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Abstract

The current study examines how children with Autism Spectrum Disorder's symptom behaviors, enacted stigma, and race influences their parents' experiences with stress. 50 parents and guardians of children with ASD completed an online survey with 93-items composed of four sections: (1) demographic data, (2) symptom behaviors experienced by their child, (3) enacted stigma, and (4) parental stress. The purpose of the current study was to (a) evaluate the differences of ASD symptom behaviors, enacted stigma, and parental stress between minority and non-minority racial groups, and (b) examine whether the symptom behaviors and enacted stigma of children with Autism Spectrum Disorder influence the parental stress experienced by their mothers/fathers. The current study found that there was no significant difference in parents' reports of the symptom behaviors experienced by their children, enacted stigma, and parental stress among parents with non-minority and minority children. The current study also found that although child's race was not a significant predictor of parental stress, the child symptom behaviors and enacted stigma were both significant predictors of parental stress.

Keywords: Autism Spectrum Disorder, Enacted Stigma, Parental Stress, Race

MONTCLAIR STATE UNIVERSITY

Parenting Children with Autism Spectrum Disorder: Child Symptom Behaviors, Stigma, and Parental Stress

among Minorities and Non-Minorities

by

Kayla Breeden

A Master's Thesis Submitted to the Faculty of

Montclair State University

In Partial Fulfillment of the Requirements

For the Degree of

Master of Arts

May 2020

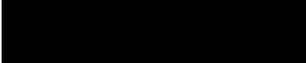
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PARENTING CHILDREN WITH AUTISM SPECTRUM DISORDER: CHILD'S
SYMPTOM BEHAVIORS, STIGMA, AND PARENTAL STRESS AMONG MINORITIES
AND NON-MINORITIES

A THESIS

Submitted in partial fulfillment of the requirements

For the degree of Master of Arts

by

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Montclair State University

Montclair, NJ

2020

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Parenting children with Autism Spectrum Disorder: Child's Symptom Behaviors, Stigma,
and Parental Stress among Minorities and Non-Minorities

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that has become increasingly prevalent over the past few years. According to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), the core elements for the criteria of ASD involve social communication impairments and repetitive/restricted behaviors or interests. ASD affects 1 in 54 children in the United States (Centers for Disease Control and Prevention, 2020), and 1 in 34 in New Jersey, which is the highest rate of ASD in the nation (CDC, 2020). To meet the DSM-5 diagnostic criteria; the core elements of ASD must display impairments early in life, affect one's functioning in various contexts, and do not represent an intellectual disability or global developmental delay (American Psychiatric Association, 2013). Although ASD is often able to be detected in a child by 18 months of age, a reliable diagnosis isn't likely to occur until the child is 2 years old (CDC, 2020). Early intervention services are also available at this time and are crucial to improving the child's functioning regarding social, play, and communication, but unfortunately there is no medical cure (Tek & Landa, 2012). ASD has been reported across genders, geographic location, and racial/ethnic groups, but there may be a difference in its detection, presentation, and developmental outcomes across groups. The current study examines whether the behaviors of a child with ASD and the enacted stigma faced are different due to racial demographics, and the influence these factors have on the stress levels of their parents.

Autism Spectrum Disorder and Race

Previous literature has found that White children are twice as likely to be diagnosed with ASD in comparison to their Black or Hispanic counterparts (Tek & Landa, 2012). Black children are also less likely to receive an early diagnosis and are more likely to be misdiagnosed or

underdiagnosed (Tek & Landa 2012; Ratto et al. 2016; Stronach & Wetherby, 2017). Due to these disparities, there is a lower reported prevalence of Black children with ASD which may be responsible for why they are under-represented in research and are at risk for under-treatment (Ratto et al., 2016). Disparities in the age of diagnosis between children who are minorities and non-minorities may be due to cultural or language barriers, or financial and educational resources (Tek & Landa, 2012). According to Ratto et al. (2016), in comparison to White American children with ASD, there are significantly higher instances of African American children lacking access to sufficient mental health services and thus their needs are being unsatisfied.

Symptom Presentation. It is also common that the symptom profiles of ASD between racial groups are inconsistent. Although there has been research done to examine the differences in the symptom presentations of ASD between White children and children from other racial groups, the results that have been gathered from different studies tend to contradict one another (Horovitz et al. 2011; Ratto et al., 2016; Tek & Landa, 2012). Horovitz et al. (2011), compared the Baby and Infant Screen for Children with Autism Traits-Part 3 scores of Black children and White children with ASD to assess their challenging behaviors associated with ASD. This study found that Black children with ASD displayed significantly more aggressive and destructive behaviors than their White peers, but no significant differences in stereotypic and self-injurious behaviors between races were found (Horovitz et al. 2011).

Other research also shows that in comparison to White children with ASD, Black children with ASD experience more impairments overall due to their symptom presentation such as displaying higher rates of verbal delays, physical delays, and intellectual disabilities (Ratto et al., 2016). Tek and Landa (2012), conducted a study examining ethnic differences in the symptom presentation of toddlers with ASD. For that study 19 minority ($M= 26.78$ months) and

65 non-minority ($M= 27.69$ months) children with ASD standardized tests' scores regarding social, motor skills, receptive and expressive language, cognition as well as their parents' reports were compared. Tek and Landa (2012) found that Black, Hispanic, and Asian children displayed more atypical language, greater communication impairment, and greater language delays than the White children according to scores on standardized tests and parental reports.

Ratto et al. (2016) similarly examined the differences of the parental reports of impairment in daily functioning between Black and White children with ASD. This research found conflicting results where in comparison to White children, Black children displayed fewer problem behaviors except with externalizing behaviors. The results showed that in terms of adaptive, social, emotional, and executive functioning Black children experienced less impairment than their White counterparts (Ratto et al., 2016). However, all of these studies only focused on the differences of the symptom presentation among younger children and several of the previous studies only examine Black and White children. In the current study these differences are assessed for Black, White, Asian, and Hispanic individuals between 3 and 21 years old.

Autism Spectrum Disorder and Enacted Stigma

The behaviors children with ASD may engage in can potentially cause them as well as their family members to experience “humiliation, social exclusion, and isolation” due to stigma (Alshaigi, Albraheem, Alsaleem, Zakaria, Jobeir, & Aldhalaan, 2019). Enacted stigma is defined as situations that involve “overt rejection or discrimination” caused by being a part of a stigmatized group (Gray, 2002). Since individuals with ASD and their families often still engage in typical social activities they are exposed to many examples of the stigmatizing reactions of others. Parents of children with ASD may use techniques such as “passing as a ‘normal’ family”

to avoid stigma but unfortunately, they cannot always engage in this. They may instead practice techniques that involve limiting the opportunity to even be exposed to stigma in the first place. These behaviors may include “restricting public encounters (Voysey, 1972), selective disclosure (West, 1986), and restricting their socializing to friends who would show ‘consideration’ for their child’s condition” (Birenbaum, 1970 as cited in Gray, 2002). Engaging in these techniques can save children with disabilities and their families from experiencing stigmatized reactions and embarrassment.

Gray (2002) conducted interviews with parents of children with high-functioning ASD on their experiences with felt and enacted stigma. From the interviews, the researcher found that the majority of the parents in this study felt that parents of typically developing children acknowledged them as being different due to their child’s disability. Half of the parents even expressed experiencing overt negative reactions (Gray, 2002). The parents felt that the judgments were critiques of their parenting abilities and lack of acceptance of their child’s disability, and they caused feelings of embarrassment. The most common form of enacted stigma was isolation or avoidance which involved not being invited to social occasions at the homes of others. They also reported experiencing adverse staring in public due to their child’s inappropriate public behaviors. Lastly, parents expressed being subjected to rude comments because of their child’s behaviors. Children who attended regular education schools encountered even more instances of stigma such as isolation, bullying, or exclusion from extracurricular activities, and their parents also reported problems in relationships with the school faculty and social rejection by the other parents (Gray, 2002).

Ellen, Fox, Aabe, Turner, Rai, and Redwood (2018), conducted similar research in the United Kingdom. In this study, 15 parents of children with ASD were interviewed on their

experiences pre- and post-diagnosis, access to services, and adapting their family life. Through the interviews, parents expressed experiencing labeling due to their child's disability and the associated stereotyping. Similar to Gray (2002), these parents also reported social separation between their child and others, and being socially isolated as a parent as well from neighbors and former friends. Lastly, parents experienced emotional responses, a lack of power, and discrimination because of their child's disability. Information provided by these parents leads to the understanding that they often feel that they are culpable for the problem behaviors of their children and are considered bad parents to the public. They also discussed experiencing negative attitudes from others in response to their child's problem behaviors (Ellen et al., 2018). Several studies examining ASD in countries including Israel (Shaked & Bilu, 2006), Hong Kong (Mak & Kwok, 2010) the United Kingdom (Ellen et al., 2018), and the United States regarding African American individuals (Dababnah, Shaia, Campion, & Nichols, 2018) demonstrated an influence of cultural factors on parents and children's experiences with stigma around the world. Cultural factors such as the knowledge or acceptance of disabilities, beliefs on medicine, acceptable parenting practices and children's behaviors, or religious views all influence the enacted and faced stigma experienced by different groups.

Enacted Stigma differences between demographic groups. Dababnah et al. (2018), examined barriers in ASD screening and services, and stigma by interviewing female caregivers of Black children with ASD. This study also found there to be an influence of cultural factors and race on the families' experiences with stigma. The caregivers described situations where they felt racism has led to their primary healthcare providers making negative assumptions about their child and their parenting. Assumptions developed by healthcare providers are significant because they potentially create a barrier against the screening, diagnosis, and intervention of

ASD, and they interfere with the parent-provider relationship. Many parents also reported the presence of ASD stigma in the Black community. The stigma has caused parents of children with ASD to live in shame or denial because of their child's disability which makes them hesitant to recognize and follow up on the presence of developmental delays. It also reduces the awareness of ASD in the community (Dababnah et al., 2018). In the interviews caregivers also discuss that in the Black community it is common for family members, especially the fathers, to dismiss the child as being labeled as having "Autism". They report some family members even suggesting disciplining the child or using prayer in response to challenging behaviors instead of viewing them as developmental delays due to a disability and pursuing professional assistance (Dababnah et al., 2018). However, this study only studied the experiences of African American mothers via interviews. The current study compares White American and Non-White American parents' experiences with enacted stigma due to their child's ASD and race.

Autism Spectrum Disorder and Parental Stress

From the time a child is diagnosed with ASD and through a parent's ongoing roles caring for a child with ASD there are several stressors that impact the lives of parents with children with ASD. Beyond being a parent, these individuals are required to preserve a structured environment, allow time for self-care, attend therapeutic appointments for their child and potentially other family members, and rely on other forms of support (Broady, Stoyles, & Morse, 2015). Fletcher, Markoulakis, & Bryden (2012), examined the experiences of female caregivers of children with ASD by conducting interviews. The study found that the demands of the various roles involved in caring for a child with ASD have been associated with higher financial/employment difficulties, declines in marriage rates, and self-neglect (Fletcher et al., 2012).

Parental Stress. According to Deater-Deckard (1998), parental stress is defined as experiencing discomfort or distress due to the demands of parenting. Parents of children with ASD experience a higher level of stress in comparison to parents of typically developing children due to their caregiving roles, limited social support and sufficient resources, their children's poor social skills, abnormal behaviors, and developmental delays (Hutchison, Feder, Abar, & Winsler, 2016). As discussed previously, early communication impairments are common symptoms among children with ASD. These impairments make it significantly difficult for these children to engage with others which affects the parent-child relationship. According to Del Bianco, Ozturk, Basadonne, Mazzoni, and Venuti (2018), the child's impaired ability to communicate has a significant impact on their parents' well-being by causing them to be anxious and worried whether they are meeting their child's needs and about their competence as parents. Parents of children with ASD reported higher levels of stress and more psychological distress than parents of typically developing children and of children with other developmental disabilities (Del Bianco et al., 2018).

Considering the various roles and additional difficulties associated with parenting a child with a disability there are several factors that may influence the stress experienced by parents of children with ASD due to the child's symptom behaviors. It was reported that the child's executive functioning difficulties such as self-regulation, self-control, and problem solving were positively associated with parental stress (Hutchison et al., 2016). Some other stressors that are commonly associated with the parental stress of parents of children with ASD include the child's problems sleeping, internal and external problem behaviors, their ASD diagnosis, social disability and adaptive functioning impairments, and the demands of accessing sufficient special needs services (Basri & Hashim, 2019). Illias et al. (2018), also found that social support, the

severity of ASD symptoms, financial difficulty, religious belief, parents' perception and understanding of ASD, and their anxiety and worries about their child's future were all factors that play a significant role in parental stress levels.

It is significant for parents of children with ASD to have adequate social support and services for their child as a way of assisting them with the stress associated with dealing with the behavioral and emotional challenges of their child. Unfortunately, stigma often interferes with parents having access to adequate social support and thus it hinders the parents' ability to alleviate stress efficiently. Cultural stigma and society's negative perceptions of ASD has also been found to contribute to parental stress (Mak & Kwok, 2010). Mak and Kwok (2010), examined the internalization of stigma across Chinese parents of children with ASD and the negative impact that it had on them through the completion of questionnaires. They found that family, friend, and professional support was negatively correlated with affiliate stigma. Affiliate stigma involves the internalization of negative attitudes from the public. They also found that affiliate stigma was positively correlated with courtesy stigma. Courtesy stigma involves being stigmatized due to the disapproval of the public. Lastly, they found that affiliate stigma was also negatively correlated with the psychological well-being of the parent. Cultural beliefs and the insufficient amount of information in particular societies have on ASD often leads to the families facing stigma. Faced stigma is commonly internalized and is associated with experiences of self-blame felt by the parents of children with ASD and recognizing the lack of control they have (Mak & Kwok, 2010). However, this study only studied the experiences of parents in China. The current study examines and compare the experiences of enacted stigma regarding parents of American children from several different racial groups.

Purpose of the Current Study and Hypotheses

Although research has been done on the symptom behaviors and enacted stigma associated with Autism Spectrum Disorder, and the relationships of these factors to parental stress, minorities with ASD are underrepresented in the research. Also, not much light has been shed on the racial differences regarding these factors. Lastly, previous research did not examine the overall influence of all of the factors being examined simultaneously.

In the current study, whether there are differences in the experienced ASD symptom behaviors of the children, enacted stigma, and parental stress between minorities and non-minorities is observed. This study examines the symptom behaviors and enacted stigma of children with ASD, and whether these factors influence the parental stress experienced by their mothers and fathers. These factors were examined from the perspective of 50 parents (mothers, fathers, and legal guardians) of children with ASD by their responses on an online self-report survey composed of four sections: (1) demographic data, (2) symptom behaviors experienced by the child, (3) enacted stigma, and (4) parental stress. The importance of the current study is to fill in the gaps in literature regarding the racial differences in the experiences of children with ASD and their parents, and the influences of the factors on parental stress. It is also important to identify the underlying mechanisms of the three contributors examined to make it easier for the field to intervene and support children with ASD and their families accordingly.

This study aims to answer the following questions: 1) Are there any differences in the experiences of parents of minority and non-minority children with ASD? 2) How do the symptom behaviors of the child and enacted stigma impact the stress levels of the parents? It was predicted that:

1. Parents of minority children with ASD will report experiencing more enacted stigma

- than parents of non-minority children with ASD.
2. The more symptom behaviors and enacted stigma experienced, than the higher the levels of parental stress will be reported. Having a child that is a minority will contribute to additional variance in parental stress.

Methods

Participants

50 parents/guardians (42 mothers, 6 fathers, and 2 legal guardians) between the ages of 28 and 60 ($M = 45.54$, $SD = 9.004$) who identified as having at least one child with ASD participated in the study. All participants reported their child being between the ages of 3 and 21 years old ($M = 12.56$, $SD = 5.845$; 40 males, 10 females). The participants identified as their child being White ($n=24$), Black/African American ($n=15$), Hispanic ($n=3$), White and Black/African American ($n=2$), White and Hispanic ($n=2$), White and Asian ($n=1$), and other not specified ($n=2$) on the demographic data section of the survey. Parents were not excluded based on their self-report of their marital status, ethnicity, child's gender, whether the child had additional disabilities etc.

The recruitment of participants initially occurred by contacting schools and service providers which offered the recruitment of the parents of children who were enrolled at their facilities. Several New Jersey schools and service providers that specialized in programs for children with ASD were contacted via email or in-person with the recruitment plea and recruitment flyer. Facilities that agreed to assist with the recruitment process distributed the recruitment flyer to the parents of the children they service either by email or by sending home printouts. Following this process, additional recruitment was done by promoting recruitment flyers through Facebook group pages devoted to parents of children with ASD and on

professional sites such as The Asperger/Autism Network and Autism NJ after permission was granted by the administrators.

Measures

Developmental Behavior Checklist- Autism Screening Algorithm. The *Developmental Behavior Checklist-Autism Screening Algorithm (DBC-ASA)* (Brereton, Tonge, Mackinnon, & Einfeld, 2002), a self-report 29-item questionnaire completed by parents/caregivers assesses behavioral and emotional problems. The DBC-ASA was established from items included in the original Developmental Behavior Checklist (Einfeld & Tonge, 1992, 1995) that represent core symptoms of Autism. Items were evaluated for being screening items in three stages. To discover what items were predictive of Autism group membership univariate logistic regression analyses were performed by evaluating 180 children who met the criteria for Autism using the DSM-IV and 180 controls. This stage concluded that there were 54 DBC items significant to Autism at $p \leq .01$. “Second, confirmatory factor analysis techniques were used to extract a single common factor from the predictive items which maximally aligned with the diagnosis of autism” (Brereton et al., 2002). Lastly, “the selected items with unit weighting were summed to form a scale which was subject to ROC analysis (Kramer, 1988) to assess the power of the DBC to discriminate between group membership and to assist determination of the most useful cut point on the scale” (Brereton, Tonge, Mackinnon, & Einfeld, 2002). This yielded 26 items with loadings that are ≥ 0.70 and 3 that are ≥ 0.62 with an internal consistency of $\alpha = .94$. The measure includes items such as “Aloof, in his/her own world” and “obsessed with idea/activity”. Respondents are directed to score items as being either 0 (*not true*), 1 (*somewhat or sometimes true*), or 2 (*very true or often true*) regarding the behaviors experienced by their child with ASD (Brereton et al., 2002). The total of their scores for all of the items provides participants with a

composite score on the DBC-ASA to determine their child's experienced symptom behaviors score.

Enacted stigma. The *enacted stigma questionnaire* (Alshaigi, Albraheem, Alsaleem, Zakaria, Jobeir, & Aldhalaan, 2019) was used to measure parents' experience of unfair treatment by others because of their child's developmental disability. This is a self-report 11-item questionnaire developed from the Beach Centre Family Quality of Life Scale and Self-stigmatizing Thinking Automaticity and Repetition Scale that assesses family life, social experiences, and resources as a parent of a child with ASD. A pilot study found the reliability of the items to be $\alpha = 0.777$. The measure includes items such as "I feel lonely after my child's diagnosis with ASD" and "My child has been discriminated against at school" (Alshaigi et al, 2019). Respondents are directed to score each item on a 5-point scale with 1 representing strongly disagree and 5 representing strongly agree regarding the presence of these experiences. The total of their scores for all of the items provides participants with a composite score on the enacted stigma questionnaire to determine their enacted stigma score.

Parenting Stress Index. The *Parenting Stress Index-Short Form (PSI-SF)* (Abidin, 1995), is a self-report 36-item questionnaire that measures stress due to parenting. The PSI-SF consists of three subscales: Parental Distress (PD), Parent-Child Dysfunctional Interaction (PCDI), and Difficult Child (DC); each subscale is made up of 12 items. The PD subscale assesses their perceptions of restrictions in their life, competence, social support/conflict due to the demands of parenting. The PCDI subscale assesses their perceptions of their interactions with the child. Lastly, the DC subscale assesses their perceptions of their child. The measure includes items such as "I often have the feeling that I cannot handle things very well" and "My child rarely does things for me that make me feel good". Respondents are directed to score each item

on a 5-point scale with 1 representing strongly disagree to 5 representing strongly agree. “Test–retest reliability coefficients of the total stress score have been reported to be 0.84. For the internal consistency of the PSI-SF, reports for total stress have been 0.91” (Abidin, 1995; Dardas & Ahmad, 2014). The total of their scores for all of the items provides participants with a composite score on the PSI-SF to determine their parental stress score.

Procedure

Individuals who met the inclusion criteria were presented with an online survey of 93 items split between four sections: (1) demographic data, (2) symptom behaviors experienced by the child, (3) enacted stigma, and (4) parental stress following their agreement to participate on the consent form. The participants had the ease to access the link to the online survey at their own time and from any location of their convenience without being under the surveillance of a researcher. The survey was available to be completed from either a computer or a mobile device. Participants were given one month from the time they were initially provided with the link to complete the online survey. The items in each section were calculated individually to provide participants with a composite score for each of the variables being examined.

Results

Descriptive Statistics

Demographics. 50 participants who identified as being parents/guardians of children with ASD (42 mothers, 6 fathers, and 2 legal guardians). All participants were between 28 and 60 years old ($M = 45.54$, $SD = 9.004$). All participants reported that their child with ASD was between 3 and 21 years old ($M = 12.56$, $SD = 5.845$). There were 40 male children and 10 female children. Children were separated into two groups based on their identified racial group(s), the minority group included Black/African American, Hispanic, White and Black/African American,

White and Hispanic, White and Asian, and other not specified children (n=25) and the non-minority group included children who were White (n=24). The primary diagnosis of all of their children was ASD, but several also had comorbidities which included Anxiety, ADHD, OCD etc. The majority of the children were reported as being enrolled in a special education school (n=32), and the remainder were either homeschooled (n=3) or receiving an education through mainstream schooling (n=15). Table 1 presents the demographic descriptive data for the parents participating in this study. The demographic descriptive data for their children is presented in Table 2.

Table 1.*Participants' Demographics Descriptive Statistics*

Variable		n	Min.	Max.	<i>M</i>	<i>SD</i>
Relationship	Mother	42				
	Father	6				
	Legal guardianship	2				
Age			28	60	45.54	9.004
Race	White	30				
	Black/AA	14				
	Hispanic	2				
	Black/AA, Other	1				
	White, Asian	1				
	White, Hispanic	1				
	Other	2				
Marital Status	Married	36				
	Divorced	6				
	Single	6				
	In a Domestic Partnership	2				
Employment	Full-time	25				
	Part-time	8				
	Unemployed	11				
	Retired	3				
	Self-employed	2				
	Student	1				
Number of Children			1	5	2.28	.970

Table 2.***Children's Demographics Descriptive Statistics***

Variable		n	Min.	Max.	<i>M</i>	<i>SD</i>
Race	White	24				
	Black/AA	15				
	Hispanic	3				
	White, Black	2				
	White, Asian	1				
	White, Hispanic	2				
	Other	2				
	Missing*	1				
Age			3	21	12.56	5.845
Gender	Male	40				
	Female	10				
Education	Special	32				
	Education	15				
	Mainstream	3				
	Homeschool					
Group	Minority	25				
	Non-Minority	24				
	Missing*	1				

Symptom Behaviors. Summary statistics for the *Symptom Behaviors* section of the survey which was composed of 29-items from the *Developmental Behaviors Checklist- Autism Screening Algorithm* (Brereton et al., 2002) are shown in Table 3. Parents' responses to the items were calculated together to provide a composite score for the *Symptom Behaviors* experienced by their child with ASD. Their composite scores range between 7 and 47, the average score for the *Symptom Behaviors* experienced by their children was 28.28 (*SD*= 10.104). According to Brereton et al. (2002), composite scores on the DBC-ASA above 17 are considered to involve high symptom behaviors. This indicates that on average the children of the parents in the study

display high levels of emotional and behavioral problems (Brereton et al., 2002). An independent t-test was performed to compare the mean total score for this variable between parents with children in the minority group to parents with children in the non-minority group. The mean composite score for parents with children in the minority group was 29.16 ($SD=9.758$) and 27.79 ($SD=10.603$) for those in the non-minority group. The findings of this t-test are shown in Table 4.

Enacted Stigma. Summary statistics for the *Enacted stigma* section of the survey which was composed of 11-items from the *Enacted Stigma questionnaire* (Alshaigi et al., 2019) are shown in Table 3. Parents' responses to the items were calculated together to provide a composite score for the *Enacted Stigma* experienced due to their child being diagnosed with ASD. Their composite scores for *Enacted Stigma* range between 11 and 50, the average score for this variable was 28.56 ($SD= 10.008$). An independent samples t-test was performed to compare the mean composite score for this variable between parents with children in the minority group to parents with children in the non-minority group. The mean composite score for parents with children in the minority group was 28.72 ($SD=11.092$) and 28.96 ($SD=8.765$) for those in the non-minority group. The findings of this t-test are shown in Table 4.

Parental Stress. Summary statistics for the *Parental stress* section of the survey was composed of 36-items from the *Parenting Stress Index-Short Form* (Abidin, 1995) are shown in Table 3. Parents' responses to the items were calculated together to provide a composite score for *Parental stress* due to experiencing Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child. From the 50 participants who participated in this study only 47 of them completed all of the items in this section. For the 47 participants who completed this section, their composite scores for *Parental stress* range between 56 and 150; the average score for this

variable was 112.48 ($SD=24.072$). According to Dardas and Ahmad (2014), composite scores on the PSI-SF can range from 36 to 180, and composite scores which are higher than 90 are considered to be “clinically significant high levels of stress scores”. This indicates that on average the parents who participated in this study experience high stress levels that are clinically significant. An independent samples t-test was performed to compare the mean composite score for this variable between parents with children in the minority group to parents with children in the non-minority group. The mean composite score for parents with children in the minority group was 112.92 ($SD=24.980$) and 113.86 ($SD=22.487$) for those in the non-minority group. The findings of this t-test are shown in Table 4.

Table 3.***Summary Statistics for Child Symptom Behaviors, Enacted Stigma, and Parental Stress***

	n	<i>M</i>	SE	<i>SD</i>	Variance	Min.	Max.
Behavior	50	28.28	1.429	10.104	102.083	7	47
Stigma	50	28.56	1.415	10.008	100.170	11	50
Parental Stress	47	112.49	3.511	24.072	579.473	56	150

Table 4.***Group Scores for Child Symptom Behaviors, Enacted Stigma, and Parental Stress***

	Group	n	<i>M</i>	<i>SD</i>	<i>SE</i>
Behavior	Non-Minority	24	27.79	10.603	2.164
	Minority	25	29.16	9.758	1.952
Stigma	Non-Minority	24	28.96	8.765	1.789
	Minority	25	28.72	11.092	2.218
Parental Stress	Non-Minority	22	113.86	22.487	4.794
	Minority	24	112.92	24.980	5.099

Statistical Analyses

Group Differences in Child Symptom Behaviors, Enacted Stigma, and Parental Stress. In order to examine Hypothesis 1 independent samples t-tests were conducted to compare the composite scores for the child's symptom behaviors, enacted stigma, and parental stress score between minority and non-minority children. The results indicated that although the composite scores for the minority group were numerically higher than the non-minority group, there was not a significant group difference on the child symptom behaviors experienced; $t(47)=-.470, p=.640$. The results also indicated that although the composite scores for the minority group were numerically lower than the non-minority group, there was not a significant group difference on the enacted stigma scores; $t(47)=.083, p=.934$. Lastly, although the composite scores for the minority group were numerically lower than the non-minority group, there was not a significant group difference on the parental stress scores; $t(44)=.135, p=.893$.

Child Symptom Behaviors and Enacted Stigma as Predictors for Parental Stress. In order to examine Hypothesis 2, a regression was performed with child symptom behaviors and enacted stigma as predictors for parental stress as the dependent variable. The results of the regression indicated that the model explains 46.6% of the variance and the model was a statistically significant predictor for the parental stress score, $F(2,44)=19.162, p<.001$, with an $R^2=.466$. The child's symptom behaviors composite score significantly contributed to the model ($B=1.162, p<.001$) and the enacted stigma composite score did as well ($B=.844, p<.05$). The results of this analysis are shown in Table 5.

Table 5.***Child Symptom Behaviors and Enacted Stigma as Predictors for Parental Stress***

Predictor	B	SE	b	t	p-value
(Constant)	55.280	9.667		5.718	.000
Stigma	.844	.276	.353	3.060	.004
Behavior	1.162	.274	.489	4.243	.000

Race as a Predictor for Parental Stress. In order to examine the latter portion of Hypothesis 2, another regression analysis was performed to examine race as a predictor along with the child symptom behaviors and enacted stigma for parental stress as the dependent variable. The results of the regression indicated that the model explains 44.2% of the variance and the model was a statistically significant predictor for the parental stress composite score, $F(3,42)=11.103$, $p<.001$ with an $R^2=.442$. While the child's behaviors composite score ($B=1.136$, $p<.001$) and enacted stigma composite score ($B=.798$, $p<.05$) significantly contributed to the model, the child's group determined by their race does not statistically contribute ($B=-.923$, $p=.865$). The results of this analysis are shown in Table 6.

Table 6.***Child Symptom Behaviors, Enacted Stigma, and Race as Predictors for Parental Stress***

Predictor	B	SE	b	t	p-value
(Constant)	58.206	10.521		5.532	.000
Stigma	.798	.284	.338	2.812	.007
Behavior	1.136	.279	.488	4.071	.000
Group	-.923	5.392	-.020	-.171	.865

Discussion

The goal of this study was to examine the following questions: 1) Are there any differences in the experiences of parents of minority and non-minority children with ASD? 2) How do the symptom behaviors of the child and enacted stigma impact the stress levels of the parents? These concepts were examined through the parents/guardians of children with Autism Spectrum Disorder completion of an online survey with 93-items composed of four sections: (1) demographic data, (2) symptom behaviors experienced by the child, (3) enacted stigma, and (4) parental stress. The surveys allowed the composite scores of each section individually to be compared between parents of minority children and parents of non-minority children, and to observe whether their child symptom behaviors and enacted stigma scores influenced the parental stress score. Based on previous research, it was expected that parents of minority and non-minority children with ASD would not differ in their reports of the child symptom behaviors. Regarding enacted stigma, it was predicted that parents of minority children with ASD would report experiencing more enacted stigma than parents of non-minority children with ASD. Lastly, it was expected that the more symptom behaviors and enacted stigma experienced than the higher the levels of parental stress will be reported, and having a child that is a minority will contribute to additional variance in parental stress.

The composite scores of parents of minority children were compared to the composite scores of parents of non-minority children with ASD on measures regarding their child's behaviors, enacted stigma, and parental stress. The results showed that parents of children in the minority group and the non-minority did not differ in the child symptom behaviors score, enacted stigma score, and parental stress composite score. From these results the first hypothesis was not supported. Contrary to the ASD symptom presentation differences among racial groups

that were displayed in other studies where minority children to display significantly more problem behaviors in some areas than their White counterparts (Horovitz et al. 2011; Tek & Landa, 2012), or others where Black children displayed fewer problem behaviors than their White counterparts (Ratto et al., 2016), differences were not found in the current study. Children with ASD in the current study experience high levels of emotional and behavioral symptom behaviors regardless of whether they minorities or non-minorities. Regarding enacted stigma, contrary to the results of Alshaigi et al. (2019) who found that 74.2% of their participants did not experience enacted stigma due to their child's ASD, children and their families in the current study face a high amount of enacted stigma. These results support parental responses on interviews conducted in Gray (2002), Farrugia (2009), and Broady et al. (2015) regarding the children and their parents' experiences with stigma in various contexts, the negative overt reactions of others due to stigma, and the influence the stigma has on these individuals. Lastly, in line with previous literature such as Miranda et al. (2019) and Pastor-Cerezuela et al. (2016), parents of children with ASD in the current study experience high stress levels that are clinically significant. Parents in the current study do not have significant differences in their experiences due to their children being a minority or non-minority.

Parents' scores on the child symptom behaviors measure and enacted stigma measure were analyzed to determine whether they were predictors for their parental stress outcome. The results showed that parents who reported that their child with ASD experienced higher levels of symptom behaviors and reported more enacted stigma had also experienced higher parental stress levels than parents with lower scores for their child's behaviors and enacted stigma. From these results, the second hypothesis was partially supported. The results of the current study also support those of Mak and Kwok (2010) who found that cultural stigma and society's negative

perceptions of ASD influence parental stress. The influence enacted stigma has on parental stress may be associated with other findings that experiencing stigma is positively correlated with the internalization of the negative attitudes (Mak & Kwok, 2010). In the current study, parents' scores on their child's symptom behaviors and on enacted stigma were both predictors of their parental stress scores.

An additional analysis was conducted to determine whether a child belonging to a minority or non-minority racial group was also a predictor for the parental stress outcome. The results showed that the child's grouping did not significantly influence the parental stress score. From these results, the latter portion of the second hypothesis was not supported. Whether the child is was a minority or a non-minority was not a predictor of the parental stress score.

Implications

From the results of this study, we can implicate that parents of children with ASD experience significantly high levels of parental stress, as also discussed in previous literature. This research can also provide the implication that the child's symptom behaviors and enacted stigma have an influence on their parents' experiences with stress. It is typical that these factors that influence parental stress may contribute to the additional problems they cause for the child and the parent. Parents of children with ASD often have to experience insufficient resources, their child having developmental delays and lacking social skills (Hutchison et al., 2016), an impaired ability to communicate with their parent (Del Bianco et al., 2018), problems sleeping, internal problem behaviors and towards the external environment, and social disability and adaptive functioning impairments (Basri & Hashim, 2019). These factors are often associated with the parent experiencing financial difficulty, anxiety and worries about their child's future (Illias et al., 2018), declines in successful marriages, experiencing self-neglect (Fletcher et al.,

2012), and limited social support (Hutchison et al., 2016). Since several of these problems are also included in the measures used in this research and they have been associated to parental stress in previous literature, an implication can be made that they can contribute to the high levels of stress experienced by parents of children with ASD. Since the increased child's symptom behaviors and increased enacted stigma of children with ASD resulted in increased parental stress scores, it is imperative that these children are provided with sufficient resources. Their parents/families also need to be provided with sufficient interventions for caring for the child and adequate social support to promote their own well-being. Studies such as Mak and Kwok (2010), found that having family, friend, and professional support decreased the internalization of negative attitudes from the public for parents of children with ASD. Social support for the parents has also been negatively correlated to emotional and social burdens, and financial difficulties while influencing life satisfaction and self-esteem (Mak & Kwok, 2010; Lu et al., 2015). Considering previous literature, it is likely that if parents of children with ASD felt that their child's needs were being sufficiently met and they had a higher sense of their well-being and role as a parent, than their parental stress could potentially be lowered. Intervening to lower the stress experienced by parents of children with ASD could benefit their child's long-term outcomes and the parent-child relationship.

Limitations

Although the current study provides important implications regarding the influence of the child symptom behaviors and enacted stigma on parental stress, there are a few limitations of this study which are significant to consider. This study only included data from 50 participants; the small sample size limits the power to detect significant differences in the experiences between parents with low and high composite scores for stress, and the experiences between those with

minority and non-minority children. Another limitation of the sample involves sampling bias. Parents were contacted by their child's school, service provider, or subscription to newsletters from specific support groups for the opportunity to participate in the study. There is a chance that parents who participated and those who did not participate in the study may have different experiences with parenting a child with ASD which are unable to be considered. The final limitation of the sample to consider is the breakdown of participants belonging to each of the racial groups. Even though the minority group (n=25) and non-minority group (n=24) were almost equivalent, the size of the minority group consisted of Black/African American (n=15), Hispanic (n=3), White and Black/African American (n=2), White and Hispanic (n=2), White and Asian (n=1), and Other not specified (n=2) whereas the non-minority group only consisted of children were identified as being White (n=24). The current study was not able to examine the factors for the racial groups individually because there were several more children who were White than there were for any of the minority groups.

There are also limitations regarding the measures utilized in the study. The current study only included questionnaires that allowed for self-report responses from the parents which could potentially lead to response bias. Self-report responses may cause participants to provide responses that are considered more socially acceptable or preferred. Their responses may also not be representative of their actual experiences because it is often difficult for people to accurately assess these factors themselves. Another limitation may be due to the order that the participants were presented the questionnaires. There is the potential that being presented with the items from the *Developmental Behavior Checklist- Autism Screening Algorithm* and the *Enacted stigma questionnaire* before the items from the *Parenting Stress Index* may prime participants to over or under respond to these items by reflecting on the previous items.

Lastly, limitations specific to the potential extraneous variables which could be associated with the results found by the current study are also important to consider. In the demographic data section of the survey participants reported on items regarding their marital status, employment, number of children, child's age, child's gender etc. but these factors were not analyzed along with the other factors examined in this study. Also, factors such as socioeconomic status, parent's highest form of education, and geographical location were not included as items in the demographic data section on the survey. Since these factors were not analyzed or examined the influence they have on parental stress cannot be determined which allows for the possibility of extraneous variables that may be affecting the results. The survey also collected data from mothers, fathers, and others with legal guardianship. This allows for several other factor differences contributed to the participant's gender and the period of time spent in the child's life which may also influence their experiences of parenting. Lastly, several of the participants completed the survey during the coronavirus pandemic. This could be considered an extraneous variable which may have involved participants providing extreme responses due to the abnormal experiences their child or themselves may be dealing specific to the current crisis which wouldn't normally be the case.

Conclusion

The findings suggest that the experienced symptom behaviors of a child with ASD and the enacted stigma influence the parental stress levels. In this study, no significant differences between parents of minority children and parents of non-minority children were found regarding their child's symptom behaviors, enacted stigma, and parental stress. The current study also did not find the child's group (minority vs. non-minority) determined by their race to be a significant predictor of parental stress, but the child symptom behaviors and enacted stigma were. Parents

who reported that their child with ASD experienced higher scores of symptom behaviors and reported facing more enacted stigma had also experienced higher parental stress than parents with lower scores on the child symptom behaviors and enacted stigma. The findings in this study can contribute to the importance of ensuring that children with ASD are provided with sufficient resources. They also emphasize the importance that their parents/families are provided with sufficient interventions on caring for the child and adequate social support to promote their own well-being. The growing awareness of ASD, and advances in ASD screening and services across our nation may be attributed to why there were no significant differences found between minorities and non-minorities. Although we can implicate that the child symptom behaviors and enacted stigma influence the high levels of stress experienced by parents of children with ASD, it would be beneficial for future research to be conducted with several more experiences of parents and children. Additionally, future work should include a comparison group of typically developing children and their parents to examine whether these parents have different stress levels and to determine how factors such as child behaviors and stigma also influence parental stress in this population. Lastly, it would be important for future research to examine whether for certain there are no differences between minorities and non-minorities, and whether there are differences in the experiences of individual racial groups.

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