Winter 2021

The ASD Parent Perspective: Stress Contributors and Perceptions of Feeling Supported and Understood

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The ASD Parent Perspective: Stress Contributors and Perceptions of Feeling Supported and Understood

by

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Accepted in Partial Completion
of the Requirements for the Degree
Master of Science

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Master's Thesis

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Chelsea Noble

2/26/2021

The ASD Parent Perspective: Stress Contributors and Perceptions of Feeling Supported and Understood

A Thesis

Presented to

The Faculty of

Western Washington University

In Partial Fulfillment

Of the Requirements for the Degree

Master of Science

by
Chelsea Noble
February 2021

Abstract

Parents of children with autism spectrum disorder (ASD) experience a great amount of stress. Evidence indicates that parent stress is associated with ASD symptom severity and potentially behavior problems. However, there are gaps in the literature examining these associations in fathers and whether these associations differ across mothers and fathers. Additionally, concepts surrounding "support" and "understanding" have been understudied in this context as well as how they are associated with parent stress. The current study addresses these gaps in the literature and expands on the research regarding fathers. We recruited 244 parents of children ages 3-5 with ASD who were diagnosed within the last 8-12 months. Parents completed the online questionnaires to assess their child's behavior problems, ASD symptom severity, as well as their stress levels. We also assessed concepts of "support" and "understanding" using open-ended questions. We found that behavior problems were significantly associated with parent stress; however, there was not a statistically significant difference in this relationship between mothers and fathers. Additionally, ASD symptom severity was significantly associated with parent stress and parent gender moderated the association between symptom severity and parent stress. Simple slope analyses indicated a greater magnitude of this association for fathers. Common themes related to "support" and "understanding was reported, and we also found that the extent to which friends understood them was significantly associated with parent stress. Clinical implications and explanations were also discussed.

Acknowledgements

First and foremost, I would like to thank my advisor and thesis committee chair, Dr. Tina Du Rocher Schudlich, for being a constant source of support and encouragement, as well as a partner, throughout the entire process of completing my master's thesis. Additionally, I would like to thank the members of my thesis committee, Dr. Kate McLean and Dr. Christie Scollon, for their additional support and patience throughout this process.

I would also like to thank the two research assistants who were integral to the qualitative data coding process. Their help and contribution were vital to completing the final portion of this project and I am incredibly grateful. I could not have done this without them.

Finally, I would like to thank all my friends and family for their support, love, patience, and encouragement during my time at WWU, and especially throughout the process of completing this project. I would especially like to thank the members of my cohort who worked alongside me every step of the way the last three years providing encouragement, compassion, and understanding as we all navigated our way through graduate school. I am truly thankful and am honored to have had the chance to learn with you.

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The ASD Parent Perspective: Stress Contributors and Perceptions of Feeling Supported and Understood

Faye is a sociology professor in California. She and her husband work full time and share one son. Their son was a typically developing child in preschool. They had no reason to be concerned with his development until his teachers began to observe that he was not very social with other children, he could not sit still in the classroom due to his high levels of anxiety, and he had abnormal reactions to certain sounds. Faye and her husband also noticed additional concerning behaviors at home. He would become aggressive and hit Faye. He would have days when he would be extremely hyperactive, and others where he was calm and collected. His parents became overwhelmed and were struggling to manage his behaviors. They spoke with many different teachers who assured them that their son was fine. However, one teacher recommended therapy.

They took him to a doctor who confirmed he had Autism Spectrum Disorder (ASD) as well as Attention Deficit Hyperactivity Disorder (ADHD). They soon realized the challenges and demands that came with raising a child with a developmental disorder: weekly behavior therapy, parent support groups, family therapy, individualized education program (IEP) meetings, extracurricular activities, as well as managing their son's behaviors. As Faye described it, "it is a never-ending challenge, but you are not truly giving if it is not unconditional. You just have to change your narrative and think positively."

Autism Spectrum Disorder (ASD)

There are many stories just like Faye's. According to a study published on the Centers for Disease Control and Prevention website reported by Baio and colleagues (2014), among eight-year-old children in the United States, 1 in 59 has been diagnosed with ASD. This reflects an

increase from 2000-2002 when the rate was 1 in 150. An overwhelming number of children are being diagnosed with ASD, which means that more children and families are in need of support and services for their child.

ASD is a neurodevelopmental disorder characterized by persistent deficits in social communication and social interaction across multiple contexts, as well as the presence of restricted, repetitive patterns of behavior, interests, and activities (American Psychiatric Association, 2013). Individuals with ASD vary in symptom manifestation. Deficits in social communication/social interaction manifest as a lack of response to social cues, issues with verbal and non-verbal communication, and difficulties maintaining social relationships. They also display a deficit in theory of mind (ToM), which is the ability to understand the thoughts, feelings, intentions, and mental states of oneself and of others (Mash & Wolfe, 2017). Restricted, repetitive behaviors can manifest as repetitive hand movements (e.g. hand flapping) or restricted interests (e.g. a fixation on trains). They can also manifest as sensitivity to sensory inputs, such as sound or touch, like in the case of Faye's son who was sensitive to high-pitched noises. ASD is defined as a spectrum disorder because individuals can vary in their level of severity, abilities, and characteristics (Mash & Wolfe, 2017). The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5; American Psychiatric Association, 2013) specifies three levels of symptom severity that reflect the amount of support required and represent the extent to which the impairment interferes with the child's functioning: Level 1 ("Requires Support"), Level 2 ("Requires Substantial Support"), and Level 3 ("Requires Severe Support"). To receive a diagnosis, the symptoms must be present during early development. Symptoms can manifest as early as six months of age, however ASD is typically diagnosed during the preschool period or later. Many children do not show core characteristics of ASD but rather show gradual change or

loss in skills such as eye contact and specific social skills starting at six months of age continuing until they are 18 months of age (Mash & Wolfe, 2017). Since these are slight, gradual changes in skills, it is common for parents to not notice them. It is around the time when children are 18-36-months of age that more noticeable changes occur in the child's behavior that are characteristic of ASD, however it is still common for most children to not receive a formal diagnosis until they are around three years of age or older.

Associated Characteristics and Related Disorders

Over 90% of children with ASD are also diagnosed with co-morbid disorders such as anxiety disorders and learning disabilities, as well as oppositional and conduct problems (Mash & Wolfe, 2017). Children with ASD can exhibit both externalizing and internalizing problem behaviors and related issues that are not a part of the core diagnostic criteria, but commonly accompany the disorder (Mcstay, Dissanayake, Scheeren, Koot, & Beeger, 2014). Externalizing behaviors, which are more visible, can include aggression, property destruction, hyperactivity, impulsiveness, self-injury, and tantrums (Bauminger, Solomon, & Rogers, 2010; Matson, Wilkins, & Macken, 2009). These are common among children with ASD. Internalizing behaviors, which are not as visible, can include depression, withdrawal, and sleep disturbances (Bauminger et al., 2010). These behaviors can occur as a result of related disorders that are common in children with ASD, such as anxiety disorders. Obsessive compulsive disorder (OCD), a type of anxiety disorder, affects approximately 37% of children diagnosed with ASD (Lewin, Wood, Gunderson, Murphy, & Storch, 2011). Individuals with OCD experience persistent and obsessive thoughts and compulsions that are generally unwanted and can cause severe anxiety (Mash & Wolfe, 2017). Children also frequently engage in self-injurious behaviors (SIBs) (Mash & Wolfe, 2017). Some common forms of these behaviors include head

banging, hand or arm biting, as well as excessive scratching or rubbing. In addition to behavior problems, children also experience difficulties with common everyday activities such as sleeping and eating. Approximately 65% of children with ASD experience issues with sleep habits and maintenance of a sleep schedule (Mash & Wolfe, 2017). Another common issue that children with ASD experience is food selectivity. In general, it is common for children with ASD, compared to typically developing children, to engage more often in food avoidance, especially when being presented with novel food items (Kral et al., 2014), especially for children who also have atypical oral sensitivity. This can lead to numerous problems for children, including fussiness and other behavior problems, such as tantrums, rendering feeding practices for parents to be extremely difficult.

During the diagnostic process for children with ASD, it is also common for the behavioral characteristics that these children exhibit to be confused with symptoms that are also characteristic of Attention Deficit Hyperactivity Disorder (ADHD; Sokolova et al., 2017). ADHD is defined by the DSM-5 as a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development (American Psychiatric Association, 2013). In a study assessing comorbid disorders in children with ASD, Leyfer and colleagues (2006) found that 31% of children had symptoms that met the DSM-IV criteria for ADHD, while a total of 55% of children were found to have an ADHD syndrome that significantly impaired their functioning. Research has shown that these two disorders have symptoms that overlap and that can be hard to distinguish. It is also difficult to determine whether the exhibited behaviors are more related to the ASD or ADHD diagnosis. For instance, within the diagnosis of ASD, children can exhibit repetitive, hyperactive behaviors, which is a similar case for children with ADHD. For some time, the two disorders were thought of as separate, where the child was either

diagnosed with ASD or ADHD, but never both. With the consistent findings related to the common overlap in symptoms, it is more common now for diagnosticians to give children a dual diagnosis of both ASD and ADHD. With all of this in mind, it is clear that children with ASD are faced with several issues unrelated to their disorder, which can be very challenging for parents to manage.

Theoretical Framework - Double ABCX Model of Adjustment and Adaptation

The original ABCX model of family stress was proposed by Hill (1949/1958; as cited in McCubbin & Patterson, 1983), which was established to identify specific variables that both contribute to stress and to the ability to adapt and adjust to stressful situations for any family experiencing stress (McCubbin & Patterson, 1983). The *A* within the model represents the stressor event. A stressor event, in this context, is defined as "a life event or transition impacting upon the family unit which produces, or has the potential of producing, change in the family social system" (McCubbin & Patterson, 1982, p. 8). The stressor event (*A*) interacts with variable *B*, which represents the family's resources for dealing with stress. Both the stressor event (*A*) and the family's resources (*B*) interact with variable *C*, which represents how the family defines/views the stressor event. The product of all these variables interacting is *X*, which represents the crisis or resulting stress. In essence, the goal of this model is to identify stressors that a family experiences and how they impact stress levels for family members, depending on how the family views the stressful event and their access to helpful resources.

Although the original Hill (1949/1958; as cited in McCubbin & Patterson, 1983) ABCX model answers important questions related to family stress, some researchers wanted to look further into the model and add on to it to answer additional questions. For example, McCubbin and Patterson (1983) put forth the Double ABCX model. This model expands upon the original

ABCX model to examine the impact that stressful life events have on the family and their ability to adjust, with the emphasis being on family adjustment over time *post*-stressful life event, whereas the original model focused solely on family adjustment immediately *during* the event. In addition to the original variables (stressful event, family resources, family definition of event), the model also includes coping strategies as another potentially impactful variable, with the idea being that research regarding family adaptations to stressful life events could improve by examining the strategies families use to cope in times of great stress (Manning, Wainwright, & Bennett, 2011). Their model has been used in research to describe parent stress of those who have a child with a developmental disability. For example, McStay, Trembath, and Dissanayake (2014) examined how the Double ABCX model could apply to a family that has a child diagnosed with ASD and how they adapt to the stress that accumulates after their child was initially diagnosed. They put forward the idea that there are child-related factors (*aA*) that can "pile up" and increase parenting demands that can negatively impact parent stress, such as the child's behavior problems and the severity of their symptoms. In addition, there are other factors that interact with the child factors to describe family stress, including the family's available resources (support from spouses, friends, neighbors, etc.) (*bB*), coping strategies (both formal and informal; *BC*) and the family's appraisal (*cC*). McStay et al (2014) found that the model significantly predicted family functioning and parent distress for families of children with ASD. The application of this model within this context also has clinical implications, such that each family's functioning abilities and levels of distress have unique contributors and clinicians should tailor their interventions to meet the needs of each family independently. The current study will seek to apply the Double ABCX Model to examine contributors to parent stress and impact of family resources for those who have children with ASD (see *Figure 2*).

Contributors to Parent Stress

Compared to parents of typically developing children, parents of children with ASD experience higher levels of stress (Padden & James, 2017; Dabrowska & Pisula, 2010). Research has also shown that compared to parents of children with other disabilities, such as Down Syndrome, parents of children with ASD experience higher levels of stress (Dabrowska & Pisula, 2010). Previous research has examined some of the many possible contributors to increased stress for parents. Simply the confirmation of a diagnosis of ASD for children can result in increased stress for the parents (Elder, Kreider, Brasher, & Ansell, 2017). This is particularly the case for parents of younger versus older children (Osborne & Reed, 2009). In addition to the typical demands of parenting, parents of children with ASD must also cope with the demands of caring for a child with specific needs and behavior problems and must work to find services for their child (Reinke & Solheim, 2015). The increase in stress from these added responsibilities can result in negative outcomes for parents such as poor mental health and maladaptive parenting practices (Hastings, 2003; Zaidman-Zait et al., 2017). Poor mental health can include heightened anxiety or depression. Maladaptive parenting practices can include poor parent-child communication as well as lower involvement with the child, such as with the child's behavioral therapy.

Severity of ASD Symptoms and Parent Stress. The symptoms of ASD typically extend across a person's lifespan (DePape & Lindsay, 2015). With therapy, many of the symptoms of ASD can improve, but they cannot completely disappear. As mentioned previously, there are different levels of severity for ASD that are assigned to each diagnostic criterion representing the extent to which the impairment interferes with the child's functioning (Mash & Wolfe, 2017). The two areas in which deficits must occur, according to the diagnostic criterion stated in the

DSM-5 (American Psychiatric Association, 2013), are social communication/social interaction and restricted, repetitive patterns of behaviors/interests/activities. In relation to parent stress, symptom severity has been somewhat researched in the ASD literature, but not in depth. In general, the findings that have examined this relationship have been inconsistent, and more research needs to be done. Thus, these deficit areas and symptom severity levels will be further assessed in the current study in relation to parent stress.

The limited amount of research that has been done has supported the notion that higher levels of ASD symptom severity are related to increased stress for parents. For example, Argumedes, Lanovaz, and Larivee (2018) recently examined the impact that both challenging behaviors and ASD symptom severity had on parent stress and found that both mothers and fathers of children who had higher symptom severity reported increased stress compared to those whose children had lower symptom severity. Those who have further examined this concept have found this could be related to the demands of parenting a child with ASD. The greater the severity of symptoms, the more likely it is that the child will depend greatly on their parents, which is associated with greater parenting stress (McStay, Dissanayake, Scheeren, Koot, & Begeer, 2014). A similar result was found in one additional study examining this relationship, where greater ASD symptom severity was found to be the greatest predictor of increased stress for parents (Lyons, Leon, Phelps, & Dunleavy, 2010).

Although this idea has been supported in the literature as a general predictor of parent stress, it should be noted that the sample sizes within this literature had a significantly low number of fathers compared to mothers. For example, in one of the articles mentioned above, the sample only included 10 fathers compared to 27 mothers (Argumedes, Lanovaz, & Larivee, 2018). Another example demonstrating this issue comes from the work done by Lyons, Leon,

Phelps, and Dunleavy (2010) in which their studied included 68 mothers and four fathers of children with ASD. Considering these small sample sizes, it is difficult to truly draw conclusions as to whether ASD symptom severity is a true predictor of stress of fathers. It should also be emphasized that the relationship between ASD symptom severity and parent stress is vastly understudied indicating that more work needs to be done. Therefore, the purpose of the current study is to further examine the relationship between parent stress and ASD symptom severity, while also further examining whether differences in this relationship are present between mothers and fathers. It has also been unclear within the literature as to what specific ASD symptoms are contributing the most to increased parent stress, which will also be explored in the current study.

Behavior Problems and Parent Stress. It is common for children with ASD to exhibit behavior problems above and beyond the core characteristics of their disorder (Matson, Wilkins, & Macken, 2009). As mentioned previously, such behaviors can be either externalizing or internalizing behaviors. Whether they exhibit externalizing behaviors, internalizing behaviors, or both varies from child to child. In addition to the core ASD symptoms, these behaviors can be very difficult to manage and have been shown to cause additional stress for parents (Osborne & Reed, 2009).

In Faye's case, her son exhibited more externalizing behaviors, such as aggression. He would continually hit both of his parents when he became overstimulated or frustrated. This continuous behavior became, and still is, very difficult for Faye and her husband to deal with. Considering that for some time they did not truly know the source of his aggression, and at times could not control what was causing him to become so overstimulated, they became increasingly frustrated and did not know how to help their son or how to control the continuous outbursts of

aggressive behavior. He also experienced heightened anxiety, which had a tendency for interfering with his daily functioning, such as performing well at school and communicating with his parents and peers. For many parents, this is a common experience. Behaviors such as aggression can occur at very sporadic times for a child with ASD, and for parents this can be particularly stressful, especially when they are out in public.

In general, the research behind the overall relationship between associated behavior problems, both external and internal, and parent stress has been consistent, with the majority of research saying that behavior problems are associated in some way to an increase in parent stress (Mcstay, Dissanayake, Scheeren, Koot, & Beeger, 2014; Osborne & Reed, 2009; Siu, Yi, Chan, Chio, Chan, & Mak, 2019). However, like the research on symptom severity in relation to parent stress, the research that has been conducted on this topic has also lacked a representative population of fathers compared to mothers, so the findings are difficult to generalize to all parents of children with ASD. Therefore, one of the aims of the current study is to further examine the relationship between child behavior problems and parent stress, while also examining whether there are differences in stress levels between mothers and fathers of children with ASD.

Finances and Parent Stress. Another significant contributor to stress is the financial strain that comes with having a child with ASD (DePape & Lindsay, 2015). The diagnostic process is not only lengthy, but costly as well. Some insurance companies cover the cost of the initial evaluation, such as Medicaid. However, some families who do not have insurance, or whose insurance companies do not cover the evaluation cost, must resort to paying out of pocket. There are several treatment options available for children with ASD, but they are costly and sometimes inaccessible due to insurance policies, lack of insurance, as well as wait times to get

children enrolled in services such as ABA. According to Sharpe and Baker (2007), possible wait times for enrollment could be more than a year. Some common treatments/interventions that children with ASD are enrolled in are things such as applied behavioral analysis (ABA) therapy, speech therapy, occupational therapy, respite care, and medical interventions (Sharpe & Baker, 2007). A study examining the cost of raising a child with ASD reported that the average amount of money spent on travel for treatment, out of pocket expenses, as well as the loss of income, annually was about $36,000 (Horlin, Falkmer, Parsons, Albrecht, & Falkmer, 2014). Another study assessing financial issues in Australia provided a quote from a parent who stated that ABA therapy specifically costs them about $23,000 USD per year (Sharpe & Baker, 2007). Treatment also has the likelihood to take a considerable amount of time, possibly through adulthood, considering ASD is a lifelong condition of which the symptoms can only be managed.

In addition to the previously identified demands of having a child with ASD and the effects they have on parents, Karst and Van Hecke (2012) explored the impact that having a child with ASD has on the family system, particularly looking at the additional demands, stress, and financial burden. They found that mothers of children with ASD work approximately eight fewer hours per week than parents of typically developing children or mothers of children with other disabilities. Losing that amount of weekly work hours can put a financial strain on the family system, which results in increased stress for all family members. The concept of financial stress is something that can be applicable to many families, especially those who have children with ASD and could possibly be a significant predictor of parenting stress in addition to the other factors previously mentioned. Therefore, it is relevant to take this factor into consideration for the current study.

Differences in Stress Contributors Between Parents. Although there is substantial literature examining stress contributors for parents of children with ASD, the research examining whether there is a difference in stress contributors between mothers and fathers is limited. Research on parenting children with ASD, which has focused exclusively on heterosexual couples, has shown that, in general, mothers and fathers differ in their stress levels (Hastings, 2003). Overall, the research indicates that mothers experience more stress compared to fathers due to the demands of parenting a child with ASD (Hastings, 2003; Tehee, Honan, & Hevey, 2009). The most common reason researchers state for this finding is that mothers are more often considered to be the primary caregivers in the home and are more involved in their children's daily care (Padden & James, 2017). However, although fathers are typically not as involved in the daily care of their children, research has shown that fathers do indeed experience stress, specifically stress related to parenting a child with ASD. For example, in a more recent study, Burrell, Ives, and Unwin (2017) interviewed eight fathers of children and/or adults with ASD and asked about their experiences. Fathers reported feeling frustrated, especially if their child was diagnosed at an earlier age, primarily due to the long-term life expectations for their child not being met. They felt as if the life they had pictured and plans that they had were no longer attainable or realistic. A limited amount of research has even stated that fathers reported more stress compared to mothers (Rivard, Terroux, Parent-Boursier, & Mercier, 2014). Some research has also stated that there was no difference in stress levels between mothers and fathers (Davis & Carter, 2008). In general, the findings related to differences in parent stress levels are inconsistent. The current study seeks to expand the literature, be more inclusive, and closely examine the parenting experience of both mothers and fathers.

Another goal of the current study is to examine which aspects of the disorder are contributing to more to stress for mothers and fathers. The literature behind this is inconsistent and contradictory. Some of the literature has examined the extent to which the child's associated behavior problems are contributing to the parent stress (Davis & Carter, 2008). For fathers, their stress was found to be associated with externalizing behavior problems, such as hyperactivity and tantrums (Davis & Carter, 2008). Contradictory to those findings, Hastings (2003) found that mothers' increased stress levels were associated with the child's behavior problems; however, this was not the case for fathers. They hypothesized that, rather than the mothers' mental health status and the child's behavior problems, there was an unidentified third variable that could possibly explain the fathers' increased stress that was not examined in their study (Hastings, 2003). In addition to behavior problems, some of the research has examined the extent to which the child's severity of symptoms were contributing to the parent stress. However, this research has also shown inconsistencies in their findings examining stress contributors for fathers. For instance, Osborne and Reed (2009) found that increased stress levels were associated with the high levels of symptom severity for fathers above and beyond the child's behavior problems, whereas McStay and colleagues (2014) found that this was not the case. Another study that examined stress in parents found that for fathers, lack of social support was significantly predictive of increases in fathers' stress levels (Falk, Norris, & Quinn, 2014). Overall, it is clear that these findings are inconsistent and contradictory and should be further examined.

Within the ASD literature, one issue that has been shown consistently across many of the studies assessing parent stress is the underrepresentation of fathers in the literature, which could be a possible contributor to the inconsistent findings mentioned above. One possible reason for the underrepresentation of fathers in the literature is that mothers are most often identified as the

primary caregiver in the household, even though it has been found that fathers are also beginning to identify more as primary caregivers (Burrell, Ives, & Unwin, 2017). The idea, then, behind focusing more on mothers than fathers, lies in the belief that the relationship between a mother and child has a greater impact on the child's development than fathers do, considering the caregiver status of a mother versus a father (Vacca, 2013). For this reason, a question will be included in the current study to address caregiver status for each mother and father that are recruited.

According to a report by Laughlin (2013) published by the United States Census Bureau, fathers are becoming increasingly more involved in the primary care for their child, and more specifically for preschool-aged children. For families in which the mothers were in the workforce, one in five fathers were the primary caregiver among those with preschool-aged children. Although in the past it has been commonly found that fathers are not as involved in caring for their children, that trend is beginning to change. With this in mind, it is important to expand on the research regarding the experiences of fathers in order to truly understand their perspective. The goal of this study is to be more inclusive and expand on the father's parenting perspective, which will hopefully highlight how impacted fathers can be when it comes to raising a child with ASD. This information will also hopefully encourage professionals working with families of children with ASD to be more inclusive in their efforts to help all members of the family, rather than just focusing on mothers.

Another possible reason for the lack of parent recruitment in general, but more specifically the lack of father recruitment, is the procedure of the experiment. It is evident in the sample sizes within some of the studies that the procedure had some effect on how many participants were recruited. For instance, a study that looked at parent stress in which they sent

out questionnaires to participants via mail recruited a total of 109 parents of children with ASD (Firth & Dryer, 2013). Similarly, in a study that assessed predictors of parent stress via online questionnaires, they were able to recruit nationally sending links to complete the questionnaires via the internet, which resulted in a sample of 250 mothers and 229 fathers. In comparison to these more convenient methods of research, Davis and Carter (2008) conducted a study in which they recruited participants to come into the lab and be interviewed regarding their stress levels in relation to parenting a toddler with ASD. They were only able to recruit 54 families for this study. Considering the differences in participant recruitment outcomes in relation to the procedure of the study, a more convenient method of research will be utilized in the current study where participants will be both recruited online as well as complete the required questionnaires online. This should hopefully increase the number of parents recruited overall, but even more so increase the number of fathers included in the study.

The Parenting Experience

The experience of parenting a child with ASD can vary for each parent. It is common for parents in these situations to feel stressed and overwhelmed. Since ASD is not a disorder that can be detected before birth, parents are many times taken aback when their child receives an ASD diagnosis. At the same time parents have also expressed that feelings of stress were conflicting with feelings of relief that their child had finally received a label. In addition to stress, researchers have shown that parents also experience feeling alone, misunderstood, and judged by those outside of their immediate family circle (Reinke & Solheim, 2015; Robinson, York, Rothenburg, & Bissell, 2015). They have also found that a lack of support can contribute greatly to parent stress and the overall wellbeing (Altiere & von Kluge, 2009; Boyd, 2002). These concepts have been relatively understudied in both the parenting and ASD literature and have

even more so understudied in relation to fathers of children with ASD. The current study will expand upon and further explore these topics as they relate to both mothers and fathers experiences of parenting a child with ASD.

Feeling Misunderstood. Within the ASD community, it has become increasingly common for parents to experience a feeling of being misunderstood from the perspective of an outside family member or friend with a typically developing child (Kinnear, Link, Ballan, & Fischbach, 2016). They have commonly reported feeling isolated, which they felt was due to their child's behavior problems. In a study that examined qualitative data gathered through interviews with eight families, parents commonly expressed that family members would consistently judge and blame them for their child's behavior problems, which affected the way they would perceive their competency as parents (Robinson, York, Rothenburg, & Bissell, 2015). While out in public, parents reported their parenting skills being criticized by complete strangers on how they are parenting their child, stating that the children were acting out because they not being disciplined enough (DePape & Lindsay, 2015). The feeling of being misunderstood encompasses a multitude of other feelings, such as feeling judged and blamed, and the limited research that has been done surrounding this concept has shown that it is a common feeling parents experience.

A real-life example of a parent experiencing this feeling is Faye. She shared that after her child was diagnosed with ASD, while they were attending a traditional elementary school, she felt a disconnect was forming between her child and the other children, as well as between their family and the other families. She reported that some parents would express shock and confusion as to why her child would become aggressive or behave in certain ways as often as he did. They

did not understand that this was a part of his ASD diagnosis and that it was not something that they, as his parents, or their child could control.

Research has examined common feelings parents experience, such as feelings of judgement, blame, and experiences with stigma. However, there has not been very much research that has specifically looked at the concept of "feeling misunderstood", especially within the field of ASD. It is a relatively underdeveloped concept and therefore has not been explored in depth in the literature. One of the purposes of this study is to explore this idea further by gathering narrative data provided by parents of children with ASD on this concept. This research, being a relatively new concept, will be exploratory in nature.

Perceptions of Support. There are several different ways that "support" can be defined. For example, Dunst, Trivette, and Cross [1986, as cited in Boyd (2002)] define the overarching concept of "social support" as a construct that includes informal support services, such as instrumental, emotional, and physical support, in addition to more formal support services, such as those that individuals can receive from professionals. Instrumental support, a type of informal support, can include services such as respite or childcare. Emotional support, another type of informal support, typically includes psychological support and comforting from family, friends, or support groups. Formal support services can be any type of support that one requires that is being offered by a professional organization or support service, such as a parent support group or therapist (Boyd, 2002). In general, research has shown that for many parents social support can help relieve the stress of being a parent of a child with ASD (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). For some parents, informal support, such as emotional and instrumental support, resulted in lower stress for parents compared to formal support, such as a parent support group (Boyd, 2002).

The level and perception of support varies from parent to parent. For example, someone who identifies as the primary caregiver might be more inclined to seek support since they are more so exposed to their child's behaviors and experience greater stress compared to a secondary caregiver (Burrell, Ives, & Unwin, 2017). Some parents feel that their greatest sources of support come from their friends and family, especially since it is more generally more accessible (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). However, for those who have do access to community support services, they generally reported feeling less stressed and more supported when they took advantage of those services compared to the support they received from family and friends (Zaidman-Zait et al., 2016). When they took advantage of those community services, they also reported feeling less isolated from the community, which is a common feeling for parents of children with a disability to experience.

The present study will expand and explore on the concepts that have been defined in the preceding sections, with the overall goal being to thoroughly understand the experience of parenting a child with ASD. Considering the goals of the study, and since these concepts are relatively understudied, for the purposes of this study we will allow the parents who are participating to define what "support" looks like for them.

The Current Study

Previous research has focused on the impact that a child with ASD has on parents in general as well as how different aspects of the diagnosis impact parents' stress levels (Osborne & Reed, 2009). However, there is limited research that looks at whether different aspects of the disorder impacts mothers and fathers differently. Considering the gap in the literature, as well as the hope to expand on past research utilizing a more convenient method of data collection, there are a few different goals that were addressed in this study.

The first goal of the current study was to examine and compare overall differences in parent stress between the sample populations (mothers and fathers). Consistent with previous literature, it was hypothesized that mothers would report greater overall parent stress compared to fathers. The second goal of the study was to determine whether specific aspects of ASD symptoms and related behavior problems would be predictive of parent stress. To achieve this goal, we examined behavior problems and ASD symptoms severity in relation to parent stress separately for mothers and fathers. This goal was simply exploratory, therefore there were no hypotheses regarding this relationship. The third goal of this study was to examine whether there was a difference in the influence of predictors on parent stress between the two sample populations. The previous research behind this has been somewhat contradictory. However, the literature has suggested that, compared to fathers, mothers are typically more involved in the day-to-day care of their children and therefore are more often aware of and deal with their child's behavior problems (Burrell, Ives, & Unwin, 2017; Vacca, 2013). Based on previous literature, it was hypothesized that the child's behavior problems would be a significant predictor of increased stress levels for mothers, whereas ASD symptom severity would be a significant predictor of stress for fathers.

The final goal of the study was to examine perceptions of support and feelings of being misunderstood through the collection of qualitative data. This research was exploratory considering there is a gap in the literature that examines these constructs specifically in relation to parents of children with ASD. Because fathers are underrepresented, and part of that reason might be the data collection method, the data in the current study was collected through an online series of questionnaires to provide a more convenient method and encourage greater participation.

Method

Participants

248 participants (123 mothers, 125 fathers) were recruited via Facebook as well as flyers that were sent via email to clinics serving families and children with ASD, such as ABA clinics, throughout the United States. Before the current study was conducted, a sample size estimate based on various effect sizes was calculated both for the total sample as well as separately for mother and father samples. Based on a total effect size of the relationship between stress for mothers and various child factors, including core ASD symptoms and behavior problems, of 1.27, which was reported by Davis and Carter (2008) and a power of .80, we estimated that we should recruit a sample size of 24 mothers of children with ASD. Based on an effect size of the relationship between stress for mothers and various child factors, including core ASD symptoms and behavior problems of 1.38, which was reported by Davis and Carter (2008) and a power of .80, we estimated that we should have aimed to recruit a sample size of 23 fathers of children with ASD. Considering the large effect size of which the previous sample estimate was based on, a separate sample size estimate based on a more conservative effect size was calculated. Based on an effect size (f^2) of .15, which is considered to be a medium effect size under G-power analysis conventions, and a power of .80, we aimed to recruit approximately 236 parents (118 mothers and 118 fathers). However, considering the target population and the method of recruitment, we aimed to recruit a sample of parents that falls somewhere between these two sample size estimates, such as 150 parents (75 mothers and 75 fathers).

To maximize father participation and due to the difficulty of obtaining whole family samples, mothers and fathers were not required to be parent dyads of the same child. Upon entering the study, parents were asked whether they considered themselves to be the “primary

caregiver" in their household. Children were required to be between three and five years of age to participate in the study. This was desired because during this time children are typically beginning to show distinct characteristics of ASD and are also typically being diagnosed around this age (American Psychiatric Association, 2013). Upon recruitment, their child was required to have had a formal diagnosis of ASD within the past eight to twelve months. If their child was not between three and five years of age, and if their child did not have a recent diagnosis, that participant was excluded from the study. This was because a recent diagnosis has been found to be related to increased stress for parents and feelings of inadequacy about their parenting abilities (Elder, Kreider, Brasher, & Ansell, 2017). Participants who had a child with an additional diagnosis, such as ADHD, were still included. Upon entering the study, they were asked if they were aware of any additional diagnoses that their child had, if any. If they stated their child did have additional diagnoses, they were asked to list what those were. Parents also had to be over the age of 18. Upon completion of the questionnaires on Qualtrics, each participant received a five-dollar Amazon electronic gift card that was sent to them via email.

The mothers present in the study were primarily White (80%) and married (91.9%) who were also primarily employed full-time (42.4%). The majority of mothers were also highly educated (63.8%), having received some level of a college degree, and reported a yearly household income above $50,000 (80.8%). It is also worth noting that 56% of mothers were enrolled in a support group at the time of enrollment and identified as the primary caregiver of the child (90.4%). The average age of mothers in the present study was 32.38 (*SD* = 4.265, range = 24-46).

The fathers present in the study were primarily white (74.8%) and married (94.4%) who were also primarily employed full-time (95.2%). The majority of fathers were also highly

educated (87.8%), having received some level of a college degree, and reported a yearly household income above $50,000 (82.3%). It is also worth noting that 58.5% of fathers were enrolled in a support group at the time of enrollment and identified as the primary caregiver of the child (92.7%). The average age of fathers in the present study was 32.65 (*SD* = 4.121, range = 25-57).

The children of the participants in the study were between the ages of three and five, with the average age being approximately four (*SD* = .746), and the majority of them were boys (66.7%). The majority of the participants identified their child as being white (76.8%). In terms of the services that the children were enrolled in at the time of the study, many of them were enrolled in ABA therapy (68.6%), Speech Therapy (64%), and Physical Therapy (50.8%), whereas only some of them were enrolled in Occupational Therapy (38.8%) and Sensory Integration Therapy (42.2%). The majority of the sample did not report any additional diagnoses (87.3%). However, for those who did report additional diagnoses (5%, n = 13), the most common diagnosis mentioned was ADHD (n = 4). The average age at which their children were diagnosed was 3.14 (*SD* = .918).

Measures and Procedures

The flyers that were sent out to clinics as well as via the Facebook ad included a link to Qualtrics to participate in the study. Once participants were directed to Qualtrics, there was a pre-screening questionnaire asking about the child's age, whether they had a formal diagnosis of ASD, and if they had a formal diagnosis, parents stated when the diagnosis was given. There was also be a question regarding whether the individual's spouse/partner who the child's other parent was had already participated in the study. The inclusion of this questionnaire helped to ensure that those who participated in the study met the inclusion criteria. Participants completed a

consent form. Following the consent form, participants answered demographic questions, as described above, as well as online surveys, including the Child Behavior Checklist (CBCL 1.5.-5; Achenbach and Rescorla, 2001), Gilliam Autism Rating Scale-3 (GARS-3; Gilliam, 2014), the Parenting Stress Index-Short Form (4th Edition) (PSI-SF; Abidin, 2012). After completing the questionnaires, participants completed a series of open-ended questions assessing two concepts: "Feeling Misunderstood" and "Perceptions of Support."

Demographic and family background. We collected information about the parents, such as parent caregiver status (primary vs. secondary), parent employment status, parent gender, household income, current marital status, number of children in the home, highest level of education completed, as well as participation in or membership of a parent support group. We also collected child information, such as child age, ethnicity, and gender, as well as their child's diagnosis (additional diagnoses other than ASD), age at diagnosis, and types/hours of intervention services they participate in within a typical week. Considering previous literature behind finances and parent stress, a question regarding whether finances was a significant source of stress for parents in this study was also included.

Parent Stress. The Parenting Stress Index-Short Form (4th Edition) (PSI-SF; Abidin, 2012) measured the parents' stress levels. It is a 36-item questionnaire and consists of three subscales: Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child. The Parental Distress subscale (12 items) measured the extent to which parents feel competent, restricted, conflicted supported, and/or depressed in their role as a parent (e.g. "Since having a child, I feel that I am almost never able to do things that I like to do"). The Parent-Child Dysfunctional Interaction subscale (12 items)measured the extent to which parents feel satisfied with their child and their interactions with them (e.g. "My child smiles at me much less than I

expected"). The Difficult Child subscale (12 items) measured how a parent perceives their child to be, whether the child is easy or difficult to take care of (e.g. "My child turned out to be more of a problem than I had expected"). Within each subscale there were 12 items of which participants rated the level to which they agree or disagree on a scale from 1 (*strongly disagree*) to 5 (*strongly agree*). We calculated a total score with higher scores indicating higher levels of total stress and lower scores indicating lower levels of total stress. This questionnaire is appropriate for participants with children ages birth-12. It is important to note that during the process of inputting the questionnaire into Qualtrics, the first question on the questionnaire was accidentally left out and the second question was included twice. An average of the scores that were reported for both instances of question two. The interpretation of the total scores should be adjusted to reflect this.

Behavior Problems. Parents completed the Child Behavior Checklist (CBCL 1.5.-5; Achenbach and Rescorla, 2001), which is a 99-item questionnaire assessing the extent to which their child was experiencing behavior problems that commonly accompany ASD. We asked parents/caregivers to rate each of the behaviors as 0 (*Not True of the child*), 1 (*Somewhat or Sometimes True*), or 2 (*Very True or Often True)* considering how the child behaved at the time the questionnaire was being completed or how they had behaved within two months prior to the questionnaire. The questionnaire also included an open-ended section in which respondents wrote down any additional problems their child has that were not covered in the 99 items and further describe those problems and any other concerns they might have about their child. The 99 items were scored on the following syndrome scales: Emotionally Reactive, Anxious/Depressed, Somatic Complaints, Withdrawn, Attention Problems, Aggressive Behavior, and Sleep Problems. The syndrome scales were also categorized into two distinct subscales: *Internalizing*

(Emotionally Reactive, Anxious/Depressed, Somatic Complaints, Withdrawn) and *Externalizing* (Attention Problems and Aggressive Behavior) problems. Example questions representing the Internalizing Problems subscale were "Avoids looking others in the eye" and "Gets too upset when separated from parents". Example questions representing the Externalizing Problems subscale were "Can't concentrate, can't pay attention for long" and "Hits others". The scale 'Sleep Problems' did not fit under either of those subscale categories. We calculated a composite score for Internalizing Problems and a composite score for Externalizing Problems, as well as for a Total Problems score that was derived from the 99 items and one item added by the parent/caregiver (if a parent/caregiver wrote in more than one additional problem, the one item with the highest score was included in the Total Problems score) (Tan, Dedrick, & Marfo, 2007).

Severity of Autism Symptoms. The Gilliam Autism Rating Scale-3 (GARS-3; Gilliam, 2014) is a 58-item questionnaire assessing ASD symptom severity of the child from the parents' perspectives. It can be completed either as a questionnaire or a structured interview for teachers, parents, and clinicians, but for the purposes of this study parents completed it as a questionnaire. Items in the GARS-3 are based on the diagnostic criteria for ASD as defined by the DSM-5. The GARS-3 consists of six subscales: Restrictive/Repetitive Behaviors, Social Interaction, Social Communication, Emotional Responses, Cognitive Style, and Maladaptive Speech. The GARS-3 also includes a question regarding whether their child is with or without verbal language The first four subscales (Restrictive/Repetitive Behaviors, Social Interaction, Social Communication, Emotional Responses) were completed by all participants whether or not their child was verbal. However, the final two subscales (Cognitive Style and Maladaptive Speech) were only completed by those whose children were without verbal language. These subscales combined to give an overall autism quotient with higher scores indicating greater symptom severity.

Respondents rated each behavior on a Likert-type scale from 0 (*not at all like the individual*) to 3 (*very much like the individual*). The questionnaire is appropriate for the assessment of individuals 3-22 years of age. The GARS-3 yielded standard scores, percentile ranks, and symptom severity level.

Perceptions of Support. Since this concept has been relatively understudied, for the purposes of this study parents were allowed to define what "support" looked like for them. We provided a prompt that described what these questions were looking at. The prompt asked parents to reflect on their experiences as a parent. We then asked a series of open-ended questions (See Appendix A), such as "Think of a time when you felt supported. What did that look like? Who was it that most supported you?". Additional questions were asked regarding perceptions of support from particular persons in their life, such as their family and friends. First, they were asked about the extent to which they felt supported by those persons. They responded with either a 1 (*Not at all*), 2 (*Occasionally or somewhat*), or 3 (*A lot*). For those who responded with either a "1" or a "3" then responded to follow-up open-ended questions asking why they did or did not feel supported in that particular scenario. Participants responded using a text box and had as much time as needed to provide a response. Those who responded with a "2" did not receive a text box and prompted to move on to the next question.

Feeling Misunderstood. For the purposes of this study, this concept was defined as the feeling of being misunderstood as a parent of a child with ASD regarding their parenting experiences. Prior to answering these questions, a prompt described what these questions were looking at, which prompted participants to reflect on their experiences as a parent. We then asked a series of open-ended questions addressing feelings of being misunderstood (See Appendix A), such as "How much do you feel that your family understands your experience of

being a parent of a child with ASD?". For this question, they responded with either a 1 (*A lot*), 2 (*A moderate amount*), or 3 (*Not at all*). Participants who responded with either a "1" or a "3" then responded to follow-up open-ended questions asking why they did or did not feel understood in that particular scenario. Participants responded using a text box and had as much time as needed to provide a response. Those who responded with a "2" did not receive a text box and prompted to move on to the next question.

Coding of Perceptions of Support and Feeling Understood. To address the final goal of the study, we conducted a thematic analysis for the qualitative data collected through the open-ended questions regarding perceptions of support and feelings of being misunderstood. Considering there were no prior hypotheses regarding these concepts, the goal was to find general themes amongst the data and then provide descriptive information regarding the themes we find. We developed a coding manual to generate and analyze the themes of the qualitative data. We took two separate approaches to developing codes. For the questions relating to "support", we developed the codes using a theoretically driven inductive approach (Syed & Nelson, 2015) which is a middle-ground approach between theoretical and data-driven approaches. Codes are generated inductively but are also based on theory and previous research. For the questions relating to "feeling understood", we took a data-driven approach to generating the codes. Since this construct was created in an exploratory way based on interest, a purely data-driven approach was the most appropriate. The data-driven approach does not use theory or past research but rather relies on the data to generate themes, which are then used to create codes. The principal investigator developed the coding manual which contained codes for both the "support" and "feeling understood" concepts (See Appendix A). We recruited research assistants to assist in coding the qualitative data, and before they were able to begin coding independently, they

completed a thorough training on the coding system to the point that we, as a coding team, attained good interrater reliability. We established interrater reliability by calculating percentage agreement and reaching an alpha level of at least .75 or greater, which is considered by Fleiss (1981; as cited in Syed & Nelson, 2015) to be an excellent alpha reliability value. The average alpha reliability value amongst the three coders and across all qualitative variables was .89 with values ranging from .663 to 1.000. Taking a quantitative analysis approach to the qualitative data, we conducted frequency analyses to assess for recurring, more prevalent themes across all participants. Finally, we conducted a multiple regression analysis to examine the relationship between the averaged codes for support and understanding and parent stress. This was an exploratory analysis therefore no hypotheses were generated.

Data Analyses Plan

Following data collection, we transferred the data from Qualtrics to SPSS. We screened and cleaned the data, and then conducted preliminary analyses. Initially we assessed the accuracy of the data by looking for out of range values and univariate outliers. Additionally, we analyzed the missing data to make sure any data that are missing are missing at random or missing completely at random (MAR/MCAR). We then examined skewness and kurtosis of the variables. When the skewness and kurtosis scores were greater than the acceptable values (±0.5 and ±1, respectively), variables were transformed appropriately. We utilized various sources to test for multicollinearity, such as zero-order correlations between the variables, p-values, as well as VIF and tolerance values. We conducted multicollinearity analyses based on which variables were being utilized in the different regression analyses (e.g. one analysis was conducted to see if CBCL Total and the GARS Autism Index were correlated, and we also conducted an analysis to

see if the six subscales of the GARS was correlated with the two subscales of the CBCL). We screened for multivariate outliers using a Mahalanobis distance test.

Before conducting the analyses addressing the main goals of the study, we conducted zero-order correlation analyses between the six subscales of ASD symptom severity assessed by the GARS-3 and parent stress, assessed by the PSI-SF, separately for both mothers and fathers. We then conducted additional zero-order correlation analyses between the two subscales of behavior problems assessed by the CBCL (1.5-5) and parent stress (PSI-SF) separately for both mothers and fathers. We controlled for caregiver status and income. Descriptive statistics were also examined, such as means and standard deviations, for all predictor variables. To address the first hypothesis, we examined stress level means and compared for both samples of interest (mothers and fathers) using an independent samples t-test.

To address the second goal of the study, we conducted hierarchical multiple regression analyses (Tabachnick & Fidell, 2018) to examine whether severity levels of specific ASD symptoms assessed by the GARS-3 were predictive of parent stress for mothers and fathers. We inputted all six of the GARS-3 subscales as predictors and conducted separate analyses for the two sample groups (mothers and fathers). The same analysis process was conducted to examine whether specific types of behavior problems assessed by the CBCL (1.5-5) were predictive of parent stress. We inputted two subscales of the CBCL (1.5-5) as predictors (externalizing and internalizing behaviors).

To address the third hypothesis, we examined whether there is a difference in the influence of predictors on parent stress between the two sample populations. To do this, we created interaction terms between the gender variable (which was coded as “0” for mothers and “1” for fathers) and total scores of each predictor variable (CBCL 1.5-5 and GARS-3) to be

entered into hierarchical regression analyses. This allowed us to see whether there were differences in how each predictor variable influenced stress based on the sample population. We conducted a set of hierarchical multiple regression analyses utilizing the PROCESS procedure in SPSS, which was chosen due to the ability to assess moderation easier and faster.

Results

Preliminary Analyses and Data Management

To analyze the data, we used IBM SPSS 27 as well as the PROCESS macro within SPSS. Upon first glance, there were some issues with the data, such as non-English words, phrases, or numbers (e.g. a Chinese symbol was used in an open-ended response question about the child's gender). We translated any non-English words, phrases, or numbers to English using Google Translate. Additionally, there was a small sample of mothers (n = 34) who reported identical wording on all items included in the open-ended portion of the survey, which was concerning due to the fact that all 34 participants responded with "no" to all questions as well as the nature of the question (open-ended rather than a simple "yes" or "no" response). We compared demographic information between this small sample of mothers (n = 34) and the remaining sample of mothers (n = 93) to identify any differences that could exist between the two samples. The mothers in this subset of the sample identified primarily as homemakers (n = 17, 50% of the sample) compared to the remaining sample of mothers, who primarily identified as full-time employees (n = 45, 48.4% of the sample). The small sample of mothers also had, on average, fewer children (M = 1.26, SD = .45) compared to the larger sample of mothers (M = 1.74, SD = 1.03). Considering there were some important differences between these two samples of mothers that could possibly contribute to their responses, we conducted analyses with and without this sample. When there were differences in results of the analyses between the subset samples of

mothers, we reported the results from both analyses, otherwise, we only reported results from analyses including the total sample of mothers. There was also a total of three participants who only completed the pre-screening questions as well as participants who reported their child's age as being outside the required range (n = 6), all of which we deleted. Additionally, we assessed for outliers. We defined outliers as any data points beyond three standard deviations from the mean .We replaced any outlier with the value of three standard deviations from the mean. We only replaced two outliers across both samples.

Little MCAR's test for missingness revealed a non-statistically significant chi-square value for both samples when assessing the missingness for the CBCL (1.5-5) raw data and PSI-SF raw data, which indicated that the data were missing completely at random. For both samples, when assessing the missingness for the GARS-3 raw data, a statistically significant chi-square value indicated that the data were not missing at random. However, the GARS-3 questionnaire generates data for children with and without verbal language. Therefore, we split the data for both mothers and fathers to assess for children with and without verbal language separately. We conducted little MCAR's analyses for all four datasets and results revealed a non-statistically significant chi-square value for all dataset, indicating that the data were missing completely at random. We conducted a regression imputation to replace the missing data. We chose this approach because it uses the data that is available to incorporate more information compared to a mean imputation, and the dataset is created based on those participants who had complete data.

We conducted Pearson's zero-order correlations between all subscale variables as well as both total scores that were utilized in the main study analyses. Results indicated that all correlations were statistically significant (See Table 2). To further assess collinearity between the variables, we conducted linear regressions to generate tolerance and VIF values. There were no

VIF values between one and ten, and, additionally, all tolerance values were above 0.2, which indicated that there were no issues of multicollinearity. However, since there were statistically significant correlations between many of the predictor variables, we centered all predictor variables around the grand mean for the whole sample to reduce the risk of multicollinearity.

Before conducting the analyses for the main goals of the study, we conducted zero-order correlations between basic demographic data and parent stress (PSI-SF). There were no statistically significant correlations between any of the variable, except for the correlation between PSI total and employment status (r = -.282, p < .001). For this reason, we included employment status as a covariate in all regression analyses. An independent samples t-test revealed that the relationship between the total PSI score and child gender was not statistically significant, $t(250) = .619$, $p = .54$. An additional independent samples t-test revealed that the relationship between the total PSI score and caregiver status was statistically significant, $t(244) = 1.946$, $p = .05$, indicating that those who identified as a primary caregiver reported higher stress levels (M = 102.59, SD = 15.25) compared to those who identified as a secondary caregiver (M = 95.94, SD = 11.59). For this reason, we included the *caregiver status* variable as a covariate in all regression analyses. Finally, we also conducted descriptive analyses for all study variables for the mothers and fathers (see Table 1).

Stress Differences between Mothers and Fathers (Goal 1)

An independent samples t-test revealed that there was a statistically significant difference in parenting stress means between mothers (n = 125) and fathers (n = 123), $t(246) = 2.863$, p = .005, 95% CI [1.69, 9.14] (See Table 3). On average, fathers reported higher levels of stress (M = 104.88, SD = 14.51) than mothers (M = 99.46, SD = 15.25). We conducted an additional independent samples t-test excluding those 34 mothers. In this case, when we excluded those 34

mothers from the analyses, there were no statistically significant differences in parenting stress means between mothers (M = 100.97, *SD* = 15.89) and fathers (M = 104.88, *SD* = 14.51), *t*(213) = 1.873, *p* = .062 (See Table 4).

Since the inclusion of the small sample of mothers clearly impacted the results of the analyses for this goal, we generated stress means for both samples of mothers and conducted an additional independent samples t-test to compare their stress means. Analyses revealed that there was not a statistically significant difference in parenting stress means between the small sample of mothers (n = 34) (*M* = 95.22, *SD* = 12.38) and the larger sample of mothers (n = 91) (*M* = 101.05, *SD* = 12.38), *t*(123) = -1.923, *p* = .057; however, the results were approaching statistical significance.

ASD Symptom Severity and Behavior Problems Predicting Parent Stress (Goal 2)

We conducted a set of hierarchical multiple regression analyses separately for mothers and fathers. Additionally, for analyses looking at GARS-3 subscales, we conducted separate analyses for mothers and fathers of children with and without verbal language. We analyzed means and standard deviations for all GARS-3 and CBCL subscales included in the analyses separately for both samples. We conducted Pearson's zero-order correlations between all subscale variables as well as both total scores that were utilized in the analyses for this goal (see Table 10).

Regression Analyses Examining CBCL Subscales

We conducted multiple independent samples t-tests between the two subscales of the CBCL (Internalizing Behaviors and Externalizing Behaviors) separately for mothers of both children with and without verbal language, and for fathers of children with and without verbal language. For mothers, there was not a statistically significant association between subscale scores between mothers of children with verbal language or without verbal language for either

the CBCL Internalizing subscale, $t(123) = .778$, $p = .438$, or the CBCL Externalizing subscale, $t(123) = -.355$, $p = .723$. Similar results were found when the small sample of mothers were removed from the analysis. For fathers there was not a statistically significant association between subscale scores between fathers of children with or without verbal language for either the CBCL Internalizing subscale, $t(121) = 1.768$, $p = .080$, or the CBCL Externalizing subscale, $t(121) = 1.148$, $p = .253$.

Mothers of children without verbal language. We calculated a multiple linear regression to predict mothers' stress levels of those with verbal children based on the child's internalizing and externalizing associated behavior problems and to examine which independent variable was significantly associated with stress (See Table 5). Results indicated that the regression model examining mothers' stress levels and child behavior problems (internalizing and externalizing) was statistically significant, $F(4,65) = 9.427$, $p < .001$, $R^2 = .328$. Further examination of the independent variables indicated that internalizing behaviors were significantly associated with stress levels ($\beta = .505$, $p = .05$). For every additional one-point standard deviation increase in the child's internalizing behavior problems there was a .505 standard deviation increase in stress for mothers. This was not the case for externalizing behaviors ($\beta = -.020$, $p = .95$).

Mothers of children with verbal language. We conducted a multiple linear regression analysis to predict mothers' stress levels for those who have children with verbal language based on the child's internalizing and externalizing associated behavior problems and to examine which predictor was significantly associated with stress (See Table 5). Results indicated that there was not a statistically significant association between mothers' stress levels and child's externalizing and internalizing behavior problems, $F(4,58) = 2.422$, $p = .059$, $R^2 = .152$.

Fathers of children without verbal language. We conducted a multiple linear regression analysis to assess whether the child's internalizing or externalizing behavior problems were significant predictors of stress for fathers of children without verbal language (See Table 6). Results indicated that there was not a statistically significant association between fathers' stress levels and child's behavior problems, $F(4,61) = 1.913$, $p = .121$, $R^2 = .118$.

Fathers of children with verbal language. We conducted a second multiple linear regression analysis to assess whether the child's internalizing or externalizing behavior problems were significantly associated with stress for fathers of children with and without verbal language (See Table 6). Results indicated that there was a statistically significant difference in the association between fathers' stress levels and child's behavior problems, $F(4,56) = 4.548$, $p = .003$, $R^2 = .245$. Further examination of the independent variables indicated that internalizing behaviors were statistically significantly associated with fathers' stress ($\beta = .639$, $p = .013$). For every additional one-point standard deviation increase in the child's internalizing behavior problems there was a .639 standard deviation increase in stress for fathers. This was not the case for externalizing behaviors in association with stress ($\beta = -.082$, $p = .800$).

Regression Analyses Examining GARS-3 Subscales

All participants completed the initial four out of six subscales of the GARS-3 regardless of whether their child was verbal or not. Before conducting the main analyses for this goal, we conducted multiple independent samples t-tests for both mothers and fathers separately to examine whether a child's verbal language ability was related to the various PSI subscale scores. When we included the small sample of 34 mothers, there was a statistically significant association between child's verbal language status and the PSI Difficult Child subscale, $t(121) = 4.014$, $p < .001$, such that mothers of children without verbal language reported on average

greater stress (*M* = 46.479, *SD* = 5.794) related to their child's difficult behaviors compared to mothers of children with verbal language (*M* = 41.798, *SD* = 7.119). Results were similar when we did not include the sample of mothers; however, additionally there was a statistically significant association between PSI Total stress score and child's mute status, $t(89) = 2.121$, $p = .037$, such that mothers with of children without verbal language reported on average greater total stress (*M* = 105.233, *SD* = 11.689) compared to mothers of children with verbal language(*M* = 98.131, *SD* = 17.495). For fathers, there was a statistically significant association between child's verbal language ability and the PSI Parental Distress subscale, $t(121) = 2.326$, $p = .022$, such that fathers of children without verbal language reported on average greater stress related to their role as a parent (*M* = 35.960, *SD* = 6.539) compared to fathers of children with verbal language (*M* = 32.835, *SD* = 8.277). There was also a statistically significant association between child's verbal language ability and the PSI Difficult Child subscale, $t(121) = -2.465$, $p = .015$, such that fathers of children with verbal language children reported on average greater stress (*M* = 44.941, *SD* = 6.454) compared to fathers of children without verbal language (*M* = 42.132, *SD* = 6.182).

We conducted multiple independent samples t-tests between the four subscale scores (Repetitive Behaviors, Social Interaction, Emotional Responses, and Social Communication) separately for mothers and fathers of children with and without verbal language. There was a statistically significant association between subscale scores for Repetitive Behaviors for mothers, $t(123) = 2.297$, $p = .023$, and Social Interaction, $t(123) = 2.670$, $p = .009$. Mothers of children without verbal language reported their children had, on average, a greater severity of restrictive/repetitive behaviors (*M* = 10.26, *SD* = 1.372) compared to those who had children with verbal language (*M* = 9.57, *SD* = 1.978). Additionally, mothers of children without verbal

language reported that their children had, on average, a greater severity of social interaction difficulties (M = 9.58, SD = 1.478) compared to mothers of children with verbal language (M = 8.75, SD = 1.997). Similar results were found for differences in the Social Interaction subscale scores when we did not include the small sample of mothers (n = 34); however, there was not a statistically significant difference in Restrictive/Repetitive Behaviors subscale scores between mothers of children with and without verbal language. Additionally, there were no statistically significant differences in subscale scores between fathers of children with and without verbal language. For the main regression analyses for this goal including mothers and fathers of children with verbal language, all six subscales were included, whereas regression analyses including parents of children without verbal language included only the four subscales (Repetitive Behaviors, Social Interaction, Social Communication, and Emotional Responses).

Mothers of children without verbal language. We conducted a multiple linear regression analysis to assess whether there was a difference in the association of mothers' stress and the various symptoms of ASD, which included the four subscale scores that were relevant for parents of children without verbal language (See Table 7). Results indicated that although there was a statistically significant difference in this association, $F(6,57) = 5.361$, $p < .001$, $R^2 = .361$, none of the independent variables were statistically significant.

Mothers of children with verbal language. We conducted a multiple linear regression analysis to assess whether there was a difference in the association of mothers' stress and the various symptoms of ASD, which included the four subscale scores that were relevant for parents of children without verbal language (See Table 7). Results indicated that there was a statistically significant difference in this association, $F(8,50) = 2.439$, $p = .026$, $R^2 = .281$. Upon further examination of the independent variables, there was a statistically significant association

between stress and Social Interaction (β = 3.574, p = .043). For every additional one-point standard deviation increase in the child's Social Interaction symptom severity there was a 3.574 standard deviation increase in stress for mothers. However, this was not the case for Repetitive Behaviors (β = -1.166, p = .527), Social Communication (β = -.168, p = .909), Emotional Responses (β = -.357, p = .777), Cognitive Style (β = -.279, p = .842), or Maladaptive Speech (β = 1.768, p = .183).

When the small sample of mothers (n = 34) were not included in the analysis, results were similar, as there was a statistically significant difference in the associations of various ASD symptoms and mothers' stress levels, $F(7,47) = 2.444$, p = .032, R^2 = .267. However, unlike when the small sample was included, upon further examination of the independent variables, there were no statistically significant associations between stress and any of the predictor variables (see Table 8).

Fathers of children without verbal language. We conducted a multiple linear regression analysis to assess whether there was a difference in the association of fathers' stress and the various symptoms of ASD, which included the four subscale scores that were relevant for parents of children without verbal language (See Table 9). Results indicated that there was a statistically significant difference in this association, $F(6,55) = 3.654$, p = .004, R^2 = .285. Upon further examination of the independent variables, there was a statistically significant association between fathers' stress and Repetitive Behaviors (β = 5.006, p = .005), such that for every additional one-point deviation increase in Repetitive Behavior symptom severity there was a 5.006 increase in stress for fathers. There was also a statistically significant association between fathers' stress and Social Communication symptoms (β = 4.491, p = .003), such that for every additional one-point deviation increase in Social Communication symptom severity there was a

4.491 increase in stress for fathers. Finally, there was a statistically significant association between fathers' stress and Emotional Responses (β = -3.765, p = .007), such that for every additional one-point deviation increase in Emotional Response symptom severity there was a 3.765 decrease in fathers' stress. However, this was not the case for Social Interaction (β = -1.525, p = .390).

Fathers of children with verbal language. We conducted a multiple linear regression analysis to assess whether there was a difference in the association of fathers' stress and the various symptoms of ASD, which included the four shared subscale scores, for mothers of children without verbal language (See Table 9). Results indicated that although there was a statistically significant difference in this association, $F(8,52) = 4.057$, $p = .001$, $R^2 = .384$, none of the independent variables of interest were statistically significant.

Differences in Influence of Predictors (Mothers vs. Fathers) (Goal #3)

We conducted a set of hierarchical regression analyses using the PROCESS macro plugin for SPSS by Hayes separately for both the total CBCL and GARS-3 Autism Index variables using the total PSI variable as the outcome variable and examining parent gender as the moderator. We also conducted all analyses without the small sample of mothers. The model examining child behavior problems as it predicts parent stress was statistically significant, $F(5, 238) = 12.561$, $p < .001$, $R^2 = .209$ (See Table 11). There was a statistically significant main effect of child behavior problems (β = .214, p = .027, CI [.025,.402]), such that for every one-point deviation increase in child behavior problems, there was a .214 increase in parent stress. However, we found that there was not a statistically significant main effect of gender (β = -1.931, p = .332, CI [-5.847, 1.985]). There was also not a statistically significant interaction effect between behavior problems and

parent gender predicting parent stress, indicating that gender was not a statistically significant moderator in this model, $F(1, 238) = .127$, $p = .722$, R^2 change < .001 (See *Figure 2*).

The model examining ASD symptom severity as it predicts parent stress was statistically significant, $F(5, 236) = 11.609$, $p < .001$, R^2 change = .197 (See Table 13). There was not a statistically significant main effect of gender ($\beta = -.843$, $p = .676$, CI [-4.808, 3.121]). However, we found that there was a statistically significant main effect of symptom severity ($\beta = .841$, $p = .0007$, CI [.361, 1.321]), such that for every one-point deviation in symptom severity, there was a .841increase in parent stress. Additionally, there was a statistically significant interaction effect between symptom severity and gender [$F(1, 236) = 3.767$, $p = .05$, R^2 change = .013] indicating that parent gender was a statistically significant moderator for this model. Upon further examination, we found that there was a statistically significant association between ASD symptom severity and stress for fathers ($\beta = .541$, $p < .001$, CI [.327, .756]) as well as for mothers ($\beta = .242$, $p = .029$, CI [.026, .458]). Considering the interaction indicated significant conditional effects for both mothers and fathers, we examined the simple slopes (See *Figure 3*) which indicated a greater magnitude of the association between symptom severity and stress for fathers compared to mothers.

The same analyses were conducted with the small sample of mothers removed from the sample and the results were different. In contrast to the sample that did include these mothers, the model examining child behavior problems as it predicts parent stress was not statistically significant, $F(5, 204) = 8.949$, $p < .001$, R^2 change = .179 (See Table 12). However, there was not a statistically significant main effect of gender ($\beta = -1.7944$, $p = .413$, CI [-6.104, 2.515]) nor of child behavior problems ($\beta = .183$, $p = .069$, CI [-.014, .379]). Additionally, there was not a statistically significant interaction effect between behavior problems and gender [$F(1, 204) =$

.005, p = .943, R^2 change < .001], indicating that parent gender was not a statistically significant moderator in this model (See *Figure 4*).

Also, similar to the results with the small sample of mothers included, the model examining ASD symptom severity as it predicts parent stress was statistically significant, $F(5,202) = 7.750$, p <.001, R^2 = .161 (See Table 14). There was not a statistically significant main effect of gender (β = -.957, p = .668, CI [-5.350, 3.437]). There was, however, a statistically significant main effect of symptom severity (β = .794, p = .002, CI [.292, 1.296]) such that for every one-point deviation increase in ASD symptom severity, there was a .794 increase in parent stress. Additionally, there was not a statistically significant interaction effect between symptom severity and parent gender [$F(1, 202) = 2.55$, p = .11, R^2 = .01], indicating that parent gender was not a statistically significant moderator in this model (see *Figure 5*).

Thematic Analysis: Perceptions of Support and Feeling Understood (Goal #4)

We conducted a thematic analysis of the qualitative data using the codes that were created and assigned for each participant's questions. We used frequency and other descriptive analyses to examine the presence of recurring themes surrounding the concepts of "Perceptions of Support" and "Feeling Understood" within the dataset (See Tables 16-23). There was a significant amount of data missing in this portion of the dataset, therefore a regression imputation was conducted to deal with the missing data prior to conducting the regression analysis. However, we conducted frequency analyses utilizing the raw coded data. Prior to conducting the analyses for this goal, we conducted a correlational analysis between the average score variables created for all "extent supported" and "extent understood" variables. There were statistically significant correlations between all variables of interest (See Table 15). Additionally, we conducted a correlational analysis between the "extent supported" and "extent understood"

variables and the CBCL Total, Autism Index, and PSI Total variables (See Table 15). There was a statistically significant correlation between the "extent supported by family members" and ASD symptom severity ($r = .140$, $p = .029$), between "extent supported by friends and acquaintances" and ASD symptom severity ($r = .140$, $p = .029$), as well as between the "extent understood by family members" and child behavior problems ($r = .138$, $p = .030$).

We presented the questions surrounding "Perceptions of Support" both in the context of "general" support as well as in the context of support relating to specific sources. In general, participants identified *psychological support* as being what "support" most often looked like to them (49.6%), with instrumental support being the second-most recurring (10.3%). Participants identified *family* as being the most recurring source of support (60.4%), with *friends and acquaintances* being the second-most recurring source (12.7%). In situations where participants described *not* feeling supported, *friends and acquaintances* were found to be the most recurring non-supportive source (38.7%), with *family* as the second most recurring (28%). As to reasons why they did not feel supported, the primary reason identified was that they either felt judged or ashamed as parents or they felt their child was being judged (28.2%). The second-most recurring response was that they simply lacked all support from those around them or a lack of any source of support (16.5%).

Participants were asked about the extent to which they felt supported by specific sources. Most participants identified feeling *occasionally or somewhat* supported by friends (53.8%, n = 135), supported *a lot* by family (54.7%, n = 139), and *occasionally or somewhat* supported by social media platforms (55.1%, n = 140). Regarding types of support, *psychological support* was identified as being the most recurring type of support that was provided by their friends (51.2%), family (57.8%), and social media platforms (54.3%). There were very few participants who

reported feeling *not at all* supported by friends (n = 8), family (n = 6), and social media (n = 12). For those who reported being *not at all* supported by friends, the most recurring reason was that their friends lacked caring or understanding (40%). Results were the same when asked why they did not feel supported by family (50%). For those who reported feeling *not at all* supported by social media, there was an equivalent number of participants who reported reasons relating to judgement (14.3%), lack of caring (14.3%), and lack of support sources (14.3%). Overall, most of the participants in this study reported feeling supported in some way by those around them.

Participants were asked about the extent to which they felt understood by specific sources. Most participants identified feeling *occasionally or somewhat* understood by family (49.4%, n = 127) as well as by friends (65.5%, n = 167). Regarding the reasons why they felt understood by both friends and family, the primary reason associated with both resources was the high quality of relationships. A common theme was stating they "received love and support" from their friends and family. There were very few participants who reported feeling *not at all* understood by family (n = 11), or friends (n = 10). For those who reported being *not at all* understood by family, the most recurring reason was due to poor quality of relationships with family members (44.4%), with the second-most recurring reason being the lack of knowledge of or experience with children diagnosed with ASD (46.3%). For those who reported feeling *not at all* understood by friends, results were the opposite. In this scenario, the most recurring reason was due to their friends' lack of knowledge of or experience with children diagnosed with ASD (62.5%), with the second-most recurring reason was due to poor quality of relationships with friends (37.5%). Overall, parents reported feeling generally understood by both family and friends in the current study.

Finally, we conducted a multiple linear regression analysis assessing the association between parent stress and the extent to which participants felt understood and supported by various sources (friends, family, and social media) (See Table 24). Interaction terms (gender x predictor) were included in the analysis to examine whether there were differences in this association between mothers and fathers. All predictor variables of interest were put in simultaneously into a single regression analysis considering there were no hypotheses put forward. The model examining this relationship was statistically significant, $F(13, 222) = 1.969$, $p = .024$, $R^2 = .103$. There was not a statistically main effect of gender ($\beta = -4.452$, $p = .725$, CI [-29.342, 20.439]). However, we found that there was a statistically significant interaction effect between the extent participants felt understood by friends and parent gender ($\beta = -9.994$, $p = .023$, CI [-18.567,-1.421]) such that there were a greater number of fathers who reported feeling understood (either "a moderate amount" or "a lot") by friends and acquaintances (96.2%) compared to mothers (93.6%). However, when the small sample of mothers was excluded from the analysis, the model examining this relationship was not statistically significant, $F(13, 189) = 1.169$, $p = .305$, $R^2 = .074$ (See Table 25).

Discussion

The goal of the study was to examine contributing factors to parent stress and to further our understanding of the experience of parenting a young child who has been newly diagnosed with ASD. Previously, the literature has focused, for the most part, on mothers, and what is unique about this study is that we have gathered information that can help us to understand the experiences of fathers as well. There have been previous studies that have compared the contributing factors of stress between parents before, which was also accomplished in this study, but what is novel is that we are also comparing experiences of support and understanding. The

concept of "feeling understood" is also novel in this study, as it is not well-defined or studied in previous literature. In addition to the intriguing novelty of the study, there were also numerous interesting and important findings that came from the current study.

Stress Differences between Mothers and Fathers (Goal #1)

The first important finding, contrary to our hypotheses, was that fathers reported, on average, greater stress compared to mothers. Additionally, these findings contradict previous research, which has indicated that mothers, on average, report higher stress levels than fathers. The fathering vulnerability hypothesis describes fathers as more susceptible to stress within the home (Goeke-Morey & Cummings, 2007). The hypothesis stipulates that fathers often rely on the mother to help define their role in the family. This dependency can come at a price to fathers if mothers are experiencing a considerable amount of stress. When mothers are stressed, this impacts the ability of mothers to provide any support to fathers. Because fathers rely on mothers, this increases their vulnerability to the stress that is impacting mom, and fathers will likely experience greater role confusion and stress. This hypothesis has been supported by additional, more recent research (e.g. van Eldik, de Haan, Arends, Belsky, & Prinzie, 2019).

Previous studies have reported that mothers are typically the primary caregiver and thus more often exposed to their child's behaviors (Falk, Norris, & Quinn, 2014; Hastings, 2003; Tehee, Honan, & Hevey, 2009). However, in the current study, most fathers identified as the primary caregiver (92.7%). Those who identify as primary caregivers, compared to other family members, are more often involved in the day-to-day care of their children. For these parents, there is a higher level of burden related to caregiving and prolonged exposure to their child's behaviors, which can negatively impact their mental health. Sung and Park (2012) discussed this idea in the context of primary caregivers who have children diagnosed with a developmental

disability. It was indicated that those who identify was primary caregivers are often the ones that take full responsibility for the day-to-day care of the child, they experience a greater level of burden and more difficulties related to their children, such as being exposed more often to problem behaviors, In the case of those who have a child with ASD, they are more often exposed to the more difficult behaviors their child exhibits, they are more involved in their care and treatment, and their stress, therefore, is considered greater. In combination with the fathering vulnerability hypothesis, this could possibly explain this unique finding.

ASD Symptom Severity and Behavior Problems Predicting Parent Stress (Goal #2)

One unique finding from this goal was that, compared to externalizing behaviors, internalizing behaviors were significantly associated with parent stress for both mothers and fathers. As defined in this study by the CBCL, internalizing behaviors could include behaviors such as anxiety, withdrawal, depression, and mood disturbance, whereas externalizing behaviors could include behaviors such as aggressive hitting, biting, or tantrums. In previous literature, externalizing behaviors, compared to internalizing behaviors, have been reported as a significant contributing factor to parent stress (Davis & Carter, 2008; Falk, Norris, & Quinn, 2014). Externalizing behaviors are more visible and often times more difficult to deal with due to the sheer nature of those behaviors and can often be associated with greater stress for parents who handle them. However, this was not the case with the parents in the current study.

There are some possible reasons as to why this unique finding could be occurring. Similar to externalizing behaviors, internalizing behavior problems can also be just as difficult for parents to manage. Nuske, Hedley, Tseng, Begeer, and Dissanayake (2017) examined the association between internalizing and externalizing behavior problems and parent quality of life and family functioning. They stated that the ability for children to regulate their emotions plays a

critical role in their ability to succeed in school and can even predict future emotional and physical health. Compared to typically developing children, young children diagnosed with ASD who exhibit higher levels of internalizing behavior problems do not have the ability to regulate their own emotions and are more dependent on other adults, such as their parents, to assist them in this task as well as manage the outbursts and other externalizing behavior problems. Externalizing behaviors, such as tantrums and aggression, have been found to come as a result of severe internalizing behavior problems and emotion dysregulation. Increased dependence on parents and higher occurrence of internalizing behavior problems has been found to result in increased stress for parents and could therefore be a possible reason behind the results of the current study. If parents do not have the skills to help their children manage behaviors and regulate their emotions, those behaviors might increase in frequency and severity (Nuske, Hedley, Tseng, Begeer, and Dissanayake, 2017). This concept was not addressed in the current study and future studies should consider examining it.

Another speculative explanation comes from a child development perspective. Considering the ages of the children in the current study, parents could be perceiving the externalizing behaviors their children exhibit as simply "age-normative behaviors," whereas internalizing symptoms could be perceived as "atypical" for their age, even with the presence of an ASD diagnosis. With this in mind, parents may be less prepared to manage these types of behaviors compared to the typical behaviors that are present in preschool-aged children.

Differences in Influence of Predictors (Mothers vs. Fathers) (Goal #3)

Although there was a sample of mothers that impacted the results of the study, there are still interesting findings stemming from analyses conducted with and without the small sample of mothers. One of the more interesting findings for this goal was that, although there were

significant main effects of both ASD symptom severity and behavior problems related to parent stress, the findings indicated that symptom severity contributed to parent stress more than behavior problems. Additionally, even though it was statistically significantly predictive for both mothers and fathers, there was a greater association between symptom severity and stress levels for fathers compared to those for mothers, which was partially consistent with the hypothesis for this particular goal. One potential reason for this could be related to the father's involvement in their child's treatment and the lack of skills taught to fathers to help manage their child's symptoms. Vacca (2013) studied the experiences of fathers parenting a child with ASD and found that fathers are not included in the training programs that are offered to parents teaching behavior management techniques related to their child's diagnosis. Therefore, fathers may not have the skills, or even the opportunity to learn the skills, necessary to manage their child's symptoms, especially those that are more severe, which could potentially increase their stress.

Additionally, the results could reflect the idea that fathers associate their child's diagnosis with the "loss of a child" which has been found to result in increased stress, anger, and frustration (Burrell, Ives, & Unwin, 2017). By comparison, mothers have been found to experience sadness. Fathers tend to focus on the future of their children once they have been diagnosed with a developmental disability such as ASD, feeling that the future they had planned for their child is not as they had pictured it to be. Again, instead of feeling sad, as mothers typically tend to feel, fathers experience stress and frustration.

The age of the children in the current study and the timing of the diagnosis could be another possible reason why symptom severity is more strongly associated with parent stress compared to the child's associated behavior problems. The initial impact of a diagnosis for a young child such as ASD has been found to have a prominent impact on parents, especially on

their stress levels (Osborne & Reed, 2009). Although parents are aware their children are exhibiting concerning behaviors prior to the diagnosis, once their child is diagnosed, they could be more hyper-focused on the diagnosis and severity of symptoms their child is exhibiting, therefore possibly resulting in increased stress for these parents.

Another unique finding was the difference in results between when the small sample of mothers (n = 34) were included and when they were not included. Contrary to the results from the analyses when the sample was included, there was not a statistically significant difference in the influence of symptom severity on parent stress. The demographic data for this small sample of mothers was also interesting and could possibly explain the differences in results for this study. This sample of mothers were primarily homemakers, and, on average, had less children, therefore, their stress levels could be lower considering employment status was significantly related to parent stress. These demographic factors, in addition to the child's behavior problems and ASD symptom severity, could possibly explain the higher level of stress for mothers.

Perceptions of Support and Feeling Understood (Goal #4)

This goal was exploratory and therefore no hypotheses were put forward. The primary goal was to explore themes that were present in the dataset regarding these two concepts. One unique finding was that fact that the primary source of support that was reported by participants was their family. This is consistent with previous literature that has discussed the types of support that have been found to be beneficial for families of children with ASD (Boyd, 2002). Additionally, the primary type of support that was identified in all scenarios was psychological support. A possible reason for this unique finding is that, compared to other sources, family members are generally more accessible than friends (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). A common family member that was mentioned in their responses was their partner or

spouse. In conjunction with this particular source, it was common that participants reported psychological support as the type of support their partner would give them in the times they felt supported (e.g. “My husband supports me a lot with his help and love” and “My wife gave me a lot of support. We work together to help our child.”). It is possible that for these participants, the majority of their time is spend in the comfort of their home with their child and partner/spouse (should that be who immediately resides in their home), thus having to rely on their partners for more support than their friends. Psychological support may have been more often reported because parents might be seeking more informal, emotional support during the time of initial diagnosis. As mentioned before, the time during which a child is being diagnosed can be a particularly sensitive and stressful time for parents. During this time, it could be that parents need comfort, love, and empathy more so than anything other type of support to cope with the stress of the situation. This might be especially the case when it comes to receiving support from their partners who are generally more accessible.

The process of coding the qualitative data for this goal brought up possible explanations for the results as well as thoughts pertaining to future directions and considerations. At first glance of the construction of the questions created for this goal, it could be said that the questions were broad and left room for interpretation. For example, we quickly noticed that there were some responses that did not quite fit under the concept of “support” according to the codes that were created. Upon further examination, the coding team discussed possibilities for why this could have occurred. First, we discussed the idea of the definition of the concept. The concept of “support,” if not clearly defined in the question, could mean many numerous things, and look differently to everyone. Questions surrounding this concept were posed to participants in such a way that it left room for them to define what support looked like to them. However, even under

clearly defined categories of support, there were still some responses that that not neatly fit within one of those categories. Rather than considering those responses as "incorrect responses," we decided to expand the definitions of the codes under this concept to accommodate for different perceptions and understandings of what support is. This is one advantage to the data-driven approach for coding. We were able to capture the voices of all participants in the study and expand on preconceived ideas of how the concept of how "support" is defined.

Additionally, when examining the responses for questions addressing the concept of "feeling understood," this brought about a similar situation. This was not a concept that was clearly defined in the literature, so the questions were posed with no expectations or hypotheses of what sort of responses they would generate. When examining these responses and generating the codes, we took a data-driven approach and let the responses dictate the codes we created. We observed that some participants associated the concept of "feeling understood" with the concept of "support." They would mention the support of their family being the reason why they felt understood "a lot" by their family. This brought up an interesting thought amongst the team. Similar to the previous concept, the definition for, or possible reasons for, why they did feel understood could possibly be attributed to the fact that they receive so much support from family, friends, and/or online support groups. This revealed that these two concepts, for many participants, are related.

Clinical Implications

The findings for this study suggest a few main points that should be discussed in the context of clinical implications. When caring for families, fathers are overlooked, not considered, or not included when it comes to either their own mental health or their child's treatment. As previously mentioned, parenting research has classically focused on more on mothers compared

to fathers. However, research has also shown that fathers play a key role in their child's development (Goeke-Morey & Cummings, 2007) and should therefore be considered clinically. Clinicians should be addressing not only the child's concerns, but the concerns and mental health of both mothers and fathers who are caring for children with ASD. It is important that both parents, especially those of children with ASD, feel heard and are supported clinically so that they may parent their child effectively. The role of a parent in the care of a child with ASD is key, especially considering children spend a considerable amount of time with their parents.

Limitations

One limitation of the current study is that the measures assessing child behavior and ASD symptoms were all parent-reported measures and the child's clinical ASD diagnosis was not formally reported. The results should be interpreted with caution as parents are reporting their child's behavior and symptoms as seen from their perspective rather than from the perspective of a trained clinician. This can inflate associations between measures when they all have shared variance due to the fact that they are reported by the same source. Additionally, the sample in the current study consisted of primarily white, highly educated, middle-class, married parents of children with ASD the majority of whom were employed full-time. This lack of diversity decreases the generalizability of the results of the study.

Another limitation to the current study is the length of the survey and nature of the data. Specifically, there was large amount of data missing from the qualitative portion of the study. Compared to the other measures in the study, these were not only personal, but they were open-ended and required more effort to answer. This could have been one of the reasons behind the amount of missing data that was present. The order of the measures in the data could have been related to this as well, being that the open-ended questions were presented at the very end of the

online survey. The CBCL 1.5-5, GARS-3, and PSI-SF were presented prior to the open-ended questions and they were somewhat lengthy questionnaires, thus fatigue and time constraints may have been an issue.

Future Directions

Future research should continue to examine parent stress and its contributors over time and across different age groups of children diagnosed with ASD, as this study only focused on preschool-aged children. Contributors to stress examined in the current study could contribute to parent stress differently for those with older children compared to younger children. Additionally, stress levels and the impact of contributors could change over time as parents are more exposed to and become more experienced with managing their child's symptoms and behaviors, which is why it would be beneficial for future studies to examine changes across age groups as well as over time. Additionally, although the concept of "support" has been well-defined in previous studies, the concept of "feeling misunderstood" is novel and warrants further definition and exploration. Finally, there were a few aspects of the Double ABCX Model (McStay, Trembath, and Dissanayake, 2014) that were not explored in the current study: coping mechanisms and family appraisal. Future studies should further explore the concepts presented in this article in addition to coping mechanisms and family appraisal to adequately examine the efficacy of the Double ABCX Model within the context of stress for parents of children with ASD.

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Appendix A

Study Flyer to Recruit Fathers

Western Washington University - Family Lab

We are interested in gaining insight into the perspective of parents with children who have been diagnosed with Autism Spectrum Disorder (ASD). Compared to mothers, the role that a father plays in their child's life is different but still central to the child's development, making it a significant aspect of family research. Fathers have been very understudied in autism research specifically and their perspective is very important. Therefore, one of the main purposes of this research study is to gain an in depth understanding into the parenting experience of fathers.

We are looking to recruit fathers of children between the ages of 3-5 who have been recently diagnosed with ASD within the past 10 months.

Parents will receive a $5 Amazon gift card for their participation in this study!

If you are interested in learning more about this study and/or are interested in participating, please follow the link below! If you are interested but have additional questions about the study, please feel free to send an email to noblec3@wwu.edu before participating.

****It would be greatly appreciated if you would pass this ad along to other dads who have a young child with ASD!****

Appendix B

Study Flyer to Recruit Mothers

Western Washington University – Family Lab

We are interested in gaining an in-depth perspective of the parenting experience of mothers with children who have been diagnosed with Autism Spectrum Disorder (ASD). Compared to fathers, mothers play a different, yet still vital role in their child's development, and their gaining an understanding of their experience is important. With this research, we will better understand the struggles and needs that mothers have, as well as the perspective of what parenting a child with ASD is like.

We are looking to recruit mothers whose child is between the ages of 3-5 and has been recently diagnosed with ASD within the past 10 months.

Parents will receive a $5 Amazon gift card for their participation in this study!

If you are interested in learning more about this study and/or are interested in participating, please click the link below! If you are interested but have additional questions about the study, please feel free to send an email to noblec3@wwu.edu before participating.

****It would be greatly appreciated if you would pass this ad along to other moms who have a young child with ASD!****

Appendix C

Open-ended Study Questions

PROMPT: The following questions are going to be related to your experience as a parent of a child with Autism Spectrum Disorder. I am going to ask you questions regarding your feelings and perspective about whether you feel understood and supported as a parent by those around you. I recognize that some of these topics might be potentially sensitive topics, but rest assured the answers you provide are for research purposes only and will remain confidential. I would greatly appreciate your perspective in order to better understand your experience as a parent. Please take your time in answering each question.

Think of a time when you felt supported. Who was it that most supported you? What was it about that support that worked? (Participants received a text box where they typed out a response to the questions)

Think of a time when you DID NOT feel supported. What did that look like? Who was it that did not support you? What was it about that support that did NOT work? (Participants received a text box where they typed out a response to the questions)

To what extent do you feel supported by friends and acquaintances?

- 1 = “Not at all”
- 2 = “Occasionally or Somewhat”
- 3 = “A lot”

- If participants choose “1”, they will then be directed to a text box where they will describe why they do not feel supported?
- If participants choose “3”, they will then be directed to a text box where they will describe why they do feel supported

To what extent do you feel supported by family members?

- 1 = “Not at all”
- 2 = “Occasionally or Somewhat”
- 3 = “A lot”

- If participants choose “1”, they will then be directed to a text box where they will describe why they **do not** feel supported.
- If participants choose “3”, they will then be directed to a text box where they will describe why they **do** feel supported.

To what extent do you feel supported by online social platforms, such as Facebook?

  - 1 = “Not at all”
  - 2 = “Occasionally or Somewhat”
  - 3 = “A lot”
- If participants choose “1”, they will then be directed to a text box where they will describe why they do not feel supported.
- If participants choose “3”, they will then be directed to a text box where they will describe why they do feel supported

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How much do you feel that your family understands your experience of being a parent of a child with ASD?

- Rate on a scale from 1 (“A lot”) to 3 (“Not at all”)
- If participants choose “1”, they will then be directed to a text box where they can explain why they **do not feel** their family understands them
- If participants choose “3”, they will then be directed to a text box where they can explain why they **do feel** that their family very much understands them

How much do you feel that your friends and acquaintances understand your experience of being a parent of a child with ASD?

- Rate on a scale from 1 (“A lot”) to 3 (“Not at all”)
- If participants choose “1”, they will then be directed to a text box where they can explain why they **do not feel** their friends and acquaintances understands them.
- If participants choose “3”, they will then be directed to a text box where they can explain why they **do feel** that their friends and acquaintances very much understand them.

Appendix D

Coding Manual

PERCEPTIONS OF SUPPORT

Psychological support

- Definition: “emotional support, which is considered compassionate and is defined as the provision of empathy, care, love, and trust, as well as the feeling of belonging and being accepted” (House 1981; as cited in Reinke & Solheim, 2015).

Informational support

- Definition: “informational support, which is practical in nature and is defined as the information provided to someone at a time of stress that is likely to aid in problem solving” (House 1981; as cited in Reinke & Solheim, 2015).

Instrumental support

- Definition: instrumental support refers to the various types of tangible help that others may provide (e.g., help with childcare/housekeeping or provision of transportation, making a meal)

Financial support

- Financial resources (money or related) provided to help ease financial burden, such as buying or making meals/purchasing food for family or paying their bills

Spiritual support

- Definition: personally supportive components of an individual's relationship with God

Types of Support for those who feel supported

1 = Psychological

- Emotional support (in the form of words or physical touch), encouragement, listen while they vent/feel heard, sympathy, love and kindness, being attentive and non-judgmental; good relationships; being understanding, caring, and supportive

2 = Informational

- Resources provided; information provided

3 = Instrumental

- Childcare provided; play dates with other children; help with household chores/errands, visiting/checking in, making a meal for the family or other related help provided to family

4 = Financial

- Bills paid for; money offered, items donated to family, food or other related items purchased for or donated to the family

5 = Spiritual

- Going to church, omnipotent help

6 = Psychological + Informational

7 = Informational + Instrumental

8 = Psychological + Instrumental

9 = Psychological + Financial

10 = Psychological + Spiritual

11 = Informational + Financial

12 = Informational + Spiritual

13 = Financial + Spiritual

14 = Instrumental + Spiritual

15 = Instrumental + Financial

16 = Unspecified support/other - referring to general support (e.g. “I feel supported”), mentioning “themselves” as a source of support

Sources of Support

1 = Familial/Informal

- Family members: grandparents, siblings, parents, spouse/significant others, children, etc.

2 = Extra-familial/Informal

- Friends, neighbors, colleagues (co-workers)
- Members of the community
- Teachers
- Other parents who have children with ASD
- Support groups or advocacy groups (Online or in-person)

3 = Formal

- Medical provider/medical team

- Therapeutic resources (psychologist, therapist)

4 = Familial + Extra-familial

5 = Familial + Formal

6 = Extra-familial + Formal

7 = Mentioned all 3 (Familial, Extra-Familial, Formal)

8 = Unspecified person(s)/type/other – referring to general support (e.g. "I feel supported"), mentioning "themselves" as a source of support

Categories for reasons why people DO NOT feel supported

1 = Judgment (parent, their child, or ASD; parent feels judged, parent feels that their children are being judged/others are opinionated/look down on them or their child)

- Others make them feel ashamed
- Too opinionated
- Lack of understanding from others

2 = Lack of empathy/caring from others

- Others don't believe child has ASD
- Discouragement
- Unhelpful advice or comments from others

3 = Lack of support/resources; simply feeling unsupported by someone (Quantity, presence of support)

- Other have objections to what they do
- No support from family/friends
- Lack of sources of support
- "Lack of family in town/lack of friends"

4 = Feeling of being ignored/not heard (resources are there and available, but they're choosing not to support the parent/family)

- "They're busy"
- "They don't listen to me"
- "I don't feel heard"

5 = Other (any response that does not fit within the other code categories)

FEELING UNDERSTOOD

Categories for reasons why others DO understand

1 = Knowledgeable about ASD – "They understand the difficulties of taking care of a child with ASD"

- Includes educating themselves (family or friends) about ASD or making strides to understand ASD or the family's situation.

2 = Quality of relationships – love and support one another; receive support and caring from family, "listen to me vent" "communicate" "they come visit"; "we are going through similar experiences"; we know each other and are close

- If participants mention that their friends or family are helpful or provide support to them, which could then mean they have a good relationship, code as a 2 (as long as they don't mention things like "taking care of their children" or "helping with chores")

3 = Participant possibly equated "understanding" with "support"

- Mentioned any support other than psychological support or tangible informational support (unless they mention self-educating or the family/friend learning about ASD)

4 = Other (any response that does not fit within the other code categories or that is vague/unclear)

- Saying things like "they are understanding" does not constitute a good response.

Categories for reasons why others DO NOT understand

1 = Lack of knowledge or experience with children with ASD: "they don't understand the child's issues or needs" "bothered by the child's behavior"

2 = Poor quality of relationships

- "they don't like me", "they make remarks"

3 = Other (any response that does not fit within the other code categories or that is vague/unclear)

- Saying things like "they are not understanding" does not constitute a good response

Table 1

Means (with Standard Deviations) of all Predictor Variables for Mothers and Fathers for the Total Sample.

Variable	Mothers (n = 125)	Fathers (n = 124)
CBCL Internal	33.31 (*10.21*)	32.74 (*11.09*)
CBCL External	23.92 (*6.95*)	23.65 (*8.65*)
CBCL Total	91.24 (*26.18*)	90.72 (*30.44*)
RB Total	20.93 (*5.50*)	20.89 (*5.55*)
SI Total	22.33 (*6.78*)	24.57 (*7.76*)
SC Total	15.36 (*5.28*)	15.68 (*4.98*)
ER Total	13.93 (*4.36*)	13.89 (*3.59*)
CS Total	10.88 (*4.18*)	10.74 (*4.09*)
MS Total	10.06 (*4.21*)	10.08 (*3.76*)
Autism Index	94.06 (*11.62*)	95.07 (*11.50*)
PSI Total	99.46 (*15.25*)	104.89 (*14.45*)

Note. CBCL = Child Behavior Checklist, RB = Repetitive Behaviors, SI = Social Interaction, SC = Social Cognition, ER = Emotion Regulation, CS = Cognitive Style, MS = Maladaptive Speech. All predictor variables were centered around their respective means before analyses.

Table 2

Bivariate Correlations Between all Predictor Variables and Parenting Stress.

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.
1. CBCL Internal	--	**.724****	**.953****	**.503****	**.316****	**.299****	**.287****	**.469****	**.474****	**.467****	**.297****
2. CBCL External	**.782****	--	**.823****	**.378****	**.191***	**.228***	**.379****	**.317***	**.312***	**.366****	**.215***
3. CBCL Total	**.950****	**.895****	--	**.463****	**.275****	**.246****	**.282****	**.487****	**.489****	**.438****	**.306****
4. RB Total	**.752****	**.649****	**.735****	--	**.633****	**.574****	**.532****	**.480****	**.667****	**.808****	.097
5. SI Total	**.303****	.131	**.244****	**.452****	--	**.648****	**.447****	**.280***	**.593****	**.780****	.162
6. SC Total	**.422****	**.398****	**.421****	**.496****	**.687****	--	**.585****	**.278***	**.453****	**.797****	.069
7. ER Total	**.439****	**.522****	**.464****	**.537****	**.433****	**.617****	--	**.339****	.249	**.749****	.065
8. CS Total	**.412****	**.469****	**.463****	**.443****	.008	**.395****	**.438****	--	**.424****	**.611****	.129
9. MS Total	**.649****	**.472****	**.616****	**.714****	**.375****	**.376****	**.399****	**.401****	--	**.739****	**.321***
10. Autism Index	**.605****	**.544****	**.597****	**.773****	**.730****	**.833****	**.770****	**.563****	**.728****	--	.137
11. PSI Total	**.391****	**.326****	**.396****	**.397****	**.433****	**.382****	**.202***	.073	**.319***	**.412****	--

Note. CBCL = Child Behavior Checklist, RB = Repetitive Behaviors, SI = Social Interaction, SC = Social Cognition, ER = Emotion Regulation, CS = Cognitive Style, MS = Maladaptive Speech, PSI = Parenting Stress Index. * $p < .05$; ** $p < .01$; *** $p < .001$. Intercorrelations of measures for mothers is on the upper diagonal and those for fathers is on the lower diagonal.

Table 3

Results of a t-test analysis comparing Parenting Stress Index Total Scores between Mothers and Fathers.

Parent Gender	n	*M* (*SD*)	*t*	df	*p*
Mothers	125	99.46 (*15.25*)	2.863	246	**.005****
Fathers	123	104.89 (*14.51*)			

*$p < .05$, **$p < .01$

Table 4

Results of a t-test analysis comparing Parenting Stress Index Total Scores between Mothers and Father without including small sample of Mothers.

Parent Gender	n	M (*SD*)	*t*	df	*p*
Mothers	92	100.97 (*15.89*)	1.873	213	.062
Fathers	123	104.88 (*14.51*)			

*$p < .05$, **$p < .01$

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Table 5

Regression Analysis for Mothers of children with and without verbal language predicting Parent Stress from Child Behavior Problems (including the small sample of mothers).

	n	*F*	*β*	*p*	95% CI
Mothers with Non-Verbal Children	66	9.427		**< .001****	
CBCL Internalizing			.505	**.05***	[.000, 1.010]
CBCL Externalizing			-.020	.95	[-.650, .610]
Mothers with Verbal Children	59	2.422		.059	
CBCL Internalizing			.475	.109	[-.110, 1.060]
CBCL Externalizing			-.156	.732	[-1.064, .752]

*$p < .05$, **$p < .01$

Table 6

Regression Analysis for Fathers of Children with and without Verbal Language predicting Parent Stress from Child Behavior Problems.

	n	*F*	β	*p*	95% CI
Fathers with Non-Verbal Children	62	1.913		.121	
CBCL Internalizing			.255	.368	[-.308, .818]
CBCL Externalizing			.404	.257	[-.302, 1.110]
Fathers with Verbal Children	61	4.548		**.003****	
CBCL Internalizing			.639	**.013***	[.142, 1.136]
CBCL Externalizing			-.082	.800	[-.725, .561]

*$p < .05$, **$p < .01$

Table 7

Regression Analysis for Mothers of Children with and without Verbal Language predicting Parent Stress from ASD Symptoms.

	n	*F*	*β*	*p*	95% CI
Mothers with Non-Verbal Children	66	5.361		**< .001****	
Restrictive/Repetitive Behaviors			-.943	.493	[-3.682, 1.795]
Social Interaction			-1.703	.163	[-4.118, .711]
Social Communication			-.772	.525	[-3.190, 1.645]
Emotional Responses			1.728	.080	[-.213, 3.670]
Mothers with Verbal Children	59	2.439		**.026***	
Restrictive/Repetitive Behaviors			-1.166	.527	[-4.844, 2.513]
Social Interaction			3.574	**.043***	[.111, 7.036]
Social Communication			-.168	.909	[-3.110, 2.774]
Emotional Responses			-.357	.777	[-2.882, 2.168]
Cognitive Style			-.279	.842	[-3.072, 2.514]
Maladaptive Speech			1.768	.183	[-.860, 4.395]

*$p < .05$, **$p < .01$

Table 8

Regression Analysis for Mothers of Children (without small sample of 34 moms) with and without Verbal Language predicting Parent Stress from ASD Symptoms.

	n	*F*	*β*	*p*	95% CI
Mothers with Non-Verbal Children	34	2.119		.084	
Restrictive/Repetitive Behaviors			.081	.959	[-3.110, 3.273]
Social Interaction			-2.079	.211	[-5.407, 1.249]
Social Communication			-2.022	.235	[-5.439, 1.395]
Emotional Responses			2.612	.052	[-.022, 5.246]
Mothers with Verbal Children	55	2.444		**.032***	
Restrictive/Repetitive Behaviors			-1.024	.594	[-4.844, 2.513]
Social Interaction			3.427	.066	[.111, 7.036]
Social Communication			-.059	.970	[-3.110, 2.774]
Emotional Responses			-.508	.699	[-2.882, 2.168]
Cognitive Style			-.238	.870	[-3.072, 2.514]
Maladaptive Speech			1.833	.187	[-.860, 4.395]

*$p < .05$, **$p < .01$

Table 9

Regression Analysis for Fathers of Children with and without Verbal Language predicting Parent Stress from ASD Symptoms.

	n	*F*	*β*	*p*	95% CI
Fathers with Non-Verbal Children	62	3.654		**.004****	
Restrictive/Repetitive Behaviors			5.006	**.005****	[1.615, 8.397]
Social Interaction			-1.525	.390	[-5.049, 1.999]
Social Communication			4.491	**.003****	[1.547, 7.435]
Emotional Responses			-3.765	**.007****	[-6.432, -1.098]
Fathers with Verbal Children	61	4.057		**.001****	
Restrictive/Repetitive Behaviors			2.777	.064	[-.172, 5.726]
Social Interaction			1.900	.090	[-.305, 4.105]
Social Communication			.993	.477	[-1.788, 3.773]
Emotional Responses			.024	.985	[-2.474, 2.521]
Cognitive Style			-1.250	.354	[-3.935, 1.434]
Maladaptive Speech			-.456	.734	[-3.135, 2.223]

*$p < .05$, **$p < .01$

Table 10

Intercorrelations Between Subscales of the Predictor Variables included in the Analyses for Goal 2 for Mothers and Fathers.

Variables	1	2	3	4	5	6	7	8
1. CBCL Internal	---	**.72****	**.50****	**.32****	**.29****	**.29****	**.46****	**.48****
2. CBCL External	**.78****	---	**.38****	**.19***	**.23***	**.37****	**.31***	**.33***
3. GARS_RB	**.75****	**.62****	---	**.63****	**.54****	**.51****	**.46****	**.63****
4. GARS_SI	**.33****	.13	**.47****	---	**.63****	**.42****	**.29***	**.59****
5. GARS_SC	**.45****	**.39****	**.52****	**.69****	---	**.59****	**.30***	**.42****
6. GARS_ER	**.41****	**.49****	**.50****	**.37****	**.56****	---	**.35****	.24
7. GARS_CS	**.36****	**.38****	**.47****	.12	**.43****	**.38****	---	**.43****
8. GARS_MS	**.64****	**.38****	**.74****	**.46****	**.45****	**.26***	**.37****	---

$* p < .05$. $** p < .01$.

Note. Father's correlation data is depicted below the diagonal and mother's correlation data is above the diagonal.

Table 11

Regression Model Examining the Difference in the Influence of Behavior Problems on Parent Stress between Mothers and Fathers.

	F	R^2	*β*	SE	*p*	95% CI
Model	12.561	.209			**< .001****	
Constant			116.263	4.328	< .001	[107.738, 124.788]
CBCL Total			.214	.096	**.027***	[.025, .402]
Parent Gender			-1.931	1.988	.332	[-5.847, 1.985]
Interaction			-.023	.064	.722	[-.149, .104]
Employment Status			-1.463	.441	**.001****	[-2.333, -.594]
Caregiver Status			-7.329	3.112	**.019***	[-13.459, -1.198]
Parent Gender x CBCL Total	.127	.0004			.723	

*$p < .05$, **$p < .01$

Note. N = 244; Interaction = Parent Gender x CBCL Total

Table 12

Regression Model Examining the Difference in the Influence of Behavior Problems on Parent Stress between Mothers and Fathers (without the small sample of mothers).

	F	R^2	*β*	SE	*p*	95% CI
Model	8.949	.179			**< .001****	
Constant			109.999	6.029	**< .001****	[98.113, 121.887]
CBCL Total			.183	.099	.069	[-.014, .379]
Parent Gender			-1.794	2.126	.413	[-6.104, 2.515]
Interaction			.005	.068	.943	[-.129, .138]
Employment Status			-.966	.554	.083	[-2.058, .127]
Caregiver Status			-2.313	4.594	.615	[-11.370, 6.745]
Parent Gender x CBCL Total	.005	< .001			.943	

*$p < .05$, **$p < .01$

Note. N = 210; Interaction = Parent Gender x CBCL Total

Table 13

Regression Model Examining the Difference in the Influence of ASD Symptom Severity on Parent Stress between Mothers and Fathers.

	F	R^2	*β*	SE	*p*	95% CI
Model	11.609	.197			**< .001****	
Constant			115.443	4.353	**< .001****	[106.866, 124.019]
Autism Index			.841	.244	**< .001****	[.361, 1.321]
Parent Gender			-.843	2.012	.676	[-4.808, 3.121]
Interaction			-.299	.154	.054	[-.604, .005]
Employment Status			-1.692	.436	**< .001****	[-2.551, -.832]
Caregiver Status			-7.803	3.146	**.014***	[-14.00, -1.606]
Parent Gender x Autism Index	3.767	.013			.054	

*$p < .05$, **$p < .01$

Note. N = 244; Interaction = Parent Gender x Autism Index

Table 14

Regression Model Examining the Difference in the Influence of ASD Symptom Severity on Parent Stress between Mothers and Fathers (without the small sample of mothers).

	F	R^2	*β*	SE	*p*	95% CI
Model	7.750	.161			**< .001****	
Constant			111.085	6.123	**< .001****	[99.011, 123.159]
Autism Index			.794	.255	**.002****	[.292, 1.296]
Parent Gender			-.957	2.228	.668	[-5.350, 3.437]
Interaction			-.259	.163	.112	[-.580, .061]
Employment Status			-1.384	.541	**.011****	[-2.450, -.319]
Caregiver Status			-3.953	4.675	.399	[-13.171, 5.266]
Parent Gender x Autism Index	2.554	.011			.112	

*$p < .05$, **$p < .01$

Note. N = 210; Interaction = Parent Gender x Autism Index

Table 15

Intercorrelations Between "Extent" Variables, CBCL Total, and Autism Index for Goal 4 for the Total Sample.

Variables	1	2	3	4	5	6	7
1.Extent Supported by Family	---						
2.Extent Supported by Friends	**.521****	---					
3.Extent Supported by Social Media	**.374****	**.403****	---				
4.Extend Understood by Family	**.304****	**.434****	**.307****	---			
5. Extent Understood by Friends	**.285****	**.247****	**.284****	**.450****	---		
6.CBCL Total	-.007	.089	.030	**.138***	.076	---	
7.Autism Index	.041	**.140***	**.140****	.046	-.008	**.505****	---

$* p < .05$. $** p < .01$.

Table 16

Frequencies of "Extent supported" and "Extent Understood" Data for the Whole Sample

Item	n	%
Extent Supported by Family		
Not at all	6	2.4
Somewhat	109	42.9
A lot	139	54.7
Extent Supported by Friends		
Not at all	8	3.2
Somewhat	135	53.8
A lot	108	43.0
Extent Supported by Social Media		
Not at all	12	4.7
Somewhat	140	55.1
A lot	102	40.2
Extent Understood by Friends		
Not at all	10	3.9
Somewhat	167	65.5
A lot	78	30.6
Extent Understood by Family		

Not at all	11	4.3
Somewhat	127	49.4
A lot	119	46.3

Note. Understood variables were reverse coded before analysis (1=3, 2=2, 3=1).

Table 17

Frequencies of "Support" Variables for Times When Participants Felt Supported

Item		n	%
Support Type			
	Psychological	58	49.6
	Informational	9	7.7
	Instrumental	12	10.3
	Financial	2	1.7
	Spiritual	1	.9
	Multiple	12	10.4
	Unspecified	23	19.7
Support Source			
	Familial	81	60.4
	Extra-Familial	17	12.7
	Formal	6	4.5
	Multiple	17	12.7
	Unspecified	13	9.7

Note. % = Valid Percent. Not all participants responded to these questions.

Table 18

Frequencies of "Support" Variables for Times When Participants Did Not Feel Supported

Item	n	%
Support Source		
Familial	26	28.0
Extra-Familial	36	38.7
Formal	2	2.2
Multiple	0	0
Unspecified	29	31.2
Reasons Not Supported		
Judgement	24	28.2
Lack of Empathy	8	9.4
Lack of Support Resources	14	16.5
Felt Ignored	11	12.9
Other	28	31.8

Note. % = Valid Percent. Not all participants responded to these questions.

Table 19

Frequencies of "Support" Variables for Times When Participants Did and Did Not Feel Supported by Friends

Item	n	%
Support Type		
Psychological	22	51.2
Informational	3	7.0
Instrumental	5	11.6
Financial	0	0
Spiritual	0	0
Multiple	3	6.9
Unspecified	10	23.3
Reasons Not Supported		
Judgement	1	20.0
Lack of Empathy	2	40.0
Lack of Support Resources	1	20.0
Felt Ignored	1	20.0

Note. % = Valid Percent. Not all participants responded to these questions.

Table 20

Frequencies of "Support" Variables for Times When Participants Did and Did Not Feel Supported by Family

Item	n	%
Support Type		
Psychological	37	57.8
Informational	1	1.6
Instrumental	8	12.5
Financial	1	1.6
Spiritual	1	1.6
Multiple	6	9.5
Unspecified	10	15.6
Reasons Not Supported		
Judgement	1	25.0
Lack of Empathy	2	50.0
Lack of Support Resources	0	0
Felt Ignored	1	25.0

Note. % = Valid Percent. Not all participants responded to these questions.

Table 21

Frequencies of "Support" Variables for Times When Participants Did and Did Not Feel Supported by Social Media

Item	n	%
Support Type		
Psychological	19	54.3
Informational	4	11.4
Instrumental	2	5.7
Financial	0	0
Spiritual	0	0
Multiple	2	5.8
Unspecified	10	22.9
Reasons Not Supported		
Judgement	1	14.3
Lack of Empathy	1	14.3
Lack of Support Resources	1	14.3
Felt Ignored	0	0
Other	4	57.1

Note. % = Valid Percent. Not all participants responded to these questions.

Table 22

Frequencies of "Understanding" Variables for Participants who Did or Did Not Feel Understood by Family

Item	n	%
Feel Understood		
Knowledgeable about ASD	10	20.8
Relationship Quality	30	62.5
Equate with Support	3	6.3
Other	5	10.4
DO NOT Feel Understood		
Lack of ASD Knowledge	3	33.3
Poor Relationship Quality	4	44.4
Other	2	22.2

Note. % = Valid Percent. Not all participants responded to these questions.

Table 23

Frequencies of "Understanding" Variables for Participants who Did or Did Not Feel Understood by Friends

Item	n	%
Feel Understood		
Knowledgeable about ASD	2	5.6
Relationship Quality	10	11.1
Equate with Support	2	11.1
Other	3	16.7
DO NOT Feel Understood		
Lack of ASD Knowledge	5	62.5
Poor Relationship Quality	3	37.5
Other	0	0

Note. % = Valid Percent. Not all participants responded to these questions.

Table 24

Regression Model Examining differences in the Association Between the Extent Supported and Understood and Parent Stress for Mothers and Fathers.

	F	R^2	*β*	SE	*p*	95% CI
Model	1.969	.103			.024	
Extent Supported by Family			2.375	7.143	.740	[-11.701, 16.451]
Extent Supported by Friends			-5.590	6.532	.393	[-18.463, 7.283]
Extent Supported by Social Media			-5.113	6.210	.411	[-17.352, 7.126]
Extend Understood by Family			-4.200	6.717	.532	[-17.438, 9.037]
Extent Understood by Friends			14.172	7.046	**.045***	[.287, 28.057]
Support Family x Gender			-.315	4.519	.945	[-9.220, 8.590]
Support Friends x Gender			3.114	4.231	.463	[-5.225, 11.453]
Support Social Media x Gender			1.247	3.990	.755	[-6.616, 9.110]
Family Understand x Gender			5.378	4.153	.197	[-2.807, 13.563]
Friends Understand x Gender			-9.994	4.350	**.023***	[-18.567, -1.421]

*$p < .05$, **$p < .01$

Note. N = 236; Parent Education and Caregiver Status were included as control variables.

Table 25

Regression Model Examining differences in the Association Between the Extent Supported and Understood and Parent Stress for Mothers and Fathers (without the small sample of mothers).

	F	R^2	*β*	SE	*p*	95% CI
Model	1.169	.074			.305	
Gender			-14.628	14.024	.298	[-42.292, 13.037]
Extent Supported by Family			.743	7.671	.923	[-14.389, 15.875]
Extent Supported by Friends			-6.194	7.071	.382	[-20.142, 7.755]
Extent Supported by Social Media			-6.924	6.643	.299	[-20.028, 6.180]
Extend Understood by Family			-2.312	7.146	.747	[-16.409, 11.785]
Extent Understood by Friends			11.152	7.548	.141	[-3.737, 26.042]
Support Family x Gender			1.070	5.097	.834	[-8.984, 11.124]
Support Friends x Gender			3.640	4.850	.454	[-5.926, 13.207]
Support Social Media x Gender			2.962	4.468	.508	[-5.853, 11.776]
Family Understand x Gender			3.676	4.599	.425	[-5.397, 12.748]
Friends Understand x Gender			-6.815	4.948	.170	[-16.575, 2.946]

*$p < .05$, **$p < .01$

Note. N = 203; Parent Education and Caregiver Status were included as control variables.

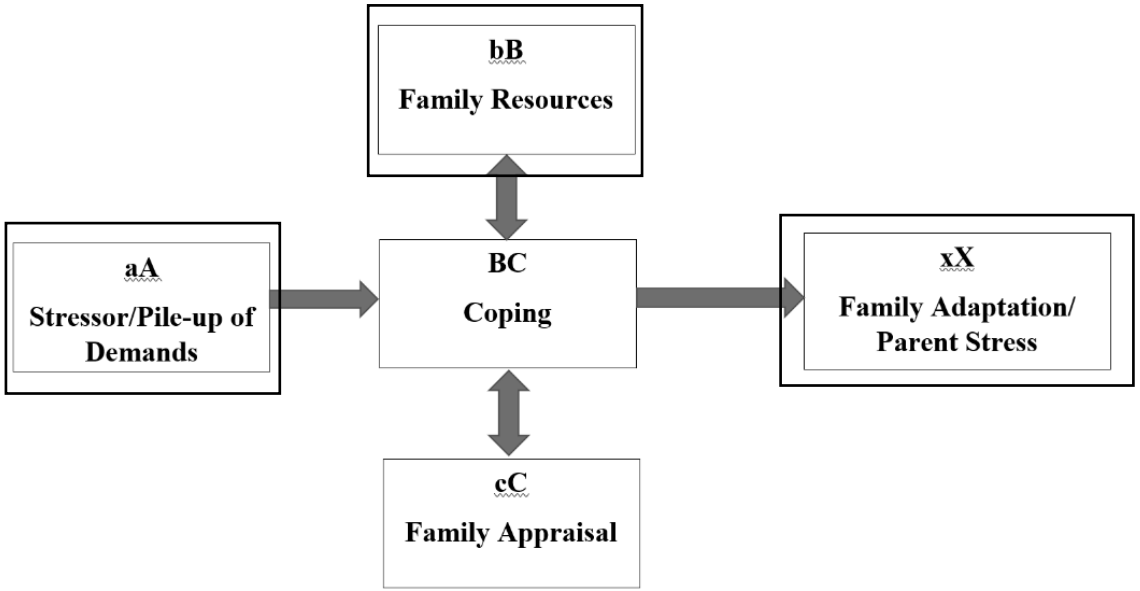

*Figure 1***.** Double ABCX model based on McCubbin and Patterson (1983) model adapted to examine stress of parents who have children with ASD (McStay, Trembath, & Dissanayake, 2014, p. 3102). The factors in red boxes represent the factors that will be the focus of the current study.

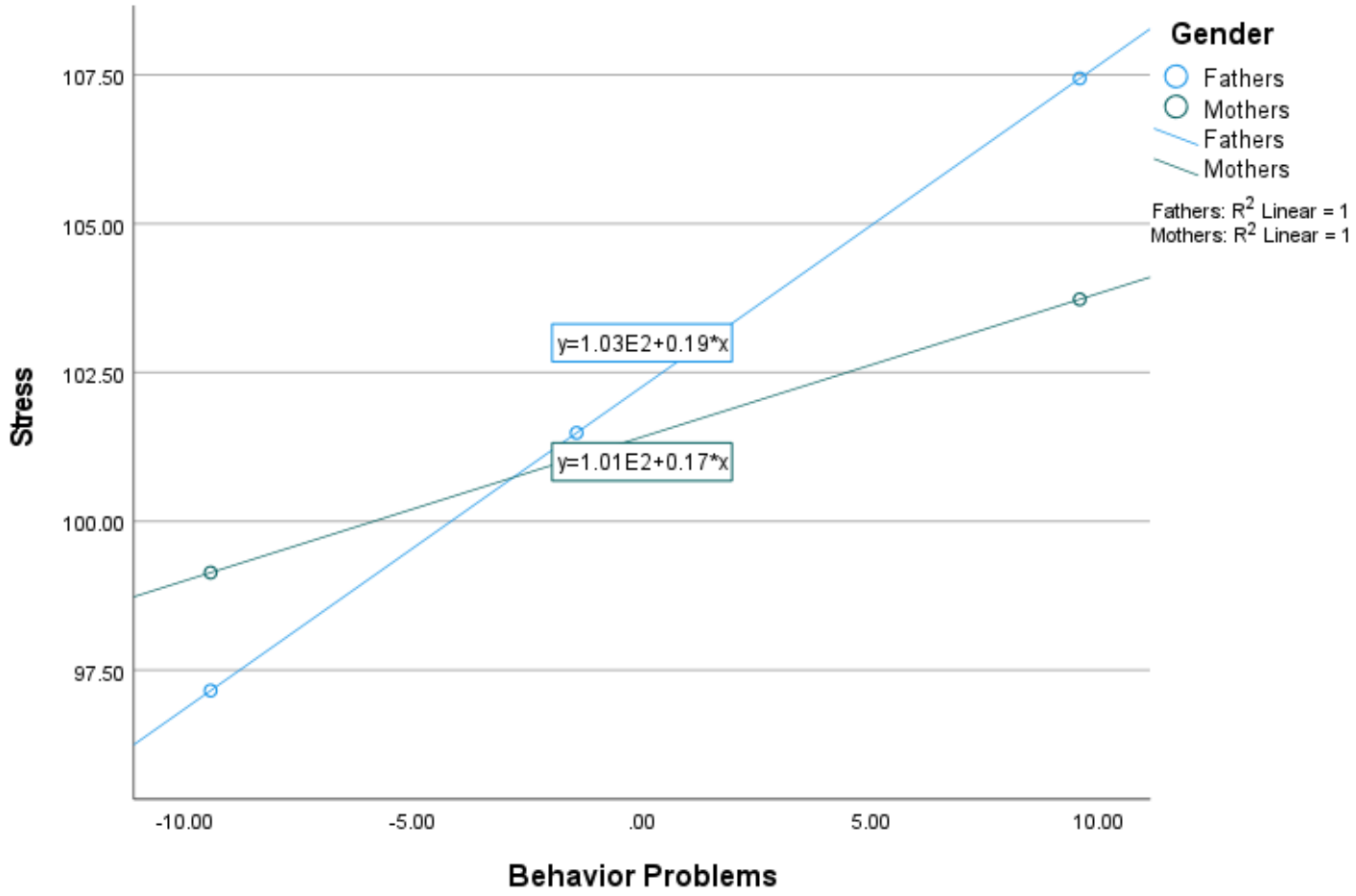

Figure 2. Influence of child behavior problems on parent stress and the difference in this relationship between fathers and mothers. This analysis included the small sample of mothers (N = 244).

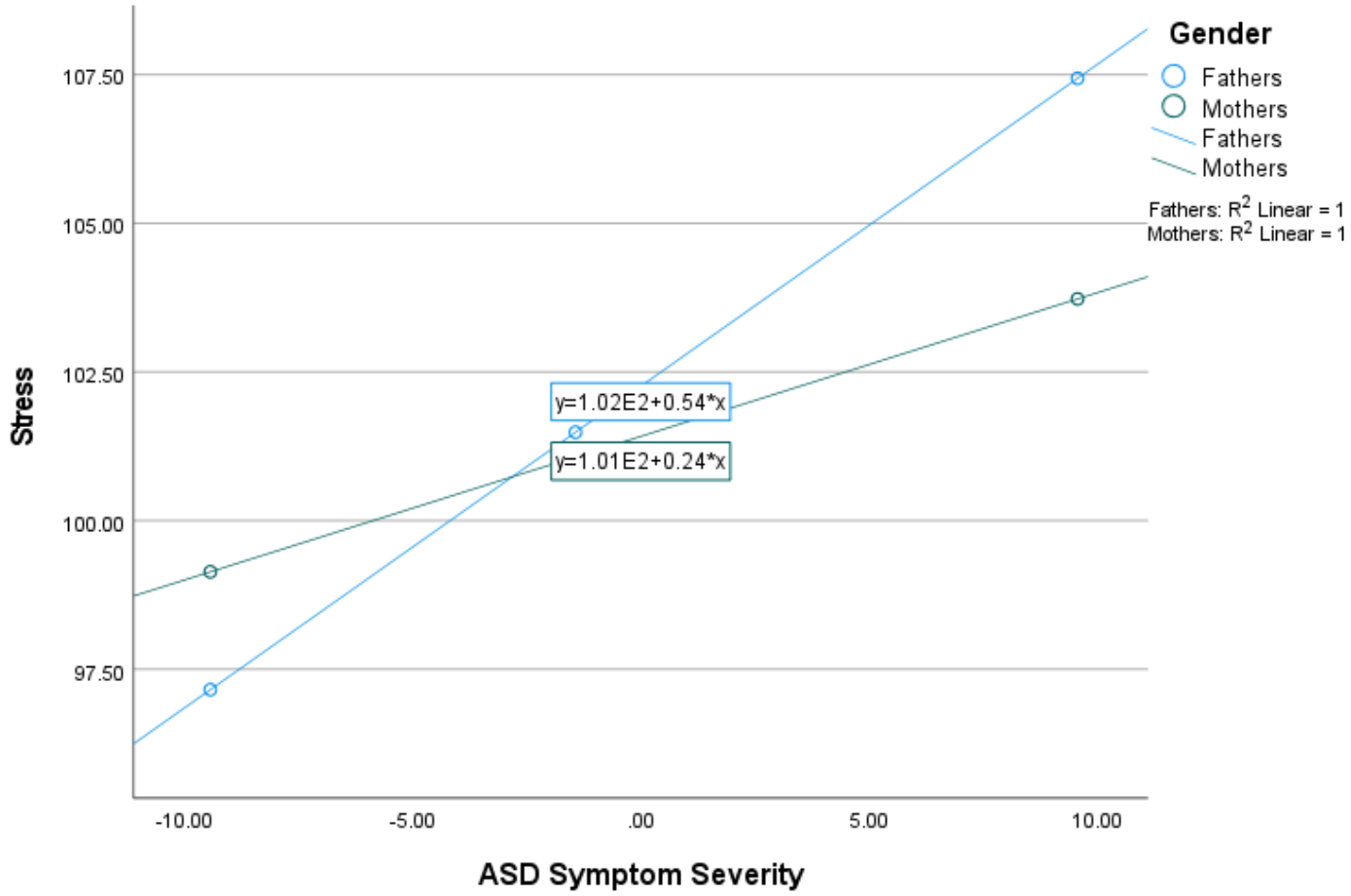

Figure 3. Influence of ASD symptom severity on parent stress and the difference in this relationship between fathers and mothers. This analysis included the small sample of mothers (N = 244).

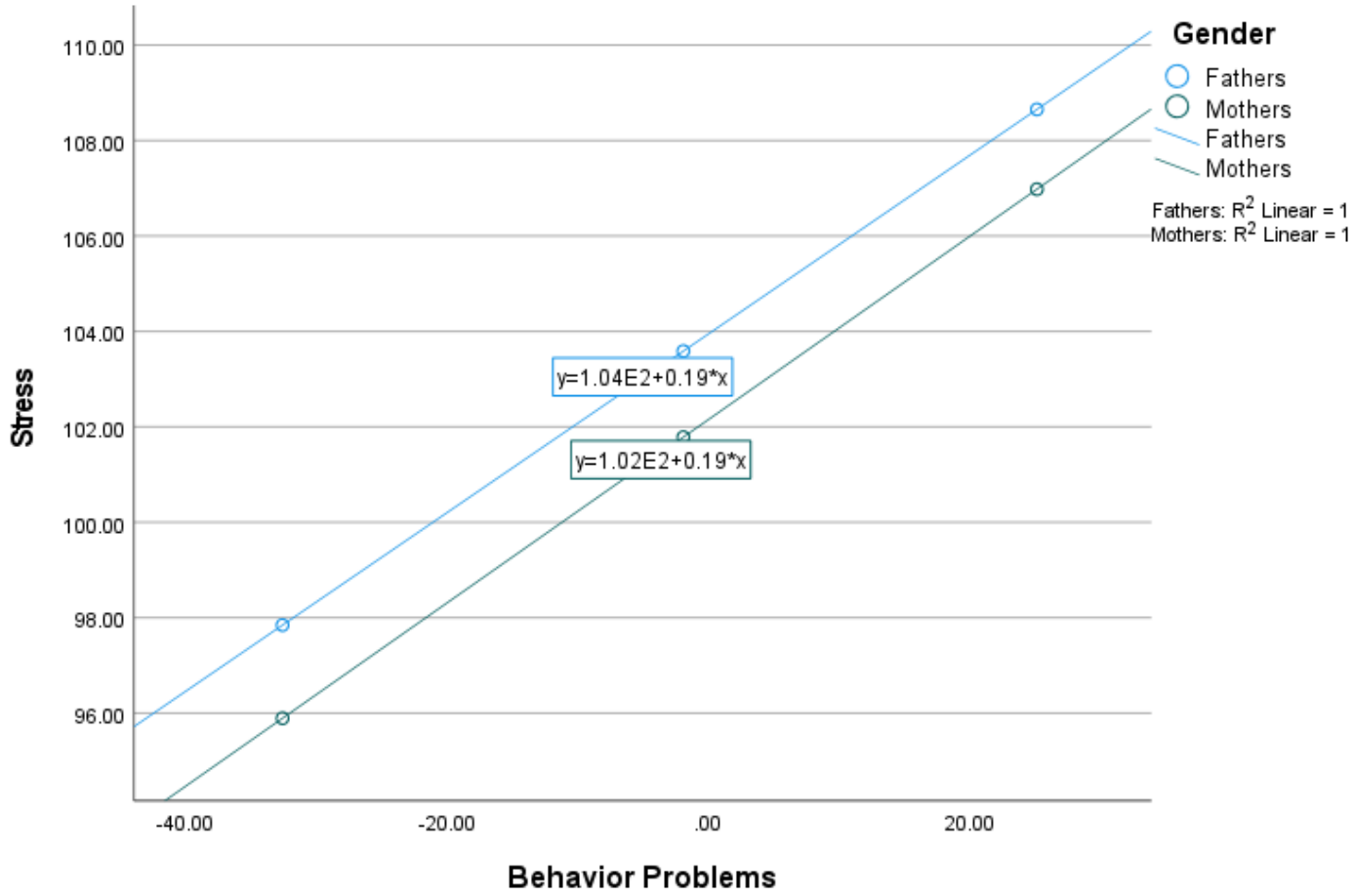

Figure 4. Influence of child behavior problems and parent stress and the difference in this relationship between fathers and mothers. This analysis included the small sample of mothers (N = 210).

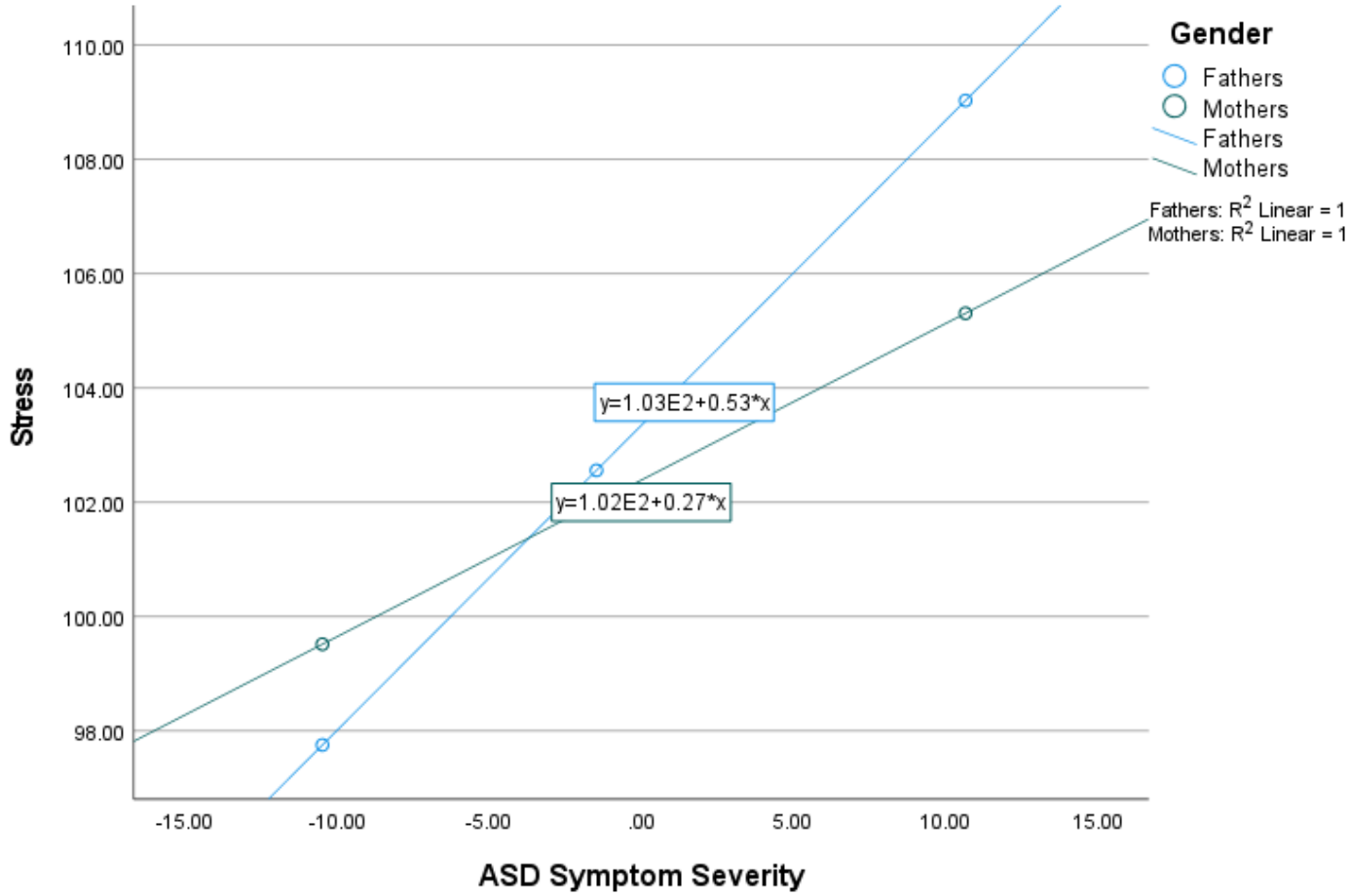

Figure 5. Influence of ASD symptom severity on parent stress and the difference in this relationship between fathers and mothers. This analysis included the small sample of mothers (N = 210).