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Factors Related to Parental Stress at Early Diagnostic Assessments for Autism Spectrum Disorder

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FACTORS RELATED TO PARENTAL STRESS AT EARLY DIAGNOSTIC ASSESSMENTS
FOR AUTISM SPECTRUM DISORDER

A Thesis

Submitted to the Graduate Faculty of the
Louisiana State University and
Agricultural and Mechanical College
in partial fulfillment of the
requirements for the degree of
Master of Arts

in

The Department of Psychology

by
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Abstract

Autism Spectrum Disorder (ASD) is marked by pervasive impairments in social communication and restricted, repetitive interests, behaviors, and activities. Parents raising a child with ASD have consistently reported higher levels of parenting stress compared to parents of typically developing children and children with other disabilities. Several different factors influence parental stress levels at different stages of their child's life, and so an understanding of the most predictive factors of parental stress at initial ASD assessments is critical to best serving the needs of families with a new diagnosis. The current study investigated several factors that may impact parenting stress at these assessments, including the severity of the autism impairments, the child's adaptive functioning, aggression problems, and symptoms of hyperactivity and inattentiveness. The full regression model of autism symptom severity, adaptive behavior, aggression, hyperactivity, and attention problems to predict parental stress (Model 4) was statistically significant; the addition of aggression, hyperactivity, and aggression problems led to a statistically significant increase in variance explained. The results may have implications for understanding changing patterns of stress and addressing issues which may impact adherence to treatment recommendations. Limitations and future directions for research are also discussed.

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by pervasive impairments in social communication and patterns of restricted and repetitive behaviors (Achkova & Manolova, 2014; American Psychiatric Association, 2013; Matson, Dempsey, & Fodstad, 2009). Individuals with ASD may exhibit impairments in joint attention, social skills, language use, have highly restricted interests, challenging behaviors (e.g., tantrums, aggression, etc.), or stereotyped movements (Bennett et al., 2014; Dawson et al., 2004; Fodstad, Rojahn, & Matson, 2012; Macintosh & Dissanayake, 2006; Matson, Dempsey, et al., 2009). Both early identification of ASD and beginning early intensive behavioral interventions (EIBI) before the age of 3 are critical for children, as they are associated with improved long-term individual and family outcomes (Howlin, Mawhood, & Rutter, 2000; Landa & Kalb, 2012; Zwaigenbaum et al., 2015). Access to EIBI can improve children's communication, adaptive behavior, and other important skills, which may lessen lifetime costs associated with treating an individual with ASD, estimated to be over \$1 million in the United States (Jacobson & Mulick, 2000). Costs of intervention services are one of many factors that may impact the levels of stress a parent of a child with ASD experiences throughout their child's life.

Parents of children with ASD consistently report higher levels of stress compared to parents of children with other developmental delays and typically developing children (Brobst, Clopton, & Hendrick, 2009; Lee et al., 2009; Pastor-Cerezuela, Fernández-Andrés, Tárraga-Mínguez, & Navarro-Peña, 2016; Wolf, Noh, Fisman, & Speechley, 1989). Several factors influence parental stress levels at different stages of their child's life, from initially obtaining a diagnosis to seeking appropriate intervention and educational services and paying for said services (Ekas, Lickenbrock, & Whitman, 2010; Tomanik, Harris, & Hawkins, 2004).

The present study aims to examine different factors that impact parental stress at early ASD assessments. First, ASD will be discussed, including the history of the disorder, current diagnostic criteria, prevalence rates, comorbid conditions, and assessment for ASD. This will be followed by a discussion of parental stress related to raising a child with ASD, the characteristics of the child with ASD associated with clinical levels of parental stress, the parent-related factors, and other environmental factors associated with higher levels of parental stress. The current study will build upon the extant literature by investigating parental stress at initial ASD assessments, thus elucidating what factors best predict levels of stress at this time.

Autism Spectrum Disorder

History of ASD

The condition now known as autism spectrum disorders was first described by Leo Kanner in 1943 as an “inborn autistic disturbance of affective contact”. In this seminal work, Kanner described 11 children who shared a similar presentation of symptoms related to communication, insistence on sameness, and most notably, social isolation. Due to their pervasive impairments, these children had been previously diagnosed as deaf, schizophrenic, or as “feeble-minded”. Regarding communication, 3 of the 11 children failed to develop any functional language, while language in the remaining children was distorted, nonfunctional, and rarely used to convey meaning. Kanner noted the high level of disturbance the children exhibited when a change occurred or a routine was broken. In addition, Kanner (1943) identified a number of associated symptoms including aggression, anxiety, adaptive functioning deficits, and stereotyped behaviors. However, it was the “extreme autistic aloneness”, or the lack of ability to relate to others, that Kanner believed was most characteristic of these children and differentiated their condition from other known pathologies (Kanner, 1943).

During the same time period but halfway around the world, Hans Asperger also published his first case studies using the same terminology (i.e., autism) to describe a group of male children presenting symptoms very similar to those described by Leo Kanner. Like Kanner, Asperger also regarded the children's social impairments as the core feature of this new disorder (Asperger, 1944). Though the children presented normal language acquisition and often above average linguistic skills, their lack of social reciprocity and social isolation impaired their daily functioning. Additionally, these children exhibited a resistance to change, varying cognitive skills (i.e., excelling in specific areas and performing poorly on others), highly restricted interests, motor clumsiness, and behavioral problems. Asperger believed his "autistic psychopathy" occurred exclusively in boys, though he did mention that girls presented with similar symptoms (Asperger, 1944). However, Asperger's observations went largely unnoticed for decades, as his original case studies were not translated into English until much later (Wing, 1981). Interestingly, Kanner and Asperger reportedly never met or consulted with one another regarding their findings, though they observed similar core impairments and both sought to differentiate the disorder from childhood schizophrenia (Barahona-Corrêa & Filipe, 2016).

These initial descriptions of infantile autism as a childhood disorder created considerable confusion from other professionals in the field who had trouble differentiating these symptoms from those associated with childhood schizophrenia. This was understandable as diagnostic criteria for schizophrenia at the time mirrored several key symptoms Kanner (1943) associated with infantile autism. Most notable among these was the "autistic thinking" that caused individuals with schizophrenia to retreat into themselves, a term first coined by Eugen Bleuler (Bleuler, 1911). However, the onset of social withdrawal in infantile autism differed significantly from childhood schizophrenia (Kanner, 1943). As Kanner argued, the social

impairments exhibited in infantile autism existed as an “innate inability to relate” to their surroundings, rather than the change in behavior seen in individuals with schizophrenia (Kanner, 1943). While hallucinations and delusions are core symptoms of schizophrenia, children with autism do not experience such symptoms (Kanner, 1951; Rutter, 1968). Symptoms of autism are also stable over the lifespan, whereas the severity of symptoms in schizophrenia may change over time (Rutter, 1968). Additionally, the sex ratio noted by Asperger and Kanner differentiated the syndrome from schizophrenia; that is, roughly equal prevalence rates were reported in males and females for schizophrenia, while autism was much more common in males (Kanner, 1944; Rutter, 1968). Finally, children diagnosed with autism had little to no family history of schizophrenia or mental illness (Kanner, 1954; Rutter, 1968). However, both Kanner and Asperger noted that the parents of children has several “autistic traits” similar to the symptoms of autism presented by their children, including extraordinary attention to detail, obsessiveness, and general lack of affection or warm-heartedness (Kanner, 1943, 1954).

Unfortunately, these preliminary observations regarding parental characteristics would fuel theories of the etiology of autism directly blaming parents for their children’s symptoms. Many medical professionals at the time emphasized the emotional coldness of parents of children with autism. The “refrigerator mother” was described extensively by Bruno Bettelheim in his book, *The Empty Fortress* (Bettelheim, 1967). In this book, Bettelheim explicitly remarks on the “attitudes of the mother as a causative factor in infantile autism”, indicating that the “precipitating factor in infantile autism is the parent’s wish that his child should not exist” (Bettelheim, 1967). These presumptions were obviously false, but the damage done by these theories led already isolated parents to become greater pariahs in their communities. Rutter (1968) argued against Bettelheim’s claims, stating that higher rates of autism would be found in

siblings of children with autism if parents were solely to blame. Asperger himself had written years before Bettelheim that he believed autism to be a complex pattern of inherited behaviors and traits (Asperger, 1944). Thankfully, researchers have grown in their understanding of both the etiology and the diagnosis of ASD itself, though remnants of the theory have continued to sway popular opinion.

ASD Diagnostic Criteria

Though autism had been described decades prior, autism as an individual diagnosis was not included in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) until its third edition (DSM-III; American Psychiatric Association, 1980). Three diagnoses were filed under the category of pervasive developmental disorders (PDD) in this edition of the DSM: Infantile Autism, Childhood Onset PDD, and Atypical PDD. Differentiation between these disorders occurred in the age of onset of symptoms and number of symptoms presented. Criteria for Infantile Autism required an age of onset before 30 months, while Childhood Onset PDD emerged between 30 months and 12 years of age. Atypical PDD was diagnosed when children did not meet criteria for Infantile Autism or Childhood Onset PDD, yet presented with “distortions in the development of multiple basic psychological functions...involved in the development of social skills and language” (American Psychiatric Association, 1980). With the *Diagnostic and Statistical Manual of Mental Disorders, Third Edition- Revised (DSM-III-R;* American Psychiatric Association, 1987), infantile autism was changed to Autistic Disorder, and atypical autism was changed to PDD Not Otherwise Specified (PDD-NOS). Criteria for Autistic Disorder now included impairments in three areas: social interaction, verbal or nonverbal communication, and restricted and repetitive behavior/interests.

With the publication of the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV;* American Psychiatric Association, 2000), the PDD category then held 5 diagnoses: Autistic Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, Asperger’s Disorder, and PDD-NOS. A diagnosis of Autistic Disorder under the DSM-IV required children to meet criteria for 6 or more symptoms in 3 domains (social interaction, communication, and restricted, repetitive patterns of behavior, interests, and activities), with at least 2 symptoms from the social interaction domain and 1 symptom each from the communication and restricted, repetitive behavior domain. Impairments in at least one of these areas must have had an age of onset before 3 years and not be accounted for by the other PDDs. Rett’s Disorder was reportedly very rare and had only been described in females. Criteria for this disorder required normal development through 5 months, followed by a period during the 5 months to 48 months range where significant regression across multiple skills and deceleration of head growth occurred. Childhood Disintegrative Disorder was diagnosed when children presented at least 2 years of normal development followed by a significant loss in previously acquired skills. Asperger’s Disorder was used to classify children who presented symptoms similar to Autistic Disorder in the social interaction and restricted, repetitive behavior domains, but showed no clinical impairments in communication, language, or cognitive development. Criteria for PDD-NOS remained similar to previous editions of the DSM.

Several changes occurred with the latest publication of the manual, the *DSM-5* (American Psychiatric Association, 2013), including the deletion of Rett’s Disorder and Childhood Disintegrative Disorder from the manual completely. The syndrome Leo Kanner first described as “early infantile autism” is now categorized under the category of Neurodevelopmental Disorders as autism spectrum disorder (ASD), which represents the merging of Autistic

Disorder, Asperger's Disorder, and PDD-NOS. Under the DSM-5, a diagnosis of ASD includes 3 levels used to differentiate severity. Level 1 indicates the individual's functional impairments require support; Level 2 indicates the impairments require substantial support, and Level 3 impairments require very substantial support. The specifiers "with or without accompanying intellectual impairments", "with or without accompanying language impairment", "associated with a known medical or genetic condition or environmental factor", "associated with another neurodevelopmental, mental, or behavioral disorder", and "with catatonia", have also been included to designate comorbidities with the diagnosis of ASD (American Psychiatric Association, 2013).

Current diagnostic criteria specify that the individual (A) has persistent deficits in social communication and interaction across multiple contexts and (B) exhibits patterns of restricted, repetitive behavior, interests, or activities. Additionally, symptoms (C) must manifest early in development, (D) cause clinically significant functional impairment, and (E) are not better explained by intellectual disability or global developmental delay, which frequently co-occur with ASD. The impairments in social communication and interaction include deficits in 1) social-emotional reciprocity, 2) nonverbal communication, and 3) developing and maintaining relationships. In the domain of restricted, repetitive behavior, the individual must evince two of the following symptoms: 1) stereotyped, repetitive speech, use of objects, or motor movements, 2) insistence on sameness or inflexible, ritualized patterns of verbal or nonverbal behavior, 3) highly restricted interests of abnormal intensity or focus; and 4) hyper- or hyporeactivity to sensory input.

Prevalence

According to the most recent reports from the Autism and Developmental Disabilities Monitoring Network of the Centers for Disease Control and Prevention, 1 in 59 children in the United States are diagnosed with autism spectrum disorder (Baio et al., 2018). This is a significant change for a disorder once considered relatively rare, occurring in as few as 4 to 5 in 10,000 children (Howlin, 2006; Matson & Kozlowski, 2011). Researchers have sought to account for this increase in prevalence, noting that expanding diagnostic criteria, improved assessment and early detection, an increase in general awareness of the disorder, and other cultural influences may all contribute to the increased prevalence rates (Fombonne, 2009; Matson & Kozlowski, 2011).

Early Detection of ASD

Early identification of ASD is critical for children to receive early intensive behavioral intervention (EIBI), which is associated with long-term improved outcomes for both the individual with ASD and their family (Howlin et al., 2000; Landa & Kalb, 2012; Zwaigenbaum et al., 2015). Parents and caregivers typically have early age of concerns ranging from 14-19 months (Baghdadli, Picot, Pascal, Pry, & Aussilloux, 2003; Matheis et al., 2016; Rosenberg, Landa, Law, Stuart, & Law, 2011). Typically, children with developmental disabilities such as ASD can be identified in one of three ways: the child may reach developmental milestones at a slower rate than expected; the child may display an uneven pattern of development across various domains; or the child may deviate from the expected course of development entirely (Accardo & Capute, 2008). Unfortunately, an ASD diagnosis can be delayed up to 3 years following the initial presentation of developmental concerns to a healthcare provider and many more children do not receive an ASD diagnosis before the age of 5, which has been found to increase parental

stress (Baron-Cohen & Bolton, 1993; Shattuck et al., 2009; Zuckerman, Lindly, & Sinche, 2015). This is especially concerning, as experienced clinicians can diagnosis ASD as early as 18 months (Ozonoff et al., 2015; Zwaigenbaum et al., 2016).

Parental Stress and ASD

Stress is an inevitable part of the human experience. It is an individual and subject product of the interaction between an individual and their environment, and it affects each individual uniquely (Folkman & Lazarus, 1985; Lazarus & Folkman, 1984). According to Lazarus (1993), stress includes four components: the external event (i.e., the stressor), cognitive appraisal of the event, coping mechanisms, and the consequential effects on the body and mind (i.e., the stress reaction). In the transactional model of stress and coping, events are perceived as stressful based on both the meaning an individual attributes to the event and the individual's perceived coping resources (Lazarus, 1999; Pastor-Cerezuela et al., 2016). If the individual's coping mechanisms do not meet the demands placed on the individual, the stress experienced will impact their mental health quality of life (Lazarus, 1999).

Parenting stress is defined as an “aversive psychological reaction to the demands of being a parent” (Deater-Deckard, 1998), and has been acknowledged as one of the most common daily concerns for parents of all children, regardless of presence of disabilities or other special needs (Chang & Fine, 2007). Abidin (1995) argued that parenting stress arises from a complex combination of three factors: those related to the child, those related to the parent, and those related to the interactions of parent and child. When a family is unable to restore adequate functioning following the introduction of parenting-related stressor, the result is higher levels of parenting stress (Hayes & Watson, 2013). Some level of parenting stress is typical and even functional for parents (Crnic & Greenberg, 1990; Deater-Deckard & Scarr, 1996); however, high

levels of parent stress can lead to increases in negative parenting and can directly impact other aspects of the child's behavior.

Research indicates that parents of children with chronic disabilities are at an increased risk of experiencing highly elevated levels of parenting stress (Hayes & Watson, 2013; Wolf et al., 1989). Mothers and fathers of children with ASD report levels of parenting stress significantly higher than parents of children with other chronic disabilities and typically developing children (Estes et al., 2009; Hayes & Watson, 2013; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Wolf et al., 1989). In fact, 2/3 of mothers of children with ASD experience clinically significant levels of parenting stress (Tomanik et al., 2004). Though the stressors involved in raising a child with ASD are demanding and challenging at all stages of the child's life, different factors may impact parenting stress at each stage. Using Abidin's (1995) conceptualization of parenting stress, these factors may be categorized by those relating to the child's characteristics and those relating to characteristics of the parents. Researchers have also noted the need for an ecological approach in understanding parenting stress, and thus, environmental factors not directly relating to the child, parents, or their interactions must also be considered (Derguy, M'Bailara, Michel, Roux, & Bouvard, 2016).

Child-Related Factors

Children with ASD evince a variety of behaviors that can increase parental stress throughout the child's development. Regarding the child's intellectual abilities, children with ASD often exhibit uneven intellectual profiles and cognitive inconsistencies that can become increasingly frustrating to parents as the child ages (Bebko, Konstantareas, & Springer, 1987). The problem behaviors (i.e., aggression, tantrums) commonly seen in children with ASD also understandably lead to higher levels of parenting stress (Davis & Carter, 2008; Estes et al., 2009;

McStay, Trembath, & Dissanayake, 2014; Samadi & McConkey, 2014). In one study, the child's social interaction skills predicted level of maternal child-related stress, though not paternal child-related stress (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005). Additional factors associated with parenting stress include: comorbid psychopathology (i.e., intellectual disability, attention-deficit/hyperactivity disorder, anxiety, etc.), few adaptive skills, and the presence of developmental delay (Falk, Norris, & Quinn, 2014; Hall & Graff, 2011; Mori, Ujiie, Smith, & Howlin, 2009).

The most consistent factor associated with high parenting stress is the overall severity of the child's autism symptoms (Bebko et al., 1987; Hayes & Watson, 2013). However, some researchers have found that parents of higher functioning children also experienced high levels of stress due to the prolonged delay in obtaining a diagnosis because of the less severe presentation of symptoms (Hill-Chapman, Herzog, & Maduro, 2013; Mori et al., 2009; Rivard, Terroux, Parent-Boursier, & Mercier, 2014). Siklos and Kerns (2007) examined parental stress specifically relating to the diagnostic process and found that parents of ASD children with more severe communication deficits reported lower stress in relation to the process of diagnosis. The authors proposed that the severity of symptoms were clear indications of significant problems for parents, making the diagnostic process more of a starting point to accessing services rather than a complete surprise (Siklos & Kerns, 2007).

Parent-Related Factors

The gender of the parent can also impact the experience of parenting stress. Samadi and McConkey (2014) found that mothers generally have higher stress levels than fathers and are four times more likely to score higher than clinical cut-offs on standardized measures of parenting stress. They also found that single mothers are more likely to experience elevated

levels of stress (Samadi & McConkey, 2014). Mothers may experience higher stress due to their perceived low parenting competency (Rodrigue, Morgan, & Geffken, 1990); mothers are also more likely to report higher levels of depression and anxiety which may impact levels of parenting stress as well (Ingersoll & Hambrick, 2011; Olsson & Hwang, 2001). Researchers have found that fathers tend to experience elevated levels of stress later in their child's development, typically during adolescence, compared to mothers (Bebko et al., 1987; Rivard et al., 2014). This may be because at this they are fully realizing the pervasiveness and chronicity of their child's impairments, whereas mothers are "relieved" to have "made it" through a long period of change and adjustment (Rivard et al., 2014).

Other parent-related factors have been explored in the literature. Parents of children with ASD consistently report high levels of stress across many ethnicities (Hoffman et al., 2009; Pozo & Sarriá, 2014; Wang et al., 2013). Not surprisingly, younger fathers and mothers also are associated with high parenting stress levels (Dardas & Ahmad, 2014b; Duarte, Bordin, Yazigi, & Mooney, 2005; Lau, Gau, Chiu, & Wu, 2014). High levels of parenting stress can have unfortunate, adverse effects on a child's cognitive, language, behavioral, and social development (Anthony et al., 2005; Farver, Xu, Eppe, & Lonigan, 2006; McGlone, Santos, Kazama, Fong, & Mueller, 2002; Pesonen et al., 2008). Parents with high levels of stress then perceive their children as difficult, exhibiting patterns of ineffective disciplining and dysfunctional parenting (Abidin, 1992). As Hastings (2003) states, these parenting behaviors then increase the child's problem behaviors which first increased the levels of parenting stress.

Environmental Factors

There are many factors beyond the child-related and parent-related factors discussed previously that impact parental stress. For example, parents of children with autism often

experience stress in accessing educational services and managing hectic therapy schedules (Derguy et al., 2016; Tomanik et al., 2004). However, one study found that following entry to an inclusive preschool program, mothers of children with ASD showed significant reductions in their child-related stress (Baker-Ericzén et al., 2005). Additional factors impacting parental stress are poor-quality interactions with extended family members, large financial strain obtaining treatments, and determining long-term care needs for the child when the time becomes appropriate (Birenbaum, Guyot, & Cohen, 1990; Bouma & Schweitzer, 1990; Ekas et al., 2010; Tomanik et al., 2004). Culture may also play a role in alleviating and elevating parental stress, and researchers have highlighted the need for more cross-cultural studies of the impact of parenting a child with developmental disabilities (Derguy et al., 2016; Families Special Interest Research Group of IASSIDD, 2014).

Many parents experience stress interacting with professionals (Goin-Kochel, Mackintosh, & Myers, 2006; Todis & Singer, 1991). One consistent negative experience reported by caregivers is the long delay between the time parents first became concerned about their child's development, their initial presentation of said concerns to a healthcare provider, and receiving a formal ASD diagnosis (Fujiwara, Okuyama, & Funahashi, 2011; P. Howlin & Moore, 1997). Parents often consult a number of professionals before a diagnosis of ASD is finally confirmed (Goin-Kochel et al., 2006). Siklos and Kerns (2007) found that the process of obtaining a diagnosis of ASD could involve a waiting time of up to 3 years and consultation with an average of 4.5 professionals. Parents who waited longer for the diagnosis were also less satisfied with the process, perhaps because, a delay in obtaining a diagnosis may hamper efforts at providing appropriate early intervention as well as diminish confidence in professionals (Todis & Singer, 1991).

As stated previously, high levels of parent stress can have an adverse impact on the child's behavioral and social development (Farver et al., 2006; Hart & Kelly, 2006; Pesonen et al., 2008). Unfortunately, increased stress can also lead parents to pursue non-evidence based treatments. The use of complementary and alternative medicine has been increasing steadily, with almost 12% of children in the United States using complementary and alternative treatments (Birdiee, Phillips, Davis, & Gardiner, 2010). Use of these alternative treatments was higher in families with increased stress and families with children with chronic disabilities, such as ASD (Birdiee et al., 2010; Christon, Mackintosh, & Myers, 2010; Sanders et al., 2003). A study by Valicenti-McDermott and colleagues (2014) found that in an ethnically diverse sample, the use of complementary and alternative medicine was significantly higher in the ASD group. Use of these treatments was found to be related to parental stress due to the child's irritability and hyperactivity (Valicenti-McDermott et al., 2014).

Measuring Parental Stress

Several different measures exist that can be used to assess parenting stress. The Autism Parenting Stress Index (APSI; Silva & Schalock, 2012) measures parenting stress specific to core symptoms of ASD and known co-morbidities. Parents rate items such as "Your child's social development", "Tantrums/meltdown", "Concerns for the future of your child being accepted by others", and "Not feeling close to your child" by how much stress the item causes the family. Items are rated as "Not stressful", "Sometimes creates stress", "Often creates stress", "Very Stressful on a daily basis", or "So stressful that sometimes we feel we cannot cope". Though the APSI has acceptable internal consistency and test-retest stability (Silva & Schalock, 2012), the specificity of items to core symptoms of ASD limit the utility of the instrument for research comparing parenting experiences.

The Questionnaire on Resources and Stress (QRS; Konstantareas, Homatidis, & Plowright, 1992) is self-report questionnaire containing 78 items that measure stress and burden of care in families of children with disabilities. Parents rate their agreement or disagreement on a four-point scale with questions that tap parental feelings about their child (e.g., “I worry about what will happen to N when I can no longer take care of him/her”, “I have difficulty leaving the house because of N”). Adequate psychometric properties have been reported, and studies have utilized the instrument in investigations of parental stress in ASD (Honey, Hastings, & McConachie, 2005).

The Parenting Stress Index, Fourth Edition (PSI-4; Abidin, 2012) is a popular tool for measuring parenting stress (Tomanik et al., 2004). The full PSI-4 consists of 101 items, with an optional 19 item “Life Stress Scale”; currently it is available for use in 28 languages. The PSI-4 can also be given in a Short Form, which consists of only 36 items and is also available in Spanish. Parents rate different items such as “I expected to have closer and warmer feelings for my child than I do, and this bothers me”, “I feel trapped by my responsibilities as a parent”, “I often have the feeling that I cannot handle things very well”, and “I feel alone and without friends” as to whether they Strongly Agree with, Agree with, Disagree with, Strongly Disagree with, or are Unsure of the statement. Analyses of the PSI-Short form in samples of parents of children with ASD found that scores on the PSI-Short form were useful for measuring the severity of parents’ distress (Dardas & Ahmad, 2014a; Zaidman-Zait et al., 2010). Compared to other measures of parental stress, the PSI-4 Short Form’s short administration time and availability in multiple languages enhance its draw for researchers and clinicians.

Purpose

Parents of children with ASD consistently report clinically significant higher stress levels compared to children with other developmental disabilities and typically developing children. Although the previous literature suggests that autism symptom severity, ability to relate to their child, and difficulties in accessing services predict clinically significant levels of parenting stress, these may differ depending on the stage of life the child is in (Derguy et al., 2016; Hayes & Watson, 2013). An understanding of the most predictive factors of parental stress at early ASD assessments is critical to best serving the needs of families with a new diagnosis. Researchers have found that reducing parent stress through coping skills has great implications for reducing the stress' impact on the family unit, increasing adaptation and confidence, and for follow through with treatment recommendations (Baker-Ericzén et al., 2005).

The current study aims to examine which factors impact maternal parenting stress at early ASD assessments. Few researchers have investigated parental stress specifically at diagnostic assessments (Siklos & Kerns, 2007), though the diagnostic process is crucial to ensuring that parents feels confident in practitioners and adhere to the treatment recommendations. Expanding the research on parental stress to diagnostic assessments may assist clinicians in directing parents toward specific resources (e.g., counseling) which could increase quality of life for the entire family and treatment outcomes (Hsiao, 2016).

The extant literature on parental stress suggests that severity of autism symptomology is associated with higher levels of parenting stress (Bebko et al., 1987; Hayes & Watson, 2013). Additionally, fewer adaptive skills and intellectual disability, problem behaviors such as aggression and tantrums, and comorbid psychopathology, such as ADHD, have also been associated with higher parental stress (Davis & Carter, 2008; Falk et al., 2014; Hall & Graff,

2011; Mori et al., 2009). It was hypothesized that beyond severity of autism symptoms, associated symptoms of adaptive behavior deficits, aggression, hyperactivity, and attention problems would predict parental stress. Clinical levels of parent elevated stress are associated with poor outcomes for the child in intervention, and thus, addressing the factors associated with higher stress levels would have implication for clinicians in treatment planning (Abidin, 1995; Baker-Ericzén et al., 2005; Sanders et al., 2003).

Method

Participants

The participants for this study were taken from a pre-existing database which included 289 children ranging from 17 to 39 months of age who were recruited through a university outpatient child clinic. All participants were children currently enrolled in EarlySteps, Louisiana's statewide early intervention program, who were referred to Louisiana State University's Psychological Services Clinic for further assessment for autism spectrum disorder (ASD). Children under 3 years of age who qualify for EarlySteps services under the Individuals with Disabilities Act, Part C, have or are at risk for having a developmental delay. Therefore, all children referred to the clinic through this program will have some form of atypical development. Participants and their families completed several assessments as part of a larger battery including demographic information, family and developmental history, diagnostic interviews, and parent rating forms. A licensed clinical psychologist provided clinical diagnoses to all children based on results from the formal assessments, parent interview, and direct observation of the children in the clinic. Participants were excluded from final analyses due to lack administration of the PSI-4 Short form or incomplete score profiles on any of the other relevant clinical measures. Of the 289 children in the database, the final sample included 83 children diagnosed with ASD who had completed all the measures necessary for the analyses (i.e., PSI-4; BISCUIT-Part 1; CARS2-ST; VABS-3; BASC-3). Participants ranged in age from 19 to 37 months ($M = 31.12$; $SD = 4.16$). Both genders were represented with there being 65 (77.4%) males and 16 (19.0%) females. The majority of the sample was Caucasian (57.1%); however, there were also individuals who were of African American (19.0%), Hispanic (3.6%), and other (14.3%) ethnic origins. See Table 1 for a summary of demographic information.

Table 1. Participant demographics (Age, Gender, Race; N = 83)

Variable	M (SD)
Age in Months	31.12 (4.16)
	<i>N</i> (%)
Gender	
Male	65 (77.4%)
Female	16 (25.5%)
	<i>N</i> (%)
Race	
African American	16 (19.0%)
Caucasian	48 (57.1%)
Hispanic	3 (3.6%)
Other	12 (14.3%)

Measures

BISCUIT-Part I Demographic Form: The Baby and Infant Screen for Children with Autism Traits, Part 1 (BISCUIT-Part 1; Matson, Boisjoli, & Wilkins, 2007) is a 62-item informant-report measure that assesses ASD symptoms across socialization/nonverbal communication, repetitive behavior/restricted interests, and communication in children 17 to 37 months of age. Parents or caregivers rate each item on a 3-point Likert scale (i.e., 0 corresponds to not different from same aged peers; 1 indicates somewhat different; 2 denotes very different). Previous research has indicated that the BISCUIT-Part 1 has an estimated internal reliability of .87 and correct classification rate of .89 (Matson, Wilkins, et al., 2009).

The BISCUIT- Part 1 includes a demographic form which collects information regarding the demographics (e.g., age, gender, ethnicity), developmental milestones, medical history, parental concerns regarding development, and family history. Parents of participants complete

this form as part of a larger assessment battery. The demographic form was used to gather demographic information for the current study regarding the child's age, gender, and ethnicity.

CARS2-ST: The Childhood Autism Rating Scale, Second Edition (CARS2; Schopler, Van Bourgondien, Wellman, & Love, 2010) is an instrument used by clinicians to assist in the diagnosis of ASD. Research on the CARS2-ST indicates it is appropriate for informing diagnosis and research, with an internal consistency reliability coefficient of .93, a sensitivity value of .88, and specificity value of .86 (Perry, Condillac, Freeman, Dunn-Geier, & Belair, 2005; Sturmey, Matson, & Sevin, 1992; Vaughan, 2011).

Using the CARS2-ST form, the clinician gathers their own observations of the child's behavior during a formal assessment and also considers parent/caregiver report of symptoms. The clinician then rates the child on a scale of 1-4 on 15 items addressing different functional areas. These items include: relating to people; imitation; emotional response, body use; object use; adaptation to change; visual response; listening response; taste, smell, and touch response and use; fear or nervousness; verbal communication; nonverbal communication; level and consistency of intellectual response, and general impressions. The obtained total score reflects the severity of the child's autism-related behaviors compared to a clinical sample of individuals diagnosed with autism. A child's total score places them in one of three categories: No symptoms of ASD; Mild to Moderate symptoms of ASD; and Severe symptoms of ASD. For this study, the CARS2-ST total score is used as an indicator of the severity of the child's autism symptoms.

VABS-3: The Vineland Adaptive Behavior Scales, Third Edition (VABS-3; Sparrow, Cicchetti, & Saulnier, 2016) include a Survey Interview Form which is designed to assess an individual's adaptive behavior via parent/caregiver report. Scoring of the Survey Interview form

yields an overall Adaptive Behavior Composite score as well as scores on four domains (Communication, Daily Living Skills, Socialization, and Motor Skills). The adaptive behavior composite score is used in this study as a measure of the child's adaptive functioning, including their social skills, communication skills, self-help, and motor skills at the time of assessment.

BASC-3: The Behavior Assessment System for Children, Third Edition (BASC-3; Reynolds & Kamphaus, 2015) is a multidimensional assessment system that evaluates both clinical and adaptive aspects of behavior and personality. It was developed to assist in differential diagnosis for a range of disorders, as well as treatment planning. While the BASC-3 includes rating scales that can be completed by the child and/or the teacher, only the Parent Rating Scale (PRS) was used in the present study. The PRS is available for three age ranges including preschool (ages 2–5 years), child (6–11 years), and adolescent (12–21 years). Only the preschool range (PRS-P; 139 items) was used in the current study. Each PRS item is rated on a four-point frequency scale (i.e., 0 = Never, 1 = Sometimes, 2 = Often, and 3 = Almost Always) and item raw scores are summed and converted into standardized T scores ($M = 50$; $SD = 10$) for interpretation. Different sets of related PRS items form nine clinical scales (i.e., Aggression, Anxiety, Attention Problems, Atypicality, Depression, Hyperactivity, Somatization, and Withdrawal) and five adaptive scales (i.e., Activities of Daily Living, Adaptability, Functional Communication, Leadership, and Social Skills). The Aggression, Hyperactivity, and Attention Problems scales were utilized in this study as measures of symptoms associated with ASD and higher levels of parental stress. The Aggression subscale includes items related to a child's tendency to act in a hostile manner (either verbally or physically) in way that is threatening to others. The Attention Problems subscale includes items related to distractibility and ability to

concentrate for a period of time. The Hyperactivity subscale includes items related to a child being overly active, rushing through activities, and acting without thinking.

PSI-4: The Parenting Stress Index Short Form (PSI-4; Abidin, 2012) consists of 36 items rated on a 5 point scale. The PSI-4 includes measures of three key constructs (i.e., parental distress, parental-child dysfunctional interactions, and the extent to which the child is perceived as “difficult”) as well as a total measure of parenting stress. Scores at or above the 90th percentile are considered clinically significant and may indicate the parent is in need of further counseling (Abidin, 1995; 2012). The total score of the PSI-4 is used as the measure of parental stress in this study. Due to the small number of fathers who completed the PSI-4 Short Form, only PSI-4 short forms completed by mothers of the 83 children were included in the final analysis.

Procedure

Prior to assessment administration, the Louisiana State University institutional review board approved the study. The parent of each child provided informed consent. All participants received a comprehensive battery of assessments and packets containing the PSI-4 Short Form, BISCUIT-Part 1, CARS2-ST, VABS-3, and BASC-3, among other measures, and these were either administered by trained graduate students in the outpatient clinic or were completed independently by the parents with a trained administrator available to answer any further questions. Although only portions of the BISCUIT, VABS-3, and BASC-3 were used during this study, all measures were administered in their entirety with other assessments that are a part of the comprehensive battery. The data used for the present study were from a research database of de-identified records.

Statistical Analyses

Power analyses were conducted in G*Power (Faul, Erdfelder, Buchner, & Lang, 2009) to determine a sufficient sample size. Using an alpha of 0.05, a power of 0.80, and a medium effect size of 0.25 for a multiple regression with 5 predictor variables, the proposed study required a sample size of at least 72 individuals.

All statistical analyses were performed using SPSS 25.0. Multivariate analyses were conducted to answer the following research question: what factors predict clinically significant parental stress at early childhood ASD assessments? The dependent variable (i.e., Total Score on the PSI-4 Short Form) is a calculated score and is therefore a continuous variable. The independent (predictor) variables of the study (e.g., CARS2-ST Total Score, VABS-3 Adaptive Behavior Composite Score, BASC-3 Aggression Subscale Score, BASC-3 Hyperactivity Subscale Score, BASC-3 Attention Problems Subscale Score) are calculated scores as well and therefore were all measured as continuous variables. A hierarchical multiple regression was conducted to determine the predictive influence of the independent variables on levels of parent stress using the PSI-4 total score.

Results

A hierarchical multiple regression was run to determine if the addition of measures of adaptive behavior, aggression, hyperactivity, and attention improved the prediction of parental stress scores, as measured by the PSI-4 short form total score, over and above autism symptom severity (i.e., CARS-2 total score) alone. See Table 2 for descriptive statistics for each clinical measure used as either the independent or predictor variables in this study. No serious violations in normality were observed for any clinical measures.

Table 2. Descriptive Statistics for Clinical Measures

Variable	M (SD)
PSI-4 Short Form Total Score	78.23 (20.23)
CARS2-ST Total Score	42.77 (11.32)
VABS-3 Adaptive Behavior Composite Score	70.89 (13.85)
BASC-3 Subscale Scores	
Aggression	48.92 (11.86)
Hyperactivity	57.45 (13.92)
Attention Problems	64.18 (12.29)

There was linearity as assessed by partial regression plots and a plot of studentized residuals against the predicted values. There was independence of residuals, as assessed by a Durbin-Watson statistic of 1.947. According to Field (2013), the Durbin-Watson statistic may vary between 0 and 4, with a value of 2 indicating that the residuals are uncorrelated. There was homoscedasticity, as assessed by visual inspection of a plot of studentized residuals versus unstandardized predicted values. Multicollinearity was then examined through tolerance and variance inflation factors (VIF), as well as examination of correlations between predictor variables. There were no evidence of multicollinearity, as assessed by tolerance values of greater

than .1, VIF values of less than 10, and correlation coefficients less than .9 (Field, 2013). There were no studentized deleted residuals greater than ± 3 standard deviations, no leverage values greater than 0.2, and values for Cook's distance above 1. The assumption of normality was met, as assessed by Q-Q Plot.

In Model 1, parental stress was not significantly predicted by autism symptom severity alone, $R^2 = .022$, $F(1, 81) = 1.78$, $p = .19$, which was consistent with expectations. The addition of the Vineland-3 Adaptive Behavior Composite score to the prediction of parental stress (Model 2) did not lead to a statistically significant increase in variance explained, $R^2 = .02$, $F(2, 80) = 1.69$, $p = .19$. However, the addition of the aggression subscale, as measured by the BASC-3, to the prediction of parental stress (Model 3) did lead to a statistically significant increase in variance explained, $R^2 = .17$, $F(3, 79) = 5.275$, $p = .002$. Moreover, the inclusion of the BASC-3 Aggression Subscale score led to $\Delta R^2 = .13$, which was also associated with a significant increase in variance explained, $\Delta F = 11.98$. The full model of autism symptom severity, adaptive behavior, aggression, hyperactivity, and attention problems to predict parental stress (Model 4) was statistically significant, $R^2 = .34$, $F(5, 77) = 7.864$, $p < .001$. The inclusion of the BASC-3 Hyperactivity and Attention Problems subscale scores led to a significant increase in variance explained, $\Delta R^2 = .17$, which was also associated with a significant increase $\Delta F = 9.95$. In the full model, the Hyperactivity subscale was the only significant predictor of parental stress.

Table 3. Hierarchical Multiple Regression Prediction Parental Stress from Autism Symptom Severity, Adaptive Behavior, Aggression, Hyperactivity, and Attention Problems

Variable	Parental Stress (PSI-4 Total Score)											
	Model 1			Model 2			Model 3			Model 4		
	<i>R</i> ²	<i>F</i>	<i>B</i> (<i>SE</i>)	<i>R</i> ²	<i>F</i>	<i>B</i> (<i>SE</i>)	<i>R</i> ²	<i>F</i>	<i>B</i> (<i>SE</i>)	<i>R</i> ²	<i>F</i>	<i>B</i> (<i>SE</i>)
	.02	1.78		.041	1.69		.17**	5.28*		.29***	7.86***	
Constant			67.01** (8.69)			95.97** (24.58)			56.30* (25.75)			35.44 (25.43)
CARS-2ST Score			.26 (.19)			.037 (.27)			.14 (.25)			.033 (.23)
VABS-3 ABC						-.273 (.22)			-.19 (.20)			-.14 (.19)
BASC-3 AGG									.61** (.18)			-.11 (.23)
BASC-3 HYP												.77*** (.20)
BASC-3 ATT												.20 (.20)

Note. *N*=83. **p* < .05, ***p* < .001, ****p* < .000

Discussion

Parenting stress is an important consideration for clinicians to address, not only in diagnostic assessments but in treatment planning as well. Because parents of children with ASD consistently report clinically significant higher stress levels compared to children with other developmental disabilities and typically developing children, it is especially important for researchers and clinicians to understand what best predicts parenting stress across developmental levels and symptom presentations, in order to reduce the stress' impact on the family unit. Although the previous literature suggests that autism symptom severity, ability to relate to their child, and difficulties in accessing services predict clinically significant levels of parenting stress, these may differ depending on the stage of life the child is in (Derguy et al., 2016; Hayes & Watson, 2013). An understanding of the most predictive factors of parental stress at early ASD assessments (i.e., before age 3) is critical to best serving the needs of families with young children and a new diagnosis.

Several factors were tested as predictors of parenting stress of 83 mothers of children with ASD. First, the severity of a child's autism symptoms, as measured by their total score on the CARS2-ST, was entered into the regression model. Specifically, for young children in this age group, autism symptoms alone were not significant predictors of parenting stress. Though this is not consistent with previous research implicating ASD symptoms as the most significant predictors of parenting stress (Bebko et al., 1987; Hayes & Watson, 2013), this could be explained by the nature of the evaluation process. Mothers responded to the PSI-4 Short Form items as part of the broader ASD assessment, and as such, they had not yet received a formal diagnosis explaining the nature of their child's impairments. At this young of an age, it is possible that parents are not particularly sensitive to autism symptoms specifically. This has

been supported in the research regarding the first concerns about a child's development reported by parents' of children later diagnosed with ASD; in fact, these parents frequently report concerns unspecific to ASD symptomology, such as motor problems, medical issues, and challenging behaviors (Guinchat et al., 2012; Kozlowski, Matson, Horovitz, Worley, & Neal, 2011; Matheis et al., 2016).

In the second model, children's adaptive behavior, as measured by their Adaptive Behavior Composite on the VABS-3, was entered as a predictor of parenting stress. This Adaptive Behavior Composite score assesses a child's communication skills, daily living skills, social skills, and motor skills. Though it was hypothesized that a child's adaptive behavior would be a significant predictor of parenting stress, results indicated no significant increase in variance. The mean Adaptive Behavior Composite standard score for this sample was $M = 70.89$ ($SD = 13.85$), which is two standard deviations from an average score of 100. Most of the children referred for assessments at this time have likely experienced delays and impairments in adaptive functioning across their short lifespan. As such, these impairments in adaptive behavior may not be as significant a stressor for parents as they would for an older child or adolescent.

The addition of the BASC-3 Aggression subscale significantly improved the model's prediction of parenting stress. Items on this subscale include whether the child throws or breaks things when angry, hits other children, or is overly aggressive. This is consistent with previous research which has found aggression, tantrums, and similar challenging behavior to be significant predictors of parenting stress (Baker, Blacher, Crnic, & Edelbrock, 2002; Emerson, 2003). A study by Fox, Keller, Grede, and Bartosz (2007) found that 24% of children (age birth to three) referred to early intervention services in their study displayed aggressive behavior, while 41% of these children exhibited tantrum behaviors. As mentioned previously, often

parents' initial concerns regarding their child's development are related to challenging behaviors. Additionally, though parents may be prepared to assist children with activities of daily living at this age, most parents would not expect aggressive behavior or severe tantrums from their young children. For those children who engage in more frequent and intense tantrum behaviors, the accompanying stress parents experience may be exacerbated by their social isolation in managing these types of behaviors, compared to other parents with typically developing children.

Overall, the full model (Model 4) including autism symptom severity, adaptive behavior, aggression, hyperactivity, and attention problems led to a significant increase in variance. This is consistent with research and supports theories regarding the stress impact of comorbidities such as ADHD and other disorders. In the full model, the Hyperactivity subscale was also the only significant predictor, decreasing the variance explained by the Aggression subscale in the previous model. Items on this BASC-3 subscale include the child being in constant motion, acting out of control, disrupting other children's activities, and having poor self-control. As stated previously, parents may not report symptoms specifically related to ASD symptomology, and thus, these clearly defined types of problem behaviors may be more evident to parents. These behaviors, as compared to those which are endorsed on the Aggression subscale, may occur at higher rates and thus increase parental stress. Though the factors that were most predictive of stress were not necessarily consistent with other sources in the parenting stress literature, it would appear that children receiving early ASD assessments have unique needs and presentations that are impacting their parents' stress.

As the clinical field continues to push early diagnosis and intervention, the results of this study have important implications for practitioners involved in programming treatment plans for newly diagnosed individuals. Interventions are often based on parent or caregiver goals for

treatment when children are as young as the sample utilized in this study. Though treatment often seeks to increase functional communication for children at this age, ensuring that aggressive and tantrum behaviors, hyperactivity, and problems with attention are addressed simultaneously and given the same level of importance could reduce parents' stress at this time and possibly increase at-home fidelity to treatment recommendations.

Limitations and Future Directions

One limitation to the current study is the lack of a comparison group. Impairments in adaptive functioning, aggressive and tantrum behavior, hyperactivity, and inattentiveness are not stressors unique to children with ASD, and as such, future research should differentiate factors among children with known comorbidities (e.g., ADHD, ID) and whether predictive factors of stress differ in these populations. A limitation of this study also presents itself in the limitation of corroborating measures of stress to the PSI-4, which is a parent's own report of their experience. Utilizing multiple informants (e.g., such as a spouse), may elucidate more complex stress patterns in a child's household. Additionally, given that children were referred from the EarlySteps intervention program if their caregivers requested an evaluation due to concerns regarding their child's development, most children in this sample evinced some sort of developmental delay or medical concern and had been previously enrolled in services for some amount of time before attending the assessment. The delay in diagnosis and access to early-intensive behavioral interventions (EIBI) without a clinical diagnosis may also lead to increases in the aggressive and hyperactive/inattentive behaviors that are predictive of parenting stress at this time. Additionally, researchers should seek to elucidate how parenting stress changes once the diagnostic conclusion has been shared, as that was possible due to the procedures of this study.

Researchers interested in parenting stress should move to the ecological model proposed by Derguy and colleagues (2016) in order to improve the current limited understanding of ASD parenting stress beyond symptoms related solely to the child with ASD. Related to this idea, another limitation to this study is the lack of predictive variables related to the mothers themselves, as data regarding many relevant factors (e.g., education level, socioeconomic status, cultural background, number of siblings in the household, parent age at time of assessment, etc.) were not collected as part of the standard assessment battery. Researchers should seek to elucidate predictive factors related to parental characteristics as well. A final direction for future research involves not only understanding what factors best predict parenting stress, but also what factors lend themselves to resiliency, which may include information on coping skills and explanatory mechanisms of stress related to parenting a child with a disability.

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Vita

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