctor during infancy was a pediatrician
• 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 $50.00 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)_____.

APPENDIX C. INFORMED CONSENT DOCUMENTS

INFORMED CONSENT DOCUMENT (Pediatrician)

Title of Study: An Integrated Exploration of Pediatrician and Lactation Consultant Knowledge of Atypical Development

Investigators: Leslie J. Dooley (researcher)
               Dr. Carla Peterson, Major Professor

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 practitioner who works with young children and their families can be both challenging and rewarding. Families who have a child 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 about practitioners knowledge of breastfeeding and early indicators of autism will be gathered through online surveys. Additionally, several mothers of children who have already been diagnosed with an autism spectrum disorder will be interviewed to explore mother’s experiences seeking help, breastfeeding, and their observations of infant behaviors.

The purpose of this study is to learn more about practitioner knowledge of breastfeeding and early indicators of autism. Additionally, a goal of this study is to learn more about the infancy of children diagnosed with autism, including breastfeeding and other behaviors, based on mother’s memories of experiences during the first years of their child’s life that could indicate the need for a child to receive further assessment.

I am looking for pediatricians who are:

- Doctor of Medicine (M.D.) or Doctor of Osteopathic Medicine (D.O.)
- American Board of Pediatrics certified
- Provide health care services to infants and toddlers

The central questions of this study will focus on mother’s experiences seeking help from lactation consultants and pediatricians regarding breastfeeding and concerns about infant behaviors. Additionally, mother's experiences breastfeeding and observations of infant behaviors will be explored.

In order to improve family’s access to services and support, it is important to understand mother’s experiences seeking help from pediatricians and lactation consultants. Understanding mother’s experiences seeking help, breastfeeding, and raising an infant 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 training for practitioners. You are being invited to participate in this study because you are pediatrician.

This study is being conducted by a graduate student at Iowa State University for the purposes of a dissertation research study required for completing a doctoral degree.
DESCRIPTION OF PROCEDURES
If you agree to participate in this study, your participation will last 45 to 55 minutes in the form of an online survey. It will involve you answering questions about breastfeeding and early indicators of autism.

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
As an incentive for your involvement in this study, you will have the option to be entered into a drawing for a $125.00 Amazon.com gift card following completion of the survey. Participation in the gift card drawing is optional.

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 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, 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. The information in this study will be used only for research purposes and in ways that will not reveal who you are. All survey responses are deidentified, stored securely, and kept confidential. You will not be identified in any publication from this study. Personal information, including name and email address, will be kept separate from survey responses. Only the research team will have access to information that identifies you to carry out this research study. Your identifying information will not be shared with others outside this research study.

FUTURE USE OF YOUR INFORMATION
De-identified information collected about you during this study may be shared with other researchers or used for future research studies. We will not obtain additional informed consent from you before sharing the de-identified data.

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
Title of Study: An Integrated Exploration of Pediatrician and Lactation Consultant Knowledge of Atypical Development

Investigators: Leslie J. Dooley (researcher)
Dr. Carla Peterson, Academic Adviser

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 practitioner who works with young children and their families can be both challenging and rewarding. Families who have a child 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 about practitioner’s knowledge of breastfeeding and early indicators of autism will be gathered through online surveys. Additionally, several mothers of children who have already been diagnosed with an autism spectrum disorder will be interviewed to explore mother’s experiences seeking help, breastfeeding, and their observations of infant behaviors.

The purpose of this study is to learn more about practitioner knowledge of breastfeeding and early indicators of autism. Additionally, a goal of this study is to learn more about the infancy of children diagnosed with autism, including breastfeeding and other behaviors, based on mother’s memories of experiences during the first years of their child’s life that could indicate the need for a child to receive further assessment.

I am looking for IBCLC’s who are:

- International Board of Lactation Consultant Examiners certified
- Provide lactation support services to mothers and infants after being discharged from the hospital
- Areas of Practice include:
  - Clinic/Birthing Center/Wards
  - Community/Public Health/WIC
  - Government/Military
  - Home Visits
  - Hospital
  - Physician's Office
  - Private Practice
  - Volunteer Support

The central questions of this study will focus on how practitioner knowledge aligns with mother’s experiences seeking help from lactation consultants and pediatricians regarding breastfeeding and concerns about infant behaviors. Additionally, mother’s experiences breastfeeding and observations of infant behaviors will be explored.
In order to improve family’s access to services and support, it is important to understand mother’s experiences seeking help from pediatricians and lactation consultants. Understanding mother’s experiences seeking help, breastfeeding, and raising an infant 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 training for practitioners. You are being invited to participate in this study because you are an International Board Certified Lactation Consultant.

This study is being conducted by a graduate student at Iowa State University for the purposes of a dissertation research study required for completing a doctoral degree.

DESCRIPTION OF PROCEDURES

If you agree to participate in this study, your participation will last 30 to 45 minutes in the form of an online survey. It will involve you answering questions about breastfeeding and early indicators of autism.

RISKS

The risks of this study are very minimal. While participating in this study, you may experience possible discomfort while completing the survey.

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

As an incentive for your involvement in this study, you will have the option to be entered into a drawing for a $125.00 Amazon.com gift card following completion of the survey. Participation in the gift card drawing is optional.

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 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, 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. The information in this study will be used only for research purposes and in ways that will not reveal who you are. All survey responses are
deidentified, stored securely, and kept confidential. You will not be identified in any publication from this study. Personal information, including name and email address, will be kept separate from survey responses. Only the research team will have access to information that identifies you to carry out this research study. Your identifying information will not be shared with others outside this research study.

**FUTURE USE OF YOUR INFORMATION**

De-identified information collected about you during this study may be shared with other researchers or used for future research studies. We will not obtain additional informed consent from you before sharing the de-identified data.

**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

*******************************************************************************
INTRODUCTION

Being a parent of a young child is both challenging and rewarding. Families who have a child 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 practitioner knowledge of breastfeeding and early indicators of autism. Additionally, this study is to learn more about the infancy of children diagnosed with autism, including breastfeeding and other behaviors, based on mother’s memories of experiences during the first years of their child’s life that could indicate the need for a child to receive further assessment.

I am looking for mothers who are:

- Over the age of 18
- Breastfed for at least 4 weeks without formula or solid food supplementation
- Sought help from a lactation consultant at least once after leaving the hospital

Whose child is:

- 13 years of age or younger
- Born at full term (after 39 weeks of pregnancy)
- Primary care doctor during infancy was a pediatrician
- 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 experiences seeking help from lactation consultants and pediatricians regarding breastfeeding and concerns about infant behaviors. Additionally, mother's experiences breastfeeding and observations of infant behaviors will be explored.

In order to improve family’s access to services and support, it is important to understand mother’s experiences seeking help from pediatricians and lactation consultants. Understanding mother’s experiences seeking help, breastfeeding, and raising an infant 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 training for practitioners. 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 10 years old or younger.

This study is being conducted by a graduate student at Iowa State University for the purposes of a dissertation research study required for completing a doctoral 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 seeking help from lactation consultants and pediatricians, breastfeeding and 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 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.

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 $50.00 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, 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.

FUTURE USE OF YOUR INFORMATION

De-identified information collected about you during this study may be shared with other researchers or used for future research studies. We will not obtain additional informed consent from you before sharing the de-identified data.

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 ldooley@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.

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.
APPENDIX D. RESEARCH SUMMARY STATEMENT

Research Summary Statement

An Integrated Exploration of Pediatrician and Lactation Consultant Knowledge of Atypical Development

Introduction

Currently, one out of every 59 infants born in the United States will later be diagnosed with autism (Baio et al., 2018). There are currently more people diagnosed with ASD than at any other time, making ASD the fastest-growing developmental disability. The rates of ASD have shown significant and continuous increases over time (Boyle et al, 2011). Families may face unique challenges related to atypical infant behaviors and feeding patterns before diagnosis of autism occurs. There is wide variation of symptoms among children with autism, however, children with autism are five times more likely to have feeding issues. 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 autism (Ahearn, 2001). Despite not being included in the current criteria for diagnosis of autism, 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 autism affects early feeding behaviors (Bandini et al., 2010; Beighley et al., 2013).

However, little is known about when feeding issues begin, how atypical behaviors impact infant caretaking needs, and whether practitioners have sufficient training to identify infants for further developmental assessment. As a result, despite evidence based early indicators of autism
during infancy, most children aren't diagnosed with autism until they begin preschool (Baio, 2014). The earlier assessment and diagnosis can occur, the sooner a child and family can begin to receive treatment and support. When practitioner views of infant feeding focus only on nutrition, atypical feeding behaviors may be overlooked as a way to identify atypical development. Infants who have behaviors associated with later diagnosis of autism may face unique challenges breastfeeding. Practitioners need to have knowledge of development, early indicators of autism, and infant feeding behaviors to provide support to parents and prevent maltreatment.

**Purpose**

The purpose of this study is to better understand pediatricians’ and lactation consultants’ knowledge of infant feeding behaviors and early indicators of autism. Practitioners’ knowledge base, attitudes, and beliefs specific to both breastfeeding and early indicators of autism during infancy will be assessed. Comparing measures of knowledge between two groups of practitioners will help to identify gaps in knowledge. Additionally, this study will examine the formal and informal networks of support that mothers of infants later diagnosed with autism accessed during her child’s infancy, and her observations of infant behaviors before a formal diagnosis of autism occurred. The study will include mothers who have a child diagnosed with autism who also breastfed for at least the first 4 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. Infants who have behaviors associated with later diagnosis of autism may face unique challenges breastfeeding. Practitioners need to have knowledge of development, early indicators of autism, and infant feeding behaviors to identify infants that can benefit from further developmental evaluation and provide support to parents. Practitioner knowledge assessments will be compared with mother’s experiences to describe the ways in which results align or deviate from each other. The impact of practitioner knowledge of lactation and autism within the context of maternal experiences breastfeeding and caring for infants later diagnosed with autism has never been explored directly. This study will describe ways practitioner can better meet mothers’ and infants’ needs, illuminate potential barriers to services and support, and provide a better understanding of the relationship between development and infant feeding behaviors.

Participants and Procedures

The goal of this project will be to better understand pediatricians’ and lactation consultants’ knowledge of infant feeding behaviors and early indicators of autism, allowing for early assessment and intervention that will support child development and promote healthy development. Examining mothers’ experiences seeking support, breastfeeding, and observations of infant behavior will allow for a better understanding of how practitioner knowledge impacts their ability to provide support. Participants will include pediatricians, lactation consultants, and mothers of children diagnosed with autism.

A national sample of pediatricians and lactation consultants will be recruited to assess practitioner knowledge through online surveys. 150 licensed pediatricians and 150 certified Lactation Consultants will be recruited.
Mothers are often the primary caregiver for infants and provide the best source of information regarding their child’s patterns of behavior and development. In an effort to improve family’s access to support and understand the feeding experiences that occur before a child receives a diagnosis of autism, information will be gathered from several mothers of children who have already been diagnosed with autism. The inclusion criteria for mothers to participate will be: 1) Mothers of a child less than thirteen years of age who has a diagnosis of autism, Asperger’s Syndrome, Pervasive Developmental Disorder), 2) who breastfed their child for at least four weeks, 3) sought help from a lactation consultant at least once while breastfeeding, not including visits from lactation consultant while still in the hospital after giving birth, 4) primary health care provider for their child with autism was a pediatrician, and 5) child with autism does not have other medical conditions that may have impacted feeding.

**Implications of the Study**

The purpose of this study is to assess practitioners’ knowledge base, attitudes, and beliefs specific to both breastfeeding and early indicators of ASD during infancy integrated within the context of mothers’ experiences and observations. This study will provide systematic evidence of what mothers observe and experience before a diagnosis of ASD occurs as well as the efficacy of their attempts to seek support for their child’s needs. The results of this study will have the potential to improve practice and influence future research exploring infant feeding from a developmental perspective, building a bridge between research and practice to help support mothers and infants.

This study will add to existing research exploring early indicators of autism, by expanding existing evidence based information of atypical infant feeding behaviors across multiple disciplines that interact with children and their families. Expected outcomes include
demographic information that may help to illuminate maternal characteristics associated with both increased risk of breastfeeding challenges and having a child with autism.

This study will help to influence future research. Future research can further explore infant feeding behaviors as a way to identify infants at risk for autism from a developmental perspective, including potential creation of developmental feeding assessments related to existing early indicators of autism. Feeding assessments would allow families to begin receiving services sooner and decrease stress while improving child outcomes. Infant feeding assessments could be further expanded to include infants who bottle feed and those who never breastfed. There is a need for future research to develop both assessment and interventions for infants who are at risk for diagnosis of autism or those who are exhibiting symptoms. In addition, this research can influence policies that would provide families who have a child with autism with access to support and interventions at an early age that will support the child’s development.

Additionally, measures of practitioner knowledge will help to clarify whether there are concepts related to both lactation and early indicators of ASD that practitioners need further training and information to better serve families. The results of this study can be used to specifically create professional development trainings for practitioners as well as influence policies that are designed to support breastfeeding mothers of infants who exhibit atypical patterns of development while promoting the importance of interdisciplinary approaches to both research and practice. The results will also highlight support services and practitioner practices that families found useful or helpful, this information is equally valuable to understand the efficacy of interventions and family support at a practitioner level. Results of this study will highlight the importance of developmental and lactation specific education for all practitioners that work with infants and families.
APPENDIX E. INTERVIEW PROTOCOL

Introductory Protocol

To facilitate my note-taking, I would like to record our conversations today. For your information, only my academic advisor, who is a faculty member at Iowa State University, and I will have access to listen to the recorded interview. 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 your 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.

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.
Demographic Questions
(demographics included in the eligibility survey)

1. How old are you?
2. How old were you when you had your first child?
3. How old were you when you had your child with ASD?
4. What is your highest level of education?

Before we begin, I have a few health-related questions.

Health Questions for Mothers

Did you experience or were you diagnosed with any of the following conditions?

- Exclusive Breastfeeding less than 6 weeks (including formula feeding in the hospital)
- If formula was given in the hospital what was the reason?
- Breast surgery
- C-Section
- Flat or Inverted nipples
- Absence of breast changes during pregnancy
- Hormonal disorder (PCOS, Thyroid)
- Please specify
- Child has additional medical disorders
- Child born before 39 weeks
- Other health conditions
In Depth Questions

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

1. Tell me about your family
   a. Probes specific to family:

2. How many children do you have?

3. What are their ages?

4. How many of your children have a diagnosis of autism spectrum disorder?

5. At what age was your child diagnosed with autism?

6. What led you to breastfeed?

7. Did you breastfeed your child that was diagnosed with autism?

8. How long did you breastfeed?

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

(If so) Tell me about your experiences breastfeeding children who do not have ASD diagnosis, were they similar or different when compared to breastfeeding your child with ASD

1. Tell me about your experiences breastfeeding child with ASD
   a. Probes specific to breastfeeding:
   b. What went well for you?
   c. What aspects of breastfeeding do you feel did not go well for you?

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

3. How did you know when you baby was full?

4. Did you seek assistance for breastfeeding?
   a. Probes specific to seeking assistance breastfeeding:
   b. If so, who helped you and what were the suggestions?
5. Tell me about that experience (Related to getting help for breastfeeding)

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

7. Probes specific to symptoms of ASD:
   a. Tell me more about that behavior
   b. Tell me how often the behavior occurred

8. 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?
   b. Tell me about how you handled those behaviors?

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

10. Tell me about the kind of support that you received?

11. Did you seek assistance from a trained professional for those behaviors?
    a. If so who?
    b. Tell me about that experience
    c. Did she tell you what her credentials were?

12. 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?

13. If you did seek help, tell me about your reaction to that experience

14. Tell me about your thoughts or feelings in reaction to that experience?
15. Is there anything else that you feel would have been helpful for you during your
child’s infancy while you were breastfeeding?

16. Tell me about your child’s transition to solid foods

17. When were solid foods introduced

18. What (or who) lead you to introduce solid foods

19. Tell me about your thoughts or feelings in reaction to that experience?

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

**Final Question**

Please choose 3 words to describe your experiences breastfeeding your child diagnosed
with autism
APPENDIX F. QUANTITATIVE MEASURES ONLINE SURVEY

Pediatrician Survey

Informed Consent

Q1 Welcome to the research study!

   By clicking the button below, you acknowledge that your participation in the study is voluntary, you are 18 years of age, and that you are aware that you may choose to terminate your participation in the study at any time and for any reason. Please note that this survey will be best displayed on a laptop or desktop computer. Some features may be less compatible for use on a mobile device.

   o I consent, begin the study
   o I do not consent, I do not wish to participate

Demographic Survey

Q2 What is your gender?
   o Male
   o Female
   o Other
   o I choose not to respond

Q3 Which category below includes your age?
   o 18-20
   o 21-29
   o 30-39
   o 40-49
   o 50-59
   o 60 or older
Q4 With which race/ethnicity do you identify? (Select ALL that apply)
- African American/ Black
- Asian
- Hispanic or Latino
- Middle Eastern
- Multiracial
- Native American/ American Indian/ Alaska Native
- Pacific Islander
- White or Caucasian

Q5 Do you have any of the following certifications? (Select ALL that apply)
- RNC Inpatient Obstetric Nursing (RNC-OB)
- RNC Low Risk Neonatal Nursing (RNC-LRN)
- RNC Maternal Newborn Nursing (RNC-MN)
- RNC Neonatal Intensive Care Nursing (RNC-NIC)
- International Board Certified Lactation Consultant (IBCLC)
- Certified Lactation Consultant (CLC)
- Certified Breastfeeding Consultant (CBC)
- Other (Please specify)

Q6 What best describes your pediatric practice style? (Check ONE Only)
- Community general pediatrician
- Academic general pediatrician
- Pediatric hospitalist

Q7 In which state do you currently practice? (Select ALL that apply)

Q8 Which of the following categories best describes your employment status?
o Employed, working 40 or more hours per week
o Employed, working 1-39 hours per week
o Not employed, looking for work
o Not employed, NOT looking for work
o Retired

Q9 What is the highest level of school that you have completed? (Check ONE Only)
o Less than high school, no GED
o High school graduate, diploma or GED
o Some college credit, but less than 1 year
o 1 or more years of college, no degree
o Associate degree (ex: AA or AS)
o Bachelor’s degree (BA, BS, AB)
o Master’s degree (MS, MA, MSW, MSN, MEd, MBA)
o Professional degree (MD, OD)
o Doctorate degree (PhD, DrPH, ScD)
o Other (please specify)

Q10 How many years of experience do you have in your current position?

Q11 How many total years of experience do you have in a maternity ward (if applicable)?

Q12 Do you have any children?
o Yes
o If Yes, how many?
o No

Q13 Do you (or your partner) have any personal experience in breastfeeding?
Q14 If you (or your partner) had personal breastfeeding experience, what was the total duration of breastfeeding (in months)?

- Personal experience breastfeeding duration (in months)
- Partner experience breastfeeding duration (in months)
- Not applicable

**Questionnaire about Breastfeeding Knowledge**

Q15 The following section of the survey will evaluate breastfeeding knowledge and skills.

*THIS IS NOT AN EXAM Please, answer the questionnaire without consulting any resources and try not to leave any questions blank.*

Q16 In case of mastitis, breastfeeding should be temporarily interrupted.

- True
- False

Q17 Babies should breastfeed every 2-3 hours for 15 minutes on each breast.

- True
- False

Q18 Exclusive formula feeding is associated with an increased risk of infectious morbidity.

- True
- False

Q19 Most babies born by cesarean section need to be supplemented with formula in the first hours of life.

- True
Q20 If a breastfed baby has problems breastfeeding and needs supplementary breast milk or formula, it should generally not be administered by bottle, especially in the first weeks of life.

- True
- False

Q21 About the breastfed newborn: a high frequency of feedings decreases the risk of requiring phototherapy.

- True
- False

Q22 Before the first breastfeeding in delivery room: a healthy term newborn should be weighed, the Apgar score checked in a crib with radiant heat, newborn should receive ophthalmic prophylaxis and a vitamin K shot.

- True
- False

Q23 In very premature infants (<32 wk) the best option is breast milk (fortified when required) and the second best is human milk from a milk bank. Supplementation with special preterm formula is the last option.

- True
- False

Q24 In the maternity ward, a breastfed newborn over 15 hours old who needs to be roused for every feed is at risk.

- True
- False
Q25 The nutrient content of breastmilk significantly decreases after 12 months of lactation when compared to the first year.
   - True
   - False

Q26 An initial assessment of a breastfed infant, with an otherwise good appearance, reveals low weight gain. The first step is to supplement with formula and reassess.
   - True
   - False

Q27 After 6 months of age, breastfeeding should be reduced to 2-3 a day, and infants should be supplemented with other foods.
   - True
   - False

Q28 “Watery milk” is the foremilk.
   - True
   - False

Q29 This picture shows a correct latch on.
Q30 What are the current WHO recommendations on breastfeeding?

- Exclusive breastfeeding (EBF) for 4 months of age, thereafter supplementation with complementary foods and breastfeeding for as long as mother and child wish.
- EBF for 6 months of age, thereafter supplementation with complementary foods, and continued breastfeeding for up to two years.
- EBF for 6 months, thereafter supplementation with complementary foods, and continued breastfeeding for up to two years or beyond as mother and child wish.

Q31 Which of the following is the most important action to be performed in a nursing mother that has cracked nipples?

- Wash with soap and water
- Apply pure lanolin after feeding
- Assess a breastfeed
- Recommend the use of nipple shields

Q32 17. Parents bring their 17 day old infant to the emergency department because of increased crying. He is exclusively breastfed and until now everything was going well, however, in the past 24 hours he cries and breastfeeds very often, sometimes every 30-60 minutes. He calms down on the breast and sucks vigorously. The baby has no appearance of disease, weight gain is good, and the physical examination is normal, but the mother has the feeling that he is still hungry. Which diagnosis and treatment decision would you make?

- Hypogalactia. I would supplement every feed with 60 ml (2 Oz) of formula and recommend follow-up with his physician.
o Growth spurt. I would assess a feed, recommend breastfeeding on demand and routine check with his physician.

o Hypogalactia. I would recommend test weight (before and after each breastfeed) and supplement with formula to complete at each feed the amount necessary to reach 150 ml (5 Oz) per kg per day divided in 8 feeds.

o Baby colic. I would recommend giving abdominal massages and balancing the child in prone position till the next feed time.

Q33 List 5 features of a correct latch you could use to assess a breastfeed:

[Broad or ambiguous responses (eg, "lips" or "mouth posture") will not be accepted. Please be specific in just 2 or 3 words]

Q34 What would you say to a pregnant woman that mentions at the office she is thinking about using artificial feeding (formula)?

   o Nothing, since that is a personal choice and I would respect it.
   o I would ask her to tell me more about it, in order to know her reasons and information, and based on respect, I would encourage her to reconsider it.
   o Given the absolute superiority of breast milk, it is irresponsible not to breastfeed when there are no contraindications.
   o Do not feel guilty, because most children grow equally well with bottle feeding.
   o All answers are correct.

Q35 About giving free samples of starter infant formula to the mothers in health centers:

   o It is a violation of the International Code of Marketing of Breast-milk Substitutes.
   o It is acceptable as partial support for low-income families.
   o It is acceptable if it is clearly written that breast milk is the best food for infants.
- It is appropriate to help mothers with breastfeeding problems.
- All answers are correct

Q36 A nursing mother consults with you about the safety of breastfeeding while starting a new medication. She is going to begin treatment with adalimumab for Crohn's disease. Her gastroenterologist has told her she should wean her 8 month old baby because the treatment is important. Where could you look up if the drug is compatible or not with breastfeeding?
  - In the technical data sheet for the drug.
  - I would refer to the information supplied by the specialist who prescribed it.
  - In my Drug Handbook (Vademecum or similar)
  - It is not necessary to consult. Assessing risks and benefits, weaning is best since child is already 8 months old.
  - On a website I know (please, specify):

Q37 You are the doctor and you're at the maternity ward. A nurse is worried about a breastfed newborn. She believes that something is going wrong with breastfeeding and she wants you to assess a breastfeed.

  - I have never assessed a newborn breastfeeding and I would not know exactly what to observe.
  - I have assessed few breastfeeds during my training period, but I do not have much experience. I believe I would only identify obvious problems.
  - I do not feel confident. I would preferably check weight loss and glycemia. If in doubt, I would recommend a supplement to prevent weight loss.
  - I have assessed many breastfeeds and I would be able to identify the most common problems and provide solutions for them.
Q38 Do you consider breastfeeding in public appropriate behavior?
   ○ Yes
   ○ No

Q39 Rate from 1 to 5 the quality of breastfeeding training received during your Internship and Residency:
   1 Very poor
   2 Quite poor
   3 Fair
   4 Quite Good
   5 Excellent

Q40 Have you ever attended a specific breastfeeding course?
   ○ Yes
   ○ No

Q41 If yes, please indicate the number of courses you have received and the total approximate duration (hours).
   ○ Number of courses
   ○ Total approximate hours of education
   ○ None

Q42 Which is your greatest source of knowledge about breastfeeding? (Multiple options are acceptable)
   ○ Courses
   ○ Textbooks / journal articles
   ○ Knowledge acquired in the degree.
Q43 Do you think you should be an expert in diagnosing and providing solutions to specific breastfeeding problems?

- Yes
- No

Q44 If yes, why? (Multiple options are acceptable)

- Because it is a frequent complaint
- For the good of my patients and their families
- Because it's part of my job
- Other (please specify)

I do not feel I need to be an expert in diagnosing and providing solutions for breastfeeding problems.

Q45 How qualified do you feel to diagnose and provide solutions specific to breastfeeding problems?

- Absolutely not
- Somewhat qualified
- Qualified
- Well qualified
- Extremely qualified
**Breastfeeding Knowledge Survey**

Q46 Thank you for your input on this study of pediatrician involvement in infant feeding practices. For the following questions, select your chosen answers specific to your experiences, beliefs and practices.

Q47 1. During the past year, how often have you:

<table>
<thead>
<tr>
<th>Observed a patient breastfeeding in a hospital or office setting?</th>
<th>Never</th>
<th>Once or twice</th>
<th>Three or four times</th>
<th>Five or more times</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counseled an expectant or newly delivered mother about infant feeding choices?</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>Taught a new mother breastfeeding techniques (e.g. latching on, infant placement)?</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>Taught a breastfeeding mother how to use a breast pump?</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>Counseled a breastfeeding mother about lactation problems (e.g. mastitis, cracked nipples)?</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
</tbody>
</table>

Q48 Of the patients you see for prenatal interviews, for how many do you provide breastfeeding counseling?
- None
- Few
- About half
- Most
- All

Q49 Do provide breastfeeding counseling more or less often than you expected when you completed residency?
- Less often
- More often
- About as much as I expected

Q50 Considering your experiences in practice, how well did your residency training prepare you to support breastfeeding mothers? Did it give you:
No preparation
Less than adequate preparation
Adequate preparation
Good preparation
Excellent preparation

Q51 How might your residency program have better prepared you for your role in breastfeeding promotion?

- More lecture time on breastfeeding
- More practice of teaching techniques
- More practice of counseling skills
- Other: Specify

Q52 Do you now think pediatrician involvement in breastfeeding is more or less important as compared with your opinion when you completed residency?

- Less important
- More important
- About the same

Q53 During the time that you have been in practice, which factors have influenced your attitudes regarding pediatrician involvement in breastfeeding? (check all that apply)

- Patient demand
- Personal experience
- Hospital expectations or policies
- Pressure from colleagues
- Continuing education activities
- Other (specify)

Q54 During the time that you have been in practice, which is the most important factor to influence your attitudes regarding pediatrician involvement in breastfeeding?

- Patient demand
- Personal experience
- Hospital expectations or policies
- Pressure from colleagues
o  Continuing education activities
o  other (specify)

Q55 9. Do you feel it is the role of pediatricians to:

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Somewhat disagree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recommend breastfeeding to expectant mothers?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assist post-delivery mothers with breastfeeding in hospital?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follow up with mothers out of hospital regarding breastfeeding?</td>
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</tbody>
</table>

Q56 With regard to the use of your time, would you say that breastfeeding promotion is:

- o  Not important
- o  Somewhat important
- o  Important
- o  Very important

Q57 With regard to the amount of time you spend providing breastfeeding counseling and support, would you say third-party reimbursement policies have:

- o  No influence
- o  Minimal influence
- o  Influence
- o  Strong influence

Q58 What is your opinion regarding the statement that exclusive breastfeeding (without supplementation) is the most beneficial form of nutrition for the first four months of an infant's life?

- o  Strongly disagree
- o  Disagree
- o  Somewhat disagree
- o  Neither agree nor disagree
Q59 Some studies have suggested various health benefits of breastfeeding. For infants in the United States, what is your opinion regarding the following statements?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Somewhat disagree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breastfeeding decrease the incidence of otitis media.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Breastfeeding protects against rubella.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Breastfeeding decreases the incidence of gastroenteritis.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Breastfeeding provides increased immune function.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

Q60 Regarding your ability to assist post-partum women in initiating breastfeeding, would you say you are:

- Not confident
- Somewhat confident
- Confident
- Very confident

Q61 When called by a breastfeeding mother concerned about her milk supply during the first two weeks of lactation, your most likely response is to: (Check only one)

- Recommend continued breastfeeding with formula supplementation
- Counsel the mother and advise that she continue exclusive breastfeeding
- Refer the mother to another person (nurse, aide, or physician) or organization
- Other (please specify):

Q62 What would you recommend for an otherwise-healthy breastfed 4 day-old infant with jaundice?

- Supplement breastfeeding with glucose or sterile water
Supplement breastfeeding with formula
Encourage more frequent breastfeeding
Stop breastfeeding and begin exclusive formula feeding
Other (please specify):

Q63 Given each of the following conditions, would you tell a mother to stop breastfeeding completely (i.e., discontinue nursing or pumping on both sides)?

<table>
<thead>
<tr>
<th>Condition</th>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Mastitis</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>2. Insufficient milk supply</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>3. Breast abcess</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>4. Teething</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>5. Frequent loose stools</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>6. Baby not seeming satiated</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
</tbody>
</table>

Q64 What is your opinion regarding the statement that supplementing breastfeeding with formula during the first two weeks of life is a cause of breastfeeding failure?

- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

Q65 How would you present the feasibility of breastfeeding to working mothers?

- Not feasible
- Somewhat feasible
- Feasible
- Very feasible
Q66 How effective do you think you are in meeting the needs of your breastfeeding patients?
   - Not effective
   - Moderately effective
   - Effective
   - Very effective

Q67 Have you or your spouse ever breastfed an infant for more than two weeks?
   - Yes
   - No

Knowledge about Early Autism Signs

Q68 Please answer all of the following questions. Do not spend a lot of time on one question relative to the others. Since it is important for us to learn about your personal knowledge in this area, please, do not rely on external information such as websites, books, or friends.

Q69 Select the response that best reflects the degree to which you agree with each of the following statements. Please complete all items and select "I don't have specific knowledge about this topic" only as your last resort.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Somewhat agree</th>
<th>Somewhat disagree</th>
<th>Mostly disagree</th>
<th>Fully disagree</th>
<th>I don't have specific knowledge about this topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Autism can be diagnosed as early as 24 months</td>
<td></td>
<td></td>
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<tr>
<td>2. The need for sameness and difficulty coping with transitions between activities are one of the early behavioral features of autism</td>
<td></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>3. A young child with autism can express his needs such as: asking for water or food</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
4. Increased head circumference relative to age is an early sign for autism

5. Premature babies have higher risk of autism

6. Delays in attaining motor milestones such as sitting and walking are not necessary sign for autism

7. Some children with autism show typical global development until the age of one and a half

8. Early developmental regression autism can occur up to the age of three years

9. Most children with autism under the age of four can draw their parent’s attention to an interesting event such as a street clown

Q70 What early signs in a baby under your care raise your concern for autism?

Q71 In your opinion, which babies are at increased risk for autism?

Q72 Are you part of a team which screens and diagnoses children with autism?

○ Yes

○ No

Q73 For each of the following statements select the response that best reflects the degree to which you agree with the statement

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel comfortable to contribute my professional opinion for diagnosing or identifying a child with autism</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I feel comfortable and confident in discussing early warning signs of ASD with my patients’ parents</td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>
3. I feel confident in my ability to make appropriate referrals for further evaluation of young children with a risk for autism

4. I feel confident in counseling parents and providers of children with autism

5. I feel I have enough knowledge and clinical training to identify a child with autism

6. I feel I have enough knowledge and clinical training to intervene with a child with autism

7. I feel that I could benefit from receiving additional training in the area of autism

**Autism Knowledge, Beliefs, and Self-Efficacy Questionnaire**

Q74 For each of the following statements select the response that best reflects the degree to which you agree with the statement

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>8. In order to be able to identify early signs of autism I feel that I need considerable training in the field of autism</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>9. My role as a clinician is to ask parents about their concerns related to autism</td>
<td></td>
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<tr>
<td>10. I am concerned of alarming or offending parents if I ask about developmental concerns related to autism</td>
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<tr>
<td>11. I am aware of resources to offer patients if there are concerns about autism</td>
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<tr>
<td>12. I have sufficient time in my work place to screen for autism</td>
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</tr>
</tbody>
</table>
13. In my work place I have colleagues to consult with about early signs of autism

14. There are sufficient resources in my community for referring children at risk for autism

Q75 Would you like to enter a raffle for the chance to win a $125 Amazon gift card?

- Yes
- No
IBCLC Survey

Informed Consent

Q1 Welcome to the research study!

By clicking the button below, you acknowledge that your participation in the study is voluntary, you are 18 years of age, and that you are aware that you may choose to terminate your participation in the study at any time and for any reason. Please note that this survey will be best displayed on a laptop or desktop computer. Some features may be less compatible for use on a mobile device.

- I consent, begin the study
- I do not consent, I do not wish to participate

Demographic Survey

Q2 What is your gender?

- Male
- Female
- Other
- I choose not to respond

Q3 Which category below includes your age?

- 18-20
- 21-29
- 30-39
- 40-49
- 50-59
- 60 or older

Q4 With which race/ethnicity do you identify? (Select ALL that apply)
○ African American/ Black
○ Asian
○ Hispanic or Latino
○ Middle Eastern
○ Multiracial
○ Native American/ American Indian/ Alaska Native
○ Pacific Islander
○ White or Caucasian

Q5 What is your current job title? (Select ALL that apply)
○ Registered Nurse
○ Certified Nursing Assistant
○ Patient Care Technician
○ OB Technician
○ Medical Doctor (MD/ OD)
○ Licensed Practical Nurse
○ Lactation Consultant
○ Other (Please specify)

Q6 Do you have any of the following certifications? (Select ALL that apply)
○ RNC Inpatient Obstetric Nursing (RNC-OB)
○ RNC Low Risk Neonatal Nursing (RNC-LRN)
○ RNC Maternal Newborn Nursing (RNC-MN)
○ RNC Neonatal Intensive Care Nursing (RNC-NIC)
○ International Board Certified Lactation Consultant (IBCLC)
Q7 What department do you work in most of the time? (Select ONE Answer)

- Labor and delivery
- Couplet care /Postpartum
- Neonatal Intensive Care Unit (NICU)
- Intermediate or Continuing Care Nursery
- Well nursery
- Family support center
- Pediatric Primary Care Clinic
- Pediatric Ward
- Multiple departments (please list)
- Other (Please specify)

Q8 In which state do you currently practice? (Select ALL that apply)

Q9 Which of the following categories best describes your employment status?

- Employed, working 40 or more hours per week
- Employed, working 1-39 hours per week
- Not employed, looking for work
- Not employed, NOT looking for work
- Retired

Q10 What is the highest level of school that you have completed? (Check ONE Only)

- Less than high school, no GED
o High school graduate, diploma or GED
o Some college credit, but less than 1 year
o 1 or more years of college, no degree
o Associate degree (ex: AA or AS)
o Bachelor’s degree (BA, BS, AB)
o Master’s degree (MS, MA, MSW, MSN, MEd, MBA)
o Professional degree (MD, OD)
o Doctorate degree (PhD, DrPH, ScD)

Q11 How many years of experience do you have in your current position?

Q12 How many total years of experience do you have in a maternity ward (if applicable)?

Q13 Do you have any children?

  o Yes

  o If Yes, how many?

  o No

Q14 Do you (or your partner) have any personal experience in breastfeeding?

  o Yes, Personal experience

  o Yes, Partner experience

Q15 If you (or your partner) had personal breastfeeding experience, what was the total duration of breastfeeding (in months)?

  o Personal experience breastfeeding duration (in months)

  o Partner experience breastfeeding duration (in months)

  o Not applicable
Questionnaire about Breastfeeding Knowledge

Q16 The following section of the survey will evaluate breastfeeding knowledge and skills. THIS IS NOT AN EXAM Please, answer the questionnaire without consulting any resources and try not to leave any questions blank.

Q17 In case of mastitis, breastfeeding should be temporarily interrupted.
- True
- False

Q18 Babies should breastfeed every 2-3 hours for 15 minutes on each breast.
- True
- False

Q19 Exclusive formula feeding is associated with an increased risk of infectious morbidity.
- True
- False

Q20 Most babies born by cesarean section need to be supplemented with formula in the first hours of life.
- True
- False

Q21 If a breastfed baby has problems breastfeeding and needs supplementary breast milk or formula, it should generally not be administered by bottle, especially in the first weeks of life.
- True
- False

Q22 About the breastfed newborn: a high frequency of feedings decreases the risk of requiring phototherapy.
- True
- False

Q23 Before the first breastfeeding in delivery room: a healthy term newborn should be weighed, the Apgar score checked in a crib with radiant heat, newborn should receive ophthalmic prophylaxis and a vitamin K shot.
- True
- False

Q24 In very premature infants (<32 wk) the best option is breast milk (fortified when required) and the second best is human milk from a milk bank. Supplementation with special preterm formula is the last option.
Q25 In the maternity ward, a breastfed newborn over 15 hours old who needs to be roused for every feed is at risk.
   o True
   o False

Q26 The nutrient content of breastmilk significantly decreases after 12 months of lactation when compared to the first year.
   o True
   o False

Q27 An initial assessment of a breastfed infant, with an otherwise good appearance, reveals low weight gain. The first step is to supplement with formula and reassess.
   o True
   o False

Q28 After 6 months of age, breastfeeding should be reduced to 2-3 a day, and infants should be supplemented with other foods.
   o True
   o False

Q29 13. “Watery milk” is the foremilk.
   o True
   o False

Q30 This picture shows a correct latch on.
Q31 What are the current WHO recommendations on breastfeeding?

- Exclusive breastfeeding (EBF) for 4 months of age, thereafter supplementation with complementary foods and breastfeeding for as long as mother and child wish.
- EBF for 6 months of age, thereafter supplementation with complementary foods, and continued breastfeeding for up to two years.
- EBF for 6 months, thereafter supplementation with complementary foods, and continued breastfeeding for up to two years or beyond as mother and child wish.

Q32 Which of the following is the most important action to be performed in a nursing mother that has cracked nipples?

- Wash with soap and water
- Apply pure lanolin after feeding
- Assess a breastfeed
- Recommend the use of nipple shields

Q33 17. Parents bring their 17 day old infant to the emergency department because of increased crying. He is exclusively breastfed and until now everything was going well, however, in the past 24 hours he cries and breastfeeds very often, sometimes every 30-60 minutes. He calms down on the breast and sucks vigorously. The baby has no appearance of disease, weight gain is good and the physical examination is normal, but the mother has the feeling that he is still hungry. Which diagnosis and treatment decision would you make?

- Hypogalactia. I would supplement every feed with 60 ml (2 Oz) of formula and recommend follow-up with his physician.
○ Growth spurt. I would assess a feed, recommend breastfeeding on demand and routine check with his physician.

○ Hypogalactia. I would recommend test weight (before and after each breastfeed) and supplement with formula to complete at each feed the amount necessary to reach 150 ml (5 Oz) per kg per day divided in 8 feeds.

○ Baby colic. I would recommend giving abdominal massages and balancing the child in prone position till the next feed time.

Q34 List 5 features of a correct latch you could use to assess a breastfeed:

[Broad or ambiguous responses (eg, "lips" or "mouth posture") will not be accepted. Please be specific in just 2 or 3 words]

Q35 What would you say to a pregnant woman that mentions at the office she is thinking about using artificial feeding (formula)?

○ Nothing, since that is a personal choice and I would respect it.

○ I would ask her to tell me more about it, in order to know her reasons and information, and based on respect, I would encourage her to reconsider it.

○ Given the absolute superiority of breast milk, it is irresponsible not to breastfeed when there are no contraindications.

○ Do not feel guilty, because most children grow equally well with bottle feeding.

○ All answers are correct.

Q36 About giving free samples of starter infant formula to the mothers in health centers:

○ It is a violation of the International Code of Marketing of Breast-milk Substitutes.

○ It is acceptable as partial support for low-income families.

○ It is acceptable if it is clearly written that breast milk is the best food for infants.
It is appropriate to help mothers with breastfeeding problems.

All answers are correct

Q37 A nursing mother consults with you about the safety of breastfeeding while starting a new medication. She is going to begin treatment with adalimumab for Crohn's disease. Her gastroenterologist has told her she should wean her 8 month old baby because the treatment is important. Where could you look up if the drug is compatible or not with breastfeeding?

- In the technical data sheet for the drug.
- I would refer to the information supplied by the specialist who prescribed it.
- In my Drug Handbook (Vademecum or similar)
- It is not necessary to consult. Assessing risks and benefits, weaning is best since child is already 8 months old.
- On a website I know (please, specify):

Q38 You are the doctor and you're at the maternity ward. A nurse is worried about a breastfed newborn. She believes that something is going wrong with breastfeeding and she wants you to assess a breastfeed.

- I have never assessed a newborn breastfeeding and I would not know exactly what to observe.
- I have assessed few breastfeeds during my training period, but I do not have much experience. I believe I would only identify obvious problems.
- I do not feel confident. I would preferably check weight loss and glycemia. If in doubt, I would recommend a supplement to prevent weight loss.
- I have assessed many breastfeeds and I would be able to identify the most common problems and provide solutions for them.

Q39 Do you consider breastfeeding in public appropriate behavior?
Q40 Rate from 1 to 5 the quality of breastfeeding training received during your Internship and Residency:

1 Very poor 
2 Quite poor 
3 Fair 
4 Quite Good 
5 Excellent

Q41 Have you ever attended a specific breastfeeding course?

- Yes 
- No

Q42 If yes, please indicate the number of courses you have received and the total approximate duration (hours).

- Number of courses 
- Total approximate hours of education 
- None

Q43 Which is your greatest source of knowledge about breastfeeding? (Multiple options are acceptable)

- Courses 
- Textbooks / journal articles 
- Knowledge acquired in the degree. 
- My senior residents (or the medical staff)
Q44 Do you think you should be an expert in diagnosing and providing solutions to specific breastfeeding problems?

- Yes
- No

Q45 If yes, why? (Multiple options are acceptable)

- Because it is a frequent complaint
- For the good of my patients and their families
- Because it's part of my job
- Other (please specify)

- I do not feel I need to be an expert in diagnosing and providing solutions for breastfeeding problems.

Q46 How qualified do you feel to diagnose and provide solutions specific to breastfeeding problems?

- Absolutely not
- Somewhat qualified
- Qualified
- Well qualified
- Extremely qualified

Knowledge about Early Autism Signs

Q47 Please answer all of the following questions. Do not spend a lot of time on one question relative to the others. Since it is important for us to learn about your personal knowledge in this area, please, do not rely on external information such as websites, books, or friends.
Q48 Select the response that best reflects the degree to which you agree with each of the following statements. Please complete all items and select "I don't have specific knowledge about this topic" only as your last resort.

Q49 What early signs in a baby under your care raise your concern for autism?
Q50 In your opinion, which babies are at increased risk for autism?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Fully agree</th>
<th>Mostly agree</th>
<th>Somewhat agree</th>
<th>Somewhat disagree</th>
<th>Mostly disagree</th>
<th>Fully disagree</th>
<th>I don't have specific knowledge about this topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Autism can be diagnosed as early as 24 months</td>
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<td>2. The need for sameness and difficulty coping with transitions between activities are one of the early behavioral features of autism</td>
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<td>3. A young child with autism can express his needs such as: asking for water or food</td>
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<td>4. Increased head circumference relative to age is an early sign for autism</td>
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<td>5. Premature babies have higher risk of autism</td>
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<td>6. Delays in attaining motor milestones such as sitting and walking are not necessary sign for autism</td>
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<td>7. Some children with autism show typical global development until the age of one and a half</td>
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<td>8. Early developmental regression autism can occur up to the age of three years</td>
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<td>9. Most children with autism under the age of four can draw their parent’s attention to an interesting event such as a street clown</td>
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Autism Knowledge, Beliefs, and Self-Efficacy Questionnaire

Q51 Are you part of a team which screens and diagnoses children with autism?
   ○ Yes
   ○ No

Q52 For each of the following statements select the response that best reflects the degree to which you agree with the statement

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>8. In order to be able to identify early signs of autism I feel that I need considerable training in the field of autism</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>9. My role as a clinician is to ask parents about their concerns related to autism</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>10. I am concerned of alarming or offending parents if I ask about developmental concerns related to autism</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>11. I am aware of resources to offer patients if there are concerns about autism</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
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<tr>
<td>12. I have sufficient time in my workplace to screen for autism</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>13. In my workplace I have colleagues to consult with about early signs of autism</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>14. There are sufficient resources in my community for referring children at risk for autism</td>
<td>○</td>
<td>○</td>
<td>○</td>
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</tbody>
</table>

Q54 Would you like to enter a raffle for the chance to win a $125 Amazon gift card?
   ○ Yes
   ○ No
<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>I felt like I was breastfeeding more/. But he was also 90th percentile so she was a rather large child/ so I wasn't sure. /Because we relied on breastfeeding to soothe her.</td>
<td>The mother felt she was breastfeeding more than other people she knew. She assumed it was because of her child’s size but she was unsure if that was why she needed to breastfeed so often. The mother relied on breastfeeding to soothe her infant.</td>
<td>The mother described increased breastfeeding frequency for age of infant. Her child was in an upper percentile for growth. The mother used breastfeeding to soothe. The mother was interventionist before diagnosis.</td>
<td>1)Breastfeeding: Challenging Behavior</td>
</tr>
<tr>
<td>We were both pretty frustrated, it turned out his tongue would flatten and so he would push my nipple out of his mouth often and led to severe nipple trauma basically. I was bleeding, he was crying so it was quite a process to figure out how to get through that.</td>
<td>The mother was frustrated with breastfeeding. The child had atypical tongue responses causing nipple trauma. The infant was distressed. The mother felt significant distress overcoming feeding issues</td>
<td>Breastfeeding issues caused distress to both mother and infant. Atypical tongue movements caused nipple trauma. Overcoming challenges was overwhelming for mother.</td>
<td>1.1 Atypical oral/ sucking behaviors</td>
</tr>
<tr>
<td>She recommended supplementing full days because he had a lot of trouble latching. It's was so stressful.</td>
<td>Mother was told to supplement and try new positions.</td>
<td>Formula was a solution to breastfeeding challenges</td>
<td>1.2 Formula for BF challenges</td>
</tr>
<tr>
<td>She showed me how to use a pacifier to help him learn how to position his tongue better. Because at that time I think that they decided that it was an issue with how he was latching.</td>
<td>Pacifier was introduced to correct tongue movements. Tongue movements were diagnosed as cause of latch issues.</td>
<td>Pacifier was solution to latch issues.</td>
<td>1.3 Trouble latching</td>
</tr>
<tr>
<td>She had a lot of troubles latching and I didn't really know what that meant or what it was supposed to feel like. I know there's pain with first time nursing for anybody. I didn't know what was a regular amount of pain.</td>
<td>Infant had trouble latching. Mom was unsure of typical breastfeeding experience. Mom believed breastfeeding should be painful.</td>
<td>Mother’s inexperience breastfeeding influenced misperceptions.</td>
<td>1.4 BF inexperience</td>
</tr>
</tbody>
</table>
APPENDIX H. OBSERVATIONAL FIELD NOTES

P3 - Twin 6/15th. a.s.

- Nurse @ 39 weeks
- Breas or formula
  - held if pain a wide found
  - fear of parents
- not as cuddly, ot of being not held
- regular body temp re-breathing issues
- 2 weeks engorgement
- Grow/gain not as fast as P1
- Hard to soothe
- "he wants to cry because he hungry"
- Choking w/ BF & Food
- "Hug me more"
- only source of comfort
- Climb in bed, but not cuddle
- Hard to bed @ 6 mos
- no awareness ot danger
- 6/7 mos. crawling
- not want to be held
- 11 mos. walking
- liked hanging-up
- Spin in circles, with toys
- light shoe preference
- Diaper side lying not get older
- worst side lying not get older

P4 - Twin 6/15th. a.s.
- Nurse @ 36 weeks
- Breast or formula
  - Held if pain a wide found
  - Fear of parents
- Not as cuddly, ot of being not held
- Regular body temp re-breathing issues
- 2 weeks engorgement
- Grow/gain not as fast as P1
- Hard to soothe
- "he wants to cry because he hungry"
- Choking w/ BF & Food
- "Hug me more"
- Only source of comfort
- Climb in bed, but not cuddle
- Hard to bed @ 6 mos
- No awareness of danger
- 6/7 mos. crawling
- Not want to be held
- 11 mos. walking
- Liked hanging-up
- Spin in circles, with toys
- Light shoe preference
- Diaper side lying not get older
- Worst side lying not get older

P1 - Caucasian @ 5 mos.
- Buggy w/ diaper
- Hard to soothe
- 4 weeks increase feeding
- Concerns w/ supply
- Buggy in car 2 minutes
- Store, people/public
- Soothing: walking, BF for soothing
- 9.75 growth/gain
- CP
- "Easy going", 90% growth
- Cuddly
- Hand held 1st week
- Multi-task @ 7 mos.
- Threw 1 mos. by BF
  - Dorothy's allergy
  - Deficient sleep
- Bottle bed 14 weeks

P2 - Hispanic @ 5 mos.
- Buggy w/ diaper
- Hard to soothe
- 4 weeks increase feeding
- Concerns w/ supply
- Buggy in car 2 minutes
- Store, people/public
- Soothing: walking, BF for soothing
- 9.75 growth/gain
- CP
- "Easy going", 90% growth
- Cuddly
- Hand held 1st week
- Multi-task @ 7 mos.
- Threw 1 mos. by BF
  - Dorothy's allergy
  - Deficient sleep
- Bottle bed 14 weeks
APPENDIX I. DESCRIPTIVE STATISTICS FIGURES

**Figure 18.** Participant age group by practitioner.

**Figure 19.** Participant years in practice by practitioner.
Figure 20. Participants responses to the question “How qualified do you feel to diagnose and provide solutions specific to breastfeeding problems?” by practitioner group.

Figure 21. Participants ratings of agreement with the statement “I feel comfortable to contribute my professional opinion for diagnosing or identifying a child with autism.” by practitioner group.
Figure 21. Thematic maps of practitioner responses to open ended questions, including codes and themes
APPENDIX K. CATEGORIAL THEME FACTOR GROUPS

Clinical Competence and Self-Efficacy in the field of Autism Categorical Themes:

Categorical Theme 1 Self-efficacy in ASD clinical skills:

Q1. I feel comfortable to contribute my professional opinion for diagnosing or identifying a child with autism

Q3. I feel confident in my ability to make appropriate referrals for further evaluation of young children with a risk for autism

Q6. I feel I have enough knowledge and clinical training to intervene with a child with autism

Q12. I have sufficient time in my workplace to screen for autism

Q5. I feel I have enough knowledge and clinical training to identify a child with autism

Categorical Theme 2 Knowledge of available resources:

Q11. I am aware of resources to offer patients if there are concerns about autism

Q13. In my workplace I have colleagues to consult with about early signs of autism

Q14. There are sufficient resources in my community for referring children at risk for autism

Categorical Theme 3 Need for ASD training:

Q7. I feel that I could benefit from receiving additional training in the area of autism

Q8. In order to be able to identify early signs of autism I feel that I need considerable training in the field of autism

Categorical Theme 4 Communicating with parents about their ASD concerns:

Q2. I feel comfortable and confident in discussing early warning signs of ASD with my patients’ parents

Q4. I feel confident in counseling parents and providers of children with autism

Q9. My role as a clinician is to ask parents about their concerns related to autism

Q10. I am concerned of alarming or offending parents if I ask about developmental concerns related to autism
Knowledge about Early Autism Signs Categorical Themes:

**Categorical Theme 1: Infant/ Child Behaviors:**

Q2. The need for sameness and difficulty coping with transitions between activities are one of the early behavioral features of autism

Q3. A young child with autism can express his needs such as: asking for water or food

Q9. Most children with autism under the age of four can draw their parent’s attention to an interesting event such as a street clown

**Categorical Theme 2: Risk/Diagnosis:**

Q5. Premature babies have higher risk of autism

Q4. Increased head circumference relative to age is an early sign for autism

Q1. Autism can be diagnosed as early as 24 months

**Categorical Theme 3 Developmental delay:**

Q6. Delays in attaining motor milestones such as sitting and walking are not necessary sign for autism

Q7. Some children with autism show typical global development until the age of one and a half

Q8. Early developmental regression autism can occur up to the age of three years
**Questionnaire about Breastfeeding Knowledge Categorical Themes:**

**Categorical Theme 1 Physiology:** Breastfeeding in normal conditions, prematurity, extended breastfeeding

Q2. Babies should breastfeed every 2-3 hours for 15 minutes on each breast.

Q13. “Watery milk” is the foremilk.

Q14. This picture shows a correct latch on.

Q18 List 5 features of a correct latch you could use to assess a breastfeed: [Broad or ambiguous responses (e.g., "lips" or "mouth posture")] will not be accepted. Please be specific in just 2 or 3 words]

**Categorical Theme 2 Public health:** Official recommendations, risks of artificial feeding

Q3. Exclusive formula feeding is associated with an increased risk of infectious morbidity.

Q8. In very premature infants (<32 wk) the best option is breast milk (fortified when required) and the second best is human milk from a milk bank. Supplementation with special preterm formula is the last option.

Q10. The nutrient content of breastmilk significantly decreases after 12 months of lactation when compared to the first year.

Q12. After 6 months of age, breastfeeding should be reduced to 2-3 a day, and infants should be supplemented with other foods.

Q15. What are the current WHO recommendations on breastfeeding?

Q20 About giving free samples of starter infant formula to the mothers in health centers:

**Categorical Theme 3 Breastfeeding Issues during the first days:** Hypoglycemia, cracks and pain while breastfeeding, mastitis, dehydration, jaundice

Q1. In case of mastitis, breastfeeding should be temporarily interrupted.
Q4. Most babies born by cesarean section need to be supplemented with formula in the first hours of life.

Q6. About the breastfed newborn: a high frequency of feedings decreases the risk of requiring phototherapy.

Q7. Before the first breastfeeding in delivery room: a healthy term newborn should be weighed, the Apgar score checked in a crib with radiant heat, newborn should receive ophthalmic prophylaxis and a vitamin K shot.

Q9. In the maternity ward, a breastfed newborn over 15 hours old who needs to be roused for every feed is at risk.

Q16 Which of the following is the most important action to be performed in a nursing mother that has cracked nipples?

**Categorical Theme 4 Late breastfeeding issues:** Inadequate production of milk/ poor weight gain, crying, breastfeeding crisis, return to work, supplementary feeding

Q5. If a breastfed baby has problems breastfeeding and needs supplementary breast milk or formula, it should generally not be administered by bottle, especially in the first weeks of life.

Q11. An initial assessment of a breastfed infant, with an otherwise good appearance, reveals low weight gain. The first step is to supplement with formula and reassess.

Q17 Parents bring their 17 day old infant to the emergency department because of increased crying. He is exclusively breastfed and until now everything was going well, however, in the past 24 hours he cries and breastfeeds very often, sometimes every 30-60 minutes. He calms down on the breast and sucks vigorously. The baby has no appearance of disease, weight gain is good and the physical examination is normal, but the mother has the feeling that he is still hungry. Which diagnosis and treatment decision would you make?
Categorical Theme 5 Assessment of breastfeeding:

Maternal factors: Drugs illness, toxic substances, prior surgery

Q21 A nursing mother consults with you about the safety of breastfeeding while starting a new medication. She is going to begin treatment with adalimumab for Crohn's disease. Her gastroenterologist has told her she should wean her 8 month old baby because the treatment is important. Where could you look up if the drug is compatible or not with breastfeeding? -

Selected Choice

Attitudes: Promotion of breastfeeding, empathy and counseling

Q19 What would you say to a pregnant woman that mentions at the office she is thinking about using artificial feeding (formula)?