

Summer 2016

Life After an Autism Spectrum Disorder Diagnosis: A Comparison of Stress and Coping Profiles of African American and Caucasian Caregivers

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**LIFE AFTER AN AUTISM SPECTRUM DISORDER DIAGNOSIS: A
COMPARISON OF STRESS AND COPING PROFILES OF
AFRICAN AMERICAN AND CAUCASIAN CAREGIVERS**

by

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A Dissertation Submitted to the Faculties of Eastern Virginia Medical School,
Norfolk State University, and Old Dominion University
in Partial Fulfillment of the Requirements for the Degree of

DOCTOR OF PHILOSOPHY

CLINICAL PSYCHOLOGY

VIRGINIA CONSORTIUM PROGRAM IN CLINICAL PSYCHOLOGY
August 2016

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ABSTRACT

LIFE AFTER AN AUTISM SPECTRUM DISORDER DIAGNOSIS: A COMPARISON OF STRESS AND COPING PROFILES OF AFRICAN AMERICAN AND CAUCASIAN CAREGIVERS

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Though the prevalence of autism spectrum disorder continues to rise, limited research to date has studied the impact of culture on stress and coping for families after they are diagnosed. This study explored the relationship between caregiver's ethnic culture and caregiver reports of stress and coping behaviors when caring for a child with autism. Specifically, this study used discriminate function analysis to contrast the stress and coping profiles of Caucasian caregivers to African American caregivers that are more acculturated with the majority culture and African American caregivers that ascribe to more traditional values. A sample of 103 participants was recruited, 52 Caucasian families and 51 African American families. Findings from this research suggest that experiences of caring for a child with autism are different across cultural groups and within the African American cultural group. African American families reported experiencing significantly more stress and utilizing more ways of coping than their Caucasian counterparts. Additional differences were found between the high and low acculturated African American groups such that low acculturated African Americans were more likely to engage in religious coping.

A secondary goal of this study was to consider caregiver stress and coping through the lifespan of the child. There were no significant differences found between

the coping and stress profiles of caregivers of children in early childhood, middle childhood, and adolescence.

This dissertation is dedicated to the children of Clinton Elementary School in Clinton, Louisiana. You continue to be my inspiration.

ACKNOWLEDGMENTS

First, I would like to express my sincere gratitude to my advisor, Dr. Kathrin Hartmann, for her clinical guidance and research support. This dissertation would not have been possible without her enthusiasm, knowledge, and passion for advocacy. I could not have asked for a better advisor to guide me through graduate school. I would also like to thank my other committee members, Dr. Scott Debb, Dr. Serina Neumann, Dr. James Paulson, and Dr. Maria Urbano, for their insight and feedback. The hours of time you poured into my training is much appreciated. I am leaving this process a better clinician and researcher because of you.

I also owe my deepest appreciation to my family, specifically my mother Terri Williams and my grandmother Dr. Kaye F. Jackson. You both are the picture of strength. Thank you for all you sacrificed to support my educational endeavors. A final thank you to my partner in life, Vertellis Garrett. Despite the long hours, stacks of papers covering the floor, and cancelled dates, your love for me never wavered.

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CHAPTER I

INTRODUCTION

Autism Spectrum Disorder (ASD) is a pervasive developmental disorder characterized by impairments in social interaction and communication. Most recent prevalence statistics estimate that one in every 68 children has been diagnosed with ASD. This represents a 30 percent rise in the prominence of ASD diagnoses since the last released estimate two years prior. ASD disproportionately affects males and in comparison to females, such that males are five times more likely to be identified with the disorder (Centers for Disease Control and Prevention [CDC], 2014).

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM), individuals with ASD have difficulties in two primary domains of interpersonal functioning: social communication and interaction, and repetitive behaviors and restricted interests. Individuals with ASD often display rigidity in their thoughts and behaviors and have difficulty handling changes to routines (Klinger, Dawson, & Renner, 2003). Those with autism may also display an inappropriate attachment to objects or unusual interests (5th ed., DSM-5; American Psychiatric Association, 2013).

Controversies, Etiology, and Current Therapies

The rise in ASD prevalence over the past several years has generated media attention and thusly controversy, especially as it pertains to etiology. Despite much evidence to the contrary, the measles-mumps-rubella (MMR) vaccine came under scrutiny because of a single article suggesting a possible link between autism and the vaccination. Holton, Weberling, Clarke, and Smith (2012) reported that 281 articles from 32 different media outlets were written about the topic. Holten et al. estimated that about

79.7 percent of the media coverage came from United Kingdom and United States sources. Importantly, a significant number of these sources cited personal opinions about the MMR vaccine, instead of relying on facts. This misinformation yielded a significant increase in selective nonreceipt of the MMR vaccine for young children (Smith, Ellenbery, Bell, & Rubin, 2008). Smith et al. reports that national rates of MMR vaccination in Britain fell 19 to 42 percent across the country. The researchers took a systematic look at the United States National Immunization Survey (NIS) cohort data. In comparison to cohorts prior to the MMR vaccination controversy, the 1995-2004 NIS cohort of children's caregivers elected to opt out of MMR vaccinations significantly more often. At the height of the controversy, in 1995, about 10 percent of 19- to 35-month-old children went unvaccinated. Overall, MMR nonreceipt (due to voluntarily opting out) increased from less than one percent in previous years to 2.2 percent for the group of children born after the MMR media controversy (Smith et al., 2008).

The most recent controversy surrounding the etiology of ASD lies with pesticides. Shelton et al. (2014) suggest that gestational exposure to pesticides, particularly organophosphates, increases a child's likelihood of having a neurodevelopmental disorder in comparison to children with no prenatal pesticide exposure.

Though the etiology of the disorder is cloaked in speculation, there is significant evidence for genetic underpinnings. The prevalence of ASD for a person with a family member previously diagnosed is 15 to 30 times greater than those in the general population. Heritability rates may be as high as 90 percent for same-sex twins. To date, there is no single gene that accounts for ASD-related symptomology (Klinger et al., 2003). Instead, a literature review conducted by Betancur (2010) identified 103 known

genetic mutations, deletions, and duplications with studied links to ASD related behaviors. Approximately five to 15 percent of individuals diagnosed with ASD have an identifiable genetic etiology and an additional ten percent of ASD cases are associated with other known genetic syndromes such as Fragile X, Tuberous sclerosis, and Rett Syndrome (Devlin & Scherer, 2012). The remaining 75 to 85 percent of ASD diagnoses have yet to be linked to an identifiable genetic cause.

While there is no cure for autism, the CDC (2015) cited four broad categories of therapies currently in use for treating children with ASD: behavior and communication approaches, dietary approaches, medication, and complementary and alternative medicine. The interventions range in approach style, cost, and targeted symptoms.

Lavelle et al. (2014) used three national data sets to estimate the health care costs for parents of children with ASD in comparison to typically developing children. After controlling for demographic differences (e.g. co-morbid conditions and allergies), Lavelle et al. estimated that parents of children with ASD spend an additional \$17,000 per year on medical expenses, ASD-related services, caregiver time, family services and educational needs in comparison to typically developing children. For a child with more severe needs, this estimate may rise to as much as \$21,000 per year.

Given the increase in popularity, research efforts have largely concentrated on understanding the nature of ASD and early intervention, but few have published about the role of cultural influences and ethnicity in living with the disorder. The present study intends to add to the literature by exploring African American caregivers' experiences when caring for a child with ASD in comparison to their ethnic majority counterparts. The purpose of this study is to focus on how to improve the quality of life for families

with the diagnosis. Specifically, I am aiming to understand the role race and cultural background play in the caregivers' stress and coping behaviors. I am also interested in exploring how coping behaviors may be different for parents across childhood and the teenage years. This knowledge will supply mental health providers with a window into understanding how racial minority caregivers' perceptions and needs differ from that of racial majority populations and how services may be best tailored to work within the caregivers' cultural framework.

CHAPTER II

REVIEW OF THE LITERATURE

Developmental Course and Associated Problems

Each phase of childhood and adolescent development brings about special challenges as it relates to the ASD diagnosis. Given the broad range of abilities and impairments inherent in the spectrum, these challenges may not be reflective of every family's experience.

Early Childhood. The early childhood years (birth to five years old) are a critical time for diagnosis and early intervention in children with ASD. Parents may begin to notice abnormalities in their baby's eye contact and social interactions before six months of age (Tantam, 2013). Though a child may be diagnosed with ASD as early as 18 to 24 months, recent estimates report that on average, children receive a diagnosis at age four (CDC, 2014). A strong body of literature suggests that early intervention during this phase, especially for speech and language, are very beneficial to the child's developmental trajectory during this window (Koegel, Koegel, Ashbaugh, & Bradshaw, 2014). Families of newly diagnosed children with ASD may find themselves learning to navigate their child's unique needs, understand the diagnosis, and explore treatment options (Tantam, 2013).

Middle Childhood. Due to typical speech development, higher functioning ASD individuals may not be diagnosed until later in childhood when social demands exceed their abilities (Daniels & Mandell, 2014; Tantam, 2013). As Tantam suggests, middle childhood, defined as ages six to twelve, is an important time period for children to learn social norms, appropriate boundaries, and consequences. This is often accomplished

through unstructured (e.g. informal play) and structured (e.g. recreational sports and hobbies) interactions with same-aged peers. Some children with ASD may struggle with the transition to school due to unfamiliar staff, alterations to previously established routines, and motor coordination and integration difficulties. Higher functioning individuals with ASD will likely notice social isolation and differences in their style of humor (Tantam, 2013).

Adolescence. Adolescence brings about an increase in autonomy and social demands. Children with ASD may encounter additional organizational demands and structural changes in middle and high school. In comparison to traditional elementary schools, upper grades will require transitions between classrooms, a larger building, and a louder, busier environment. Even if the adolescent is able to handle the academic rigors, middle and high school can be socially isolating experiences coupled with negative peer pressure and bullying. Leblanc, Riley, and Goldsmith (2008) note that given the concrete nature of individuals with ASD, they are especially prone to victimization. Higher functioning teenagers with ASD may feel as if they cannot cope with the social climate and consequently engage in suicidal ideation and attempts (Fitzgerald, 2007). Perhaps because of the social isolation and peer difficulties, adolescents with autism present with higher rates of co-morbid diagnoses of anxiety and depression (Tantam, 2013). In an analysis of four studies on this topic, Hannon and Taylor (2013) reported that individuals with ASD aged 12 to 20 are at the highest risk for attempting suicidal behaviors.

Interest in romantic relationships is also a hallmark experience of adolescence. In fact, literature indicates that adolescents with ASD display a romantic interest in others, but often lack the social savvy and training to successfully initiate interactions (Stokes,

Newton, & Kaur, 2007; Urbano, Hartmann, Deutsch, Bondi Polychronopoulos, & Dorbin, 2013). Individuals with ASD may inadvertently engage in stalking or other inappropriate behaviors because of naivety concerning the social norms for dating (Stokes et al., 2007; Tantam, 2013). When adolescents with ASD are able to successfully engage in intimate relationships, they may struggle to understand subtle emotional cues from their partner. The ASD characteristics of rigidity and repetition may also serve as barriers in romantic partnerships. Individuals with ASD may have strict boundaries and expectations about relationships, with little room for compromise (Urbano et al., 2013).

Autism and Ethnic Minorities

Substantial epidemiological research suggests that autism is a universal disorder that affects individuals from all racial, ethnic, and socioeconomic backgrounds (Klinger et al., 2003; CDC, 2014), yet ethnic minorities are often under diagnosed and go without treatment (Begeer, Bouk, Boussaid, Terwogt, & Koot, 2009; CDC, 2014). Recently CDC (2014) data suggests that non-Hispanic White children are 30 percent more likely to be diagnosed with ASD than non-Hispanic Black children. Almost half (48%) of Black children diagnosed with ASD are also classified as intellectually disabled in comparison to one quarter (25%) of White children with an ASD diagnosis.

Tek and Landa's (2012) research provides some evidence that the presentation of autism may differ among ethnic groups. To assess characteristics of autism and early development, the researchers administered the Autism Diagnostic Observation Schedule (ADOS) and an early development measure to majority- and minority-race toddlers with a previous diagnosis of ASD. After controlling for socioeconomic status, ethnic minority toddlers with autism displayed significantly more delayed and atypical communication

abilities in comparison to majority-race toddlers with autism. Additionally, minority-race toddlers with autism showed significantly less gross motor ability in comparison to their majority counterparts. Despite the obvious need and in some respects a more severe presentation, the literature and CDC data suggest that ethnic minorities are less likely to receive an official diagnosis.

Several studies indicate that the diagnostic process is often more cumbersome and longer for ethnic minority families. In an international study, Begeer et al. (2009) provided pediatricians with clinical vignettes of a child that differed only in the reported ethnic background. The researchers asked pediatricians to provide a diagnosis for the child. On average, non-minority children in the vignettes were more likely to receive an ASD diagnosis as compared to minority children. Begeer et al. propose that this finding may be due to clinician bias. Clinicians may be wrongly attributing language delays to cultural factors. The researchers also retroactively examined case files of children diagnosed with ASD at assessment centers and institutions. They concluded that given the current ethnic proportions in the population, the actual number of minority children involved in ASD assessment and treatment was significantly smaller than the expected number of minority children. Mandell et al. (2009) further supported Begeer et al.'s findings by reporting that after adjusting for intellectual ability, eight year-old ethnic minority children were less likely to have a documented diagnosis of autism than their same-age, Caucasian counterparts.

These difficulties with the diagnostic process illustrate a barrier for ethnic minority children in obtaining appropriate early intervention services, government funding, and community resources because they do not have an official diagnosis. A

study conducted by Magaña, Parish, Rose, Timberlake, and Swaine (2012) indicated that the gap in access to quality health care for minority families extends beyond socioeconomic status. After controlling for socioeconomic status, minority parents still reported feeling less informed, understood, and included in making decisions regarding their child's ASD diagnosis and treatment when compared to their Euro-American counterparts (Magaña et al., 2012).

Stress and Caring for a Child with ASD

Parental stress is significant because of the detrimental effects it may have on a child's wellbeing. High parental stress is associated with maternal low self-esteem and self-efficacy, parental depression, anxiety, and use of harsh parenting techniques. Parents with higher parental stress are also more prone to insecure attachments with their children (Chang et al., 2004).

A growing body of research provides evidence that caring for a child with special needs increases the risk of parental stress and psychological distress (Estes et al., 2013). Further still, disparities exist within populations of caregivers concerning parental stress. Griffith, Hastings, Nash, and Hill's (2010) findings suggest that caring for a child with an Autism Spectrum Disorder is correlated with an increase in maternal stress and a decrease in positive perceptions of the child in comparison to children with Down syndrome and other intellectual disabilities. The researchers attributed the differences in caregiver perceived stress to the higher levels of acting out or externalizing behaviors (e.g. temper tantrums and physical aggression) associated with ASD profiles (Griffith et al., 2010; Davis & Carter, 2008).

Results from several studies (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Blacher & McIntyre, 2006; Rivard, Terroux, Parent-Boursier, & Mercier, 2014) report a consistent finding that parents of children with ASD score in the clinically significant range for reported parental stress (above the 95th percentile). In one such study (Rivard et al., 2014), fathers indicated significantly higher levels of stress in comparison to mothers. The authors explain this finding by noting that most of the fathers in their study were the primary financial heads of their households. Due to the constraints of the fathers' jobs, they were unable to participate in important treatment planning decisions and missed information, which led to higher levels of stress when interacting with their child.

Despite the pervasive nature of the disorder, it is clear from the literature that children with autism do not have access to quality treatment in comparison to children with other health care needs (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Thomas et al. noted that parental educational level and insurance payment for needed services were decisive factors in the caregivers' ability to access a variety of treatment options for their children.

The developmental age of the child may also be relevant to perceptions of stress. Evidence suggests that caring for younger children is more demanding of time and resources in comparison to older children who are more autonomous. This may intensify caregiver stress. In order to determine how parents allocate their time, Bryant and Zick (1996) collected time diaries from parents of typically developing children. Results from their study suggest that age is the greatest determinant for how parents spend their time. Time devoted to childrearing is negatively correlated with age, such that older children require less shared time (Bryant & Zick, 1996). In a sample of caregivers for children

diagnosed with intellectual disabilities, caregivers of younger children, especially mothers, report devoting more time toward caregiving activities and experiencing greater caregiver burden in comparison to those with older children (Heller, Hsieh, & Rowitz, 1997). This finding provides support for the adaptational hypothesis of caregiving (Townsend, Noelker, Deimling, & Bass, 1989), which posits that caregivers have the ability to acclimate to stressors over time and thusly experience more stress at the onset of caregiving duties.

Longitudinal research also supports the notion that caring for a child with ASD is more difficult during early childhood. Azad, Blacher, and Marcoulides' (2013) study measured family impact of caring for a child with a developmental disability at eight time points in the child's life, from ages three to thirteen. Families reported lower levels of stress and family impact with age such that the middle childhood phase was less stressful in comparison to early childhood. Results from a ten-year longitudinal study (Barker et al., 2011) of adolescents and adults with autism suggests that maternal anxiety and depression decreases with time, a sign of positive adaptation and coping.

Conversely, some research indicates that parents report higher levels of stress and perceived negative impact as their child ages. Carr and Lord (2013) noted that both African American and Caucasian mothers report a more negative impact on family dynamics as their child transitions to adolescence. Participants in another study of parental stress of children with ASD (Tehee, Honan, & Hevey, 2009) reported experiencing the most stress during middle childhood and feeling least supported during this phase. Of note, the sample size was small for this study with only 23 families represented. A single study (McStay, Dissanayake, Scheeren, Koot, & Begeer, 2014)

indicated no differences between the stress levels of parents with children at different developmental ages. Instead, the researchers suggest that problem behaviors of the child better account for parental stress regardless of age.

Although there is some evidence to the contrary, most studies in this field agree that caring for younger children with exceptional needs may result in heightened feelings of caregiver stress in comparison to caring for older children.

African American Culture and Mistrust

African Americans have a distinctive history in America in comparison to other ethnic minority groups. The history of Africans in America started in the early 1600s with the arrival of indentured servants to Virginia and marks over 250 years of slavery and oppression. During this time frame, African Americans were constitutionally considered less human than their Caucasian counterparts. After gaining legal freedom in the 1860s, African Americans faced a season of “separate, but equal” treatment, which left them ostracized from the majority and promoted mistrust of Caucasian people and organizations (Education Broadcasting Corporation, 2002).

The early 1930s brought about the hallmark Tuskegee Study of Untreated Syphilis in which 400 rural, impoverished, African American men with a syphilis diagnosis were recruited to analyze the progression of the disease. Participants were never told about their diagnosis and were actively denied treatment, even after penicillin became the standard cure two decades into the experiment. As a result, many infected men spread the disease to their wives and children during the birthing process (Thomas & Quinn, 1991). The absence of accurate information and transparency between patients and doctors fueled a mistrust of health care providers in the African American

community. It changed the mindset for seeking help and yielded lower rates of health care use and adherence. White's (2005) research reflected this mistrust of health care providers and skepticism of the information provided by medical authority figures. Seventy-five percent of the African Americans in White's sample believed that men in the original Tuskegee study were purposely injected with syphilis. Two-thirds of African Americans sampled reported beliefs that African Americans are treated poorly by doctors, and in research studies in comparison to Caucasian individuals.

Armstrong et al. (2008) surveyed 236 African American and Caucasian patients in primary health care and emergency room settings about their beliefs and trust of the health care system. Though African American's reported feeling that medical professionals were competent, similar to their Caucasian counterparts, most African Americans felt as if the health care system lacked moral integrity. African American respondents reported significantly higher beliefs that health care systems lie to make money and experiment on patients without consent. African Americans in this study also reported worse health outcomes than their Caucasian peers (36.9 % versus 14.4% reporting fair/poor health respectively).

Today, culture is often defined outwardly by differences in media, food preferences, spirituality, and social behaviors. Culture also encompasses the core beliefs, values, and mantras of a group (Landrine & Klonoff, 1996). African American culture is described as collectivistic, with a strong respect for elders and giving back to the community (Sue & Sue, 2013; Kelly, Maynigo, Wesley, & Durham, 2013). African Americans that ascribe to traditional beliefs are more likely to be actively engaged in their community (Reid, Brown, Peterson, Snowden, & Hines, 2009). African American

families are typically matriarchal where female figures play a pivotal role in making family decisions (Sue & Sue, 2013).

Black culture is ever evolving and expressed through the arts such as music and physical representations via fashion and ethnic hairstyles (Burton, 2006). Hip hop music was initially created to be an expressive means of social and political beliefs. African American culture also lays claim to a distinctive type of cuisine that was heavily influenced by slavery and the Caribbean. Rations of left over and undesirable meats and vegetables were often provided for slaves to consume. Though African Americans now have access to choice foods, many traditional cooking methods, including the use of salt and fat, are common today. In fact, a genre of food coined, “soul food” is a celebrated version of these earlier cooking traditions (Prettyman, 2006). Language is also an important facet of African American culture. Often mislabeled as slang, African American English (AAE) is used widely among African American individuals around the country. AAE differs from traditional English in the pronunciation of sounds, and words borrowed from popular African American music. AAE may also be used during verbal sparring, sometimes referred to as toasting or roasting (Green, 2006). Sue and Sue (2013) note that other ethnicities, especially Euro-Americans, may interpret this communication style as hostile and aggressive.

Religion has been fundamental in the African American community, with churches often serving at the epicenter of social movements and support (Sernett & Robinson, 2006). Religion is often conceptualized as structured, community-based, organization, with set traditions and norms designed to facilitate intimacy with a higher being (Chatters, Taylor, Bullard, & Jackson, 2008). Religion has evolved for African

Americans from more indigenous African beliefs to a version of Christianity adapted from Euro-American beliefs. African American religious services are often euphoric, marked by music, dancing, clapping, and shouting. African American spirituality is generally characterized by a less formal structure, and more subjective and individual practices to relate to a higher being (Chatters et al., 2008). Commonly, the higher being for African Americans is benevolent, omniscient, and omnipresent (Newlin, Knafl, & Melkus, 2002).

The African American Acculturation Process

The field of acculturation research is vast, and acculturation is often conceptualized as shifts in thoughts and behaviors as a result of interactions with one or more differing cultures (Fox, Merz, Solórzano, & Roesch, 2013). Exterior changes in dress and food preferences are often accompanied by changes in social activities and communication. An accepted definition of acculturation as cited by Sam and Berry (2010) is, “those phenomena which result when groups of individuals having different cultures come into continuous first-hand contact, with subsequent changes in the original culture patterns of either or both groups... under this definition acculturation is to be distinguished from...assimilation, which is at times a phase of acculturation” (p. 473). The person-centered model of acculturation (Berry, 1995) suggests that individuals from the minority culture may have a variety of responses ranging from complete rejection of the majority culture to total assimilation with the majority and rejection of their heritage culture. Other ethnic minorities may find a way to integrate aspects of both cultures (Fu, Shen, & Marquez, 2014; Sam & Berry, 2010). Stress often accompanies the acculturation process as it brings about conflict and tension between one’s original cultural beliefs and

identity. The literature notes that women and those that are socially isolated are particularly susceptible to acculturation-related stress (Berry, 1995).

Acculturation has been extensively studied in other ethnic groups, especially immigrant populations, however acculturation of Black Americans is underrepresented in the literature (Landrine & Klonoff, 2006). By its very definition, acculturation shifts one's thoughts and behaviors away from more traditional cultural mannerisms toward a version of the majority culture. Though it is clear that African Americans undergo a version of acculturation, Landrine and Klonoff posit that researchers neglect to study this group because science and psychology relate African American as a socially constructed race without a distinct culture. As discussed earlier, African Americans have distinct cultural mores, media outlets, food preferences, and dialects that are susceptible to influence by and immersion with the majority culture.

One's level of acculturation is meaningful with respect to behavioral and psychological differences in ethnic minorities. Landrine and Klonoff (2006) reported an association between acculturation of African Americans and cigarette smoking. The research suggested that African Americans with more traditional health beliefs were more likely to smoke in comparison to African Americans in the sample that were acculturated to the majority culture. In a second study, Landrine and Klonoff determined that there was also a strong negative correlation between acculturation and hypertension among African American individuals. These two studies indicate that African Americans that are more acculturated to the majority culture have distinctively different food and health behaviors associated with hypertension. Kroon Van Diest, Tartakovsky, Stachon, Pettiet, and Perez (2014) studied ethnic minority women, acculturation, and body dissatisfaction.

Remarkably, the researchers found that African American women were the most influenced by stress related to acculturation in comparison to Asian American and Latino women. African American women in the study had a significant correlation between their acculturative stress and body image dissatisfaction. This research provides evidence that African American women who ascribe to more traditional culture beliefs reap the benefits of the healthier body images promoted by African American culture in comparison to the thinner body images that are celebrated in mainstream culture. One study described by Landrine and Klonoff (1996) explored predictors of anxiety, depression, low self-esteem, somatization, and obsessive-compulsive traits in African Americans. Acculturation was the best predictor of psychiatric difficulties above and beyond education, income, skin color, generic life events and stressors, and encounters with racism. Acculturation accounted for 13.7% to 21.1% of the variance associated with psychiatric difficulties.

Coping with Stress

Coping is an important concept as it encompasses behaviors and reactions to stress. Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen (1986) define coping as, “the person’s constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person’s resources.” (p. 993). This definition emphasizes the reactions one may have to a given situation and highlights how individualized and contextual these responses may be. Coping behaviors are typically implemented in order to help one regulate difficult or conflicting emotions and to assist with reducing or altering the source of the stress (Folkman et al., 1986).

Based on Folkman et al.'s (1986) early model, coping strategies are often sorted into one of two groups: problem-focused or emotion-focused. Problem-focused coping requires engaging with the source of stress (e.g. problem solving) or actively attempting to alleviate symptoms (e.g. restructuring thoughts, seeking social support, and expressing feelings). Conversely, emotion-focused coping involves distancing from the source of stress (e.g. avoiding the problem, wishing the situation were different, withdrawing from others, and self-blame). Research suggests that one's perception of control in the situation influences the type of coping styles used (Brantley, O'Hea, Jones, & Mehan, 2002). Individuals are more likely to rely on active coping skills when the source of stress is acute and within their locus of control. More avoidant or disengaged coping styles are implemented when stressors are chronic or when a person has little control (Brantley et al., 2002).

The coping behaviors discussed above are all reactions to the presence of a particular stressor. However, some individuals engage in proactive coping as a means of diminishing the impact of potential stressors. Proactive coping entails preplanning, and establishing goals in order to maximize resources. This coping style requires mental flexibility to reframe situations and generate solutions (Moring, Fuhrman, & Zauszniewski, 2011). Davis and Asliturk (2011) noted that those who engage in proactive coping are often more optimistic, resilient, and future-oriented.

Coping Strategies of African Americans

In addition to the stressors addressed for families of children with ASD, African American families traditionally face additional stressors including structural racism, discrimination, unsafe neighborhoods, fewer financial resources, single parent homes,

and imprisonment (Fu et al., 2014; Kelly et al., 2013; Sue & Sue, 2013). African Americans may also experience a more subtle form of racism, racial microaggressions. Racial microaggressions are insulting, invalidating, or demeaning remarks directed toward a person with minority status (Sue, Capodilupo, & Holder, 2008). They may be intentional or unconscious on behalf of the perpetrator. Sue et al. conducted a qualitative study with African American graduate students. The graduate students in their study reported that microaggressions were more difficult to reconcile in comparison to overt racism because they often questioned their perceptions of the offender's intent and motivation. After experiencing microaggressions, the graduate students reported relying on support from other ethnic minorities to make sense of the event and conflicting feelings regarding the offender (Sue et al., 2008).

One study suggests that these additional stressors, especially instances of racism and discrimination, promote more anticipatory coping behaviors in African Americans in comparison to Caucasians (LaVeist, Thorpe, Pierre, Mance, & Williams, 2014). African Americans may be culturally primed to proactively think about their behaviors and actions as a means of mitigating these stressors. Plummer and Slane's (1996) research examined differences in use of coping strategies between middle-income, African American and Caucasian participants. The researchers reported that African American participants endorsed more frequent use of all coping behaviors in comparison to their Caucasian peers. Plummer and Slane suggested that the additional stressors African Americans face give rise to a greater use of coping behaviors.

A review of the literature suggests that African Americans historically and culturally draw upon cultural strengths in order to cope with general life and culturally

specific stressors. African Americans typically rely on the family unit and extended family networks for support (Kelly et al., 2013; Sue & Sue, 2013). In a study of African American adolescents, those involved in community groups had higher psychological functioning and felt more empowered (McMahon, Singh, Garner, & Benhorin, 2004).

As previously noted, religion and spirituality are important structures in the African American community and a source of emotional support (Sue & Sue, 2013). As reported by Kelly et al. (2013), 76 percent of African Americans report praying daily and 53 percent indicate that they attend religious services at least once per week. Association and engagement in organized religion has been linked with positive adjustment, guidance, and peace in African Americans (Newlin et al., 2002). Those ascribing to more traditional African American spiritual and religious practices are significantly less likely to experience suicidal ideation (Kimbrough, Molock, & Walton, 1996). African Americans may be more inclined to seek help regarding mental health concerns from a spiritual leader rather than a mental health provider (Chatters et al., 2008).

For ethnic minorities, their level of acculturation also influences coping behaviors. Landrine and Klonoff (1996) studied coping style differences among African Americans by acculturation group (high acculturation versus low acculturation). Their results provide evidence that African Americans that are less acculturated tend to utilize denial, distancing, and avoidance to cope whereas highly acculturated African Americans tend to blame themselves and take more responsibility for problems. It is difficult to determine if one style of coping is better than another because adaptive coping is context specific. However, in general ruminating and self-blame is maladaptive because it does not address the problem or allow one to create psychological distance.

Hypotheses

The present study aimed to build upon the previous literature by understanding the unique stress and coping profiles of caregivers of children diagnosed with ASD from different cultural backgrounds. Previous literature suggests that parenting a child with ASD is more stressful than parenting a typically developing child or a child with other developmental disorders. It is also clear that parental stress management is vital to the well being of the child. No study to date has compared the caregiver's perceptions of their stress and coping behaviors within the context of culture.

In an effort to capture the demands of child rearing, the present study will also explore differences in stress and coping behaviors of caregivers of children and adolescents. Previous literature suggests that younger children require more of their parents' time than older children. Additionally, some theories posit that parents adapt to their child's specific needs with time, and therefore feel less stressed.

Studying caregiver stress and coping within the framework of culture allows clinicians the opportunity to tailor their treatment and support recommendations in a culturally sensitive manner. Thus, this study was guided by the following specific research questions:

1. Can reports of stress be accurately predicted by ethnic group membership (i.e. Caucasian caregivers, African American caregivers with low acculturation to the majority culture, and African American caregivers with high acculturation to the majority culture)?

2. With respect to proactive coping and coping behaviors, are there predictable differences, and thusly standard profiles, for the three aforementioned groups?
3. Regardless of racial identity and acculturation, are caregivers of younger children (under the age of five), elementary school-aged children (aged five to twelve) and adolescents (aged 13 to 17) reporting different stress patterns and coping behaviors?

Given the literature review, specific study hypotheses included the following:

- There will be differences in reported levels of stress such that Caucasian caregivers will report the highest levels of stress, followed by African American caregivers that are more acculturated to the majority culture. African American caregivers that are less acculturated will report the least amount of stress.
- Overall, there will be significant differences in the coping behaviors between the three groups of caregivers (African Americans with low acculturation, African Americans with high acculturation, and Caucasians)
 - African American caregivers that are less acculturated will report the most frequent use of coping behaviors, especially proactive coping, between the three groups, followed by highly acculturated African Americans.
 - African American caregivers that are less acculturated to the majority culture will report more frequent use of spirituality for coping.

- Regardless of race, families with older children will report less stress and more frequent use of engagement and proactive coping skills.

CHAPTER III

METHOD

Participants

Participants were primary caretakers of children with ASD. Eligible parents included those with a child under the age of 18 who had previously been diagnosed with ASD. Caregivers were recruited from the patient populations of psychiatrists and psychologists at two hospitals in the South Eastern United States. Additionally, this survey was publicized nationally on autism advocacy organizations websites, autism electronic mailing lists, and social media groups for autism families. As we were particularly interested in cultural influences, caregivers that did not identify as African American or Caucasian were excluded from the sample. Caregivers that identified as Caucasian and another race were excluded such that our Caucasian sample does not include any other racial minority groups.

Measures

Seven questionnaires were administered to all participants using the Qualtrics Online Survey Platform. These questionnaires gathered information about the child's symptoms related to autism, the caregiver's perceived level of stress related to caring for the child, and coping behaviors enlisted to alleviate stress. Participants also provided demographic data concerning their highest level of education, socioeconomic status, and ethnic background, variables that may relate to stress. African American caregivers completed an additional measure to assess their acculturation to the majority culture. See Appendix A for a complete copy of the questionnaires used.

Demographic Questionnaire. An adapted version of the Parental Perception of

the Development of Autism in their Children Questionnaire developed by Goin-Kochel, Mackintosh, and Myers (2009) was used to collect basic information about the child's diagnoses, a listing of previous treatment interventions implemented, and parent demographic data. The questionnaire contained 19 items that were used to control for demographic differences such as education and socioeconomic status that may impact the variables of interest.

Autism Symptoms. The Autism Spectrum Rating Scale (ASRS) Short Form is a 15-item measure adapted from the original 71-item measure and is frequently used to identify symptoms and behaviors commonly associated with ASD in children and adolescents ages 2 to 18 (Goldstein and Naglieri, 2010). There are two versions of the short form intended to capture preschool-aged children (2-5 years) and school-aged youth (6-18 years). Parents were administered the version that corresponded with their reported child's age. Parents were asked to select one of five options ranging from *Never* to *Very Frequently* to short statements regarding the child's behavior over the past month such as, "During the past four weeks, how often did the child play with others," and "During the past four weeks, how often did the child become upset if routines were changed?" A sum of the 15 items provided a raw score, which was converted to percentiles. Based on the percentiles, the child's presenting behaviors associated with ASD may be classified as Low, Average, Slightly Elevated, Elevated, or Very Elevated.

The ASRS maintains excellent psychometric characteristics. Both the preschool-aged and school-aged versions' Cronbach's Alphas ranged from .77 to .98 in a clinical sample. Additionally, the ASRS shows strong test-retest reliability with a corrected r range of .78 to .92 for the total scores across all versions of the form. Additionally, the

ASRS is moderately correlated with other ASD rating forms including the Gilliam Autism Rating Scale ($r = .80$), and the Gilliam Asperger's Disorder Scale ($r = .71$), an indication of validity. (Goldstein and Naglieri, 2010).

Parental Stress. The Parenting Stress Index, Fourth Edition (PSI-4) Short Form is a 36-item version of the 120-item measure developed by Richard Abidin to assess for stress pertaining to caring for a child ages 1 month to 12 years. The PSI-4 is comprised of two domains- Child and Parent, with six subscales each. The child domain evaluates stress associated with specific personality traits such as distractibility/hyperactivity, adaptability, reinforcement of the parent, demandingness, mood, and acceptability. The parent domain measures parental characteristics that may affect the parent-child relationship: competence, isolation, attachment, health, role restriction, depression, and spouse/parenting partner relationship. Parents were asked to circle one of five choices ranging from *Strongly Agree* to *Strongly Disagree* to short statements from each of the above-mentioned domains such as, "My child is so active that it exhausts me," and "I feel alone and without friends." Participants received a total score of parental stress.

This measure has been used extensively clinically and in research settings and is considered a reliable and valid measure of the aforementioned domains. The PSI-4's coefficient alphas ranged from .75 to .88, demonstrating high internal consistency. Across four separate studies of the PSI, test-retest reliability correlations ranged from .65 to .96 indicating that it is relatively stable scores across time. The PSI-4 total stress subscale correlated highly (.99) with the PSI-3 total stress subscale, a previously validated measure of parental stress (Abidin, 2012).

Autism-Related Parental Stress. The Autism Parenting Stress Index (APSI) is a relatively new measure developed by Silva and Schalock (2012) to assess parental stress related to specific autism characteristics. This 13-item measure asks parents to rate how much stress certain aspects of their child's health creates for them. A sample item includes, "How much stress does your child's self-injurious behavior cause you?" Parents were asked to rate these questions on a 0 (*Not Stressful*) to 5 (*So Stressful Sometimes We Feel We Can't Cope*) Likert Scale. A sum of the 13 items provides a total score.

This measure has not yet been used extensively in research, however there is some evidence that it is psychometrically sound. The APSI Cronbach's alphas for parent's of children with ASD was .83, demonstrating high internal consistency. This measure also showed high test-retest stability, with a co-efficient of .88 four months later. The APSI also showed strong discriminate validity. Parents of children with ASD reported significantly higher levels of stress in comparison to parents of children with developmental delays and those with typically developing children. The APSI was also significantly positively correlated with the Pervasive Developmental Disorders Behavior Inventory, a pre-established measure of autistic characteristics (Silva & Schalock, 2012).

Proactive Coping. The Proactive Coping Inventory (PCI) (Greenglass, Schwarzer, Jakubiec, Fiksenbaum, & Taubert, 1999) is an instrument designed to assess an individual's coping behaviors across seven separate subscales (proactive coping, reflective coping, strategic planning, preventive coping, instrumental social support seeking, emotional support seeking, and avoidance coping). It is intended to measure a person's inclination to believe and envision success. The scales look at one's ability to

pre-plan for events and effectively utilize resources. For the purposes of this study, we were particularly interested in the Proactive Coping (14 items) and Strategic Planning (4 items) subscales, which encompasses 18 total items. These two subscales get at the crux of foresight and preplanning that may alleviate stress. Participants ranked statements such as, “I try to pinpoint what I need to succeed,” and “I make a plan and follow it.” on a 1 (*Not true at all*) to 4 (*Completely true*) Likert scale. Two subscale scores were computed by summing the individual’s responses to the 18 items.

The PCI was initially developed and validated using a Canadian and Polish-Canadian sample. However, the inventory has since been translated into 17 languages and adapted for teenagers (Greenglass et al., 1999). In the initial validation of the instrument, the Proactive Coping Index showed high internal consistency ($\alpha = .80 - .85$). The Strategic Planning Index had acceptable internal consistency ($\alpha = .71$). With respect to validity, the PCI showed strong convergent validity and correlated positively with the Proactive Attitude Scale ($r = .76$), and the General Perceived Self-Efficacy Scale ($r = .78$). The PCI showed good divergent validity and correlated negatively with measures of Denial ($r = -.12$), Behavioral Disengagement ($r = -.03 - .06$), Self-Blame ($r = -.05 - .18$), and Depression ($r = -.08 - .17$) (Greenglass et al., 1999).

Coping Behaviors. The Coping Strategies Inventory-Short Form (CSI-SF) is a 32-item version of the original 72-item measure. The CSI-SF identifies coping strategies one may use when he or she is faced with a stressful situation (Tobin, 2001). The structure of the scale is based upon the Ways of Coping Checklist (Tobin, Holroyd, Reynolds, & Wigal, 1989) and measures eight different coping behaviors that are divided into two major domains: Engagement (problem solving, cognitive restructuring, social

support, and expressing emotion) and Disengagement (problem avoidance, wishful thinking, social withdrawal, and self-criticism). The Engagement coping behaviors reflect an individual's attempts to actively manage or change the stressful event. The Disengagement domain reflects one's attempts to avoid, or distance themselves during stressful times. Participants were asked to identify a particularly stressful situation from the past month and to keep that event in mind while responding to the measure. Participants rated questions like, "I told myself things that helped me feel better," and "I blamed myself" on a 1 (*Not At All*) to 5 (*Very Much*) Likert scale. Participants received a sum score for the Engagement and Disengagement domains.

All of the original CSI subscales maintain good reliability (coefficient α ranged from 0.71 to 0.94), with the Engagement ($\alpha = .90$) and Disengagement ($\alpha = .89$) scales demonstrating high reliability. The CSI-SF Engagement and Disengagement scales averaged an alpha of .90. Given the transient nature of coping and responses to stress, test-retest reliability is not an accurate reflection of reliability. This measure asks participants to think of a specific event while responding to the questions, and during re-tests, participants often referenced different events. As such, it is expected that participants may employ different coping skills in the face of different stressors. A hierarchical factor analysis supports a primary, secondary, and tertiary model of coping, with eight primary factors (Tobin et al., 1989). The CSI also displayed good construct validity and Tobin (2001) notes that this measure is particularly proficient at predicting depressive symptoms for those under stress. Additionally, reports of self-efficacy were positively correlated with the Engagement subscale and negatively correlated with the Disengagement subscale of the CSI (Tobin, 2001).

Spirituality-Based Coping Behaviors. As previously noted, spiritual and religious coping methods are a hallmark of the African American community, and central to one of the hypotheses of this study. Pargament, Koenig, and Perez (2000) developed the RCOPE and the Brief RCOPE to assess potentially positive and negative religious coping behaviors. Participants were asked to think of a stressful event they encountered recently and to rate 14 statements (7 each measuring positive and negative religious coping) on a 1 (*Not At all*) to 4 (*A Great Deal*) Likert Scale. Sample items include, “I sought God’s love and care.” and “I questioned the power of God.” Respondents were given a sum score for both positive and negative religious coping.

The Brief RCOPE was validated using individuals from college and elderly populations. A confirmatory factor analysis demonstrated acceptable goodness of fit for the two-factor model. All subscales showed acceptable reliability ($\alpha > .75$). The positive and negative religious coping behaviors were significantly, positively correlated ($r = .17-.18$), however this was a relatively low correlation, suggesting that these two scales are measuring distinct qualities. With regard to validity, the RCOPE positive religious coping scale was significantly correlated with measures of positive religious changes ($r = .61$) and stress-related growth ($r = .41$). The RCOPE negative religious coping scale was significantly correlated with individual’s rankings of their current distress ($r = .16$). Current distress was not correlated with the positive religious coping scale ($r = .04$) (Pargament et al., 2000; Pargament, Smith, Koenig, & Perez, 1998).

Acculturation. The African American Acculturation Scale-Revised (AAAS-R) is a 47-item version of its precursor and was developed by Klonoff and Landrine (2000) to assess African Americans’ cultural orientation. The measure has eight subscales

(Religious Beliefs and Practices, Preferences for things African American, Interracial Attitudes, Family Practices, Health Beliefs and Practices, Cultural Superstitions, Racial Segregation, and Family Values). Participants respond to questions in the different domains by using a 1 (*I totally disagree/Not True at all*) to 7 (*I strongly Agree/Absolutely True*) Likert Scale. Sample items include, “I like gospel music,” “I feel more comfortable around Blacks than around Whites,” and “I currently live in a mostly Black neighborhood.” A total score was calculated by summing responses to all of the questionnaire items. Higher scores on the subscales and the Total AAAS-R score reflect a preference for traditional African American values, and traditional cultural beliefs. Lower scores indicate more immersion in the majority culture and less subscription to typical African American mores.

The AAAS was the first measure of its kind to be developed and has been used extensively in the literature by the creators and other research teams. The shortened version, the AAAS-R, maintains high internal consistency (coefficient α ranged from 0.67 to 0.93). The revised version correlated nearly perfectly with the original AAAS ($r = .97$). In the initial psychometric evaluation, the researchers noted a wide range of scores on each of the subtests. As this is intended to be a measure of African American cultural identity, the authors also compared African American responses to other ethnic groups. Individuals in other ethnic groups scored significantly lower than the African American sample. This provides some evidence of divergent validity. Furthermore, the AAAS-R was not meaningfully correlated with age or proxies for socioeconomic status, education and income, indicating that the scale addresses African American cultural beliefs that go beyond these variables (Klonoff & Landrine, 2000).

Procedure

Caregivers were recruited from the patient populations of health professionals from two hospitals in the South Eastern United States. This study was also advertised nationally via social media and autism advocacy organizations. Caregivers interested in participating in the research sent an email to a designated email address advertised on the flyers or contacted the EVMS ASD research coordinator. Participants were emailed a link to complete the survey online via the Qualtrics Survey Platform. Participants' e-mail addresses were not linked to their study responses. Due to licensing agreements and permission to use copyrighted questionnaires, this survey was password protected. The password ensured that only individuals enrolled in the study have access to the questionnaire items. The Qualtrics link directed caregivers to an introductory letter that welcomed them to the study and briefly explained the purpose. Caregivers were then directed to the informed consent page where they were reminded of their rights as a participant in this voluntary project. Participants received a \$10 electronic gift card as compensation for their participation in the study. Parents with two children with an ASD diagnosis were randomly assigned to complete the measures based on the first letter of their last name. If the caregiver's last name started with A through L, they were directed to report on their youngest child with an ASD diagnosis. Caregivers with a last name beginning in L through Z reported on their oldest child. Caregivers with three children with a diagnosis of ASD reported on their middle child. Once participants have completed all measures, caregivers were given the option to indicate their desire for a copy of summarized study results by providing an e-mail address. This e-mail address

was not linked to participant's responses. Each caregiver was assigned a randomized identification number coding and analyses.

CHAPTER IV

RESULTS

Prior to the analyses for main hypotheses, frequencies and descriptive statistics for primary variables were calculated. Assumptions for the proposed models were then checked. Descriptive statistics were screened for extreme outliers, floor and ceiling effects, and distribution shape. With the exception of family income, all other variables showed roughly normal distributions with no significant outliers. The three outliers for family income were excluded from analyses of differences between groups related to demographic information.

Profile of Sample

One hundred thirty-one surveys were started through the online link. Given the sensitivity of the measures to missing data, a total score was not calculated for any measure missing more than ten percent of test items. Additionally, the analysis used, discriminant function analysis, excluded participants that did not have a score for every variable of interest because it could not accurately account for the variation between the groups with missing data. Twenty participants were removed from the sample due to incomplete measures. Another eight participants were excluded from the sample because they did not identify racially as Caucasian only or African American. Sample characteristics (N=103) can be seen in Tables 1-4. The sample was evenly distributed between the two racial groups with 50.5% of the sample identifying as Caucasian (n=52) and 49.5% of the sample identifying as African American (n=51). The African American participants in the sample were further classified as having high or low acculturation to the majority American culture based on their score on the African American

Acculturation Scale- Revised (AAAS-R). The median AAAS-R score for this sample was 208 and those with a score above the median were classified as low acculturation to the majority culture and ascribing to more traditional African American values. Those with a score below the median were considered high acculturation to the majority culture; less traditionally African American. Klonoff (personal communication, August 21, 2014) suggests using a median split to determine acculturation group membership as standardized norms for the AAAS-R have not been created. In their initial study of the AAAS-R, Klonoff and Landrine (2000) reported a mean total score of 220.46 with a standard deviation of 40.88 for their sample. Participants recruited from this geographical region (District of Columbia, Maryland, North Carolina, South Carolina, Virginia, and West Virginia) comprised 68% of this research sample. Approximately two-thirds (63%, n=65) of the participants were mothers and fathers comprised 36% (n=37) of the respondents. One participant identified as the grandmother of a child with ASD (1%). The majority of participants reported being married or in a domestic partnership (80%, n=82). Forty-five percent (n=47) of the sample reported obtaining a Bachelor's Degree or higher level of education and this is slightly above the reported national average for higher education of 34% (U.S. Department of Education, 2015). Participants reported a wide range in annual family income from \$12,000 to 400,000. There were two reported incomes more than one standard deviation below the mean and one reported income more than two standard deviations above the mean. Once these three incomes were excluded from the analysis, there was no significant difference between the three cultural groups for reported income. Our Caucasian participants' income aligned with the national reported median income for Caucasian, non Hispanic

families (U.S. Census Bureau, 2015), but the African American participants in this sample reported salaries higher than the national average for African American families. In 2014, the reported median family income for Caucasian families in the United States was \$60,256 and the reported median income for African American families was \$35,398. There was a significant difference between African American and Caucasian respondents by educational level, but not by income $F(2, 100) = 6.00, p < .01$. Caucasian participants had significantly higher levels of education than African American participants ($p < .01$).

The majority of the participants surveyed reported having one or two children in the home (74%, $n = 76$), and only one child with a diagnosis of ASD (90%, $n = 93$). Eight families (8%) reported having two children with a diagnosis of ASD and two families indicated having three children with ASD (2%). Families with multiple children with a diagnosis of ASD were randomly assigned to report on their oldest, youngest, or middle child based on the last letter of their last name. This random assignment affected 10% of the sample ($n = 10$). With respect to the children included in this sample, the majority were male (78%, $n = 80$) and all participants were aged 1 to 18. The sample was evenly split between early childhood (30%, $n = 31$), middle childhood (33%, $n = 34$), and adolescence (37%, $n = 38$). Most of the children included in this sample were diagnosed during early childhood (76%, $n = 78$) and only five percent were diagnosed age 12 or later ($n = 5$). There was a significant difference in age at diagnosis between the three cultural groups $F(2, 96) = 4.89, p = .01$. Low acculturation African Americans were diagnosed approximately two years earlier than their Caucasian counterparts ($p = .01$).

Table 1

Demographic Information by Cultural Group

<u>Demographic</u>	<u>Caucasian</u> (n= 52)	<u>High Acculturation</u> <u>African American</u> (n= 25)	<u>Low Acculturation</u> <u>African American</u> (n=26)	<u>Total</u> (n=103)
Mean Caregiver Age (Years)	40.88	36.44	35.65	38.48
Mean Family Income	\$69,630	\$58,375	\$54,692	\$63,045
Parental Education				
Middle School	-	-	1 (3.8%)	1 (1%)
Some High School	-	1 (4%)	1 (3.8%)	2 (1.9%)
High School/GED	6 (11.5%)	6 (24%)	7 (26.9%)	19 (18.4%)
Technical School	2 (3.8%)	-	5 (19.2%)	7 (6.8%)
Associates Degree	8 (15.4%)	4 (16%)	4 (15.4%)	16 (15.5%)
Some College	11 (21.2%)	1 (4%)	-	12 (11.7%)
Bachelor's Degree	16 (30.8%)	5 (20%)	8 (30.8%)	29 (28.2%)
Master's Degree	8 (15.4%)	8 (32%)	-	16 (15.5%)
Doctoral Degree	1 (1.9%)	-	-	1 (1%)
Endorsed Religious Affiliation	n=45 (88%)	n=17 (68%)	n=24 (92%)	n=86 (84.3%)
Mean Child Age (Years)	10.52	8.50	6.87	9.12
Mean Child Age at Diagnosis (Years)	4.96	3.88	2.78	4.19

Another important demographic variable for this research was conceptualizing ASD symptom severity. All participants were administered the Autism Spectrum Rating Scale appropriate for their age. All scores on this measure fell in the Slightly to Very Elevated range, 88th to 99th percentile. There were no significant differences in ASRS scores between the three cultural groups, suggesting that all participants in this study

exhibited symptoms consistent with a diagnosis of autism. See Table 2 for a comparison of ASRS scores by child age and cultural group.

Table 2

Autism Spectrum Rating Scale Scores by Cultural Group and Child Age

	<u>Caucasian</u>	<u>High Acculturation</u>	<u>Low Acculturation</u>
		<u>African American</u>	<u>African American</u>
2-5 Years			
Mean	44.50	53.58	57.07
Percentile	99 th	99 th	99 th
Clinical Category	Very Elevated	Very Elevated	Very Elevated
6-18 Years			
Mean	38.04	41.93	47.09
Percentile	99 th	99 th	99 th
Clinical Category	Very Elevated	Very Elevated	Very Elevated

There were a number of comorbid diagnoses endorsed by parents in this sample. In a large study of over 2,000 individuals diagnosed with ASD, 83% of the sample was diagnosed with a co-morbid developmental diagnosis and 10% carried a co-morbid psychiatric diagnosis (Levy et al., 2010). Two of the groups in the present sample, Caucasian and Low Acculturation African American, evidenced higher rates of Attention Deficit Hyperactivity Disorder (ADHD) in comparison to the estimated 21% prevalence rate suggested by the population research. Additionally, our population reported significantly higher rates of anxiety diagnoses in comparison to the 3.4% prevalence rate cited in the population study. As noted in the literature review, previous research also indicated higher rates of misdiagnosis for ethnic minority children, specifically a

diagnosis of Oppositional Defiant Disorder (ODD) instead of autism. The African Americans in this sample reported higher rates of ODD, consistent with the previous research. None of the African Americans in the Low Acculturation group reported a diagnosis related to sensory integration difficulties. This diagnosis is typically given by occupational or physical therapists and may reflect less access to these types of services for Low Acculturation African Americans. Table 3 highlights the number of participants diagnosed with a psychiatric co-morbidity by cultural group.

Table 3

Number of Participants Endorsing Comorbid Diagnoses by Cultural Group

	<u>Caucasian</u> (n= 52)	<u>High Acculturation</u> <u>African American</u> (n= 25)	<u>Low Acculturation</u> <u>African American</u> (n=26)
Attention Deficit Hyperactivity Disorder	19 (37%)	4 (16%)	14 (54%)
Anxiety	17 (33%)	17 (68%)	22 (85%)
Depression	7 (13%)	5 (20%)	1 (4%)
Oppositional Defiant Disorder	3 (6%)	8 (32%)	4 (15%)
Intellectual Disability	6 (12%)	4 (16%)	2 (8%)
Brain Damage	1 (2%)	4 (16%)	3 (12%)
Fragile X Syndrome	2 (4%)	0	0
Seizures	2 (4%)	0	2 (8%)

Sensory Processing Disorder	10 (19%)	7 (28%)	0
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Analyses

The first objective of this study was to understand the stress and coping profiles of African American caregivers of children with ASD in comparison to Caucasian caregivers. A hierarchical Discriminant Function Analysis (DFA) was used to predict group membership based on the variables of interest. This analysis method distinguishes profiles and response patterns between naturally occurring groups. When certain assumptions are met (e.g. normality of the data, covarianace between variables), discriminant analysis is more statistically powerful and efficient in comparison to multinomial logistic regression (Pohar, Blas, & Turk, 2004).

Participants were categorized into one of three cultural groups: Caucasians, African Americans that are highly acculturated to the majority culture, and African Americans that are less acculturated to the majority culture. A median split of acculturation scores was used to designate high or low acculturation. The initial DFA had five predictor variables of interest: Total PSI score, APSI Total Score, Proactive Coping Total Score, CSI Engagement Score, CSI Disengagement Score. Mean scores and 95% confidence intervals for each racial group are reported in Table 4.

Table 4

Mean Scores for Each Variable of Interest By Cultural Groups

<u>Variable</u>	<u>Caucasian</u>	<u>High Acculturation</u>	<u>Low Acculturation</u>	<u>Total</u>
	<u>n= 48 (46%)</u>	<u>African American</u>	<u>African American</u>	<u>n=103</u>
		<u>n= 23 (22%)</u>	<u>n=26 (25%)</u>	
Parenting Stress Index (Range: 36-180)	115 (CI 109-121) [Z-Score -.41]	130 (CI 120-138) [Z-Score .29]	134 (CI 126-143) [Z-Score .49]	123
Autism Parenting Stress Index (Range: 0-65)	23 (CI 21-26) [Z-Score -.46]	29 (CI 25-32) [Z-Score .19]	34 (CI 31-37) [Z-Score .68]	27
Proactive Coping (Range: 18-72)	53 (CI 51-55) [Z-Score .14]	52 (CI 46-57) [Z-Score .12]	57 (CI 51-63) [Z-Score -.33]	52
Engaged Coping (Range: 16-80)	48 (CI 45-51) [Z-Score -.29]	57 (CI 51-63) [Z-Score .42]	56 (CI 51-61) [Z-Score .27]	52
Disengaged Coping (Range: 16-80)	42 (CI 39-46) [Z-Score -.28]	45 (CI 41-49) [Z-Score .18]	47 (CI 42-51) [Z-Score .23]	44

Confidence intervals are reported at the 95th percentile

The data was checked to ensure all assumptions for DFA were met prior to running the analysis. The first three assumptions relate to study design: continuous predictor variables, categorical dependent variable with two or more groups, and independence of observations. All three of these assumptions were achieved. There were no outliers that needed to be addressed regarding the variables included in the DFA model. Additionally, all variables maintained adequate skewness and kurtosis. The data was also analyzed for patterns of missing values. All variables included in the model had missing value percentages between 0-4.5%, indicating that at minimum 96% of participants completed each item of the measures.

DFA was used to determine if there were significant differences between the three racial groups on the above-mentioned predictors and if the model reliably predicted membership to a given racial group based on the predictor variables. With three cultural groups, the model created two orthogonal discriminate functions. The first function aimed to maximize the discrimination and produce as much separation as possible among the three cultural levels. The second function accounted for any remaining variance in the model and maximized the discrimination between these groups. The Wilks' Lambda for the first function of this DFA was significant ($\Lambda = .57, p < .01$), which indicates that it significantly discriminates between the cultural groups based on the stress and coping variables. The function yielded group centroid values, an average discriminate score across all of the measures used. Group centroid values that are further away represent greater discrimination or difference between those groups. A comparison of the functions at group centroids for the first function suggests that low acculturation African Americans (Centroid= .99) experience more stress and use more coping than high acculturation African Americans (Centroid= .56) and Caucasians (Centroid= -.81). A further exploration of the standardized discriminate function coefficients, a measure of relative importance for each of the variables, indicates that stress variables are the most distinguishing measures between the three groups. To a lesser extent, disengaged and engaged forms of coping also contributed to distinguishing the profiles of the three racial groups. In this function, proactive coping did not assist in differentiating the three groups. The second function was not significant ($\Lambda = .95, p = .37$). This suggests a singular classification profile of cultural groups. See Table 5 for standardized discriminate function coefficients for function one of the model.

Table 5

Standardized Discriminate Function Coefficients for Overall DFA by Cultural Group, Function 1

Parenting Stress Index	.53
Autism Parenting Stress Index	.64
Engaged Coping	.39
Disengaged Coping	.26
Proactive Coping	-.23

This model accurately predicted group membership using stress and coping variables for 62.9% of participants. Stress and coping variables allowed for the most accurate prediction of Caucasian participants (77% accuracy rate) and accurately placed low acculturation African American participants 58% of the time. The model had greater difficulty distinguishing highly acculturated African Americans and only accurately placed those participants in the appropriate group 39% of the time.

A second DFA was used to explore the impact of religion and spirituality on coping and stress for the three cultural groups. Group membership remained the same, but RCOPE Positive Score, and RCOPE Negative Score were added to the other predictor variables to account for religion. Only participants that endorsed a religious or spiritual affiliation were included in this analysis. In excluding those that are not religious or spiritual, approximately 35% of the high acculturation African American participants were eliminated from the sample. This is a stark contrast to only losing 15% and 8% from the Caucasian and low acculturation African American groups respectively. Refer to table 6 for mean scores for each of measures by cultural groups. Confidence intervals (95%) are provided in parentheses for each measure.

Table 6

Mean Scores for Variables of Interest, Including Religion By Cultural Groups

<u>Variable</u>	<u>Caucasian</u>	<u>High Acculturation</u>	<u>Low Acculturation</u>	<u>Total</u>
	<u>n= 41 (51%)</u>	<u>African American</u>	<u>African American</u>	<u>n=80</u>
		<u>n= 15 (18%)</u>	<u>n=24 (30%)</u>	
Parenting Stress Index (Range: 36-180)	113 (CI 107-120) [Z Score -.45]	123 (CI 111-134) [Z Score -.02]	133 (CI 124-141) [Z Score .41]	121
Autism Parenting Stress Index (Range: 0-65)	23 (CI 20-26) [Z Score -.46]	27 (CI 23-31) [Z Score -.04]	34 (CI 31-37) [Z Score .65]	27
Proactive Coping (Range: 18-72)	53 (CI 51-56) [Z Score -.04]	56 (CI 49-62) [Z Score .39]	49 (CI 44-54) [Z Score -.25]	53
Engaged Coping (Range: 16-80)	49 (CI 45-52) [Z Score -.28]	60 (CI 52-68) [Z Score .62]	56 (CI 51-62) [Z Score .33]	53
Disengaged Coping (Range: 16-80)	40 (CI 37-44) [Z Score -.37]	44 (CI 40-49) [Z Score .02]	46 (CI 42-50) [Z Score .18]	43
Positive Religious Coping (Range: 7-28)	15 (CI 13-17) [Z Score -.20]	20 (CI 18-23) [Z Score .66]	21 (CI 20-22) [Z Score .78]	18
Negative Religious Coping (Range: 7-28)	10 (CI 9-12) [Z Score -.34]	12 (CI 9-14) [Z Score -.07]	16 (CI 13-18) [Z Score .71]	12

Confidence intervals in parentheses are reported at the 95th percentile

These functions each independently compare the relative importance of the stress and coping variables, including religious coping, in the model. The Wilks' Lambda for the first function of this DFA was significant ($\Lambda = .43, p < .01$), which indicates the ability to significantly discriminate between the groups using the stress and coping variables. As with the first DFA, the functions yield group centroid values, an average discriminate score across all of the measures used. A comparison of the functions at group centroids for the first function suggests that low acculturation African Americans

(Centroid= 1.27) experience more stress and use more coping than high acculturation African American (Centroid= .58) and Caucasian participants (Centroid= -.96). A further exploration of the standardized discriminate coefficients indicates that positive religious coping is the most distinguishing measure between the groups followed by negative religious coping. Similarly to the DFA that included the entire sample, stress variables and disengaged and engaged forms of coping also contributed to distinguishing the profiles of the three cultural groups. In this function, proactive coping did not assist in differentiating the three groups. The second function was not significant ($\Lambda = .88, p = .16$), suggesting no additional ability to discriminate between the groups beyond what is accounted for from function one. See Table 7 for standardized discriminate function coefficients for function one of this DFA.

Table 7

Standardized Discriminate Function Coefficients for DFA Including Religious Coping, Function 1

Parenting Stress Index	.40
Autism Parenting Stress Index	.50
Engaged Coping	.34
Disengaged Coping	.26
Proactive Coping	-.15
Positive Religious Coping	.62
Negative Religious Coping	.45

Overall this model accurately predicted group membership using stress and coping variables for 70% of participants. The addition of religious coping increased the prediction accuracy of the model for religious persons by 8%. When looking just at religious and spiritual participants, stress and coping variables allowed for the most accurate prediction of low acculturation African American participants (75% accuracy rate) followed by Caucasian participants (68% accuracy rate) and highly acculturated African Americans (67% accuracy rate).

The final objective of the study focused on understanding stress and coping profile differences between caregivers caring for children of different ages. This objective utilized the same DFA procedure outlined for the three cultural groups. Caregivers were assigned to one of three groups: caring for a child under the age of five, a child aged five to twelve, and an adolescent aged thirteen to seventeen. These groups mirrored typical transitions for children in the American school system. The first five variables of interest were used and excluded religious coping. Table 8 provides mean scores for each variable included in the DFA and confidence intervals at the 95th percentile.

Table 8

Mean Scores for Each Variable of Interest By Child Age Groups

<u>Variable</u>	<u>Early Childhood</u>	<u>Middle Childhood</u>	<u>Adolescents</u>	<u>Total</u>
	<u>n=31(30%)</u>	<u>n= 34(33%)</u>	<u>n= 38 (37%)</u>	<u>n=103</u>
Parenting Stress Index (Range: 36-180)	127 (117-136) [Z Score .15]	125 (117-133) [Z Score .07]	119 (113-125) [Z Score -.18]	123

Table 8 continued

<u>Variable</u>	<u>Early Childhood</u> n=31(30%)	<u>Middle Childhood</u> n= 34(33%)	<u>Adolescents</u> n= 38 (37%)	<u>Total</u> n=103
Autism Parenting Stress Index (Range: 0-65)	30 (27-34) [Z Score .33]	28 (25-32) [Z Score .12]	24 (21-26) [Z Score -.39]	27
Proactive Coping (Range: 18-72)	51 (47-56) [Z Score .00]	51 (48-54) [Z Score -.07]	53 (50-56) [Z Score .07]	52
Engaged Coping (Range: 16-80)	55 (50-60) [Z Score .27]	51 (46-56) [Z Score -.11]	51 (47-52) [Z Score -.19]	52
Disengaged Coping (Range: 16-80)	43 (40-47) [Z Score -.08]	44 (41-48) [Z Score .04]	44 (41-48) [Z Score -.06]	44

Confidence intervals in parentheses are reported at the 95th percentile

The Wilks' Lambdas for both functions of this DFA was not significant ($\Lambda = .86$, $p = .15$; $\Lambda = .99$, $p = .90$). This suggests that neither of these functions is apt at distinguishing the three age groups using the stress and coping variables. Overall this model accurately predicted group membership using stress and coping variables for 51.5% of participants. Stress and coping variables allowed for the most accurate prediction of caregivers with children in early childhood (68% accuracy rate) and accurately placed caregivers of adolescents 60% of the time. The model had greater difficulty distinguishing caregivers of children in middle childhood and only accurately placed those participants in the appropriate group 26% of the time.

CHAPTER V

DISCUSSION

With the 30 percent rise in the prominence of diagnoses over the previous estimates, the autism community has received a great deal of public attention in recent years. However, the popularity of the diagnosis has largely resulted in understanding the biological underpinnings of ASD and early intervention, and relatively little is published about the role of cultural influences and ethnicity in living with the disorder. The present study intended to add to the scientific literature by exploring African American caregivers' experience when caring for a child with ASD in comparison to their ethnic majority counterparts.

Principal Hypotheses

Despite evidence suggesting African Americans experience more stressors than ethnic majorities, there is a strong literature base describing the historical mistrust African Americans have toward healthcare professionals and their reticence to disclose health information. As such, I anticipated that Caucasian caregivers would report higher levels of stress in comparison to the two African American groups. This hypothesis was not supported and the low acculturation African American group reported the highest levels of stress. There were no significant differences in reported symptom severity, so this finding was not impacted by the severity of the presentation of ASD. One potential explanation for this finding might be the anonymity of the survey. Respondents, including African American participants, may have felt more freedom to be forthright in their responses because they were anonymous. An alternative explanation for this

finding might be that families that experience higher levels of stress are more inclined to report as a means of getting additional assistance or access to services.

Additionally, it was hypothesized that African Americans in the low acculturation group would report the most frequent use of coping behaviors across the three domains: proactive coping, engaged coping, and disengaged coping. In this population, proactive coping reflects strategic thinking and organizing to prevent avoidable negative consequences. For caregivers of children with ASD, this may include packing favorite items, avoiding sensory aversions, or requesting meetings with staff to plan for the school year. Engaged and disengaged coping are both responses to an already present problem. Engaged coping evidences the ability to actively generate solutions to alleviate the stressor or feelings related to the stressor. This may involve talking with another person, utilizing resources in the community, or making a plan of action. Disengaged coping is a person's ability to distance themselves from problems that are outside of their locus of control. For example, caregivers of children with autism may not be able to prevent every tantrum or control every loud environment. Not activity engaging in coping in these situations is likely most adaptive.

Indeed, low acculturation African Americans did report the most frequent use of coping styles across the three cultural groups. However, proactive coping was not a discriminating measure in any of the models. The range for the proactive coping measure used in this study was 18-72. All of the groups involved in this research averaged scores of 52, indicating a high use of proactive coping for all families in this study. This suggests that parenting a child with exceptionalities requires a high amount of strategic planning and forwarding thinking regardless of culture. This study was unable to account

for the specific theory that African Americans use more proactive coping skills because they are primed by the chronic stressors traditionally impacting ethnic minorities.

The results of this study suggest that African Americans, regardless of acculturation level, utilize engaged and disengaged coping more than their Caucasian counterparts. This is in alignment with previous literature noting that African Americans experience additional stressors such as discrimination, neighborhood violence, and loss of a family member to incarceration, which demands activation of additional coping skills.

Another consideration for this study was the role of religion and spirituality on coping for the three racial groups. Historically, involvement in the church and religion have been cornerstones of African American culture. It was hypothesized that low acculturation African American caregivers will report more frequent use of spirituality for coping. This hypothesis was supported by the discriminant function analysis. Low acculturation African Americans were more likely to engage in positive and negative religious coping in comparison to Caucasian and high acculturation African American caregivers. In this sample, religion seemed to serve as a distinguishing characteristic between high and low acculturation African American families.

The final hypothesis explored caregiving across the lifespan. The literature for parental stress across different stages of childhood is conflicting. Some studies suggest that earlier stages of childhood are more stressful because parents are adjusting to their new roles, while other studies report that parenting stressors change over time and parenting continues to be stressful. Given the specific challenges of parenting a child with autism and navigating the diagnostic process, I anticipated that families with older children would report less stress and more frequent use of engagement and proactive

coping skills. This hypothesis was not supported and there were no differences in reported stress or coping behaviors between parents of children in early childhood, middle childhood, and adolescence. These findings support previous research suggesting that parents experience parental stress at all age levels (McStay et al., 2014). Many of the studies regarding parental stress use a typically developing population. For caregivers of children with ASD, the great needs of these children may cloak any significant differences in caregiver stress across the lifespan.

Clinical Implications

The primary purpose of this study was to understand the impact culture might have on caregivers of children after they receive a diagnosis of ASD. In this study, there were significant differences in the reported stress and coping for Caucasian caregivers versus African American caregivers. African American families seem to experience more stress, resulting in higher demands for coping in comparison to their Caucasian counterparts. The literature suggests a strong correlation between higher levels of parental stress and maladaptive outcomes for parents (e.g. increased anxiety, depression, harsher parenting techniques). This research highlights the importance of routinely assessing stress in parents and potentially intervening before parental stress affects the family system. The Autism Parenting Stress Index used in this research is one example of a quick screener that could be used to assist in monitoring caregiver stress. In addition to a thorough clinical interview, the APSI could be administered at intervals in the course of therapy to monitor specific characteristics of ASD that maybe most stressful for individual families. As an illustration, one family may be especially stressed by aggressive behaviors toward siblings and another may have more concerns about sleep

difficulties. By administering the APSI or a similar measure, clinicians can tailor treatment to meet specific family needs and relieve related parental stress.

Acculturation was also an important factor in considering the way African American families experience stress and coping. In this study, acculturation did account for some differences in stress and coping between the African American groups. Across all measures, low acculturation African Americans reported higher levels of stress and greater use of coping skills in comparison to high acculturation African Americans. While acculturation is difficult to assess, clinicians should make an effort to familiarize themselves with African American culture and unique stressors these families encounter. Broaching difficult topics such as the family's experiences with structural racism or prejudice in medical care may enhance the therapeutic alliance and reveal stressors that are not typically covered in a basic clinical interview. Additional questions that may be pertinent include financial concerns, access to medical care (e.g. transportation or limitations with insurance copays), structure of the family (e.g. matriarchal), and work and home environments (e.g. multiple jobs and safety).

Most remarkable was the role of religion for low acculturation African American caregivers. These participants were more likely to endorse being religious or spiritual and to report using religion to cope. They engaged in positive and negative religious coping more frequently than their Caucasian and high acculturation counterparts. An assessment for traditional African American values (e.g. attending church, living in a Black community, collectivistic traits) may enhance clinician understanding of the families' risk for stress and resultant negative outcomes. When working with African American families, clinicians should specifically ask about the role religion and

spiritually may play for these families. Clinicians should be mindful of how religious coping could be maladaptive and add additional stress. As an illustration, caregivers may think “God is punishing me/my child with this illness,” and these thoughts may lead to unhelpful behaviors such as distancing from supportive religious communities. By asking about the role of religion in families’ lives, clinicians can assess for potential negative religious coping and address it in therapy.

The results of this study also suggest that parenting a child with exceptionalities is stressful across all three stages of childhood. Caregivers of children in early childhood, middle childhood, and adolescents reported significant levels of stress and endorsed frequent use of coping skills. This provides support for earlier studies that parenting a child with exceptional needs continues to be demanding throughout childhood and the stressors may change with time. Clinicians should continue to monitor stress and coping for caregivers of children of all ages. Assumptions that a parent of an older child with ASD or a parent with experience caring for another child with ASD copes adaptively or is not stressed may be inaccurate.

Clinicians may be especially useful in helping caregivers to identify what type of coping, proactive, engaged, or disengaged, would be most beneficial for particular situations. For example, clinicians may help parents to pre-plan for stressful situations that are known triggers for their child with ASD. Clinicians also serve an important purpose in helping families to accept situations that are chronically stressful and for which they have little control. The literature suggests that disengaging from chronically stressful stimuli is more adaptive than ruminating on situations that cannot be controlled or continuing to pour physical or emotional resources into a situation with limited benefit.

Methodological Limitations

There were some methodological limitations of this study foremost of which is its online format. While this allowed for a broader collection of participants, the researchers were limited in their capacity to oversee completion of the measures and ensure the participant was a caregiver of a child with ASD. To limit risk, the researchers recruited from known patient populations and reputable autism advocacy organizations. Additionally, the survey platform used had the capacity to track geographic locations and IP addresses. In order to maintain fidelity of this research study, any participant with duplicate IP addresses was removed from the analyses.

Another limitation to the online presentation was the inability to monitor how participants perceived the questions. All measures selected were for ease of reading ability and comprehension, but some questions may have had a different meaning for individual participants. Though the questions were written to be clear and concise, we were unable to assess how the participants actually interpreted the individual items. This research faced a measure-specific limitation related to the acculturation measure used in this study. The AAAS-R was published in 2000 and as such was standardized on a young adult population 16 years ago. Culture is dynamic and ever evolving, so some of the questions may have been considered out of date or no longer applicable. Despite its age, the AAAS-R is the most applicable African American culture scale available at present.

Additionally, this study has a relatively small sample size ($n= 103$). This study was financially limited in size due to fees for measure copyright licenses and participant compensation. The study may also have been subject to selection bias with participants.

We used local and national autism organizations and local healthcare providers to recruit participants. As a result, this study includes participants that are already well connected to support groups and medical providers. In contrast to a significant body of research, African American families in this study reported significantly lower ages at diagnosis for their children in comparison to Caucasian families. This may suggest that the ethnic minority sample obtained is better connected to providers and resources than most minority families. This sample may not be wholly representative of all caregiver experiences.

Lastly, the autism diagnosis for this study was confirmed using the Autism Spectrum Rating Scale screener. Previous medical records were not requested and this study did not require confirmation of diagnosis via an observational tool such as the Autism Diagnostic Observational Schedule. The online design of this study made collection of these materials infeasible.

Directions for Future Research

There are a number of directions that could continue to explore the unique role culture may play in understanding the stress and coping experiences of caregivers of children with ASD. One gap highlighted by this study is the lack of understanding of specific stressors experienced by families. Future researchers may wish to gather data, quantitative and qualitative, regarding the specific stressors for parents of children with ASD at different stages across the lifespan. Additionally, this study restricted the age range to caregivers of children under age 18, however the nature of autism frequently requires great parental support well into adulthood. Future research may replicate this study and expand the age range to consider the experiences of caregivers for young adults

with ASD. A final survey-based direction may be to begin to explore caregivers of children with ASD belonging to other racial minority groups. Undoubtedly, the African American experience is not representative of all racial minorities and future studies should highlight the unique experience of these groups.

This study may have been improved by conducting an item-by-item comparison of the responses given between the three cultural groups. Some of the measures did not yield a significant difference in total scores between the groups (e.g. proactive coping), however it is possible that there are item differences between the groups that are masked by the total scores. One future direction would be to conduct item-by-item analyses for each of these measures to see if the cultural or age groups are responding differently to individual questions. This would be especially beneficial for proactive coping as totals on this measure were unable to distinguish between the groups. Caregivers in the cultural groups may be approaching proactive coping differently and this would be highlighted using item-by-item analyses.

This study relied heavily on parent report of their stress levels. These measures were all face-valid means of assessing stress and as such are subjected to bias. A beneficial next step would be to compare parent reports of their stress with an objective or physiological measure of stress such as cortisol levels or heart rate variability.

This topic also lends itself well to using a randomized control trial methodological design. This study highlights how important interventions with caregivers are for the health of the entire family system. Though specific coping interventions were not evaluated, many of the techniques taught in evidence-based therapies such as diaphragmatic breathing, mindfulness, and progress muscle relaxation would likely be

applicable. Clinicians may provide an intervention such as teaching coping skills to caregivers and monitoring changes in stress and coping patterns of these parents, dynamics between parent and child, and changes in child behavior. This type of design may address some of the limitations of this study including allowing for additional, in-person confirmation of the ASD diagnosis.

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APPENDIX A**MEASURES**

Demographic Questionnaire (Adapted from Goin-Kochel, Mackintosh, & Myers, 2009)

Each child with autism is unique, and we are interested in learning more about your child. Please complete the following questions on your child with autism.

1. Child's Gender
 - Male
 - Female
 - Transgender
 - Other

2. Child's Age
 - Years _____ Months _____

3. Child's Race
 - White
 - Black, African American
 - Hispanic, Latino
 - Asian
 - Native American
 - Bi-racial, Multi-racial, Mixed
 - Other _____

4. Where does your child spend his or her day? Please mark all that apply.
 - Home
 - Child-care center or babysitter
 - Preschool or nursery school
 - Elementary, Middle, or High school
 - Day-treatment Center
 - Sheltered Workshop
 - Vocational Training or College
 - Job/Supportive Employment
 - Other _____

5. Please indicate what kind of school your child attends
 - Inclusive Classroom
 - Special Education Classroom at a public or private school
 - School Exclusively for children with special needs
 - Vocational Training or technical school
 - My child does not attend school

6. What other diagnoses has your child received? (select all that apply)
 - Anxiety Disorder

- Depression
 - ADD/ADHD
 - Brain Damage
 - Fragile X
 - Mental Retardation
 - Seizure Disorder
 - Sensory Integration Processing Disorder
 - Tuberous Sclerosis
 - Other _____
7. How old was your child when he or she received a formal diagnosis of Autism Spectrum Disorder?
- Years _____ Months _____
8. Who gave the formal diagnosis of Autism Spectrum Disorder?
- Family physician/ primary care provider
 - Specialist doctor
 - Psychiatrist
 - Psychologist
 - Other _____
9. How many individuals or professionals did you and your child see in the process of getting an Autism Spectrum Disorder?
- _____
10. How satisfied were you with the process of getting an Autism Spectrum diagnosis?
- | | | | | |
|-------------------------|---|-------------------------|---|------------------------|
| Not at All
Satisfied | | Moderately
Satisfied | | Extremely
Satisfied |
| 1 | 2 | 3 | 4 | 5 |
11. What treatments and therapies have you tried in order to assist with your child's diagnosis of ASD? (Please mark all that apply)
- Applied Behavior Analysis (ABA), Behavior Modification, (Lovaas)
 - Auditory Integration Therapy
 - Detox (Chelation)
 - Early Intervention Services
 - Music Therapy
 - Neurofeedback
 - Occupational Therapy
 - Picture Exchange System
 - Physical Therapy
 - Positive Behavioral Support/ Reward Charts
 - Sensory Integration
 - Social Skills Training
 - Social Stories
 - TEACCH
 - Food Allergy Treatments
 - Medications (Psychopharmacological Treatments)

- Special Diet
- Vitamin Supplements
- Other _____

Please complete the following about you, the caregiver.

12. What is your gender?
- Male
 - Female
 - Transgender
 - Other
13. What is your age in years?
- _____
14. What is your race?
- White
 - Black, African American
 - Hispanic, Latino
 - Asian
 - Native American
 - Bi-racial, Multi-racial, Mixed
 - Other _____
15. What is your marital status?
- Single
 - Married
 - Life Partner/Domestic Partnership
 - Separated
 - Divorced
 - Widowed
 - Other _____
16. What's the highest level of education you have completed?
- Elementary school (1st- 5th grade)
 - Middle school (6th- 8th grade)
 - Some High School
 - High School Diploma/GED/Equivalent
 - Technical School
 - Associates Degree (AA)
 - Some College
 - Bachelor's Degree (BA, BS)
 - Master's Degree (MA)
 - Doctoral Degree (MD, PhD, PsyD, JD, EdD)
17. Do you practice a particular spirituality or religion?
- Christian
 - Muslim
 - Jewish
 - Buddhist
 - Hindu
 - Wiccan

- Primal- indigenous (e.g. African Traditional)
- Other _____
- I am spiritual, but do not practice a particular religion
- I am not religious or spiritual

18. What is your approximate household income per year?

19. What is your zip code?

20. What is your relationship to the child?

- Mother
- Father
- Step-Mother
- Step-Father
- Grandmother
- Grandfather
- Sibling
- Other Relative
- Foster Parent
- Other _____

The Autism Spectrum Rating Scales (Ages 2-5 years and 6-18 years) are the intellectual property of Drs. Sam Goldstein and Jack Naglieri and cannot be reproduced in its entirety. Select items from the scale include:

1. During the past four weeks, how often did your child play with others?
2. During the past four weeks, how often did your child become upset if routines were changed?

Complete copies of these scales may be purchased from Multi-Health Systems Inc.

Website: <http://www.mhs.com/product.aspx?gr=edu&id=overview&prod=asrs>

The Parenting Stress Index is the intellectual property of Dr. Richard Abidin and cannot be reproduced in its entirety. Select items from the scale include:

1. My child is so active that it exhausts me.
2. I feel alone and without friends.

A complete copy of this scale may be purchased from PAR Inc.

Website: <http://www4.parinc.com/products/Product.aspx?ProductID=PSI-4>

Autism Parenting Stress Index (Silva & Schalock, 2012)

Please rate the following aspects of your child's health according to how much stress it causes you and/or your family

	Not Stressful	Sometimes Creates Stress	Often Creates Stress	Very Stressful on a Daily Basis	So stressful sometimes we feel we can't cope
Your child's social development	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your child's ability to communicate.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tantrums/meltdowns	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aggressive behavior (siblings, peers)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Self-injurious behavior	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty making transitions from one activity to another	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleep problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your child's diet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bowel problems (diarrhea, constipation)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Potty training	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not feeling close to your child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Concern for the future of your child being accepted by others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Concern for the future of your child living independently	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Proactive Coping Inventory (Greenglass, Schwarzer, Jakubiec, Fiksenbaum, & Taubert, 1999)

The following statements deal with reactions you may have to various situations. Indicate how true each of these statements is depending on how you feel.

	Not At all True	Barely True	Somewhat True	Completely True
I am a "take charge" person.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try to let things work out on their own	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
After attaining a goal, I look for another, more challenging one.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I like challenges and beating the odds.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I visualize my dreams and try to achieve them.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Despite numerous setbacks, I usually succeed in getting what I want.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try to pinpoint what I need to succeed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I always try to find a way to work around obstacles; nothing really stops me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I often see myself failing so I don't get my hopes up too high.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I apply for a position, I imagine myself filling it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I turn obstacles into positive experiences.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If someone tells me I can't do something, you can be sure I will do it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I experience a problem, I take the initiative in resolving it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I have a problem, I usually see myself in a no-win situation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I often find ways to break down difficult problems into manageable components.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I make a plan and follow it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I break down a problem into smaller parts and do one part at a time.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I makes lists and try to focus on the most important things.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Coping Strategies Inventory- Short Form (Tobin, 2001)

The purpose of this questionnaire is to find out the kinds of situations that trouble people in their day-to-day lives and how people deal with them. Take a few moments and think about an event or situation that has been very stressful for you during the last month. By stressful we mean a situation that was troubling you, either because it made you feel bad or because it took effort to deal with it. It might have been with your family, with school, with your job, or with your friends. Please think about the specific event. Think about what happened; the place, who was involved, what made it important to you, and what you did. The situation could be one that is going on right now or one that has already happened. As you read through the following items please answer them based on how you handled your event.

	Not at all	A little	Somewhat	Much	Very Much
I worked on solving the problems in the situation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I looked for the silver lining, so to speak; I tried to look on the bright side of things.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I let out my feelings to reduce the stress.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found somebody who was a good listener.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I went along as if nothing were happening.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I hoped a miracle would happen.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I realized that I was personally responsible for my difficulties and really lectured myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I spent more time alone.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I made a plan of action and followed it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I looked at things in a different light and tried to make the best of what was available.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I let my feelings out somehow.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I talked to someone about how I was feeling.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I tried to forget the whole thing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wished that the situation would go away or somehow be over with.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I blamed myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I avoided my family and friends.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I tackled the problem head on.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I asked myself what was really important, and discovered that things weren't so bad after all.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I let my emotions out.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I talked to someone that I was very close to.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I didn't let it get to me; I refused to think about it too much.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wished that the situation had never started.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I criticized myself for what happened.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I avoided being with people.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I knew what had to be done, so I doubled my efforts and tried harder to make things work.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I convinced myself that things aren't quite as bad as they seem.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I got in touch with my feelings and just let them go.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I asked a friend or relative I respect for advice.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I avoided thinking or doing anything about the situation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I hoped that if I waited long enough, things would turn out OK.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Since what happened was my fault I really chewed myself out.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I spent some time by myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Brief RCOPE (Pargament, Koenig, & Perez, 2000)

Continue to think about the negative event in your life. Each item says something about a particular way of coping. We want to know to what extent you did what the item says. Don't answer on the basis of what worked or not- just whether or not you did it. Try to rate each item separately in your mind from the others. Make your answers true FOR YOU. Some of the questions below ask about God. God may have a different meaning for many people. Please use your own definition of God. You may also select "Not At All" or skip questions that are not relevant to you

	Not at All	Somewhat	Quite a Bit	A Great Deal
Looked for a stronger connection with God.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sought God's love and care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sought help from God in letting go of my anger.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tried to put my plans into action together with God.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tried to see how God might be trying to strengthen me in this situation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asked for forgiveness for my sins.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Focused on religion to stop worrying about my problems.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wondered whether God had abandoned me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Felt punished by God for my lack of devotion.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wondered what I did for God to punish me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Questioned God's love for me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wondered whether my church had abandoned me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Decided the devil made this happen.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Questioned the power of God.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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- 2011 – 2014** **Norfolk State University**
 M.A., Community and Clinical Psychology
- 2009** **Albion College**
 B.A., Psychology, *cum laude*

CLINICAL TRAINING

- 2016 – 2017** **Post-doctoral Internship**
 Children’s Hospital of the King’s Daughters
 Pediatric Consultation Liaison Psychology
- 2015 – 2016** **Pre-doctoral Internship**
 Eastern Virginia Medical School,
 Pediatric Behavioral Medicine

SELECTED PRESENTATIONS

- Hacker, D., **Williams, T.**, & Haywood, J. (2015, October). *Comparison of Risk Perception of Sexual Behaviors and Actual Sexual Behaviors of African American Male Student Athletes*. Presented at the Black Families, Black Relationships, and Black Sexuality Conference, Philadelphia, PA
- Hartmann, K., & **Williams, T.** (2014, November). *Adolescence and Autism*. Presented at the Peninsula School for Autism, Newport News, VA
- Williams, T.** (2014, May). *Perceived Versus Physiological Stress of Parents of Children with ASD: A Pilot Study*. Presented at the Annual Eastern Virginia Medical School Psychiatry and Behavioral Sciences Research Day, Norfolk, VA
- Williams, T.**, Urbano, M., Hartmann, K., & Santher, S. (2014, April). *Cultural Considerations with Stress and Parenting a Child with Autism Spectrum Disorder*. Presented at the Annual Virginia Psychological Association Spring Convention, Norfolk, VA