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UNDERSTANDING THE PARENT EXPERIENCE OF RECEIVING AN EARLY
CHILDHOOD AUTISM DIAGNOSIS

A Dissertation

Presented to the Faculty of
Antioch University New England

In partial fulfillment for the degree of
DOCTOR OF PSYCHOLOGY

by

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UNDERSTANDING THE PARENT EXPERIENCE OF RECEIVING AN EARLY
CHILDHOOD AUTISM DIAGNOSIS

This dissertation, by Elizabeth Fuss, has
been approved by the committee members signed below
who recommend that it be accepted by the faculty of
Antioch University New England
in partial fulfillment of requirements for the degree of

DOCTOR OF PSYCHOLOGY

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Abstract

The current qualitative study addresses parents' experience when their child receives an autism spectrum disorder (ASD) diagnosis in early childhood. Specifically, the study explores the parent-child relationship, the participants' perception of autism, and parents' overall mood before and after their child was diagnosed with ASD. The study used a semistructured interview to collect data from five mothers recruited from the Rhode Island Consortium of Autism Research and Treatment (RICART). The data were analyzed using interpretive phenomenological analysis, which divided the data into superordinate and emergent themes. The discussion section includes discussion of the data in the context of previous literature, limitations, and clinical implications. Finally, the dissertation concludes with my personal reflections on the study and the conclusion. This dissertation is available in open access at AURA (<https://aura.antioch.edu>) and OhioLINK ETD Center (<https://etd.ohiolink.edu>).

Keywords: autism spectrum disorder, parent-child relationship, parents, diagnosis, IPA

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UNDERSTANDING THE PARENT EXPERIENCE OF AN EARLY CHILDHOOD AUTISM DIAGNOSIS

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that affects 1 in 54 children and their families (Centers for Disease Control and Prevention [CDC], 2020b).

Neurodevelopmental disorders typically manifest early in development, before a child enters grade school, and are identified by deficits in the child's daily functioning (American Psychiatric Association, 2013). Because ASD varies in severity, the presentation of symptoms differs among individuals with the diagnosis.

According to the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (DSM-5), autism includes five hallmark symptoms (American Psychiatric Association, 2013). The first characteristic of autism is “persistent deficits in social communication and social interaction across multiple contexts,” which includes deficits in nonverbal communication, deficits in social-emotional reciprocity, and difficulty developing and understanding relationships (American Psychiatric Association, 2013, p. 50). Additionally, a diagnosis of autism requires the individual to have repetitive behaviors or interests, manifested in at least two ways. Manifestations can include restricted interests, inflexibility, or repetitive motor movements, along with a variety of other symptoms. In addition, symptoms must be present, but not necessarily fully manifested, during the early developmental period. Finally, symptoms must cause clinically significant impairment and must not be better explained by intellectual disability or global developmental delay (American Psychiatric Association, 2013).

Researchers and clinicians continue to gain knowledge about ASD. Early diagnosis and intervention have proven to be beneficial in the treatment of ASD and its symptoms (Jagan &

Sathiyaseelan, 2016). However, we know little about the experience of parents whose children receive an early childhood autism diagnosis. What little research exists has shown that parents whose children receive this diagnosis may react in a variety of ways. One research study found that Caucasian mothers were relieved of feelings of guilt, while Latina mothers felt guiltier once receiving the diagnosis (Lopez et al., 2018). Some parents cry, some are in shock, some are relieved at knowing what is wrong, and some do not know how to react. Understanding the parental experience of a child receiving an early diagnosis can lead to clinicians becoming more mindful of the impact of this diagnosis, and better able to help families at a challenging time.

Literature Review

The Effect of Autism on Parental Stress

Parents and caregivers of children with autism spectrum disorder (ASD) experience stressors that are unique to their child's needs (Karst & Van Hecke, 2012). Not only do parents experience stress from caring for their child, but they also face the pressure of making decisions about treatment (Johnson et al., 2011). Huang et al. (2014), found that parents of children with mild to moderate autism-related behavior problems perceived more stress than those with children with no or severe autism-related behavior problems. The higher perception of stress might be related to the perception that children with mild to moderate behaviors are able to improve their behavioral problems, placing pressure on parents (Huang et al., 2014).

While the hallmark symptoms of autism are often assumed to be the primary cause of parental stress, Karst and Van Hecke (2012) found “that the unique combination of emotional, functional, and behavioral problems common in children with ASD, in conjunction with the pervasive and often severe impact of the disorder, affect parents more than the ‘core symptoms’ of autism” (p. 250). For example, significant financial stress is present in households of children

with autism. The cost of caring for a child with autism can add up to nearly \$3 million for the child's lifetime (Krakovich et al., 2016). In addition to financial stressors, researchers have identified other common stressors for parents of children with ASD (Krakovich et al., 2016). Some identified stressors are the demands of an ASD diagnosis, finding available resources and social supports, and the family's appraisal of the situation (Krakovich et al., 2016).

Demands associated with an ASD diagnosis are largely impacted by the child-related factors (Krakovich et al., 2016). Child-related factors associated with increased stress include "number and severity of problem behaviors, poorer social relatedness, lower levels of adaptive behavior, older age of the child, and restricted and repetitive behaviors and communication impairments" (Krakovich et al., 2016, p. 2043). Other child characteristics related to parental stress levels include demandingness, adaptability, and level of distraction (Cameron et al., 1991). In addition to child-related factors, family factors also impact parental stress, such as marital stress, economic distress, and having additional children in the home. To relieve the stressors, parents may utilize resources, such as respite care and informal supports (e.g., family members and friends). Conversely, lower levels of social supports have been linked to greater parental stress. Access to resources may be limited depending on external and internal factors. External factors that may affect one's access to resources include whether one lives in a rural or urban area. Internal factors that influence resource accessibility are income level, education level, and race (Krakovich et al., 2016).

Caretaking demands are correlated with parental stress levels, especially in the primary caregiver (Baker-Ericzen et al., 2005). Parents experience significant stress from caretaking demands, such as communicating with healthcare providers and the challenges associated with obtaining treatment and related services. Although providers will likely recommend a course of

treatment, parents are tasked with making sense “of significant amounts of information about the diagnosis and recommended intervention methods” (Baker-Ericzen et al., 2005, p. 195). In addition, they may receive information and advertisements about alternative methods of treatment (e.g., eliminating casein from the child’s diet) that can increase stress levels. A final stressor that is common in parents of children with autism is the possibility of providing long-term, or potentially lifelong, care for their children and the limitations associated with this possibility (Baker-Ericzen et al., 2005).

The Effect of Parenting Stress on Mental Health

According to Karst and Van Hecke (2012), parenting a child with ASD can lead “to a general decrease in parental well-being and increase in mental health concerns” (p. 251). Negative well-being outcomes in mothers of children with autism were evident by the time children were five years old (Jones et al., 2018). When compared to parents of typically developing children and parents of children with other developmental disabilities, Jones et al. (2018) found that parental mental health concerns were elevated in parents of children with ASD. Parental stress has also been reported with a lower quality of life in mothers of children with ASD compared to mothers of children with intellectual disabilities who do not have an autism diagnosis (Karst & Van Hecke, 2012). When comparing maternal and paternal mental health concerns, mothers of children with ASD report significantly greater distress than fathers. Mothers also report higher anxiety and clinically significant depression than fathers of children with autism. However, single mothers report the highest amount of stress when compared to mothers living with a partner (Karst & Van Hecke, 2012).

While there have been numerous findings regarding a correlation between parental stress and mental health concerns, the effects “are largely contingent on specific parent and child characteristics” (Karst & Van Hecke, 2012, p. 251). Individual variables such as perceived self-efficacy, anxiety levels, social support, child behavior, and competencies are all related to elevated depression. Researchers have also discovered a correlation between child symptom severity and parental depression, thus indicating that the more behavioral problems noted, the higher the risk for parental depression (Karst & Van Hecke, 2012).

The Impact of Parenting Stress on Children and Treatment

While many interventions exist for children with autism, “a difficulty with existing interventions is a potential lack of attention to stressors other than with [intellectual and developmental disabilities], with many parents exposed to a variety of stressors both directly and indirectly associated with their child” (Jones et al., 2018, p. 17). When examining parental stressors, researchers often attribute parental stress to child-related factors. Just as child-related factors affect the parents, parenting stress affects the child. Researchers found that early interventions that target and effectively reduce parenting stress, also reduce autism-related child behaviors (Hayes & Watson, 2012). These results posit that reducing parental stress can improve family functioning and mitigate the impact of child-related behaviors (Hayes & Watson, 2012).

Further evidence shows that interventions that focus on changing the parent-child relationship can lead to a reduction in symptom severity in children with ASD (Beurkens et al., 2013). Additionally, such interventions can lessen the impact of symptoms on the parent-child relationship (Beurkens et al., 2013). Research has proven that not only is there a reduction in parenting stress and fewer ASD-related symptoms, but also that lower parenting stress is related to the child making greater progress in treatment (Robbins et al., 1991). These implications

demonstrate the importance of the wellbeing of parents on not only the child, but also the child's own progress in treatment.

Several interventions are available for children with ASD. Karst and Van Hecke (2012) noted that the number of available interventions can confuse parents. Young children with ASD were on average involved in seven different interventions at once (Karst & Van Hecke, 2012). Literature suggests that the differences in presentations of autism are likely the reason behind the high variability in treatment (Karst & Van Hecke, 2012). However, a common factor in many treatments is parent involvement. In a review of early childhood interventions for ASD, researchers discovered that 52% of interventions support the parent-child relationship and 59% directly involve the parent (Schertz et al., 2011). Parental stress can lead to negative or diminished effects of interventions (Karst & Van Hecke, 2012). Researchers have found that higher parental stress had statistically significant effects on educational and adaptive behavioral functioning in children with ASD (Osborne et al., 2008). Higher reported parental stress was negatively correlated to gains made in educational interventions in children with autism.

The Diagnostic Process

A French study on parents' experience of the diagnostic process indicated that parents typically suspected developmental delays within the first two years of their child's life (Chamak et al., 2011). The researchers examined their participants' experience of the diagnostic process using quantitative and qualitative methods. Their results indicated greater surprise and difficulty accepting a diagnosis for autism when a child was diagnosed younger than 4. In contrast, 43% of parents felt relieved when their child was 4 years or older at the time of diagnosis. Overall, the study focused on the factors associated with the diagnostic process, such as how the information was presented and the time between the diagnostic interview and receiving the diagnosis

(Chamak et al., 2011). Additionally, Chamak et al. (2011) found that parents were more able to accept their child's autism diagnosis when the information was delivered in clear language, and when families were provided a list of resources.

Neurodiversity and Autism Acceptance

Organizations, such as Autism Speaks and Defeat Autism Now (DAN), advocate for a cure for ASD (Cascio, 2012). Conversely, neurodiversity advocacy promotes autism pride and views it as a variation in one's brain rather than a disability. Neurodiversity advocates support the philosophy that interventions should not focus on changing autistic individuals, but rather toward helping them manage their symptoms. Although the neurodiversity model is prevalent, many parents continue to seek ways to eliminate their child's symptoms of autism entirely (Shute, 2010). Such contrast of beliefs can lead to disagreements or feelings of discouragement among parents of children with autism (Cascio, 2012).

Purpose of the Study

Researchers and clinicians continue to stress the importance of diagnosing children with autism as early as possible so that early intervention can be provided (Jagan & Sathiyaseelan, 2016). They continue to formulate treatment modalities and research to gain more knowledge about this disorder. However, we know little about the parent experience of receiving an autism diagnosis in early childhood. As found in prior research, when children were diagnosed with autism before the age of 4, parents experienced more stress than when they were diagnosed later (Chamak et al., 2011). However, Jagan and Sathiyaseelan (2016) emphasized the importance of early diagnosis and better treatment outcomes. The purpose of this study was to better understand how an autism diagnosis affects parents in many aspects of their lives. The research questions focused on the potential differences between the parents' experiences before and after

the diagnosis. This study aimed to examine how receiving an autism diagnosis affected parents' experiences including overall mood, knowledge of the disorder, perception of autism, and their perception of the parent-child relationship. In addition, it examined the feelings associated with receiving the diagnosis. Clinicians may be able to utilize the data to better help families with a child with ASD.

Method

Research Paradigm and Method Rationale

This study was conducted as a qualitative study using a semistructured interview, within the constructivist paradigm, which recognizes that reality is socially constructed. While all participants had some common experiences in receiving the autism diagnosis, their experiences were likely shaped by multiple factors. For example, their experiences might have been impacted by their race, ethnicity, socioeconomic class, religion, social support, and other individual factors that shape social interactions. In order to adhere to the constructivist paradigm, this research emphasized representing all views fairly, along with building rapport through authenticity during the interviews. The constructivist paradigm was most fitting for this project because the focus of the research was an exploration of the perceptions and constructed reality of the participants in the sample. The qualitative design provided a narrative of each participant's experience when their child was diagnosed with autism.

The current study utilized a phenomenological approach, which provided an emphasis on each participant's subjective experience (Mertens, 2015). While the qualitative data were collected, I recognized my involvement with this topic, as well as any biases I may have had throughout the study. My clinical interest in ASD led to my extensive experience in evaluating and diagnosing children with autism. As a result, I am familiar with the process that many

centers utilize for diagnosis. I have observed the varying reactions of parents throughout the assessment experience and their reaction when their child receives a diagnosis of autism. In addition, I have personal biases toward the diagnosis being provided by a psychologist. My bias stems from psychologists' training in providing support to individuals experiencing strong emotional reactions. In order to suspend my biases throughout the interviews, I was mindful about recognizing my bias. I also withheld my beliefs from the participants, so they could feel as comfortable describing their experiences as possible. Additionally, I had a colleague audit the coding of the data in order to ensure the themes did not reflect my personal biases. The participants disclosed personal and vulnerable information about an emotional experience. A phenomenological and constructivist approach was a good fit for this study, as it illuminated both unique and common phenomena among the participants' experiences of receiving the autism diagnosis.

Participants

The study included five participants, all of whom were female. Of the participants, four identified as Caucasian/White and one identified as Korean. The participants' ages ranged from 32–40 years old, with a median age of 37 and a mean age of 36.6. All the participants lived in the United States at the time of the interviews, specifically in Southern New England. Their children, all of whom were male, were diagnosed with autism between the ages of 2 and 4.5 years. All diagnoses were received between 2016 and 2018. The participants identified that their children were diagnosed with ASD by a clinical psychologist, psychologist, or developmental pediatrician. One participant was unsure of the title of the clinician who diagnosed her child with autism.

Measures

A semistructured interview was developed specifically for this research project (See Appendix A). The interviews lasted between 15 and 50 minutes, which was dependent on the length of the answers from each participant. An example of a question in the semistructured interview was “How would you describe your relationship with your child before they received an autism diagnosis?” I asked additional follow-up questions, as fit with each participant to gain additional information about their experience, (e.g., “What were family relationships like at the time?”). At times, I asked questions to encourage participants to provide more detail. The interview concluded with giving participants the opportunity to add any additional comments about their experience that were not covered by the semistructured questions.

Procedure

Participants were recruited via the Rhode Island Consortium for Autism Research and Treatment (RICART). A research assistant affiliated with RICART digitally distributed an invitation for research participation to individuals who met the participation criteria. Those who were interested in participating responded to the RICART research assistant, who then provided me with a list of potential participants. I contacted potential participants via telephone or email to provide detail about participation requirements and asked if they would like to continue with participation.

Prior to participating in the semistructured interview, I informed the participants of the nature of the questions. I also explained that they could elaborate as little or as much as they wanted to answer the interview questions. Interested participants were provided with an informed consent form (see Appendix B) and were required to respond, “I consent to participate”, via email to indicate their willingness to participate. At the beginning of the

interview, participants were given notice that they had the option to end the interview at any point, and that they could refuse to answer any question they did not wish to answer. All participants were presented with the interview questions in the same order, with follow-up questions and prompts being used as applicable to ensure understanding of their answers. However, many participants answered questions from later in the interview before they were even asked. If the participant provided an answer earlier in the interview, I reiterated and clarified their answer when we reached the corresponding interview prompt. Therefore, while the interview prompts were presented in the same order, it was not possible to ensure that the interview questions were answered in the same order during each interview.

Analysis

The data from the interviews were analyzed using interpretive phenomenological analysis (IPA; Smith et al., 2009). Prior to coding, the audio recording of each interview was transcribed. The transcription included participants' pausing and repetition of words and phrases throughout the interview. This aspect of the transcription is important in IPA, as it conveys the participants' nonverbal communication throughout the interview. Following the transcription of the interviews, I followed the guidelines for IPA.

Reading the Data and Initial Noting

First, I read and re-read each transcript in order to familiarize myself with the content of each interview (Smith et al., 2009). Reading and re-reading the transcript prepared me for the initial noting process and for gathering my thoughts about the content that had been collected. After reading each transcript twice, I began the initial noting process. During this step, I wrote notes in one margin of the transcript that fit one of three categories: descriptive comments, linguistic comments, and conceptual comments. Descriptive comments include initial reactions

to the text and the beginning of themes seen throughout the interview. Linguistic comments focus on the language used by the participant, tone of voice, and nonverbal cues, such as laughter. Conceptual comments are broad comments made with consideration to both the linguistic and descriptive comments. These comments can be questions about the comment or broader comments about themes based on the linguistic and descriptive comments (Smith et al., 2009).

Noting Emergent Themes

Once the initial note-taking process was complete, I wrote emergent themes in the left margin of the transcript. The emergent themes were created using the initial notes for each transcript. The themes focused on important aspects of the transcript (e.g., lack of trust in provider). Once the emergent themes were written, I identified similar themes and created clusters. Then, I examined the theme clusters and created a fitting superordinate theme (e.g., relationship with provider). The reading and re-reading, initial noting, and emergent theme processes were repeated with all five transcripts.

Common Themes

After completing the initial analysis for each participant, I looked for patterns among the interviews. The phenomenological research approach focuses on both the similarities and differences among individuals with similar experiences. As a result, I looked for similarities among the superordinate themes for each participant. Additionally, I was careful not to eliminate a theme if it was not widely used by participants with the goal of including each individual's experience.

Auditing the Themes

To ensure the accuracy of the themes within the data set, I recruited a volunteer to audit the themes and conduct a peer review. The volunteer was a doctoral level psychology student with research experience. The auditor ensured all research procedures were followed properly, and the analysis was consistent with the data content and without bias. During the audit, the auditor read through each transcript while examining the table of themes within that interview. After completing this for all five interviews, she examined the superordinate theme table to check for any inconsistencies, as well as any grammar or spelling errors. The auditor provided her feedback via email using the comment function in Microsoft Word. Following the audit, the auditor and I met to discuss her findings and the accuracy of the data. The auditor confirmed the analysis was accurate and an additional auditor was not required.

Results

The summary of themes across all five transcripts are detailed in Table 1. To examine differences between before and after the diagnosis, themes are divided into two sections to exhibit the chronology of the themes in each participant's personal experience, where applicable (Appendix C).

Table 1***Superordinate Themes and Emergent Themes***

Superordinate Theme	Emergent Theme
Challenges with Diagnostic Process (N = 5)	Uncertainty Long Waitlist and Process Dissatisfaction
Mother Knows Best (N = 5)	Mother's Intuition: Intuition about development Mother's Intuition: To meet child's needs Parent as Expert
Autism as a Disability (N = 4)	Lack of Skills: Delayed Development Lack of Skills: Regression
Parent-Child Relationship (N = 5)	Consistently Positive Relationship Stressful Family Relationships Before the Diagnosis: Frustration with Child Before the Diagnosis: Child in Control Improved Relationship after Diagnosis
Perception of Autism (N = 5)	Increased Knowledge Positive Perception After Diagnosis Alternate Explanation for Symptoms Autism is not an Excuse
Feelings Prior to Diagnosis (N = 5)	Worry about Atypical Development No Concern Loneliness Shock
Initial Reaction to Diagnosis (N = 5)	Devastation Heartbreak Stress Grief
Advocacy and Persistence (N = 2)	Advocating for Child's Needs
Provider Relationship (N = 3)	Before the Diagnosis: Being Dismissed After the Diagnosis: Discomfort with Provider After the Diagnosis: Satisfaction with Provider
Challenges and Hurdles (N = 4)	Accommodation to Child's Challenges Educating Others Struggles with Services

Superordinate Theme	Emergent Theme
The Future (N = 3)	Worries about the Future Optimism

Challenges During the Diagnostic Process

The interviews of all five participants indicated challenges with the diagnostic process. Three emergent themes appeared significant in the participants' experiences with the process of obtaining a diagnosis of autism for their child. Specifically, participants indicated uncertainty about the diagnostic process, long waitlists until their child could be diagnosed, and feelings of dissatisfaction.

Uncertainty

Three of the five participants responded with hesitation and/or stated that they were uncertain about the type of assessment that was used to diagnose their child with autism. Some participants were able to provide examples of activities that their child participated in but sounded unsure of the purpose of these measures. For example, Participant 1 stated, "...the first part was just like questions for us and then they did some sort of evaluation where they had him play with different toys and they would observe what he did with them." Similarly, Participant 2 replied, "That I don't specifically know," when asked of the types of measures used to diagnose her son's autism. She continued to explain that she believed that the assessments were standardized and that she and her son were observed by the examiner. Participant 2 was able to recall or guess the measures used once the examiner listed the names of common autism assessment measures as well as basic descriptions.

While many participants were able to identify the type of provider who delivered their child's autism diagnosis (e.g., developmental pediatrician, or psychologist), Participant 5 was

unable to recall the type of provider who assessed and diagnosed her child. Her uncertainty was indicated by the upward inflection of her voice while she stated, “She was, I imagine a psychiatrist? I know she does—works with the schools as well to give the diagnosis.”

Long Waitlist and Process

Of the five participants, three commented on the length of the waitlist to begin the diagnostic process or the length of the assessment itself. Participant 2 noted that the assessment, was “maybe a four- or five-hour appointment.” She also remarked on seeking out a provider to diagnose her child, “I believe it was maybe a couple months’ wait...” She continued to remark that she was on a last-minute cancellation list for appointments and was able to bypass the waitlist. However, other participants faced the challenge of a long wait between their referral for assessment and their first testing appointment. Participant 3 explained, “I think it was probably around November that they had brought up to me about having him diagnosed...and we didn’t get an appointment until February.” Due to provider disbelief, Participant 1 had the longest wait of all participants. She stated:

And we went to his 15-month appointment, and I brought it up to the pediatrician then, and I recommended that he be referred for a developmental pediatrician appointment and the pediatrician at that point said, “I’ll refer you, but they’re probably going to say that we’re crazy for referring him. There’s nothing wrong.” And so our first appointment with the [diagnostic clinic] was about five months after that. He was probably like 20 months old.

Dissatisfaction

Two of the participants described dissatisfaction with the diagnostic process. Participant 1 described feeling uncomfortable with the feedback session. She noted that her child was

assessed at a teaching clinic. While she said she understood why there were residents involved in the process, she had mixed emotions about the number of people involved in the feedback session. She stated, “I was like ‘Who are these three strangers that I didn’t meet until now. You’re telling me bad news and they’re all here?’” Conversely, Participant 4’s dissatisfaction is a product of her beliefs about autism. When asked to describe the assessment process, she described, “There was um a psych eval and that was it. Then you see the doctor. Which it feels now it’s ridiculous. Because I believe you can’t really diagnose autism spectrum until they are...a little older.” She continued to explain that she believed that the clinician that diagnosed her child did not ask enough questions about her son’s medical history:

I wish they don’t *sic* spend with the child for an hour and diagnose a child. I just don’t think that that’s fair. I understand they have professional knowledge of looking at the symptom, looking up the symptoms and all that. But I think I want them to be more in depth. I want them to look at all his history, not just the symptoms that he’s exhibiting. I want them to go through their medicals just for the case of my son, let alone speech. If you had looked into medical issues as well as you looked into his symptoms, I think we could have had this figured out much quicker.

Mother Knows Best

All five participants included the theme of “mother knows best” within the content of their interviews. The emergent themes in this category are mother’s intuition and parent as expert. The mother’s intuition theme typically was present in the interview content about their experience prior to receiving the diagnosis. In contrast, the parent as expert theme was described as being experienced both before and after the participants’ children received their diagnoses of ASD.

Mother's Intuition

All the participants noted that mother's intuition was an important part of receiving the autism diagnosis for their child. Some participants noted that their mother's intuition was about their child's atypical development. Other participants described that their intuition as a mother helped them meet their child's needs, despite significant developmental challenges (e.g., underdeveloped speech skills).

Intuition about Development. Participant 1 suspected that her son had autism when he was approximately 12 months old. In order to get him diagnosed, she stated, "I recommended that he be referred for a developmental pediatrician appointment." Despite providers telling her that her child did not have any delays, she stated that she wanted to continue the diagnostic process. She explained, "And then we went back [to the clinic], which was in October right after he turned two and they diagnosed him at the second appointment." Similarly, Participant 5 had challenges beginning the diagnostic process. She described, "And then I really noticed more and mother's intuition *sic* so I was very persistent."

Participant 1 had knowledge about autism due to her career in the medical field. Participant 2 did not have a similar education, but still suspected that her child's development was not typical. She stated, "Mother's intuition told me for some reason I was like, 'It's autism.'" Participant 2 continued to explain that she was in denial at first but continued to have a sense that her child had ASD, despite what she wanted to believe. When asked about her knowledge of autism, she stated that she only knew what was portrayed in media, such as television shows. She continued:

But again, I could not tell you that why, when I started noticing what [he] was doing, why autism flashed across my brain. I just couldn't even—the only possible explanation is

mother's intuition. That's the only thing I could possibly tell you. Because it's not like anyone's seen some of the things he did and said, "He may have autism." Or like, nobody ever suggested it to me.

Intuition to Meet Child's Needs. Three participants mentioned their innate ability to meet the child's needs because of their intuition as a mother. Participant 4 explained that her son is primarily nonverbal but learned sign language to communicate. As a mother, she explained having a certain feeling about her son's skills and abilities. She noted, "That kind of got me started to think [*sic*]... 'I think he has no problem learning things and I think there's something else is blocking him. Something else in the way of him communicating.'"

Other mothers emphasized the importance that their intuition played in communicating with their nonverbal children. When asked about challenges prior to her son's diagnosis, Participant 3 stated that she did not have any challenges. Instead, she explained, "you don't always need them to talk to be able to know what they want." Due to her sense of understanding of her child, she felt that others may have faced challenges that she did not. Participant 2 expressed a similar sentiment. Despite teaching her son to gesture to communicate his needs, she stated, "because I was with him so much, like 80% of the time, he didn't even have to gesture. I just knew what he wanted." The way she explained this experience highlighted her sense of confidence in her ability to help her child and meet his needs.

Parent as Expert

Two of the five participants spoke of their feelings of knowing their child best and asserting themselves as an expert throughout the diagnostic process. Participant 5 highlighted the amount of knowledge she acquired about autism and her role in communicating to the school systems after her child was diagnosed. When attending individualized education plan (IEP)

meetings for her son she used the knowledge she acquired. She stated, “I knew the laws. I knew everything.” Participant 4 does not seem to agree with her son’s autism diagnosis but utilized the diagnosis to gain access to resources and intervention. She asserted, “My son in my inprofessional *sic* opinion, he’s a medical kid.”

Autism as a Disability

Four of the five participants spoke of autism as a disability and the lack of skills that led to their child being diagnosed with autism. The participants spoke of the atypicality of their child’s developmental trajectory as the catalyst that led them to seeking an evaluation.

Lack of Skills

Two of the participants, Participant 1 and Participant 4, described their child’s lack of skills in the context of skills that were late or never developed in their child. The other two participants who endorsed autism as a disability, described that their children regressed, or lost skills that they once had, both of whom endorsed loss of speech and language skills.

Delayed Development. Participant 1 explained that her concern for her son’s development arose when he was not communicating nonverbally, as she expected. She detailed that when her son was approximately one year old, “He wouldn’t point, he wouldn’t copy any actions. Those are the two big things...He was just very quiet. He didn’t babble, he didn’t make any sounds.” Similarly, Participant 4 explained that she began early intervention services because her son “wasn’t talking until at 20 months.” The early intervention services ultimately led to a referral to psychological evaluation services.

Regression. Participant 2 and Participant 3 explained that their sons lost skills that they once had. In the context of suspecting her child had autism, Participant 2 described the moment where her concern arose, “He would always say name of character in that episode. For some

reason it caught my attention that he wasn't saying it anymore. And gradually a lot of the words and sentences he was saying, he completely stopped saying." Participant 3 had a sense of exasperation when describing her son's regression. She asked her son's doctor if he was selectively mute because, "he talked! He talked and interacted with you, and he laughed and had fun and all the things. And they just kind of slowly like disappeared."

Parent–Child Relationship

Due to the nature of the interview questions, the participants were asked to reflect on the parent-child relationship before and after their child received an autism diagnosis. Four emergent themes were apparent within the interviews: a consistently positive relationship, stressful family relationships, relationship before the autism diagnosis, and an improved relationship after the autism diagnosis.

Consistently Positive Relationship

Four participants explained that their relationship with their child was consistently positive, regardless of their child receiving a diagnosis of autism. Participant 5 described her relationship with her son as the "same it is now. Very loving." Similarly, Participant 3 explained, "You know, we had—we had a great relationship. We still have a great relationship." She continued to describe her experience her elation about being pregnant with her son and said she "loved every little moment, and [she] took a million pictures." Participant 2 also identified her relationship with her son as consistently positive. Participant 1 echoed the same sentiment when describing her relationship. She replied, "Good. It was good. It was always good."

Stressful Family Relationships

Three participants stated that they were their child's caregiver of choice. The context in which this was mentioned was often when discussing challenging aspects of their relationship

with their child. Participant 3 stated that her family relationships are positive, but explained, “The only problem anybody has is when he just wants Mom. He can’t go asleep without me. That makes things very hard on everybody if I’m not around.” While Participant 3 stated that his preference for her was challenging to others, Participant 2 stated that it was stressful for her to be her son’s preferred caregiver. She explained:

I mean there was a period where he would only sleep on me. Just things like that. He was very, very, very attached to me. I mean he’d always want me to hold him, pick him up.

And at the time, I’d be like “This is a lot.”

She also mentioned that he is currently more independent than he was at a younger age.

Participant 5 detailed similar challenges to Participant 2 surrounding her relationship with her son. When asked about familial relationships, Participant 5 explained, “He also would—he was very obsessed with me. If he would have to be sent to his room for something, only I could get him out.” She mentioned that this was frustrating for her husband because he wanted to be as involved as she was.

Relationship Before the Diagnosis

As the participants were asked to reflect on their relationship with their children, four of the participants noted significantly challenging aspects within the parent-child relationship. Two participants noted mutual frustration between themselves and their children before knowing their child had autism. In addition, two participants reported that their child was in control relationally prior to the autism diagnosis.

Mutual Frustration. At first, Participant 4 stated that her relationship with her son was not different before the diagnosis in comparison to how it was currently. However, after some reflection she noted feelings of frustration. She explained, “There was some frustration because

he wasn't talking...I did see his frustration at times, so I tried to accommodate him, come up with a strategy to get the frustration, to get the anger out." Participant 2 noticed that her son seemed frustrated with her because of his inability to communicate. She stated:

When the regression happened, he had lost the verbal capability of communicating with me. He would get extremely frustrated with me. Especially if I couldn't figure it out. He would have a meltdown in the sense of, he would never hurt himself or anybody else, but like a tantrum.

Child in Control. Due to challenging behaviors, two participants emphasized that their children preferred to control the environment. Participant 3 described her husband's challenges within relating to his son due to the child's need for control. She explained, "Unless you are a part of his kind of consistent, rigid environment, then he didn't really wanna have much to do with you." The child's rigidity permeated the play environment, as well as family routines and bedtime. She continued to explain that her husband became frustrated and wants to appease their child's need for his routines, such as Participant 3 doing the bedtime routine.

Participant 5 expressed her child's need for control in an animated matter. She explained an instance in which her child became emotional about wanting to control his environment. She recalled:

So I got him some milk and I put it on the table, and he was like, "No! Give it to me, give it to me!" I was like, "I put it on the table, honey. It's right there." And he's like, "No, no, no, Mommy! Touch it! Touch it!" He was very, very obsessed with having me actually hand it to him.

Her child's insistence on controlling his environment resulted in a temper tantrum and left Participant 5 feeling heartbroken.

Improved Relationship After the Diagnosis

One participant, Participant 4, described her unique experience of having an improved relationship with her son after he was diagnosed with autism. When asked about her current relationship with her son, she replied, “Very good. We are—now especially this year we had a dramatic, remarkable year when solving his medical issues and all that. So we are better than ever right now.”

Feelings Before Diagnosis

All five participants were asked about how they felt when they noticed their child’s development was atypical (Appendix A). Four emergent themes emerged from the interviews detailing the participants’ emotions: worried, no concern, loneliness, and shock. These feelings occurred either when the parent noticed their child was not meeting developmental milestones, or a provider referred their child to be assessed for autism. In addition, the participants endorsed feelings of loneliness in the context of the parent-child relationship or family relationships.

Worried

Two participants described feelings of worry when they noticed their child was not developing as expected. Participant 2 noted significant worry when she noticed her son had lost skills that he once had. She reported:

I was extremely worried. I was extremely worried because I—you don’t know what’s going on. Regardless of what flashed in my head, you have no idea what’s going on. It’s like one day you see your child doing all these things and it didn’t—at least for my son, it—like it all didn’t happen overnight, but it felt like it happened like a light switch. Like it did happen overnight. It felt—it was a very quick transition. It wasn’t like something

that took place over seven months. It did happen over the course of like a month, a month and a half.

Similarly, Participant 1 described her mood as “probably anxious” when she realized her son was not developing typically.

No Concern

In contrast to the participants who were worried, two participants stated that they did not have significant concern about their child’s atypical development. Participant 4 attributed her child’s delayed speech and language skills to her teaching him more than one language. She explained, “So I just thought that it was somewhat natural...I wasn’t that much concerned at that point.” However, she proceeded to enroll her child in early intervention services because she decided it would not do harm. After listing the aspects of her son’s development that were atypical, Participant 5 remarked, “So those were some things that I found different. Not alarming, were just different.”

Loneliness

Two participants endorsed feelings of loneliness before their children were diagnosed with autism. Due to her son’s verbal challenges, Participant 4 explained:

I’m spending time with a child and he understands me on certain level, but then he doesn’t know how to respond even though you want to, you know? So, I think that time to get me—I was lonely I think in some way that I wish he would respond to me.

Participant 3 had feelings of loneliness because of challenging relationships between her child and other family members. She stated, “They kind of threw in the towel with helping a lot of the time. Everybody that was a shared responsibility suddenly stopped.” She explained that she no

longer felt like she had support in caring for her son because others felt they could not meet his needs.

Shock

Two of the five participants were shocked by providers suggesting their children should be assessed for autism. Participant 2 agreed to have early intervention specialists come into her home to evaluate her child's developmental progress. At the end of the appointment, the early intervention specialists sat down with Participant 2 and her husband. Participant 2 elaborated:

[The early intervention providers] had brought up a neurologist, so I was like, "Neurologist? What do you mean a neurologist—" "Well, I mean like we said we're not doctors. We're just telling you the findings of information and this is where he hit." At this point now, I'm not even listening to anything they're saying. And so they kind of just got up and left and I look at my husband and I just broke down and I started crying because ultimately I knew what I was going to hear.

Participant 3 explained her shock when her autistic older son's provider suggested that she should have her younger son evaluated, as well. She continued, "So for him to present so dramatically differently—I just never in a million years even considered it."

Feelings After the Diagnosis

For all participants, their initial reactions to their child being diagnosed with autism were negative. Within the superordinate themes, the emergent themes included: devastation, heartbreak, stress, and grief.

Devastation

Two of the five participants described their initial feeling when being told their child had autism as, "devastated." Participant 3 recalled the hardships she faced when her autistic older son

was diagnosed, which influenced her reaction to her younger son being diagnosed. She remembered, “Well I mean, I was—I was devastated [when the doctor pointed it out]. It was really, really hard for me not just because he was autistic, but because I had the experiences before—the experiences before traumatized me.” She continued to explain that her older son faced significant social hardships and she could not help but imagine a similar future for her younger son.

Similar to Participant 3, Participant 2 described her experience receiving the diagnosis:

The best word that comes to mind is “devastation.” It’s the best way I can explain it because at that point, I went to only what I know about ASD. I just started—I specifically remember [the psychologist] handing me a tissue. He was like, “I understand. Do you have any questions?” And the one thing I said to him was—and I was almost hysterically crying—I was like, “Does that mean [my son] is not gonna hug and kiss me anymore? He’s gonna stop doing that?”

She explained that her concerns came from her prior knowledge of ASD, which were soothed by the provider.

Heartbreak

Two participants endorsed feelings of heartbreak after their children received an autism diagnosis. Participant 5 explained that her child’s diagnosis led to mixed emotions, one of which was heartbreak. She mentioned, “It was a little heartbreaking. I kind of didn’t sit on it for a long time, like the sadness.” In contrast, Participant 2 expressed that she continues to have feelings of heartbreak because of her child’s challenges due to his autism. She stated, “And those for me are bad days, as a mother, to not know what’s going on it’s heartbreaking ‘cause all you want to do

is make it right.” Then, she explained that she felt helpless at times because she does not always know how to best help her child.

Stress

Of the five participants, two participants mentioned feelings of stress after the diagnosis. Participant 1 reported stress related to the number of appointments she had to take her son to following his diagnosis. “It was a very stressful period,” she explained. Participant 5 experienced stress related to her son’s behavioral dysregulation. She stated, “There was a little bit of time where there was a big stress in the house.” She continued to explain that the severity of her child’s aggression led to stress levels due to not knowing how to best help him.

Grief

Feelings of grief arose for two of the participants. Participant 3 detailed the interests that her child lost once his skills regressed. Her voice was tinged with sadness and grief as she reminisced saying, “We’d do something, we’d dance after dinner, we’d have a good time. Those are things we can’t do anymore. But even singing Happy Birthday you can’t do it... he loved fireworks. He hates them. He hates all that now.” Participant 5 admitted to feelings of grief when her child was diagnosed. She explained that, “once [she] grieved it,” she began to problem-solve and figure out how to best help her son.

Perception of Autism

All five participants were asked about their perception of autism before and after their child was diagnosed with autism. Four emergent themes were present in the data: increased knowledge of autism, positive perception after the diagnosis, alternate explanation for symptoms, and autism is not an excuse. The emergent themes were present in different parts of the interview despite the two specific questions related to the participants’ perception of autism.

Increased Knowledge

Three of the five participants emphasized that their knowledge of autism increased after their child was diagnosed with autism. Participant 2 endorsed that many changes occurred in how she viewed ASD. She detailed, “I wanted to learn as much about it as possible. And when I say that I don’t mean like Googling it and looking any of that stuff up. I wanted to get involved with things in the community.” She explained that the changes did not occur immediately after her child was diagnosed with autism, but rather gradually over time. Although she has two children with autism, Participant 3 noted that her younger son’s presentation was drastically different than that of her teenaged son. When asked if her perception of autism changed, she answered, “Well yes, because now I know that regression—regression really is a thing.” Participant 5 reflected on the differences between her knowledge about autism before and after her son was diagnosed. She stated, “I researched a lot. I would say probably 40% of all the knowledge I know now.”

Positive Perception After Diagnosis

Two participants explained that their perception of autism changed positively after their child had symptoms of autism. Participant 1 explained that her perception occurred once she noticed that her child had symptoms that were indicative of autism. She stated:

I think it definitely changed our view because when you think of children with autism and you don’t know one personally, you kind of think of that more severe end of the spectrum. When you have a child like ours, it does change the way you think about it.

Prior to her child exhibiting symptoms, her perception of autism was based on working with adults in the medical field. Participant 2 had similar perceptions that all individuals with autism presented on the severe end of the spectrum. Following her child’s autism diagnosis, she became

involved in classes with a parent support group. She explained, “And it was from those classes that—it really taught me what this is. And that it’s not—it’s not like—I hate putting it this way. I’m sorry. It’s not like a death sentence.”

Alternate Explanation for Symptoms

Despite accepting a diagnosis of autism, Participant 3 and Participant 4 explained that they believed their child’s symptoms were a result of other factors. Participant 3 explained that her son’s symptoms and regression occurred following multiple immunizations, despite research disproving this theory (Centers for Disease Control, 2020a). She mentioned that she did not initially believe that his diagnosis could be a result, but after talking with professionals, she changed her point of view. She noted, “But when he got his immunizations, he ended up with like a 106 fever for like three days. He had a lot of issues after then, but again it all coincided with everything that was going on.”

Participant 4 detailed the many medical challenges that her son faces in addition to his autism diagnosis. As aforementioned, she stated that she utilizes his diagnosis as a method to obtain interventions and services. Participant 4 explained:

He’s a medical kid. He has medical issues, such as sleep apnea. And severe obstructions with apnea leads to ADHD [attention-deficit/hyperactivity disorder] symptoms and also severe like sleep apnea with the tonsils. You know inflamed tonsils; they tend to not to talk until they remove the tonsils which was a case of my son.

Autism is Not an Excuse

Two participants explained that they do not perceive autism as an excuse for their child to act out. Specifically, they mentioned the importance of this concept when disciplining and as a way to provide their child with a sense of normalcy. Participant 5 expressed that she feels some

parents utilize autism as an excuse to allow their child to behave however they want. She explained, “You know he’s still a child. And he’s gonna try to get away with what he wants to get away with. We kind of treated him pretty much the same.” Participant 2 hopes for her friends and family to treat her son just as they would any other child. She expressed, “I always tell people, ‘He has an autism diagnosis. It’s not a big thing. It’s not a ‘get out of jail free card.’ You don’t get to put your hands on people or hurt other people.’”

Advocacy and Persistence

Two participants described situations in which they had to advocate for their children. One participant also had an emergent theme of persistence when she had to advocate for her child’s needs.

Advocating for Child’s Needs

Participant 1 had to advocate for her child to get services covered by their insurance plan. She explained, “For the first six months trying to, so we had to fight with insurance because they wouldn’t pay for ABA [applied behavior analysis] therapy.” As a result, she and her husband had to pay for his services out of pocket. Both Participant 1 and Participant 5 began advocating for their sons to have them assessed for autism. When describing her knowledge about autism, Participant 1 stated, “I’ve never worked with children, only adults, but I would say it would have taken a lot longer if I wouldn’t have advocated for him and kind of pointed out that I felt something was wrong.” Participant 5 mentioned, “[My son] was like two and half or three and then I started calling around places to get neuropsych done.” However, she was not able to have her son assessed immediately. Her advocacy continued in individualized education plan meetings. When describing her role at the meetings, she stated, “I came in, not like a jerk, but I

said, ‘This is whatever, and I know this.’” She felt as though she needed to assert herself or her son’s needs would not be accommodated.

Provider Relationship

Across the data, three participants described their relationships with providers before and after their children were diagnosed with autism. Three emergent themes were present in the data: being dismissed, discomfort with provider, and satisfaction with provider.

Before Diagnosis

Two participants described their feelings during interactions with providers in the process leading up to the autism diagnosis. Specifically, they described feelings of being dismissed when they voiced their concerns about their child’s development.

Being Dismissed. Participant 5 expressed her concerns to her child’s pediatrician when her son was 3 years old. She explained, “I brought it up to his doctor a few times how he was a little oral and when he would get really excited. He said, ‘Oh you know, I don’t think we need early intervention or anything.’” Participant 1 felt as though multiple providers dismissed her concerns about her child. She reflected:

I personally think early intervention was a detriment to him being diagnosed because the speech therapist would... make comments in front of my husband like, “There’s no way he has autism,” “He makes great eye contact,” “He’s too social,” and it was kind of deterring him from thinking there was something wrong.

In addition, when she expressed concern to her child’s pediatrician, she explained that he expressed his skepticism when making the referral. She stated, “The pediatrician at that point said ‘I refer you, but they’re probably going to say that we’re crazy for referring him. There’s nothing wrong.’”

After Diagnosis

Four participants described their provider relationship after their child was diagnosed with autism. Two emergent themes arose in the analysis: discomfort with the provider, and satisfaction with provider.

Discomfort With Provider. Two of the five participants expressed discomfort with the providers when their child was diagnosed with autism. Participant 4 explained that she was skeptical of her son being diagnosed with autism. Her skepticism stemmed partially from her relationship with her provider. She explained, “But at the same time there was doubt in my doctor. Like 50/50, you know. That I wasn’t really trusting.” As aforementioned, Participant 1 experienced discomfort when providers she had not met attended the diagnostic feedback session. She explained that she felt vulnerable receiving the diagnosis with new individuals in the room.

Satisfaction With Provider. Two individuals expressed their appreciation of and satisfaction with providers they interacted with throughout and after the diagnostic process. Participant 2 described, “[Our provider] was just extremely gracious and very understanding and kind.” She explained that the psychologist’s demeanor eased her nerves when her child received his autism diagnosis. Participant 5 spoke fondly of a provider with whom her child is currently receiving services. She explained, “As of now, he just has his [home based therapeutic services] therapist. She comes—right now we only get nine hours a week. She is absolutely amazing.”

Challenges and Hurdles

Of the five participants, four participants described challenges and hurdles they faced before and after their child was diagnosed with autism. Three emergent themes were present in the data: accommodation to child’s challenges, educating others, and struggling with services.

Accommodation to Child's Challenges

Three participants reported having to accommodate their child's challenges related to their symptoms of autism. When asked about activities she enjoyed with her child prior to his diagnosis, Participant 4 explained, "I think I was trying to do as much as my boy could enjoy without getting frustrated, which was I think more toward the activity like physical activity." Similarly, Participant 2 accommodated her son's speech and language challenges. She stated, "I tried to teach him other ways of communicating with me to get his point across." In relation to her son's hobbies, Participant 5 noted, "We homemade paint because he was very oral." She continues to accommodate his challenges in their daily life. She reported, "We never really put him in that high intense environment[s]" due to the child's behaviors when overwhelmed. She continued to explain that prior to going to new places, she tries to show her son online videos of the environment to ease his anxiety.

Educating Others

Two participants described experiencing the responsibility of educating others about their child's diagnosis. Participant 3 explained that she and her son have a small group of friends in their homeschooling group. She and the other parents of the group, "are starting to teach the kids, 'Okay this is [child's name]. These are what may hinder clearer communication. This is how we can work with him.'" Participant 5 offered to educate friends and family when she told them her son was diagnosed with autism. She said, "They'd either be feeling bad or whatever. And I'm like, 'Dude, it's okay. Do you have questions? Ask me. I'm an open book. I'd rather have questions than do whatever.'"

Struggling With Services

Three participants expressed that they struggle with interventions and services. Each participant described varying concerns related to their child's services. Participant 5 explained her challenges in the context of the COVID-19 pandemic by stating, "His therapy had to stop because doing it on Facetime or whatever, Zoom, is pointless. Because he'll find a piece of glitter and have a whole world with it." She also expressed, "I do wish that we had some more time. It's scarce right now with any group. I even tried to get with another program and they're like, 'Yeah we don't really have anybody to send out.'" It is not possible to discern if her challenges were related specifically to restrictions at the time of the COVID-19 pandemic, or if the concerns were present prior to COVID-19-related changes.

The location in which Participant 3 and her family live creates challenges in receiving her desired services. When comparing her prior experience in another state with her older son, Participant 3 stated, "I've never struggled so hard to try to get services for my children than I do here." She also described her challenges when stating the city in which she lives:

There are a lot of services around if you can find them. Finding them and then willing to drive. When I would try make appointments and see different people, even for evaluations...they're like, "This is in [city name] or past [city name,] ...Are you actually going to come to this appointment if I make it? Because most people from your area end up as no-shows."

She continued to state that a parenting support group occasionally has classes near her home. However, she often has to drive an hour in order to participate in services.

Participant 4 explained that she wishes there were greater variety in the services offered for her son. First, she stated that she wished her child could receive music therapy services. In

addition, she reported, “Also, I wish... you know, animal therapy, riding horses and stuff like that... There is—there is couple places...one place is [out of state], so I don’t know if they accept [my] insurance.” She continued to express her beliefs that she views new experiences as therapeutic for her son.

The Future

The future was a superordinate theme present in the narratives of four of the participants. Specifically, participants expressed two emergent themes: worries about their child’s future, and optimism about the future.

Worries About Child’s Future

Four participants expressed worry about their child’s future because of their diagnosis of autism. As her son aged, Participant 4’s worry grew. She noted, “As he was getting 8 and things were still too delayed and other things were still not—I don’t want to say normal, but they did not look in the same in his age group.” Participant 2 explained that her concern about her child’s future manifested as questions about her son’s prognosis. She detailed asking the provider countless questions about how her son would present as he aged. She recalled:

Every time we’d have an appointment with [our provider], I would say, “So what do you think is the percentage rate of kids on the spectrum that like lose their speech and skills that gain them back?” Or um—one of my biggest fears, especially in that moment when [the provider] told us what was going on, you hear people with developmental disabilities a lot of them can’t care for themselves.

She described a feeling of being instantly forced to consider her child’s adulthood while he was only a toddler.

Participant 3 explained that considering her son's future was quite difficult for her and her husband. She noted, "All the hopes and dreams that you have for your first child has to be reassessed. You have to sit there and wonder about those things." Similarly, Participant 5 was left wondering what types of obstacles her son would face. She expressed, "My husband and myself feel like he will probably be with us for a very long time." However, she also expressed that she was hopeful for his future.

Optimism

Three of five participants expressed feelings of optimism and hopefulness when considering their child's future. Participant 2 drew her inspiration from media posts of successful autistic adults. She mentioned, "I think to be in it and seeing where some people started and seeing where they're ending, it's like the possibilities are endless with my son." Participant 3 explained, "Every day we have a little more optimism." She continued to note his intellectual strengths and the progress he has made over time. Right after receiving the autism diagnosis, Participant 5 recalled feeling motivated. She said, "Okay this is a little roadblock, but we're going to get over it. And thankfully he reached all of his milestone immaculately early. At 9 months he was walking. He was a brilliant child. He still is."

Summary of Results

Overall, the participants had varying experiences before, during, and after the autism diagnostic process. Some participants were caught by surprise when their child was referred for assessment, while others suspected their child had autism since they presented atypically. Several participants described dissatisfaction with the diagnostic process due to provider relationships and their beliefs as a parent on how autism should be diagnosed. Nearly all participants stated that they always had a positive relationship with their child before and after their child had an

autism diagnosis. Finally, many participants reported worries about their child's future and some stated that they were optimistic.

Discussion

The purpose of this study was to explore parents' experiences before, during, and after their child received a diagnosis of autism spectrum disorder (ASD). Specifically, the study gleaned information about numerous themes including the following: (a) the parent-child relationship before and after the child received a diagnosis of ASD, (b) the diagnostic process and the provider relationship, (c) the parents' perception of ASD before and after the autism diagnosis, (d) overall parent mood before and after the autism diagnosis, (e) parents' initial reaction to their child's diagnosis, (f) challenges and hurdles parents faced before and after their child was diagnosed with ASD, and (g) the worries and hopes associated with their child's future. This section will discuss how the results relate to these themes, as well as relevant literature. Additionally, it will examine the implications of the findings for parents of children with autism, as well as clinical and systemic implications.

The Parent-Child Relationship Before and After the Diagnosis

Many parents in this study initially described their relationship as consistently positive with their child. However, as the interview progressed, several participants reflected on challenges within the parent-child relationship before their child was diagnosed with autism. Three participants described stress associated with being their child's preferred caregiver (e.g., child only wanting their mother to put them to sleep). This stress is similar to the stressors related to caretaking demands that were reported in prior research (Baker-Ericzen et al., 2005; Cameron et al., 1991). As a result, some participants noted this as a strain on their relationship with their child. A participant reflected that she valued her relationship with her son but felt overwhelmed

at his demandingness for her to be his sole caregiver. The same participants mentioned comparable stress after their child received an autism diagnosis. However, one of the participants spoke about her child's demandingness as an associated factor of autism. It is possible that the participants became more understanding and accepting of atypical behavior and significant preferences due to the knowledge of their child's diagnosis.

Krakovich et al. (2016) found that parental stress is often correlated with child-related factors, such as symptoms of autism. Similarly, the study participants mentioned that the mutual frustration between themselves and their children stemmed from their child's inability to verbally communicate. Most of the participants reported that their child had delayed language, which is a symptom of autism (American Psychiatric Association, 2013). Some participants reported frustration between themselves and their child due to the language delays. Specifically, their frustration led to stress in not understanding how to best meet their child's needs. Additionally, some participants noted that their child attempted to be in control of their environment, such as dictating how their caregivers handed them dishes and interacted in their play. Behavioral rigidity is a common symptom associated with ASD and is likely the symptom influencing the child's need for control (American Psychiatric Association, 2013). The two participants who detailed these challenges expressed feelings of heartbreak and frustration, which led to greater feelings of parental stress.

As indicated in the results, most participants described their relationship as consistently positive with their children both before and after the diagnosis. However, one participant stated that her relationship with her son improved after he was diagnosed with autism due to additional answers provided about his symptoms. She explained that following the diagnosis, she had a better sense of how to meet her child's needs, thus improving their interactions. In addition, she

stated that the changes in their relationship were correlated with increased language use. This participant endorsed feelings of stress related to her son's language delays prior to his autism diagnosis. When asked to reflect on her experience after her son was diagnosed, she explained that she viewed her son's diagnosis of ASD as a tool to gain access to necessary services, such as speech and language therapy. Consistent with prior research, her stress levels reduced due to the progress her son was making in treatment (Robbins et al., 1991).

Diagnostic Process and the Provider Relationship

Prior research indicated that many parents suspect their child's development is atypical before the age of 2 (Chamak et al., 2011). Consistent with prior research, participants in this study stated that they suspected that their child's development was not progressing as expected. However, not all participants suspected that their child was on the autism spectrum. Other explanations to which their parents attributed their child's delays in language use were selective mutism, trauma, and living in a bilingual household. As aforementioned, Chamak et al. (2011) reported greater parental satisfaction with diagnoses provided for children over the age of 4. The participants' children received their diagnoses between 2 years and 4.5 years old. The correlation between diagnostic satisfaction and age was not explicitly examined in this study. However, the participant (Participant 4) whose child received the latest diagnosis appeared the least satisfied with his diagnosis. Due to the small sample size, this case is not likely representative of the experience indicated in larger studies, but rather is indicative of the single experience of one participant. It is possible that the relationship between age at diagnosis and parent stress is a complicated one. Literature states that greater familial understanding of and acceptance of autism is associated with early intervention (Jagan & Sathiyaseelan, 2016). All five participants reported that they found the services that their children and family received helpful. The earlier a child is

diagnosed with autism, the earlier the child will receive such interventions. Despite the findings of Chamak et al. (2011) associated with diagnostic satisfaction, the findings of my study imply that the relationship is more complex, and that delaying diagnosis may not be beneficial if it also delays effective intervention. In the present study, improved communication and adaptive behavior through early intervention were associated with decreased parental stress.

Themes of uncertainty about and dissatisfaction with the diagnostic process were present in some interviews. Participants' uncertainty was uncovered when they were asked about the measures that were a part of the diagnostic process. Many individuals could not recall specifics, but rather stated the types of measures, such as checklists or observation. Understanding how assessments contributed to the diagnosis can be important in knowing why their child was diagnosed with autism. In addition, almost all participants reported a long delay between mentioning their child's atypical development to providers and beginning the assessment process. One participant reported dissatisfaction with the depth of the evaluation process and indicated that she believed providers should consider a child's medical history and have a longer evaluation process.

The literature focuses primarily on the child parent-relationship. However, my study illuminated the importance of parents' relationships with their providers throughout the diagnostic process. The participants' satisfaction with the diagnostic experience seemed to relate to their relationship with providers throughout the process. Multiple participants mentioned provider-patient relationships in their interviews. Prior to receiving their child's autism diagnosis, some participants reported feeling dismissed by their providers about their concerns. Specifically, the participants noted that they mentioned concerns about their child's development and the providers stated that they did not see anything worrisome about the child.

The findings of the study indicated feelings of frustration and significant challenges in pursuing autism assessment because of providers dismissing parents' concerns. These results are similar to the literature that states that parents were at times dismissed by providers when they expressed their anxiety about their children's development (Chamak et al., 2011). When parents are dismissed by providers, it delays the assessment process. This implies that pediatricians, psychologists, and other providers could spend more time listening to and considering parents' reasons for voicing concerns about autism. Due to the emphasis on early autism diagnosis, it is important that providers recognize that parents have more observations of their children than the provider, and not dismiss parental concerns. In addition, if a provider is reluctant to refer a patient for autism assessment, it would be useful for them to monitor caregivers' concerns over time, especially in relation to developmental delays. Dismissing a parent's concerns could lead to a rupture of the provider-patient relationship and create feelings of tension or distrust. The provider relationship during and after the assessment process is equally as important.

Participants detailed their relationships with their providers following the diagnosis of autism. Two participants reported discomfort with the providers who gave the autism diagnosis. One participant stated that she did not fully trust the provider in giving a correct diagnosis. The other participant reported feeling uncomfortable because of several providers attending the diagnostic feedback session that she had not met. In contrast, some participants described positive relationships with their providers. One participant repeatedly emphasized her fondness for the psychologist that diagnosed her son. Another participant detailed the positive relationship she and her son had with one of his at-home therapists. It is important to note that the participants were not specifically asked about their relationship with providers. However, the findings of the study suggest that providers who are involved before, during, or after the

diagnostic process have a significant impact, both positive and negative, on parents and their children.

The relationship between provider-parent rapport and parental satisfaction implies that creating a strong therapeutic rapport is an important aspect of the autism diagnostic process. It is common for the autism diagnostic interview to be the first contact between a family and a provider. As a result, providers must build rapport quickly with a family while gathering important diagnostic information. The results of my study imply that providers should focus on making the families feel as comfortable as possible throughout the process. Additionally, the data emphasize the importance of building a relationship with caregivers during the diagnostic assessment process.

Parent Perception of ASD Before and After the Diagnosis

Due to the prevalence of the neurodiversity movement in the United States (Cascio, 2012), my study sought to explore whether the participants' perceptions of ASD changed once their child received a diagnosis. All five participants noted a change in how they viewed autism or the amount of knowledge they held about ASD. Over half of the participants noted an increase in knowledge about ASD since their child was diagnosed. Prior to the diagnosis, their knowledge stemmed from media portrayals of individuals with autism, as well as knowledge from their career. However, after their child was diagnosed, they gained knowledge from personal experience, as well as involvement in the autism community and parent groups.

Of the five participants, two provided alternate explanations for their child's symptoms of autism. One participant believed her child's autism symptoms were a result of vaccine injury, despite research disproving a link between immunizations and ASD (CDC, 2020a). She noted that she had once believed that there was not a correlation between the two, but now believed in

the causation due to her personal experience. The second participant stated that her son's symptoms were not because of ASD but were a result of medical complications. Parent rejection of diagnosis was not noted in previous literature but is interesting to consider clinically. Although both participants reported an alternate explanation for their child's diagnosis, their relationship with the autism diagnosis differed. The mother who believed her son's diagnosis was related to vaccine injury did not disagree with the diagnosis of autism. Instead, she disagreed with the cause of the disorder. In contrast, the mother who believed her son's symptoms were a result of medical complications did not agree that her son had autism. These results are important to consider as such views would likely impact how parents engage with their children's providers after the diagnosis is given. These findings imply that providers might benefit from asking caregivers to express any concerns, reactions, or opinions that they have in relation to the diagnosis. As a result, providers may better understand parent reluctance and its impact on treatment, and be able to offer additional psychoeducation and support resources to those parents.

Two participants stated that their perception of autism has changed positively since their child received an ASD diagnosis. Both participants noted that before their child was diagnosed with autism, they believed that all symptoms presented similarly to individuals with severe ASD. Since the diagnosis, they realized that autism symptoms are variable and are not always consistent with what is portrayed in the media. The current study also showed that some participants felt that autism was not an excuse for their child's behavior. They noted that they sought to treat their child just as they would if they were typically developing. These findings are consistent with literature detailing the neurodiversity movement, as they are not looking to cure their child's symptoms and instead view autism as a different world view (Cascio, 2012). This

study exemplifies the vast difference in the perceptions that parents with children with autism hold. Some parents are accepting of their child's diagnosis, while others seek alternate explanations despite the results of the child's autism evaluation.

Overall Parent Mood Before and After the Autism Diagnosis

As a part of the interview, participants reflected on their mood before and after their children were diagnosed with ASD. Overall, the participants did not note significant changes in their moods. Feelings that were mentioned in the interviews prior to the autism diagnosis were as follows: worry, shock, loneliness, and lack of concern. The participants did not explicitly describe changes in their mood after their child was diagnosed, despite being asked if their mood changed. Instead, they described their current life situations or reiterated their feelings prior to the diagnosis. In future research, it might be useful to consider alternate ways to gain a more in-depth comparison of participants' mood changes before and after the diagnosis, and over time after the diagnosis as well.

Before the Diagnosis

The participants that endorsed feelings of worry reported that they were worried about their child's development once they noticed an atypical trajectory. In contrast, two participants mentioned that they were not concerned about their children's atypical development. One participant attributed her son's delayed speech to living in a bilingual household. The other participant reported that she noticed her son's development was different, but not alarming. The literature states that the family's appraisal of the situation influences parents' susceptibility to stress (Krakovich et al., 2016). The current study's results showed similar findings in that the parents who were not as worried about their child's development reported less stress and worry prior to their child's ASD diagnosis.

Some participants reported feelings of loneliness prior to their children being diagnosed with autism. One participant stated that she felt lonely because her son was not able to verbally respond to her. In addition, her spouse was not involved in raising her son. The other explained that her family faced significant challenges in helping her son, which led to her becoming the sole caretaker of her child. This is consistent with results of prior research studying paternal involvement in raising children with autism (Hay, 2016).

Hay (2016) found that some fathers engaged in passive parenting of their children with autism. Their passive parenting styles were attributed to being tired from work or from mothers being more attuned to their children. All five participants reported being stay-at-home mothers. Some participants noted that they quit their job once their child was diagnosed with autism. In addition, all of the participants expressed feeling tired from caring for their children throughout the day. While Hay's research detailed fathers' explanations for passive parenting, it is possible that mothers appeared more attuned to their children because they stayed at home, rather than just the reverse. The findings of my study implicate the importance of providers providing recommendations for support groups, stress management, mental health care, and respite care services.

Previous literature stated that parents are dissatisfied with the way in which a diagnosis of autism is delivered. However, my study highlighted additional information that was not reported in previous literature. The findings of my study illuminated the shock felt by unsuspecting parents when providers suggested they have their child evaluated for autism. Some participants reported that they did not suspect that their child had autism. One participant reported that she was surprised when early intervention specialists stated that her son had symptoms of ASD. She then stated that the providers left the home abruptly, which may have contributed to feelings of

devastation. Another participant stated that a provider suggested her child should be evaluated for autism, despite her considering a different diagnosis for her child. The shock in these situations may have led to enhanced negative feelings in comparison to parents who suspected that their child was on the autism spectrum. Furthermore, the consistent feelings of surprise indicate that providers should consider how they suggest that a child has symptoms of autism. While it will not be less surprising, it would be useful for providers to consider the emotional response that caregivers might have whether or not they previously suspected their child had autism.

After the Diagnosis

Chamak et al. (2011) found that parents had variable reactions to their child's diagnosis of autism, which was contingent on variables such as how the diagnosis was delivered and the child's age at the time of diagnosis. My study found that the five participants had consistently negative reactions to their child being diagnosed with ASD. The participants mentioned feeling the following when their child was diagnosed: devastation, heartbreak, stress, and grief. Contrary to my expectations, none of the five participants reported feelings of relief when their child was diagnosed with autism. It is possible that a larger sample size might include participants who experienced relief at having an explanation for their child's atypical development.

The parents did not report correlations between their reaction to the diagnosis and factors such as the child's age, whether they suspected autism, or the parent-provider relationship. However, this study was too small to adequately evaluate such relationships. Instead, the participants' reactions appeared related to their expectations for the future, as well as their perceptions of the significance of an autism diagnosis. Two participants reported devastation as they considered the implications of an autism diagnosis on their child's future. Some participants

also noted feeling heartbroken after their child was diagnosed with autism. One mother felt heartbroken when her child was first diagnosed, while another reported that she continued to feel heartbroken in instances in which she could not meet her child's needs.

Two participants specifically reported feeling stressed soon after receiving the diagnosis. One participant's stress was correlated with finding resources for their child, while the other participant's stress was a result of the child's severe and concerning autism symptoms. Some participants also felt grief after their child was diagnosed with autism. Specifically, they grieved a change in the child's personality or hopes and dreams that they had for their son's future. The findings of my study are consistent with the findings of previous literature. Particularly, Krakovich et al. (2016) found that the level of child's impairment significantly impacts parental stress. In addition, researchers reported that parenting stress increased when parents of children with autism considered the possibility of their child requiring lifelong care (Baker-Ericzen et al., 2005). Due to the consistently negative feelings that parents experienced when their child was diagnosed, it is important for providers to consider the intense emotional reactions that caregivers experience when children are diagnosed with autism. The findings of my study imply that providers might benefit from allowing time to provide caregivers with emotional support in addition to providing assessment feedback. A follow-up appointment would allow parents to ask relevant questions and to discuss future treatment options after the initial impact of hearing the diagnosis.

Challenges, Hurdles, and Advocacy

All five participants reported significant challenges associated with parenting a child with ASD. According to the literature, parental stress is negatively correlated with child adaptability (Krakovich et al., 2016). My study findings were similar to the literature. Over half of the

participants reported having to make significant accommodations before they knew their child was on the autism spectrum. Specifically, the participants explained that they accommodated their child's lack of language or sensory seeking behaviors. The results imply that parents might experience a reduction in stress if children gain skills of adaptability through interventions. Additionally, parents could benefit from support groups for parents of children with autism.

Some participants reported challenges related to advocacy for their child that occurred before and after their children were diagnosed. One participant reported that she had to advocate to have her child evaluated. Another participant reported that she had to advocate to have insurance recommended to treat her son. Additional challenges that participants faced occurred following the autism diagnosis. The challenges included educating others on ASD and struggling to find services for their children. In addition to caring for their children, two participants explained that they felt they had to educate others about the challenges that their children face and how to best accommodate them. Three participants mentioned that they wished for greater availability for services in their area including a variety of therapeutic treatments and more provider availability.

Karst and Van Hecke (2012) reported that parents are often confused as a result of the overwhelming number of available services. The findings of my study contrast significantly with this finding, as the participants reported a need for a greater number of services. It is possible that this finding is a result of the geographic location of the participants, insurance coverage, or the availability of services during the COVID-19 pandemic. Additionally, caregivers might benefit from clinicians providing information about available resources or contact information organizations that could assist in finding services.

Worries and Hopes About the Child's Future

The final area I highlight in the discussion section is the participants' worries and hopes for their children's future. Four of the five participants reported significant concern about their children's future. The literature stated that parents often worry about the lasting effects of autism on their children's future, specifically the potential for long-term care (Baker-Ericzen et al., 2005). While one participant noted similar concerns to the literature, my study found that participants reported a wide array of concerns about their children's future. In addition to one participant recognizing her child may live with her through adulthood, other participants worried about their children's symptom development and progression of skills. Another participant reported that she and her husband had to reassess the hopes and dreams that they had for their son's future.

In contrast, three participants also emphasized the optimism they had for their sons' futures. The literature does not often mention the positive feelings parents have in relation to their children diagnosed with autism. The findings of my study noted significant feelings of hope and optimism held by over half of the participants. Two of the participants noted optimism about the near future and their children's ability to acquire skills. The third participant reported that she was optimistic about her child's long-term accomplishments and the possibilities that his future holds. Overall, the findings indicate the push and pull that the parents of children with autism face when considering the potential outcomes of their children's future. In addition, the findings imply that the clinicians who provide long term treatment should regularly reassess caregivers' outlooks on their children's future. Furthermore, providers might benefit from expecting caregivers to ask questions about prognosis and outcome both when initially diagnosing a child

with autism, as well as throughout treatment. In doing so, they could carefully consider how to provide psychoeducation to families about ASD and long-term outcomes.

Limitations and Future Research

The current study had a few limitations. The first limitation is the small sample size. IPA encourages a small sample size to gain a depth of knowledge on a particular topic (Smith et al., 2009). However, the sample size was limited due to the challenges I faced when recruiting participants during the COVID-19 pandemic. In addition, the small sample size did not yield the diversity that I hoped to recruit. As noted, the participants all identified as female and were the mothers of sons with autism. Thus, the results are not able to be generalized to the experience of parents with varying gender identities, such as fathers. In addition, the results may have differed if some participants had daughters with ASD, as autism presents differently in females (Hull et al., 2020). Previous research examined fathers' experiences in parenting a child with autism (Hay, 2016). In order to expand the results of this study, additional research could focus on recruiting fathers of children with autism, as well as individuals with daughters with autism.

A second limitation of the study was the geographic limitations of the participants. When I first proposed my study, I hoped to recruit participants in more than one geographic region. However, I was unsuccessful in recruiting participants through methods other than members of the Rhode Island Consortium for Autism Research and Treatment (RICART). Therefore, the participants likely had similar experiences due to similar resource availability. The results are likely not entirely applicable to individuals across the nation, as well as internationally. In the future, recruitment efforts may focus on gathering participants from varying geographic regions to gain information about a more diverse diagnostic experience.

A third limitation to my study is that I did not collect information specifically about parental mental health. In order to understand the experience of this population, it may have been helpful to obtain information on if the parents have any challenges with their mental health and if they had mental health diagnoses prior to the birth of their child with autism.

Clinical Implications

The study had multiple clinical implications. First, the participants detailed the importance of the provider–patient relationship. They emphasized the challenges and strengths of their relationships with medical providers, the provider who diagnosed the child with autism, and therapy providers following the diagnosis. The data generated in the interviews highlight the impact of providers dismissing parents’ concerns, as well as the power of a supportive provider. Psychologists, pediatricians, and other providers can utilize this information when interacting clinically with patients and providing feedback about the patient’s concerns. The providers that diagnose children with autism might become desensitized to the weight of the diagnoses they provide because of the frequency at which they conduct assessments. Based on the findings, providers could benefit from considering the method in which they provide the diagnosis, as well as who is present during the diagnostic feedback session. Furthermore, practitioners need to attend to a caregiver’s report of atypical development. Specifically, providers should be careful not to dismiss concerns of autism due to the importance of early intervention services (Jagan & Sathiyaseelan, 2016).

Participants indicated that they were not educated on the purposes of the assessments administered throughout the diagnostic process. Despite the complicated nature of autism assessment, providers may find it useful to better provide explanations to families about the measures that they administer to parents and children in order to diagnose the child. Finally, the

research illuminates the complicated feelings associated with parenting a child with autism. The findings indicate that parents feel mixed emotions before and after their child is diagnosed with ASD, which are likely to change over time. It is important to consider the individualized needs of both clients and parents throughout the assessment and treatment process. In addition, providers might find it helpful to consider the ever-changing perspective of parents throughout and after the diagnostic process and respond uniquely and openly when working clinically.

Conclusion

The findings of this study highlighted important commonalities that parents faced when their child was diagnosed with autism. Their experiences led to several implications clinically and systemically. Although providers are experts in their chosen career, parents are experts in their children. While they may not be familiar with symptoms of disorders such as autism, they are quite familiar with their children and what to expect throughout development. When caregivers express their concerns about their children, providers dismissing their concerns can negatively impact a parent's relationship with the practitioner and delay important treatment. Some providers may be hesitant to refer children for autism assessment but should not be quick to dismiss caregivers' worries. Instead, they should monitor children over time, especially those with developmental delays.

Caregivers experience significant negative emotions before and after their children are diagnosed with autism. It is important for practitioners to consider the challenges that led parents to having their child assessed with autism, and the emotions that may follow diagnosis. To most effectively help children with autism and their family members, providers must work to form a positive relationship with caregivers throughout the assessment process. Building a strong therapeutic rapport might lead to a more positive assessment experience and greater parent

satisfaction with the diagnosis and receptivity to treatment. Furthermore, practitioners must be aware of parents' reactions when providing a diagnosis of autism to them. They should acknowledge the impact of the diagnosis on parents, and will likely need to provide emotional support. Providing treatment recommendations for children is an important part of the diagnostic assessment, and may need to be detailed after there is time for the diagnosis to "sink in." However, clinicians often overlook providing recommendations for parents. Due to the significant negative feelings many parents of children with autism experience, it would be beneficial for practitioners to provide parents with resources to support not only the children, but the parents themselves.

Personal Reflection

One of my primary clinical interests is working with children and adolescents on the autism spectrum. My graduate training included assessing children for ASD and ultimately providing countless autism diagnoses. When I have provided children with autism diagnoses, I have witnessed a multitude of parent reactions from fear, grief, sadness, and relief. Witnessing these differences inspired the topic for this research study. I felt that parents were often overlooked in this process because clinicians focus on providing diagnostic feedback and highlighting clinical recommendations for the child who was assessed, with insufficient attention to the impact of this diagnosis on parents. I hoped that this research would provide a window into a world that was not widely explored.

Recruiting participants throughout a global pandemic was difficult and often led to worries about the recruitment and the information that was obtained. However, I was inspired by the willingness to share and the openness of my five participants. While my sample size was smaller than expected, I believe that the findings of my research can prove to be useful for

providers. As a clinical psychologist in training, I will certainly reflect on the narratives I was provided when I am diagnosing children with autism. I will be more intentionally mindful in my interactions with parents, and consider the hardships that families may have faced prior to meeting with me, and may face in the future.

Finally, I will remind myself of the intense emotions that caregivers experience when their child receives a diagnosis of autism. When you have conducted numerous assessments for autism and provided several autism diagnoses, it can be easy for it to feel like “another day at the office.” It is sometimes challenging to remember the intense and life-changing impact an autism diagnosis can have on families. After completing this research, I was reminded that parents typically remember the day their child was diagnosed with autism years after the appointment. The findings of my study provided a viewpoint I would have not been privy to otherwise. I am thankful to the participants for their vulnerability, as I will now be able to approach my clinical work differently and provide a more therapeutic experience for my patients in the future.

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APPENDIX A: SEMISTRUCTURED INTERVIEW QUESTIONS

1. How old was your child when they received their autism diagnosis? (Date)
2. What type of provider diagnosed your child? (i.e., pediatrician, psychologist, etc.)
3. If you remember, what type of evaluations were used for this diagnosis? (i.e., M-CHAT symptom checklist, cognitive testing [i.e., Wechsler Scales or Bayley scales], diagnostic scales [i.e., Autism Diagnostic Observation Schedule])
4. Prior to receiving the diagnosis of autism, did you suspect that your child had autism?
 - a. How early? What made you suspect that they had autism??
 - b. If no, did you have another diagnosis in mind for your child?
5. How long did it take for you to receive this diagnosis after realizing something was not typical?
6. How much did you know about autism prior to your child being diagnosed?
 - a. Where did this information come from? (i.e., family member or friend with autism, someone else you knew or knew of, media, internet/search engines)
7. How would you describe your overall mood when you realized your child's development seemed atypical?
8. How would you describe your relationship with your child before they received a diagnosis of autism?
 - a. What were family relationships like at the time? (i.e., child made all the rules, very stressful/a lot of tension, etc.)
 - b. What did you enjoy doing together? What did other family members enjoy doing with your child?

- c. What challenges did you face in your relationship with your child? What challenges did other family members face in relationship with your child?
9. What was your initial feeling/reaction when your child was diagnosed?
10. Do you find that your perception of autism changed after your child was diagnosed? In what ways? When did those changes occur?
11. Have there been any changes in your overall mood since the diagnosis?
12. How would you describe your relationship with your child after the diagnosis?
 - a. What are current family relationships like? (see prompts, above)
13. What types of interventions and services is your child/family receiving related to the diagnosis of autism?
14. Are there services or resources you wish were available, but you cannot access?
15. Is there anything else you would like to say about receiving this diagnosis?
16. Any other comments about our discussion today, or anything you would like to share that I haven't asked about?

APPENDIX B: INFORMED CONSENT**TITLE OF STUDY**

Understanding the Parent Experience of Receiving and Early Childhood Autism Diagnosis

PRINCIPAL INVESTIGATOR

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ADVISOR

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PURPOSE OF STUDY

You are being asked to take part in a research study. I am a doctoral student in clinical psychology, and am conducting this study as part of my dissertation requirements. Before you decide to participate in this study, it is important that you understand why the research is being done and what it will involve. Please read the following information carefully. Please ask the researcher if there is anything that is not clear or if you need more information.

The purpose of this study is to understand how parents experienced their child receiving an autism spectrum disorder diagnosis. The researcher hopes the data collected from this study will

help clinicians gain a better understanding of the impact of this diagnosis on parents, and to inform clinicians of how they can be more mindful throughout the diagnostic process.

STUDY PROCEDURES

You will be asked to participate in an interview with the researcher via telephone or in person at a public meeting place (e.g. a library conference room). If the you are unable to participate via phone call or in person, email responses will be acceptable. Note: If responding via email, the researcher may email you with follow-up questions or asking for elaboration on your responses. The interview will last approximately 30 to 60 minutes. The questions in the interview will ask you to reflect on your thoughts and experiences before and after your child was diagnosed with autism spectrum disorder. The researcher may ask follow-up questions or prompt for elaboration if need.

To accurately remember the content of the interview, I will use audio recording during the interview. Following the analysis of the data, the recording will be deleted.

RISKS

Risks of participating in this research are no more than everyday life. You may feel sad or emotional when reflecting on some aspects of your experience of being a parent of a child with autism. You may decline to answer any or all questions and you may end your involvement at any time if you choose.

BENEFITS

There will be no direct benefit for you from participating in this research other than knowing the information may help clinicians better help families with a child with autism.

CONFIDENTIALITY

I will make every effort to preserve your confidentiality including the following:

- I will code names/numbers for you and the other participants that will be used on all research notes and documents.
- Only I will have access to the key that indicates which number corresponds to each participant.

Participant data will be kept confidential except in cases where the researcher is legally obligated to report specific incidents. These incidents include, but may not be limited to, incidents of abuse and suicide risk.

CONTACT INFORMATION

If you have questions at any time about this study, you may contact: Elizabeth Fuss at [primary email] or her advisor: [Name of Faculty Advisor] at [faculty advisor's email address]. If you have questions regarding your rights as a research participant, or if problems arise which you do not feel you can discuss with me, please contact [Name of Chair], chair of the Antioch University New England Institutional Review Board at [chair's phone number].

VOLUNTARY PARTICIPATION

Your participation in this study is voluntary. It is up to you to decide whether or not to take part in this study. If you decide to take part in this study, you will be asked to sign a consent form. If participating via email or telephone call, you will be asked to give written consent via email. After you sign the consent form, you are still free to withdraw at any time and without giving a reason. Withdrawing from this study will not affect the relationship you have, if any, with the researcher. If you withdraw from the study before data collection is completed, your data will be destroyed.

CONSENT

I have read and I understand the provided information and have had the opportunity to ask

questions. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without any consequences. I understand that I will be given a copy of this consent form. I voluntarily agree to take part in this study.

Participant's signature _____ Date _____

Investigator's signature _____ Date _____

APPENDIX C: THEMES AND EXAMPLES

Superordinate Themes	Emergent Themes	Transcript Examples
<p>Challenges with Diagnostic Process (N = 5)</p>	<p>Uncertainty (N = 3)</p>	<p>“...the first part was just like questions for us and then they did some sort of evaluation where they had him play with different toys and they would observe what he did with them.” (Participant 1)</p> <p>“That I don’t specifically know...I know we had one intake, and the actual diagnostic appointment. We were there for quite a few hours. I know there was an observation of myself and my son alone. Then I want to say there were a couple of...I want to say standardized testing that [my son] himself did. I want to say maybe a four- or five-hour appointment.” (Participant 2)</p> <p>“She was, I imagine a psychiatrist? I know she does—works with the schools as well to give the diagnosis.” (Participant 3)</p>
	<p>Long Waitlist and Process (N = 3)</p>	<p>“I believe it was maybe a couple months wait...” “I want to say maybe a four- or five-hour appointment.” (Participant 2)</p> <p>“I think it was probably around November that they had brought up to me about having him diagnosed, because that’s usually when we go for [his older brother’s] check-ups. So that’s when they brought it up and we didn’t get an appointment until February.” (Participant 3)</p> <p>“And we went to his 15-month appointment and I brought it up to the pediatrician then and I recommended that he be</p>

		referred for a developmental pediatrician appointment and the pediatrician at that point said “I refer you, but they’re probably going to say that we’re crazy for referring him. There’s nothing wrong.” And so our first appointment with the [clinic] was about 5 months after that. He was probably like 20 months old.” (Participant 1)
	Dissatisfaction (N = 2)	<p>“I was like ‘Who are these three strangers that I didn’t meet until now. You’re telling me bad news and they’re all here?’” (Participant 1)</p> <p>“I wish they don’t [<i>sic</i>] spend with the child for an hour and diagnose a child. I just don’t think that that’s fair. I understand the have professional knowledge of looking at the symptom, looking up the symptoms and all that. But I think I want them to be more in depth. I want them to look at all his history, not just the symptoms that he’s exhibiting. I want them to go through their medicals just for the case of my son, let alone speech. If you had looked into medical issues as well as you looked into his symptoms, I think we could have had this figured out much quicker.” (Participant 4)</p>
Mother Knows Best (N = 5)	Mother’s Intuition <i>Intuition about development</i> (N = 3)	<p>“I recommended that he be referred for a developmental pediatrician appointment.” “And then we went back [to the clinic], which was in October right after he turned two and they diagnosed him at the second appointment.” (Participant 1)</p> <p>“Mother’s intuition told me for some reason I was like, ‘it’s autism.’” “But again, I could not</p>

	<p>tell you that why when I started noticing what [he] was doing, why autism flashed across my brain. I just couldn't even—the only possible explanation is mother's intuition. That's the only thing I could possibly tell you. Because it's not like anyone's seen some of the things he did and said, 'He may have autism.' Or like, nobody ever suggested it to me.” (Participant 2)</p> <p>“And then I really noticed more and mother's intuition [sic] so I was very persistent.” (Participant 5)</p>
<p>Mother's intuition <i>To meet child's needs (N = 3)</i></p>	<p>“That kind of got me started to think [sic]... ‘I think he has no problem learning things and I think there's something else is blocking him. Something else in the way of him communicating.’” (Participant 4)</p> <p>“you don't always need them to talk to be able to know what they want.” (Participant 3)</p> <p>“because I was with him so much, like 80% of the time, he didn't even have to gesture. I just knew what he wanted.” (Participant 2)</p>
<p>Parent as Expert (N=2)</p>	<p>I knew the laws. I knew everything. (Participant 5)</p> <p>“my son in my inprofessional [sic] opinion, he's a medical kid.” (Participant 4)</p>
<p>Autism as a disability (N = 4)</p> <p>Lack of skills (N = 4) <i>Delayed Development (N = 2)</i></p>	<p>“He wouldn't point, he wouldn't copy any actions. Those are the two big things. He would...when he was overwhelmed, he would do this thing where he would put his hands on the floor and like bend over at the waist. He was just very quiet. He didn't babble, he</p>

		<p>didn't make any sounds.” (Participant 1)</p> <p>“So obviously [he] did not talk until—so he wasn't talking until at 20 months so I was—so I was—I thought it would be helpful he was in also—you know I'm a bilingual so I was also talking to him in two different language. So I thought just he was just be a little late and he's boy.” (Participant 4)</p>
	<p>Lack of Skills <i>Regression (N = 2)</i></p>	<p>“He talked! He talked and interacted with you and he laughed and had fun and all the things. And they just kind of slowly like disappeared” (Participant 3)</p> <p>“He would always say name of character in that episode. For some reason it caught my attention that he wasn't saying it anymore. And gradually a lot of the words and sentences he was saying, he completely stopped saying.” (Participant 2)</p>
<p>Parent-Child Relationship (N =5)</p>	<p>Consistently Positive Relationship (N = 4)</p>	<p>“Same it is now. Very loving.” (Participant 5)</p> <p>“You know, we had—we had a great relationship. We still have a great relationship.” “I loved every little moment, and I took a million pictures.” (Participant 3)</p> <p>“Good. It was good. It was always good.” (Participant 1)</p>
	<p>Stressful Family Relationships (N = 3)</p>	<p>“The only problem anybody has is when he just wants mom. He can't go asleep without me. That makes things very hard on everybody if I'm not around.” (Participant 3)</p> <p>“I mean there was a period where he would only sleep on me. Just things like that. He was very, very, very attached to me.</p>

	<p>I mean he'd always want me to hold him, pick him up. And at the time, I'd be like 'This is a lot.'" (Participant 2)</p> <p>"He also would—he was very obsessed with me. If he would have to be sent to his room for something, only I could get him out." (Participant 5)</p>
<p>Before the Diagnosis Frustration with child (N = 2)</p>	<p>"There was some frustration because he wasn't talking...I did see his frustration at times, so I tried to accommodate him, come up with a strategy to get the frustration, to get the anger out. But, as far as just the relationship, nothing's really changed." (Participant 4)</p> <p>"When the regression happened, he had lost the verbal capability of communicating with me. He would get extremely frustrated with me. Especially if I couldn't figure it out. He would have a meltdown in the sense of, he would never hurt himself or anybody else, but like a tantrum." (Participant 2)</p>
<p>Before the Diagnosis Child in control (N = 2)</p>	<p>"Unless you are a part of his kind of consistent, rigid environment, then he didn't really wanna have much to do with you." (Participant 3)</p> <p>"So I got him some milk and I put it on the table, and he was like, 'No! Give it to me, give it to me!' I was like, 'I put it on the table, honey. It's right there.' And he's like, 'No, no, no, Mommy! Touch it! Touch it!' He was very, very obsessed with having me actually hand it to him." (Participant 4)</p>
<p>Improved Relationship after Diagnosis (N = 1)</p>	<p>"Very good. We are—now especially this year we had a dramatic, remarkable year when solving his medical issues and</p>

		all that. So we are better than ever right now.”
Perception of Autism (N = 5)	Increased Knowledge (N = 3)	<p>“I wanted to learn as much about it as possible. And when I say that I don’t mean like Googling it and looking any of that stuff up. I wanted to get involved with things in the community.” (Participant 2)</p> <p>“Well yes, because now I know that regression—regression really is a thing.” (Participant 3)</p> <p>“I researched a lot. I would say probably 40% of all the knowledge I know now.” (Participant 5)</p>
	Positive Perception after Diagnosis (N=2)	<p>“I think it definitely changed our view because when you think of children with autism and you don’t know one personally, you kind of think of that more severe end of the spectrum. When you have a child like ours, it does change the way you think about it.” (Participant 1)</p> <p>“And it was from those classes that—it really taught me what this is. And that it’s not—it’s not like—I hate putting it this way. I’m sorry. It’s not like a death sentence.” (Participant 2)</p>
	Alternate Explanation for Symptoms (N = 2)	<p>“But when he got his immunizations, he ended up with like a 106 fever for like 3 days. He had a lot of issues after then, but again it all coincided with everything that was going on.” (Participant 3)</p> <p>“He’s a medical kid. He has medical issues, such as sleep apnea. And severe obstructions with apnea leads to ADHD symptoms and also severe like sleep apnea with the tonsils. You know inflamed tonsils; they tend to not to talk until they</p>

		remove the tonsils which was a case of my son.” (Participant 4)
	Autism is not an excuse (N = 2)	<p>“You know he’s still a child. And he’s gonna try to get away with what he wants to get away with. We kind of treated him pretty much the same.” (Participant 5)</p> <p>“I always tell people, ‘He has an autism diagnosis. It’s not a big thing. It’s not a ‘get out of jail free card.’ You don’t get to put your hands on people or hurt other people.” (Participant 2)</p>
Feelings Prior to Diagnosis (N = 5)	Worry about atypical development (N = 2)	<p>“I was extremely worried. I was extremely worried because I—you don’t know what’s going on. Regardless of what flashed in my head, you have no idea what’s going on. It’s like one day you see your child doing all these things and it didn’t—at least for my son, it—like it all didn’t happen overnight, but it felt like it happened like a light switch. Like it did happen overnight. It felt—it was a very quick transition. It wasn’t like something that took place over seven months. It did happen over the course of like a month, a month and a half.” (Participant 2)</p> <p>“Probably anxious.” (Participant 1)</p>
	No concern (N = 2)	<p>“So I just thought that it was somewhat natural...I wasn’t that much concerned at that point.” (Participant 4)</p> <p>“So those were some things that I found different. Not alarming, were just different.” (Participant 5)</p>
	Loneliness (N = 2)	“I’m spending time with a child and he understands me on certain level, but then he doesn’t know how to respond even

	<p>though you want to, you know? So, I think that time to get me—I was lonely I think in some way that I wish he would respond to me.” (Participant 4)</p> <p>“They kind of threw in the towel with helping a lot of the time. Everybody that was a shared responsibility suddenly stopped.” (Participant 3)</p>
Shock (N = 2)	<p>“[The early intervention providers] had brought up a neurologist, so I was like, ‘Neurologist? What do you mean a neurologist—’ ‘Well, I mean like we said we’re not doctors. We’re just telling you the findings of information and this is where he hit.’ At this point now, I’m not even listening to anything they’re saying. And so they kind of just got up and left and I look at my husband and I just broke down and I started crying because ultimately I knew what I was going to hear.” (Participant 2)</p> <p>“So for him to present so dramatically differently—I just never in a million years even considered it.” (Participant 3)</p>
Initial Reaction to Diagnosis (N = 5)	<p>Devastation (N = 2)</p> <p>“Well I mean, I was—I was devastated [when the doctor pointed it out]. It was really, really hard for me not just because he was autistic, but because I had the experiences before—the experiences before traumatized me.” (Participant 3)</p> <p>“The best word that comes to mind is ‘devastation.’ It’s the best way I can explain it because at that point, I went to only what I know about ASD. I just started—I specifically remember [the psychologist] handing me a tissue. He was like, ‘I understand. Do you have any</p>

		questions?’ And the one thing I said to him was—and I was almost hysterically crying—I was like, ‘Does that mean [my son] is not gonna hug and kiss me anymore? He’s gonna stop doing that?’” (Participant 2)
	Heartbreak (N = 2)	<p>“It was a little heartbreaking. I kind of didn’t sit on it for a long time, like the sadness.” (Participant 5)</p> <p>“And those for me are bad days, as a mother, to not know what’s going on it’s heartbreaking ‘cause all you want to do is make it right.” (Participant 2)</p>
	Stress (N = 2)	<p>“It was a very stressful period.” (Participant 1)</p> <p>“There was a little bit of time where there was a big stress in the house.” (Participant 5)</p>
	Grief (N = 2)	<p>“We’d do something, we’d dance after dinner, we’d have a good time. Those are things we can’t do anymore. But even singing Happy Birthday you can’t do it... he loved fireworks. He hates them. He hates all that now.” (Participant 3)</p> <p>“Once I grieved it” (Participant 5)</p>
Advocacy and Persistence (N = 2)	Advocating for child’s needs (N = 2)	<p>“For the first 6 months trying to, so we had to fight with insurance because they wouldn’t pay for ABA therapy.” (Participant 1)</p> <p>“[My son] was like two and half or three and then I started calling around places to get neuropsych done.” “I came in, not like a jerk, but I said ‘This is whatever, and I know this.’” (Participant 5)</p>
Provider Relationship (N = 3)	Before the Diagnosis Being Dismissed (N = 2)	<p>“I brought it up to his doctor a few times how he was a little oral and when he would get</p>

		<p>really excited. He said, ‘Oh you know, I don’t think we need early intervention or anything.’” (Participant 5)</p> <p>“I personally think early intervention was a detriment to him being diagnosed because the speech therapist would... make comments in front of my husband like, ‘There’s no way he has autism,’ ‘He makes great eye contact,’ ‘He’s too social’ and it was kind of deterring him from thinking there was something wrong.” “The pediatrician at that point said ‘I refer you, but they’re probably going to say that we’re crazy for referring him. There’s nothing wrong.’” (Participant 1)</p>
	<p>After the diagnosis Discomfort with Provider (N = 2)</p>	<p>“But at the same time there was doubt in my doctor. Like 50/50, you know. That I wasn’t really trusting.” (Participant 4)</p> <p>“I was like ‘Who are these three strangers that I didn’t meet until now. You’re telling me bad news and they’re all here?’” (Participant 1)</p>
	<p>After the diagnosis Satisfaction with Provider (N = 2)</p>	<p>“[Our provider] was just extremely gracious and very understanding and kind.” (Participant 2)</p> <p>“As of now, he just has his [home based therapeutic services] therapist. She comes—right now we only get 9 hours a week. She is absolutely amazing.” (Participant 1)</p>
Challenges and Hurdles (N =4)	Accommodation to Child’s Challenges (N = 3)	<p>“I think I was trying to do as much as my boy could enjoy without getting frustrated, which was I think more toward the activity like physical activity.” (Participant 4)</p>

	<p>“I tried to teach him other ways of communicating with me to get his point across.” (Participant 2)</p> <p>“We homemade paint because he was very oral.” “We never really put him in that high intense environment.” (Participant 5)</p>
Educating Others (N = 2)	<p>“We are starting to teach the kids, ‘Okay this is [child’s name]. These are what may hinder clearer communication. This is how we can work with him.’” (Participant 3)</p> <p>“They’d either be feeling bad or whatever. And I’m like, ‘Dude, it’s okay. Do you have questions? Ask me. I’m an open book. I’d rather have questions than do whatever.’” (Participant 5)</p>
Struggles with Services (N = 3)	<p>“His therapy had to stop because doing it on facetime or whatever, Zoom, is pointless. Because he’ll find a piece of glitter and have a whole world with it.” “I do wish that we had some more time. So, the group that we’re working with, with his home therapy and clinician, offer more time, but it would be with another individual. It’s scarce right now with any group. I even tried to get with another program and they’re like, ‘Yeah we don’t really have anybody to send out.’” (Participant 5)</p> <p>“I’ve never struggled so hard to try to get services for my children than I do here.” There are a lot of services around if you can find them. Finding them and then willing to drive. When I would try make appointments and see different people, even for evaluations...they’re like “this is in [city name] or past</p>

		<p>[city name,] ...Are you actually going to come to this appointment if I make it? Because most people from your area end up as no-shows.” (Participant 3)</p> <p>“Also, I wish... you know, animal therapy, riding horses and stuff like that... There is—there is couple places...one place is [out of state], so I don’t know if they accept [my] insurance.” (Participant 4)</p>
The Future (N = 4)	Worries about the future (N = 4)	<p>“As he was getting 8 and things were still too delayed and other things were still not—I don’t want to say normal, but they did not look in the same in his age group.” (Participant 4)</p> <p>“Every time we’d have an appointment with [our provider], I would say, ‘So what do you think is the percentage rate of kids on the spectrum that like lose their speech and skills that gain them back?’ Or um—one of my biggest fears, especially in that moment when [the provider] told us what was going on, you hear people with developmental disabilities a lot of them can’t care for themselves.” (Participant 2)</p> <p>“All the hopes and dreams that you have for your first child has to be reassessed. You have to sit there and wonder about those things.” (Participant 3)</p> <p>“My husband and myself feel like he will probably be with us for a very long time.” (Participant 5)</p>
	Optimism (N = 3)	<p>“I think to be in it and seeing where some people started and seeing where they’re ending, it’s like the possibilities are endless with my son.” (Participant 2)</p>

“Every day we have a little more optimism” (Participant 3)

““Okay this is a little roadblock, but we’re going to get over it.’ And thankfully he reached all of his milestone immaculately early. At 9 months he was walking. He was a brilliant child. He still is.” (Participant 5)