CAREGIVER ADAPTATION AMONG BLACK AND WHITE FAMILIES OF INDIVIDUALS WITH AUTISM SPECTRUM DISORDER AND THE COMPARISON OF THE TWO RACIAL GROUPS

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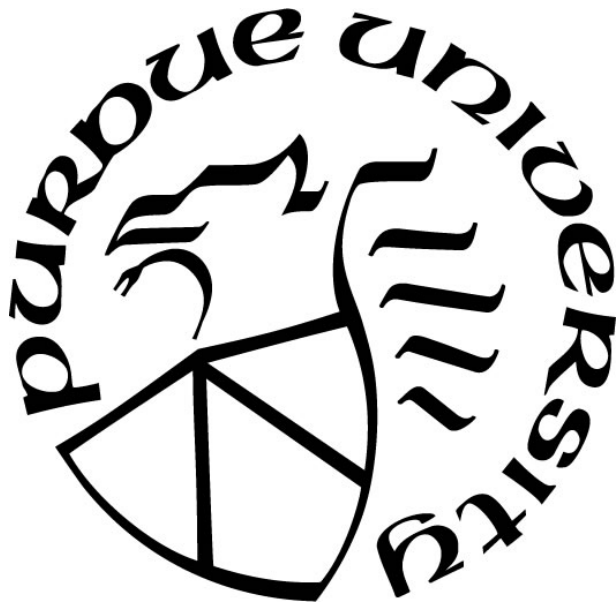
Yue Yu

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STATEMENT OF COMMITTEE APPROVAL

Dr. John McGrew, Chair

Department of Psychology

Dr. Catherine Mosher

Department of Psychology

Dr. Tamika Zapolski

Department of Psychology

Dr. Wei Wu

Department of Psychology

Dr. Lisa Ruble

Department of Educational, School, and Counseling Psychology

Approved by:

Dr. Jesse Stuart

To my parents and Sophia

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ABSTRACT

To date, only two studies, both using the same sample at two different time points, have quantitatively examined outcomes in Black caregivers of individuals with autism spectrum disorder (ASD). This study examined family adaptational outcomes in Black and White caregivers of individuals with ASD using the double ABCX model of family adaptation to examine the impacts of stressors, the A in the model (e.g., autism symptom severity, general life demands), resources/supports, the B in the model (e.g., social support), and individual coping/stress appraisal styles, the C in the model (e.g., cognitive appraisal, religious coping) on caregiver positive and negative adaptation outcomes, the X in the model, (e.g., caregiver strain, benefit finding, family quality of life). Black and White caregivers were compared on adaptation outcomes at the family, dyadic, and individual level, including both positively valenced (e.g., benefit finding) and negatively valenced outcomes (e.g., depression, caregiver strain). Participants were Black (N = 24) and White (N = 32) primary caregivers of individuals with ASD. Racial differences were found for both the general and racial-specific factors in the ABCX model. White and Black caregivers reported moderate and equal levels of caregiver strain. However, Black caregivers reported greater levels of anxiety and depression and lower levels of life satisfaction. When adjusting for potential ABC covariates, racial differences in outcomes were no longer significant. That is, racial differences in outcomes could be explained by differences in the proximal elements represented by the ABC variables of the model (e.g., passive-avoidance coping, religious coping). Black caregivers reported higher levels of pile-up of demands, formal social support, threat appraisal, passive-avoidance coping, and positive and negative religious coping than White caregivers. Different factors were related to caregiver strain in the two racial groups. Conscientiousness was a protective factor against caregiver strain for Black caregivers, whereas greater use of passive-avoidance coping and threat appraisal, higher levels of neuroticism and barriers to care, and lower levels of satisfaction with services, parenting self-efficacy, and formal social support were explanatory factors for increased caregiver strain among White caregivers. These results are helpful in informing interventions and support the cultural adaptation of care as provided to Black caregivers of individuals with ASD.

INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by deficits in social communication and the presence of restricted, repetitive, and stereotyped behaviors (American Psychiatric Association, 2013). Once considered rare, current estimates are that 1 in 54 children in the United States are diagnosed with ASD (Maenner et al., 2020). Due in part to the challenges posed by the dramatic increases in prevalence, renewed attention has been given to the health and well-being of caregivers of those with ASD. Compared to caregivers of neurotypical children and children with other developmental disabilities, caregivers of children with ASD experience greater levels of parenting stress (Hayes & Watson, 2013), caregiver strain (Abbeduto et al., 2004; McGrew & Keyes, 2014), depression and anxiety (Dumas, Wolf, Fisman, & Culligan, 1991; Pakenham, Samios, & Sofronoff, 2005) and lower levels of life satisfaction, psychological and physical well-being (Benson & Kersh, 2011; Ekas, Lickenbrock, & Whitman, 2010), quality of life, and marital satisfaction (Siman-Tov & Kaniel, 2011).

The Double ABCX Model of Family Adaptation

The double ABCX model of family adaptation (McCubbin & Patterson, 1983) has been used successfully for investigating family adaptation in response to stressful situations such as caring for a child with a disability (Mcstay, Trembath, & Dissanayake, 2014). The model (see Figure 1) starts with an assessment of the stressors facing the family, which includes the focal stressful life event that impacts the family (A) as well as any additional stressors, such as financial stress (aA). The next component addresses the existing and expanded family resources and supports for meeting the demands of the stressor (e.g., social support from family and community; B and bB). The third factor assesses the meaning the family assigns to the situation, including the family's perception of the situation and coping strategies (C and cC). Finally, the outcome is the level of family adaptation/functioning resulting from the interaction of the other factors (X and xX).

Several studies of caregiver adaptation in the ASD literature have adopted the double ABCX model of family adaptation as the framework for examining family functioning when raising children with ASD (Bristol, 1987; Hall & Graff, 2012; Manning, Wainwright, & Bennett,

2011; Mcstay et al., 2014; Pakenham et al., 2005; Pozo, Sarriá, & Brioso, 2013; Stuart & McGrew, 2009; Yu, McGrew, Rand, & Mosher, 2018). The findings of ASD caregiver studies that did not use the double ABCX framework also can be usefully synthesized within this framework (Pickard & Ingersoll, 2017). The following section reviews the general literature on caregiving adaptation in ASD using the double ABCX model as a guiding framework.

Stressors and Pile-up of Stressors (A & aA)

The severity of both autism-specific stressors (e.g., symptom severity, problem behaviors, and adaptive behaviors) and general life stressors have been shown to be strong predictors of adaptational outcomes in those caring for someone with ASD. Specifically, the severity of behavioral problems of the person with ASD has consistently been shown to negatively and strongly impact caregiver outcomes (Davis & Carter, 2008; Hastings & Brown, 2002; Manning et al., 2011). Increased autism symptom severity also has been associated with higher levels of individual and family strain (Stuart & McGrew, 2009), poorer maternal adjustment, and increased depression, anxiety, and parenting stress in caregivers of individuals with ASD (Ingersoll & Hambrick, 2011; Pakenham et al., 2005).

Additional life stressors, sometimes called pile-up of demands, which may not be related to autism (e.g., illness, divorce, and job loss), also can intensify negative outcomes in caregivers. Specifically, greater pile-up of demands have been associated with poor adjustment (e.g., depression, anxiety, and subjective physical health) in caregivers of those with ASD (Pakenham et al., 2005).

Family Resources and Supports (B & bB)

Family resources (e.g., social support, personality) help to meet the demands of the stressors and thus can serve to alleviate adverse family outcomes. For example, social support has been studied as a stress buffer and can provide family resources to reduce stress. Specifically, higher levels of perceived social support and higher satisfaction with social support have been shown to predict better mental health-related quality of life and lower maternal distress among caregivers of individuals with ASD (Bekhet et al., 2012; Ekas et al., 2010; Khanna et al., 2011; Smith, Greenberg, & Seltzer, 2012; Tobing & Glenwick, 2006).

Social support can be categorized into formal and informal support (Bristol & Schopler, 1983). Formal support includes support from physicians, other medical staff, psychologists, speech therapists, special educators, etc. Informal support includes the immediate and extended family, friends, neighbors, and other parents of the child (Bristol & Schopler, 1983). Research has shown that informal support is more effective than formal support. For example, White and Hasting (2004) found that informal sources of support (e.g., spouse, family, friends, etc.), but not formal professional support, were associated with well-being in parents of adolescents with intellectual disabilities. Similarly, in caregivers of children with ASD, informal support seems to be a more effective stress buffer than formal support (Boyd, 2002; Stuart & McGrew, 2009; Yu et al., 2018).

Resources or their absence can act both positively and negatively. Parent characteristics, such as traits or personality factors, are another personal "resource" that may be helpful or unhelpful in adapting to stress. Specifically, personality traits (e.g., "big five") have been shown to impact caregiver adaptation, positively and negatively. For example, higher neuroticism and lower extraversion have been related to greater worries and fewer rewards in caregivers of individuals with developmental disabilities (Jobe & Glidden, 2008) and lower quality of life in caregivers of children with pervasive developmental disabilities (Yamada et al., 2012). Similarly, Yu and colleagues (2018) reported that higher neuroticism scores exhibited the strongest association with increased caregiver strain across the big five personality traits, whereas higher levels of extraversion and conscientiousness were related to lower caregiver strain in caregivers of those with ASD.

Another trait that has been examined with respect to ASD is the broader autism phenotype (BAP). Specifically, BAP refers to subclinical levels of characteristics associated with ASD that may be exhibited by persons related to someone with ASD. BAP has been associated with negative personality characteristics, such as rigidity, aloofness, and hypersensitivity to criticism (Murphy et al., 2000) and with interpersonal difficulties (Piven, Palmer, Jacobi, Childress, & Arndt, 1997). Recently, Ingersoll and Hambrick (2011) found that parents with higher levels of BAP also reported greater parenting stress and more depressive symptoms.

Caregiver Perceptions and Coping Strategies (C & cC)

Caregiver perceptions alter how the individual views the potential stressor and chooses to respond or cope with the demands. Use of different cognitive appraisal styles has been consistently related to caregiver adaptation. For example, greater use of challenge appraisals (e.g., viewing the stressor as an opportunity) has been associated with lower levels of parent stress in families of school-aged children with ASD (Manning et al., 2011). Similarly, an increased sense of coherence (i.e., the ability to view a situation as significant, predictable and manageable) has been related to greater parental well-being (Pozo et al., 2013). In contrast, greater use of threat appraisals (e.g., viewing the stressor as potentially threatening) has been consistently related to negative outcomes (e.g., anxiety, depression, strain, poor marital adjustment) in caregivers of children with ASD (McGrew & Keyes, 2014; Pakenham et al., 2005; Stuart & McGrew, 2009; Yu et al., 2018).

How individuals respond to or cope with the perceived stressor also can greatly impact adaptational outcomes. Lazarus and Folkman (1984) proposed two general coping strategy categories, problem-focused coping and emotion-focused coping. Individuals who engage in problem-focused coping attempt to solve the problem or initiate actions to alter the situation, such as planning or taking action to address the problem, whereas individuals who engage in emotion-focused coping focus on reducing or managing feelings of distress associated with the stressor, such as denying or delaying focus on the problem, focusing on and venting of emotions associated with the stressor, or using other means to reduce the effects of the stressor (Abbeduto et al., 2004). Emotion-focused coping is often further subdivided into emotional approach (e.g., positive reappraisal) and passive-avoidance coping strategies (e.g., substance use, behavioral disengagement, denial, or avoidance).

The results of studies of the association between caregiver outcomes and problem-focused coping are mixed. Some studies indicate an association between increased problem-focused coping and lower levels of psychological distress (Abbeduto et al., 2004; Benson, 2010; Dunn & Burbine, 2001), whereas other studies fail to find such relationship (Hastings et al., 2005) or find the opposite association (Pottie & Ingram, 2008; Stuart & McGrew, 2009; Yu et al., 2018). It is possible that both findings of negative and positive correlations between problem-focused coping and distress are correct. For example, greater use of problem solving may reduce the impact of the stress and therefore decrease distress (negative correlation). Alternately, the use

of higher levels of problem-focused coping may be the result and not the cause of higher levels of stress (positive correlation) because greater efforts to cope are necessary when the situation is highly stressful. However, determining the direction (or bi-directionality) of the association between problem-focused coping and stress is difficult because the vast majority of studies have been cross-sectional, precluding our ability to examine variable precedence. Longitudinal research will be needed to more clearly understand these potential relationships.

The relationship between stress and emotion-focused coping depends on whether the individual uses emotional approach or passive-avoidance elements. Caregivers who positively restructure or reframe their perceptions about the stressors, i.e., emotional approach, tend to report lower levels of burden. For example, Hastings et al. (2005) found that parents of children with ASD who used more positive reframing and humor reported less depressive symptoms. In contrast, passive and avoidance coping has been consistently shown to be the strongest predictor of stress both longitudinally and in meta-analyses in the general population (Holahan, Moos, Holahan, Brennan, & Schutte, 2005; Penley, Tomaka, & Wiebe, 2002). Similarly, ASD caregivers who use passive-avoidance coping have consistently reported greater strain, anxiety, depression, and parenting stress and lower marital adjustment (Hastings et al., 2005; McGrew & Keyes, 2014; Paynter, Riley, Beamish, Davies, & Milford, 2013; Stuart & McGrew, 2009; Yu et al., 2018). For example, Yu and colleagues (2018) reported that passive-avoidance coping was the strongest predictor of ASD caregiver strain of variables in the double ABCX model (e.g., social support, threat appraisals, problem behaviors), both bivariately and adjusting for potential covariates. Moreover, passive-avoidance coping also mediated the association between personality traits (i.e., neuroticism, extraversion, conscientiousness) and caregiver strain (Yu et al., 2018).

A further individual difference variable that can impact an individual's ability to respond to caregiving stress is self-efficacy. Self-efficacy refers to people's perception of their ability to achieve a goal or outcome. With respect to caregiving, parental self-efficacy, specifically, refers to parents' perceptions and confidence in their parenting and caretaking competency (Teti & Gelfand, 1991). Parental self-efficacy has been related to behavioral persistence so that parents who believe their efforts will be successful are more likely to persist (Bandura, 1986). In addition, parental self-efficacy has been associated with caregiver well-being (Kuhn & Carter,

2006) and has been shown to mediate the effect of child problem behaviors on anxiety and depression in mothers of children with ASD (Hastings & Brown, 2002).

Caregiver Adaptation (X & xX)

Family or caregiver adaptation is the outcome of the double ABCX model. The model is flexible and allows researchers great latitude in selecting various types (e.g., depression, anxiety, strain, distress) and levels (e.g., family, dyadic, individual) of family outcome measures. The literature reflects this variety in measures used to assess ASD caregiver adaptation, such as parenting stress (Dabrowska & Pisula, 2010; Hayes & Watson, 2013), caregiver strain (Abbeduto et al., 2004; McGrew & Keyes, 2014; Yu et al., 2018), and depression and anxiety (Dumas et al., 1991; Pakenham et al., 2005). One general limitation is that most studies focus on caregivers' negative adaptational outcomes with very few studies examining possible positive adjustment, e.g., benefit finding and life satisfaction (Benson & Kersh, 2011; Ekas et al., 2010; Mcstay et al., 2014; Pozo et al., 2013). Given the growing emphasis on understanding potential caregiver growth, both negative and positive outcomes should be examined (McStay et al., 2014). A further limitation is that most studies examine only one or two levels (Hasting, 2003; Hsiao, 2016) rather than the multiple levels impacting family adaptation (i.e., individual, dyadic, family). The work of McGrew and colleagues is a notable exception (McGrew & Keyes, 2014; Stuart & McGrew, 2009).

Family and Caregiver Adaptation in Black/African American Families

Black/African Americans have been shown to experience disparities in various areas. They are more like to experience economic, social, and psychological disadvantages (e.g., lack of access, discrimination). Racial/ethnic minority families often experience greater hardships in general (e.g., racism, discrimination, immigration, SES; Arno, Levine, & Memmott, 1999; Magaña & Smith, 2006), and this may be especially true for families of children with disabilities, such as those with ASD. There are only two quantitative studies of Black/African American ASD caregivers. There is a similar dearth of studies of race/ethnicity and the characteristics and experiences of individuals with ASD. The following section reviews studies that have examined race/ethnicity as it relates both to caregivers of those with ASD and individuals with ASD.

A few studies indicate differences in clinical characteristics between Black/African American and White individuals with ASD. For example, ASD diagnosis prevalence rate varies by race/ethnicity. Specifically, prevalence appears to be highest among White children, with a rate 7% lower for Black/African Americans. This difference is not due to variations in phenotypic presentation between Black/African American and White children with ASD (Cuccaro et al., 2007; Sell, Giarelli, Blum, Hanlon, & Levy, 2012; Stronach & Wetherby, 2017). Rather the discrepancies in prevalence are thought to represent underdiagnosis, with attendant potential delays in access to treatment (Begeer, Bouk, Boussaid, Terwogt, & Koot, 2009). In fact, Mandell et al. (2002) observed that many Black/African American children are not diagnosed until they attend school, thus, the age of first diagnosis in this population is significantly later than White children, delaying the onset of treatment (Burkett, Morris, Anthony, Shambley-Ebron, & Manning-Courtney, 2017; Mandell et al., 2009). Also, Black/African American children with ASD were usually diagnosed with ADHD, conduct disorder, or adjustment disorder on their first specialty health-care visit (Mandell et al., 2009). Consistent with these findings, Black/African American families have reported higher levels of dissatisfaction with health care received compared to White families (Liptak et al., 2008; Sansosti, Lavik, & Sansosti, 2012).

Studies also have shown some differences in ASD presentation for Black/African American compared to White individuals. For example, Cuccaro and colleagues (2007) found that compared to White children, Black/African American individuals with ASD showed greater delay in language acquisition of first words and phrase speech, but no difference on the core autism features. Similarly, Becerra et al. (2014) found that Black/African American children are more likely to present with ASD and concurrent intellectual disability, emotional outbursts, and expressive language impairments than White children. Further, Horovitz et al. (2011) reported that Black/African American toddlers with ASD demonstrated higher levels of certain aggressive/destructive behaviors (e.g., kicking objects, throwing objects at others, aggression towards others, pull other's hair) than their White counterparts. However, no differences were found between Black/African American and White toddlers with ASD on stereotypic behaviors or self-injurious behaviors.

There also is some evidence of differences in outcomes for Black/African American vs. White adults with ASD. Specifically, Black/African American young adults with ASD have lower rates of involvement in employment and educational activities (e.g., obtain paid

employment, attend 2-year, 4-year, or vocational programs; Roux et al., 2013; Shattuck et al., 2012). In addition, Black/African American individuals with ASD were at increased risk for disengagement from therapeutic services after leaving high school (Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011).

With respect to caregivers, a limited number of studies have examined the experience of racial/ethnic minority families in caring for individuals with developmental disabilities in general, and even fewer have examined caregiving of individuals with ASD specifically. In fact, only three studies have examined family adaptation in Black/African American caregivers of children with ASD (Bishop et al., 2007; Burkett et al., 2017; Carr & Lord, 2013). Bishop and colleagues (2007) conducted the first such study and examined perceived negative impact in 30 Black/African American and 80 White mothers of children with ASD. Perceived negative impact was conceptualized as caregivers' negative experiences across five different domains (i.e., finances, romantic relationship, personal/leisure activities, and physical and mental health) as a result of caring for a child with a disability. For the sample as a whole, caregiver negative impact was greater when caring for children with ASD with increased restrictive and repetitive behaviors and lower levels of adaptive behavior scores, and when caregivers reported fewer children in the family and lower levels of perceived social support. Interestingly, race/ethnicity was the most robust predictor of perceived negative caregiving impact. Specifically, Black/African American mothers reported significantly lower levels of perceived negative impact than did White mothers.

Building on the findings of Bishop et al. (2007), Carr and Lord (2013) followed up with the same sample five-years later and examined changes in maternal perceptions of negative impact over time and the child and maternal characteristics predicting change. The authors found that both Black/African American and White mothers reported higher levels of negative impact as their child transitioned to adolescence. Also, there was a significant interaction between race/ethnicity and maternal education level. Specifically, Black/African American mothers with fewer than four years of college reported lower levels of negative impact compared to Black/African American mothers with four years of college or more and compared to White mothers regardless of education. Furthermore, in the overall sample, higher perceived negative impact was predicted by lower levels of perceived social support and adaptive behaviors, having

an autism diagnosis (rather than a PDD-NOS diagnosis), higher nonverbal IQ scores and higher levels of behavior problems, and receiving more hours of individual treatment.

Although these studies are important because they are the only ones to examine Black/African American ASD caregivers, some of the findings seem counterintuitive. First, although a typical finding is that Black/African American individuals tend to have poorer physical and mental health outcomes in response to chronic stress compared to White counterparts (Juster, McEwen, & Lupien, 2010; Stronks et al., 2013), these studies suggest that Black/African American ASD caregivers have <u>lower</u> levels of negative caregiving impact than White caregivers in response to a chronic stress. Interestingly, similar findings have been reported in the non-ASD caregiver literature. Specifically, Black/African American caregivers of elderly report lower levels of caregiving burden than White caregivers (Knight, Silverstein, McCallum, & Fox, 2000; Pinquart & Sörensen, 2005). It was speculated that the lower levels of negative caregiving outcomes may be due to more effective appraisal and coping strategies used among Black/African American caregivers (Bishop et al., 2007). For example, Black/African American caregivers of individuals with dementia reported lower levels of negative and higher levels of positive caregiving appraisals, and they also reported higher levels of religious coping than White caregivers (Haley et al., 2004; Pinquart & Sörensen, 2005). Nevertheless, no study has examined specifically whether coping and appraisal strategies underlie the increased resilience in Black/African American caregivers. Additionally, reporting lower burden in caregiving does not offset the economic, social, and psychological costs and impact of caregiving (Arno, Levine, & Memmott, 1999) and the lack of resources and disadvantages (e.g., lack of access, discrimination) experienced in this group. Racial/ethnic minority families often experience greater hardships in general (e.g., racism, discrimination, immigration, SES; Magaña & Smith, 2006), and this may be especially true for families of children with disabilities. For example, racial/ethnic minority families of children with developmental disabilities experience more unmet needs and greater difficulty entering and navigating the health care system, which can result in greater negative caregiver outcomes (McManus et al., 2011). In addition, Black/African American caregivers of older adults or those with dementia reported poorer physical health and more unhealthy behaviors than White caregivers (Haley et al., 2004; Pinquart & Sörensen, 2005). Furthermore, the positive results for negative impact or burden for Black/African American ASD caregivers may not necessarily extend to other outcome measures.

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Specifically, although Black/African American caregivers of those with dementia have reported lower levels of anxiety and depression than White caregivers in some studies (Haley et al., 2004; Pinquart & Sörensen, 2005), others have shown equal levels of depression and anxiety in Black/African American caregivers compared to non-Black/African American caregivers (Knight et al., 2000). Accordingly, further study is warranted to attempt to replicate these initial findings.

Another counterintuitive finding was that Black/African American ASD caregivers with lower educational levels reported the lowest level of negative caregiving impact (Carr & Lord, 2013). Because education attainment is strongly related to employment status and income, and lack of employment and reduced income levels can lead to significant stress in individuals and families (Melchert, 2015), a finding that caregivers with higher levels of education attainment report higher levels of stress is unexpected. In contrast, Black/African American women with low educational attainment have been found to be less able to handle daily stress (Jackson & Mustillo, 2001). Nevertheless, Kring and colleagues (2010) found that higher levels of maternal education were associated with higher levels of problem behaviors in their adolescent and adult child with ASD. It is possible that high levels of educational attainment are not helpful in reducing negative outcomes related to caregiving, but may be helpful in reducing general stress; however, no study has examined this in Black/African American caregivers of those with ASD. Moreover, there are no similar reports of the advantages of lower levels of education among Black/African American caregivers for other caregiving groups.

Another unexpected finding was that having fewer children in the family was related to higher perceived negative impact (Bishop et al., 2007). In the general literature, the relationship between the number of children in the family and caregiver outcomes has been mixed. Specifically, although the number of children in the family was unrelated to stress in parents of children with fragile X syndrome (McCarthy, Cuskelly, van Kraayenoord, & Cohen, 2006), other studies have found that having more children in the family was related to better quality of life in caregivers of children with ASD (Dardas & Ahmad, 2014; Lee et al., 2009). However, the impact of other children and additional caregiving roles may be moderated by the number of hours of caregiving required; extra hours for caretaking tended to add burden when caregivers are already overwhelmed (Stoller & Pugliesi, 1989). Regardless, additional investigation is warranted within Black/African American families of children with ASD.

In addition to the problems represented by these counterintuitive results, both studies had further limitations. For example, both studies included far fewer Black/African American families than White families. Specifically, in Bishop et al. (2007), Black/African American participants were about one fourth of the total sample, and the ratio was one fifth in Carr and Lord (2013). Perhaps due to the small and unequal sample sizes, neither study reported whether the two racial groups differed on some of the potential predictors of the outcome (e.g., social support) or explored the factors that may have contributed to the significant differences in perceived negative impact between the two groups. Also, although Carr and Lord (2013) measured parental well-being at the second time point, Bishop et al. (2007), did not include any other parental outcome measures to assess positive impact or growth in caregivers. Further, the two studies only measured caregiver outcomes at an individual level and did not examine family or dyadic level outcomes. Another concern is that both studies failed to examine theoretically important potential predictors (e.g., coping strategies, appraisal styles, personality, etc.). More importantly, neither study used a conceptual framework (e.g., double ABCX model) to examine potential contributory factors in family adaptation. Finally, as already noted, Bishop et al. (2007) and Carr and Lord (2013) essentially used the same caregiver sample; one study reported the baseline results and one study reported the 5-year follow-up results. That is, the entire extant quantitative literature on outcomes in Black/African American ASD caregivers is based on one sample. Clearly, more studies are needed to examine caregiver outcomes in Black/African American families of those with ASD.

Recently, however, Burkett et al. (2017) reported a qualitative study examining parenting practice and family values in Black/African American families of children with ASD. Burkett and colleagues (2017) interviewed 24 Black/African American family members (e.g., mothers, fathers, grandmothers, siblings, aunts, and cousins) caring for children with ASD from 8 families and 28 professionals who work with families of children with ASD (e.g., physicians, psychologists, speech and language pathologists, occupational therapists, etc.). Parents reported coping strategies they used to manage the stress caring for a child with ASD, such as relying on other family members and coping with religion. Although the study provided meaningful information on parenting, family values, and certain coping methods in Black/African American families, because it did not quantitatively examine parental adaptation, it could provide only

limited information on predictors of caregiver adaptational outcomes in Black/African American families of children with ASD.

Finally, Manning and colleagues (2011) recruited a racially diverse sample of caregivers of children with ASD, including White, Black/African American, Multiracial, Latino, Asian, and Native American. However, only 19% of the sample was Black/African American, and the authors did not examine outcomes for this group separately or compared to other racial/ethnic groups. Thus, although the study adopted the double ABCX model, had a diverse sample, and explored adjustment in ASD caregivers, its contribution in exploring caregiver adaptions in Black/African American families is very limited. Given the clear gaps identified above in the existing literature, there is a clear need for additional studies both to examine adaptation outcomes among Black/African American caregivers of those with ASD and to identify potential predictive factors using a conceptual framework.

A Conceptual Framework

The generalizability of the double ABCX model of family adaptation has been demonstrated by its successful application in the study of many different populations and ethnicities. For example, the model has been used as a framework in examining the caregiving experience of inner-city fathers of children with chronic illness (Kobylianskii et al., 2018), family adaptation in racially diverse families of school-aged children with autism (Manning et al., 2011), empowerment in culturally diverse families of young children with disabilities (Xu, 2007), satisfaction with grandparenting and life satisfaction in Korean American grandparents (Sohn, 2008), the relationship between coping strategies and chronic hypertensive cardiovascular disease in Black/African American families (Lang, 2003), and caregiving experience in Black/African American and Hispanic parents of children with asthma (Waters et al., 2017).

Moreover, multiple characteristics of the child, parent, and family have been examined and usefully synthesized and accommodated within the double ABCX conceptual framework, albeit, mostly in White caregiving samples. However, race/ethnicity provides an important additional context for caregiving (Dilworth-Anderson & Anderson, 1994). When examining adaption outcomes and potential predictors in Black/African American caregivers of children with ASD, it is important to consider these contextual factors. Specifically, one model of interest is that of Dilworth-Anderson and Anderson (1994) who provided a contextual approach for

studying Black/African American caregivers of people with dementia and identified important aspects of Black/African American experience that may impact their adaptational outcomes. Those factors include sociocultural (e.g., employment status, education), interpersonal (e.g., social support), situational (e.g., disability-related stressors and additional life demands), temporal (i.e., timing of caregiving in the life cycle), and personal (e.g., coping styles, physical health) contexts. It is worth noting that this conceptual framework, developed specifically from Black/African American caregivers, closely parallels the double ABCX model of family adaptation. Nevertheless, the framework takes racial-specific factors into account, such as racial identity, financial strain, religious coping, and earlier onset of caregiving role, which is particularly important among Black/African American dementia caregivers. Accordingly, these racial specific factors were integrated into the double ABCX model. That is, both general and racial-specific factors were examined and included in the double ABCX model. The following section, reviews in detail what is known, and more often unknown, about family adaptation in Black/African American caregivers, organized using the double ABCX model and expanded with racial specific factors suggested by Dilworth-Anderson and Anderson (1994).

Stressors and pile-up of stressors (A & aA)

Autism-related child characteristics that impact Black/African American caregivers of children with ASD seem to be consistent with the general ASD caregiver literature (Bishop et al., 2007; Carr & Lord, 2013). That is, higher levels of problem behaviors and lower levels of adaptive behaviors have been related to higher levels of negative impact in both Black/African American and White mothers of children with ASD.

Besides child characteristics, other contextual stressors may also impact caregiver adaptation across different racial groups. Black/African American families have been shown to underutilize mental health services (US Center for Mental Health Services, 2001), and factors thought to contribute to this include economic disparities, stigma, and lack of trust (Thurston & Phares, 2008). Specifically, Owens et al. (2002) examined parents' perception of barriers to children's mental health services. Among the Black/African American parents in the sample, more than a third of the families reported barriers entering and or staying in mental health services, including lack of provider availability, long waiting lists, lack of insurance, etc.

However, the potential impact of perceived barriers to services has not been studied with respect to caregiver strain.

In addition to autism-related stressors, other daily life demands are also stressors to caregivers. For example, financial strain can be a stressor both at the level of the individual and as a parent. For example, Black/African American women with lower incomes were found to be less able to handle everyday stress (Jackson & Mustillo, 2001). Similarly, financial concerns were a significant stressor for inner city (e.g., low-income, unemployed, immigrant, refugee, ethnic minority, living in an urban area) fathers of children with chronic illnesses (Kobylianskii et al., 2018).

Additional caregiving roles may be another stressor. It has been shown that compared to White, Black/African Americans develop health problems (e.g., hypertension, alcohol abuse; Anderson, Myers, Pickering, & Jackson, 1989), and the disabilities that are related to these illnesses (e.g., dementia) earlier. Consequently, the onset of the caregiving role in offspring of Black/African Americans with dementia occurs earlier in life (Dilworth-Anderson & Anderson, 1994). Therefore, it is important to assess whether Black/African American ASD caregivers also have other caregiving roles in the family. Thus, in addition to general autism-related stressors, pile-up of demands for Black/African American ASD caregivers should include an assessment of difficulties or barriers in accessing physical and mental health services, financial strain, and additional caregiving roles.

Family resources and supports (B & bB)

As suggested by Dilworth-Anderson and Anderson (1994), contextual factors should include sociocultural factors, such as child, parent, and family demographic information (e.g., SES, education, number of individual treatment hours, number of children in the family), which provide information on the existing family resources or their absence that may impact family and caregiver adaptational outcomes (Xu, 2007).

Social support is an important personal resource for Black/African American families caring for a child with a disability (Christian, Al-Mateen, Webb, & Donatelli, 2000). For example, lower levels of social support were associated with greater negative caregiving impacts in Black/African American mothers of children with ASD (Carr & Lord, 2013). Similarly, Black/African American caregivers of children with autism have reported that help from their

family members eased the stress of caring for their child, with other family members providing emotional and physical care support (Burkett et al., 2017). Moreover, compared to other racial/ethnic groups (e.g., White, Latino), social support had the largest impact on alleviating parental strain in Black/African American families of children with ADHD (Hinojosa et al., 2012).

As noted above, social support can be categorized into formal and informal social support. Research has indicated that in mostly White ASD caregiver samples, informal support is more effective than formal support (White & Hastings, 2004). However, whether this is also true for Black/African American caregivers of those with ASD is unknown because it has not been examined previously (Bishop et al., 2005; Carr & Lord, 2013). Also, it is unclear whether Black/African American and White caregivers of individuals with ASD report different levels of informal and formal social support. Based on the literature on caregivers of the elderly, there are mixed findings concerning informal support for different racial/ethnic groups. Some studies indicated that Black/African American caregivers received more support from family members (i.e., informal support) than White caregivers (Cox, 1993; Wood & Parham, 1990), whereas other studies found the reverse (Adams, Aranda, Kemp, & Takagi, 2002). In terms of formal support, in general minority caregivers report less service use (Aranda & Knight, 1997) and thus may perceive lower levels of formal support than their White counterparts.

Currently, there are no studies of the potential impact of personality traits, such as the "big 5" (Costa & McCrae, 1992), or of other individual difference variables like self-efficacy or BAP on outcomes of Black/African American caregivers of individuals with ASD. An additional potential individual difference variable of interest for exploring adaptation among Black/African American caregivers is racial identity. Racial identity defines the extent to which a person adopts mainstream cultural views versus engages in traditional values and beliefs. People who are identified as less acculturated may endorse more traditional values or beliefs. In Black/African American culture, traditional values and beliefs may include respect for elders, emphasis on filial obligations, and beliefs in religion and prayers (Landrine & Klonoff, 1996). Racial identity has been related to quality of life in other Black/African American caregiving groups. For example, in African American caregivers of children with asthma, higher levels of traditional religious beliefs and practice were related to higher overall quality of life (Everhart, Miadich, Leibach, Borschuk, & Koinis-Mitchell, 2016). However, racial identity and adherence to traditional

beliefs has not been investigated in Black/African American ASD caregivers. Therefore, to help fill the gaps in the literature, demographic information potentially related to caregiving adaptation (e.g., employment, education), levels of perceived formal and informal support, personality and individual difference variables associated with adaptation, and racial identity in Black/African American ASD caregivers should be examined.

Caregiver Perceptions and Coping Strategies (C & cC)

The appraisal styles of Black/African American caregivers have been examined for non-ASD caregiving groups. For example, African American caregivers of persons with dementia report more positive perceptions of caregiving, greater self-gains, and perceived rewards than their White counterparts (Haley et al., 2004; Knight & McCallum, 1998). However, neither the levels of appraisal styles nor the potential relationship between cognitive appraisal styles and strain/stress has been examined in Black/African American caregivers of children with ASD.

Another factor impacting outcomes is how caregivers cope with the stressors. As mentioned earlier, Lazarus and Folkman (1984) divided coping into two types, problem-focused and emotion-focused coping. Both types are widely applicable to different racial/ethnic groups. For example, Smyth and Yarandi (1996) examined coping strategies in Black/African American women using the Ways of Coping Questionnaire (Folkman & Lazarus, 1988) and found three factors that explained two-thirds of the total variance using factor analysis: active coping, avoidance coping, and minimizing the situation. However, for Black/African Americans, another key coping strategy is religious faith or coping (Broman, 1996; Charman et al., 2017; Haley et al., 2004). For example, Haley et al. (2004) examined well-being and coping strategies in Black/African American and White caregivers of people with dementia and found that Black/African American caregivers reported higher frequency of prayers, attendance at religious services, and greater importance of religion than White caregivers. Similar findings were reported in a qualitative study of Black/African American ASD caregivers (Burkett et al., 2017). Black/African American families described how their faith helped them cope with caring for a child with ASD and to view the situation more positively (e.g., caring for a child with ASD led to personal and spiritual growth, made the family emotionally closer due to caring for their child; Burkett et al., 2017). Nevertheless, to date, the potential association between caregiver outcomes and appraisals and religious coping has not been examined quantitatively among Black/African

American ASD caregivers. Thus, several factors under family perception and coping should be examined to help fill the gap in understanding adaptation for this caregiver group, i.e., cognitive appraisal styles, perception of the care system, coping strategies.

Caregiver adaptation (X & xX)

Caregiver outcomes from the two extant studies of Black/African American ASD caregivers indicate areas of both challenge and strength. Specifically, both Bishop et al. (2007) and Carr and Lord (2013) examined perceived caregiving negative impact in Black/African American and White mothers of children with ASD, when their children were nine years old (Bishop et al., 2007) or transitioning to early adolescence (Carr & Lord, 2013). Both studies found that Black/African American mothers reported lower levels of perceived negative impact of having a child with ASD than White mothers. However, both studies focused exclusively on a single caregiver outcome, i.e., perceived negative caregiving impact. Although Carr and Lord (2013) also assessed caregiver well-being, its association with other potential predictors was not examined. Also, as mentioned above, other psychosocial outcomes (e.g., anxiety, depression) in addition to caregiving outcomes should also be examined to see if there are differences between the two racial groups in those caregiver outcomes. Third, family outcomes can and should be assessed at different levels as noted previously, e.g., family, dyadic, and individual. To date, only individual level outcomes have been examined in Black/African American caregivers of those with ASD.

Further, Lawton et al. (1991) suggested that caregivers may experience both distress and psychological satisfaction and growth. In contrast, the vast majority of studies of caregiving have focused only on assessing negative outcomes (Hastings, 2003; Jones & Passey, 2004). However, as reported in a recent survey of people who provide long-term care services to relatives or friends (National Opinion Research Center, 2014), 83% of caregivers viewed caregiving as a positive experience, including personal growth and increased meaning and purpose in one's life. For example, spousal caregivers in hospice also report that they find benefits in their role and activity (Haley et al., 2004). Therefore, besides assessing the negative impact on the individual level of caregivers, it is also important to examine caregiver growth (i.e., benefit finding) and caregiving satisfaction.

Current Study

As reviewed above, the literature examining family adaptation in Black/African American caregivers of children with ASD is scarce. Moreover, extant studies failed to examine several potential critical factors that may impact caregiver adaptation (e.g., appraisal styles, coping strategies, personality traits), examined a narrow set of outcomes, and did not use a conceptual framework to organize their studies. The current study used the double ABCX model of family adaptation (McCubbin & Patterson, 1983) as a framework to examine the additive impacts of demands/stressors, resources/supports, and individual coping/stress appraisal styles on psychosocial outcomes in Black/African American caregivers. In addition, given that limited studies have examined *positive* adjustment in caregivers in the general ASD literature and the growing emphasis on understanding potential caregiver growth (Haley et al., 2004), both negative and positive aspects were assessed.

This cross-sectional study had three aims: (a) to examine and compare racial differences in the mean levels of the general and racial-specific elements of the double ABCX model (i.e., the *ABC* elements of the model); (b) to examine the levels of positive and negative adaptational outcomes in Black/African American caregivers of those with ASD and to compare the adaptational outcomes between the two racial groups (i.e., the *X* in the double ABCX model); (c) to examine the association between caregiver strain specifically and general and racial-specific elements of the double ABCX model in Black/African American and White ASD caregivers.

METHODS

Participants

Various methods were used to attempt to recruit participants. Some participants were recruited from Amazon Mechanical Turk (MTurk, n_{Black} =2, n_{White} = 31), an online marketplace that has been used in recruiting participants for research (e.g., Dworkin et al., 2016). Local autism organizations (e.g., Autism Speaks Indiana, Autism Society of Indiana, The Arc Indiana) and professionals and providers also were contacted, and they helped distribute the study flyer and shared the study information with other providers, listservs, social media, and organizations. In addition, contacts were made with national autism organizations (e.g., Autism Speaks; Autism Speaks research website), and with researchers and professionals serving persons with ASD about participant recruitment. An advertisement was posted in a local newspaper in Indianapolis (IndyStar), and contacts were made with churches in Indiana primarily serving the Black community who volunteered to post flyers or make announcements about the study (n_{Black} = 22, n_{White} = 1).

To be included in the study, participants had to be the primary caregiver of an individual with ASD of any age. The child's ASD status was confirmed both by self-reported formal diagnosis from either a health service provider or the child's school and by scores on the Social Communication Questionnaire consistent with the presence of ASD (SCQ score ≥11; Rutter, Bailey, & Lord, 2003).

This was a cross-sectional observational study. The primary caregivers of individuals with ASD completed questionnaires either using Qualtrics directly through MTurk or via an email link. MTurk participants received MTurk credits. Other participants received e-gift cards.

Measures

Demographic information

Demographic information was collected from all participants. Child demographic characteristics were obtained from the caregiver. Caregiver demographic characteristics included caregiver's relationship to the child, gender, age, race/ethnicity, educational attainment, marital

status, income, other caregiving roles in the family (e.g., elderly), and hours required for ASD caregiving and for other caregiving roles.

Symptom severity and problem behaviors (A)

The Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003) was used to confirm the diagnosis of ASD and to provide an overall indication of the severity of autism symptoms. The Current form of the SCQ was utilized. It consists of 40 yes-or-no questions, which are summed to obtain a total score. Higher scores indicate greater autism symptom severity. Scores equal to or greater than 11 indicate that the individual is likely to have a diagnosis of autism (Norris & Lecavalier, 2010). The scale has demonstrated good sensitivity and specificity in identifying autism (sensitivity = .85, specificity = .75; Norris & Lecavalier, 2010) and showed acceptable internal consistency reliability in prior studies (Cronbach's alpha = .80; Manning et al., 2011; McStay et al., 2014) and in the current study (α = .68).

The 30-item Problem Behavior Rating Scale (PBRS; Stone et al., 2010) was used to measure problem behaviors of individuals with ASD. Items were rated on a four-point Likert scale (1 = not at all problematic to 4 = very problematic). The scale has been shown to have high internal consistency reliability in prior research (Cronbach's alpha = .88; Stone et al., 2010) and in the current sample (α = .87).

Pile-up of demands (aA)

A modified version of the Social Readjustment Rating Scale (SRRS; Holmes & Rahe, 1967) was used to assess general stressful life events. Participants were asked to rate each of the 43 items on a six-point Likert scale (0 = not experienced to 5 = experienced with extreme distress). A total score was calculated by summing the ratings of all items. The internal consistency reliability was good in a prior study of ASD caregivers (Cronbach's alpha = .87; Stuart & McGrew, 2009) and in the current study (α = .84).

A measure of barriers to care was administered consisting of 15 dichotomous items (0 = no, 1 = yes) assessing barriers caregivers may face when they seek services for their child (Brannan & Heflinger, 2006). The barriers fell into the following three categories: location/time barriers, provider/payer barriers, and family perceptions. For each category, a total score was calculated by summing the endorsed barriers. Location/time barriers included transportation

problems, inconvenient location, and inconvenient appointment times. Provider/payer barriers included no program available or no space in an existing program, provider would not help or would not take their insurance, long waiting time until service could be received, their insurance did not cover the service, and family did not have money to pay for services. Barriers relating to family perceptions included fear that the child would be labeled, expectation that treatment would not help, not knowing where to go, concern that the child would refuse to go, fear of what family and friends would think, and thinking that the problems were not serious enough (Brannan & Heflinger, 2006). The scale has been used to examine the relationship between barriers to care in child mental health service systems and caregiving strain (Brannan & Heflinger, 2006). The internal consistency reliability for the total score was .70 in the current study.

Overall ease of using health care services was assessed with the following question: "Thinking about the services [your child] needs, are those services organized in a way that makes them easy to use?" in a 4-point Likert scale (1 = very dissatisfied to 4 = very satisfied; Ngui & Flores, 2006).

Family Resources (B & bB)

The 12-item Multidimensional Scale of Perceived Social Support (MSPSS; Zimet et al., 1988) was used to measure perceived general social support. Items were rated on a seven-point Likert scale (1 = very strongly disagree to 7 = very strongly agree). A mean score was calculated; higher scores indicate greater social support. Internal consistency reliability for the MSPSS was good in prior studies (Cronbach's alpha = .92; Zimet, 1998) and in the current sample (α = .96).

To measure objective levels of received formal social support Marsack and Samuel's (2017) checklist of 15 types of formal social support was used. Checklist items included autism support groups, social work, national organizations for caregivers of individuals with autism, state organizations for caregivers of individuals with autism, community support groups for caregivers, respite care, community mental health, speech therapy, counseling, day care, psychiatric services, occupational therapy, physical therapy, financial support from private or public organizations/sources, and care for a chronic condition. It has been used in prior studies to measure types of formal social support in parents of adults with autism (Marsack & Samuel,

2017). In the current study, participants were asked to indicate (0 = no, 1 = yes) which of the support services they have had access to and were currently utilizing. They were also asked to indicate helpfulness of the formal social support services on a 5-point Likert scale (1 = not helpful at all to 5 = very helpful). Participants had the option to indicate (in text) other types of formal social support that they have received or are currently receiving, also rating their helpfulness. The total number of selected types of formal social support was counted to assess objective levels of received formal social support, and the mean score from the helpfulness ratings was used to indicate perceived or subjective levels of formal social support. The internal consistency reliability for the objective use of formal social support was .74, and was .87 for helpfulness.

The 60-item NEO Five-Factor Index 3 (NEO-FFI-3; McCrae & Costa, 2004) was used to measure the five factor model of personality. It consists of 12 items for each of the five traits. Items were rated using a 5-point Likert scale (1=strongly disagree to 5=strongly agree). Test-retest reliability has not been studied for the NEO-FFI-3 (McCrae & Costa, 2004), but test-retest reliability has been good for the NEO-FFI (test-retest reliability = .86 to .90; Murray, Rawlings, Allen, & Trinder, 2003; Robins, Fraley, Roberts, & Trzesniewski, 2001). Internal consistency reliability of the NEO-FFI-3 was good in prior studies (internal consistency reliabilities = .78 to .86; McCrae & Costa, 2007; Walton, Cantor, & Lykins, 2017). The internal consistencies of the 60-item NEO Five Factor Inventory-3 in prior studies with African Americans has been shown to be adequate (Conscientiousness α = .77, Extraversion α = .75, Openness to Experience α = .67, Neuroticism α = .79, and Agreeableness α = .75; Clark et al., 2018). The internal consistency reliability in the current sample ranged from .27 to .88 (Neuroticism α = .88, Conscientiousness α = .84, Extraversion α = .80, Agreeableness α = .28, and Openness α = .27). Because the internal consistency reliability was well below acceptable standards for the Agreeableness and Openness subscales, these two personality traits were not included in the analyses.

A 10-item Autism Spectrum Quotient (AQ-10; Allison, Auyeung, & Baron-Cohen, 2012) was used to measure if caregivers exhibited subclinical characteristics of autism (i.e., BAP). Each item was rated on a 4-point scale (1 = definitely agree to 4 = definitely disagree) and was scored as either absent (score=0) or present (score=1) (e.g., Definitely or Slightly Agree) according to the scoring instructions. Higher scores indicated greater levels of expression of the

BAP. Internal consistency reliability has been good in prior studies (Cronbach's alpha = .85; Allison et al., 2012) and was acceptable in the current sample (α = .61).

The 27-item Multidimensional Inventory of Black Identity - Short Form (MIBI-S; Martin, Wout, Nguyen, Sellers & Gonzalez, 2008), a shortened version of the MIBI (Sellers, Rowley, Chavous, Shelton, & Smith, 1997), was used to measure racial identity in caregivers. Items are rated on a 7-point Likert scale (1 = strongly disagree to 7 = strongly agree). The measure consists of three stable dimensions of racial identity, Centrality, Regard, and Ideology, and is comprised of a total of seven subscales. The Centrality scale (4 items) measures the extent to which being an Black/African American is central to one's definition of self (α = .83; White-Johnson, Ford, & Sellers, 2010). The regard scale consists of two subscales (i.e., Private regard and Public regard) and measures the extent to which one has positive feelings towards African Americans in general and feels that other groups have positive feelings toward Black/African Americans. A higher score indicates more positive feelings (private regard: α = .69; Public Regard: α = .80; White-Johnson, Ford, & Sellers, 2010). The Ideology scale has four subscales (i.e., Assimilation, Humanist, Minority, and Nationalist). The Assimilation subscale (4 items) measures the extent to which one emphasizes the similarities among all races. The Humanist subscale (4 items) assesses the extent to which one emphasizes the similarities between all races. The Minority subscale (4 items) measures the extent to which one emphasizes the similarities between Black/African Americans and other minority groups. The Nationalist subscale (4 items) measures the extent to which one emphasizes the uniqueness of being a Black/African American (α = .61-73; White-Johnson, Ford, & Sellers, 2010). The internal consistency reliability was .75 for the overall scale in the current sample. Internal consistency reliabilities for the three overarching dimensions were .51 (Centrality), .21 (Regard), and .65 (Ideology). The dimensions were not intended to be used as variables, however, instead seven subscales were created. Internal consistency for the subscales in the current sample ranged between .38 -.88 (Centrality α = .51; Private Regard α = .80; Public Regard α = .88; Assimilation α = .67; Humanist α = .38; Minority α = .46; Nationalist α = .55). The low internal consistency reliability for some of the subscales may relate to few items in each subscale. Due to the low internal consistencies, the following subscales were not included in the analyses: Humanist, Minority, Nationalist, and Centrality.

Cognitive appraisal and Coping strategies (C & cC)

Threat and challenge appraisals related to caring for a child with ASD (8-items) were measured using a modified Stress Appraisal Measure (SAM; Peacock & Wong, 1990). Each subscale consists of four items. An example item for threat appraisal is "Does this situation make me feel anxious?" An example item for challenge appraisal is "Is this going to have a positive impact on me?" Items were rated on a 5-point Likert scale (1 = Not at all to 5 = Extremely). Subscale scores were calculated from the item means. Internal consistency reliability for the subscales was adequate to good in prior studies (Cronbach's alpha = .71 to .90; Kausar & Powell, 1999) and in the current sample (α = .80-.85).

Satisfaction with health care services was assessed with the following question: "Thinking about [your child's] health needs and the service (he/ she) receives, how satisfied or dissatisfied are you with those services?" on a 4-point Likert scale (1 = very dissatisfied to 4 = very satisfied; Ngui & Flores, 2006).

The 28-item Brief COPE (Carver, 1997) was used to assess coping strategies. Items were rated on a 4-point Likert scale (1 = I haven't been doing this at all to 4 = I've been doing this a lot) and were coded into 14 coping strategies (active coping, seeking instrumental support and planning, seeking emotional support, positive reframing, humor, acceptance, turning to religion, self-distraction, denial, substance use, behavioral disengagement, venting of emotions, and self-blame items), which were then categorized into three subscales: problem-focused, emotional approach, or passive-avoidance coping. Internal consistency reliability for the three subscales when used in a sample of parents of children with ASD ranged from adequate to good (Cronbach's alpha = .60 to .81; Stuart & McGrew, 2009) and was good in the current sample (α = .77 to .85).

The 14-item Brief RCOPE (Pargament, Smith, Koenig, & Perez, 1998) was used to measure religious coping. Items were rated on a 4-point Likert scale (1 = not at all to 4 = a great deal). Both negative and positive religious coping were measured. Specifically, positive religious coping reflects benevolent religious involvement (e.g., sought God's love and support), and negative religious coping reflects struggles in coping (e.g., wondered whether my church had abandoned me). The measure had good internal consistency reliability in previous studies (positive scale Cronbach's alphas = .87; negative scale Cronbach's alphas = .69; Pargament et al., 1998) and in the current sample (positive scale α = .96; negative scale α = .95).

Parenting self-efficacy was assessed using the efficacy subscale of the Parenting Sense of Competence scale (PSOC; Johnston & Mash, 1989). The 16-item PSOC has two subscales. The Satisfaction subscale (9 items) assesses enjoyment, motivation and satisfaction in the parenting role. The Efficacy subscale (7 items), which assesses perceived knowledge, confidence, and competence in parenting, has been used previously with caregivers of children with ASD (García-López, Sarriá, Pozo, & Recio, 2016; Giallo, Wood, Jellett, & Porter, 2013). Only the Efficacy subscale was used in this study. The Efficacy subscale has been shown to have good internal consistency reliability in mothers of children with ASD (Cronbach's alpha = .76; Giallo et al., 2013). It was .80 in the current sample.

Family Adaptation Variables - Individual Level

The 21-item Caregiver Strain Questionnaire (CGSQ; Brannan, Heflinger, & Bickman, 1997) was used to measure caregiver strain. Items were rated using a five-point Likert scale (1 = not at all a problem to 5 = very much a problem). Higher scores indicated greater caregiver strain. Internal consistency reliability was good in prior studies (Cronbach's alpha = .94; Stuart & McGrew, 2009) and in the current sample (α = .92).

Caregiving satisfaction was measured with a six-item scale developed by Lawton and colleagues (1989). This scale has been used in several caregiving studies (Lawton et al., 1991; Miltiades & Pruchno, 2002; Pruchno & Resch, 1989; Pruchno, Burant, & Peters, 1994). Items were rated on a 5-point Likert scale (1 = never to 5 = nearly always or 1 = Disagree a lot to 5 = Agree a lot). Caregivers were asked to indicate the extent to which they feel a sense of satisfaction from taking care of their child, enjoyment from being with their child, closer to their child due to caregiving, a self-esteem boost because of caregiving, pleasure from their child's pleasure, and that caregiving added meaning to their life. A total score was used, with a higher score indicating greater caregiving satisfaction. Internal consistency reliability has been good in prior studies (Cronbach's alpha = .78; Miltiades & Pruchno, 2002) and in the current sample (α = .78).

The 21-item Depression, Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995) was used to measure distress. Items were rated on a 4-point Likert scale (0 = not at all to 3 = very much/most of the time). Internal consistency reliability was good in prior studies

(Cronbach's alpha = .85 - .93; Samios, Pakenham, & Sofronoff, 2008) and the current study (α = .83 to .91).

The Satisfaction with Life Scale (SWLS; Pavot & Diener, 1993) was a 5-item questionnaire used to assess global cognitive judgments about one's life overall. Using a 7-point Likert scale, participants were asked to indicate the extent to which they agree with each statement (1 = strongly disagree to 7 = strongly agree). A high score indicated higher satisfaction. The SWLS has high internal consistency and good test–retest reliability (Pavot & Diener, 1993). Cronbach's alpha was .85 when used with a sample of caregivers of individuals with ASD (Ekas et al., 2010) and .88 in the current study.

The 17-item Benefit Finding Scale was used to measure the extent to which caregivers find meaning and experience personal growth from caring for their child with ASD (Antoni et al., 2001). Items were rated using a 5-point Likert scale (1 = not at all to 5 = extremely). The composite score had good internal consistency in a prior study (Cronbach's alpha = 0.95; Kim, Schulz, & Carver, 2007) and in the current study (α = .91).

Family Adaptation - Family Level

The 25-item Family Quality of Life (FQOL; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006) questionnaire has been used to measure the quality of life of families of children with disabilities. The questionnaire was used to assess the degree of satisfaction with family interaction, parenting, emotional wellbeing, physical/material wellbeing, and disability-related support in families raising a child with ASD. Items were rated on a 5-point Likert scale (1 = very dissatisfied to 5 = very satisfied). The total score was used. Higher scores indicated greater satisfaction with family life. The FQOL had good internal reliability in prior studies (Cronbach's alphas ranging from 0.88 to 0.95; Mcstay et al., 2014; Pozo et al., 2013) and in the current sample (α = .95).

Family Adaptation - Dyadic Level

The 32-item Dyadic Adjustment Scale (Spanier, 1976) was used to assess the overall quality of adjustment in marital or committed relationships. The majority of items were measured using a 6-point Likert scale assessing the extent of agreement/disagreement with the statement, with two items rated dichotomously. A total score was used, with higher scores

reflecting greater adjustment. High internal consistency (Cronbach's alpha = 0.96; Spanier, 1976) has been previously established, and it was .95 in the current sample. See Table 1 for a list of constructs and measures. See Table 2 for a full list of internal consistency reliability for all of the variables by race.

Attention Check

As a validity check for the data, to ensure participants' attentiveness while completing the survey, three attention-check items were inserted at various points within the overall survey. Attention-check items are questions easy to answer so that all individuals should answer in the same way. The following attention-check items were used: Please respond to this item by selecting "Neutral"; Respond to this item by selecting "8"; Please select "Disagree."

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Statistical Design and Data Analysis

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Statistical analysis was performed using SPSS 23.0 (IBM Corp. Released, 2015). Descriptive statistics were used to characterize demographic information and ABCX factors. Simple and multiple regression analyses were used. Chi-square and independent t-tests were used to examine if there were group differences in demographic characteristics.

Missing data were analyzed using pairwise deletion. Overall, the missing data rate was low. At the survey-item level, 208 of the 438 survey items (47%) had no missing data; 198 items (45%) had missing data from 1 participant, 10 items (2%) had missing data from 2 participants, 18 items (4%) had missing data from 3 participants, and 4 items (1%) had missing data from 1 participant. However, one participant missed 42% of the items. When this participant was dropped from the data analyses, 360 of the 438 survey items (82%) had no missing data; 56 items (13%) had missing data from 1 participant, 18 items (4%) had missing data from 2 participants, and 4 items (1%) had missing data from 3 participants.

For Aim 1, to examine and compare group differences in the mean levels of the general and racial-specific elements of the double ABCX model bivariately (i.e., the *ABC* in the model), a dummy variable, race (1 = White, 2 = Black), was created. This dummy variable served as the IV in the regression analyses comparing racial groups, and the general and racial-specific elements of the double ABCX model were DVs (analogous to doing t-tests).

The second aim was to examine the levels of positive and negative adaptational outcomes in Black/African American caregivers of those with ASD and to compare the adaptational outcomes between the two racial groups (i.e., the *X* in the double ABCX model). Two sets of analyses were performed. The first simply compared raw outcomes (the X in the model) bivariately between racial groups unadjusted for possible explanatory variables (the ABC elements in the model). This is analogous to performing simple t-tests. Then, the regression analyses were repeated using race and potential explanatory variables/covariates as the IVs and the family adaptation outcomes as the DVs. Covariates were potential general or racial-specific ABC Model variables identified in Aim 1 that were significantly related to race ($p<.05$) and thus might explain possible bivariate, unadjusted racial group differences in outcomes.

For Study Aim 3, to examine the association between caregiver outcomes and general and racial-specific elements of the double ABCX model in Black/African American and White ASD caregivers, the analysis focused on caregiver strain as the outcome variable because it is the only variable that has been consistently examined in the literature. Three sets of analyses were completed, one within the White sample, one within the Black sample, and one for the combined sample. First, independent correlation analyses within each of the two racial groups were conducted to examine the bivariate relationships between the adaptational outcomes and the elements of the double ABCX model within each group. Next, multiple regressions were conducted separately within the two racial groups, respectively to look at the relationships between the caregiver outcomes and general and racial-specific elements within each group. Finally, in the third analysis, the combined sample was used to test for possible group moderation. For all three multiple regressions (separately within the two racial groups and for the combined group), caregiver strain was the DV. Variables that were significantly correlated with caregiver strain ($p<.05$) were included as IVs. Finally, for the regression using the combined sample, variable interaction terms were created from the product of the IVs and race (i.e., variable X Race) and included as a second set of IVs. A significant beta weight for any of the interaction terms would indicate that racial group moderated the relationship between the predictor variable and the outcome. Due to the small sample size and multiple tests, to reduce the Type I error, for the study's main analyses results were considered significant when p<.01 and significant at a trend level when p<.05.

RESULTS

A total of 62 participants completed the survey. Six participants were excluded from the data analyses for not meeting the inclusion criteria (e.g., SCQ<11) and answering one or more attention-check questions incorrectly. Of the 56 participants, 33 were recruited via MTurk (n_{Black} =2, n_{White} = 31) and 23 (n_{Black} = 22, n_{White} = 1) via other methods. The data were then examined for outliers and normality.

Of the 56 participants, 23 identified as Black/African American, 32 identified as White, and 1 identified as multi-racial (and was included under the Black/African American group). The average age of the participants was 41.18 ($SD = 6.58$, $M_{Black} = 40.21$, $SD_{Black} = 4.40$; $M_{White} = 41.94$, $SD_{White} = 7.85$). A total of seven participants identified as fathers, and 49 were mothers of individuals with ASD. Over half of the participants were married (67.9%) and working full time (55.4%). Close to half of the participants had a college degree (46.4%). Child's age in this sample ranged from 2 to 26 years old ($M = 12.10$; $N = 40$). Due to some confusion in the formatting of the family demographic question about numbers, ages and gender of offspring, gender of the child with ASD was only reliably reported for 39 of the sample. Of these, 38 were male, and 7 were females (with five families reporting multiple children with ASD), producing a male to female ratio of 5.4:1, which is consistent with other samples of children with ASD (Lazoff et al., 2010). The child's average age at diagnosis was 5.20 ($SD = 2.68$; $M_{Black} = 5.17$, $SD_{Black} = 2.49$; $M_{White} = 5.23$, $SD_{White} = 2.86$). About 50% of participants had annual household incomes below $60,000 (46.4%). Besides being the caregiver for other children and spouse in the house, only one participant reported being the caregiver of his/her parent. See Table 3.

Caregiver education (4 year college or more vs. some college or less), marital status (married or living with a partner vs. single or widowed), and income (below $60,000 or above $60,000) were coded into dichotomized variables. Chi-square tests indicated that the two groups significantly differed in relationship status, $\chi^2 = 4.28$, $p = .039$. That is, more White participants reported being single or widowed than the Black/African American participants. No group differences were found in child gender, $\chi^2 = 4.63$, $p = .50$. The results of the independent t-tests indicated no group differences in caregiver age [$t(53) = .97$, $p = .34$)] or age of ASD diagnosis between the two racial groups [$t(54) = .09$, $p = .93$].

Race Differences in the General and Racial-Specific Elements of the Double ABCX Model

The first aim of the study was to examine and compare group differences in the general and racial-specific elements of the double ABCX model (i.e., the *ABC* in the model). As noted above, a dummy variable was created for race (1= White, 2 = Black). Regression analyses were conducted with general and racial-specific elements of the double ABCX model as dependent variables, and race as the independent variable to examine group differences (analogous to running a series of t-tests). The results of the simple regressions indicated that race was significantly related to pile-up of demands [$R^2 = .14$, $F(1, 53) = 8.75$, $\beta = .38$, $p = .005$], formal social support [$R^2 = .19$, $F(1, 52) = 12.31$, $\beta = .44$, p = .001], threat appraisal [$R^2 = .24$, $F(1, 53) = 17.07$, $\beta = .49$, $p = .000$], passive-avoidance coping [$R^2 = .28$, $F(1, 53) = 20.59$, $\beta = .53$, $p = .000$], positive religious coping [$R^2 = .33$, $F(1, 53) = 25.51$, $\beta = .57$, $p = .000$], and negative religious coping [$R^2 = .39$, $F(1, 53) = 34.50$, $\beta = .63$, $p = .000$]. In addition, race was also related to problem behaviors at a trend level [$R^2 = .09$, $F(1, 53) = 5.32$, $\beta = -.30$, $p = .025$]. That is, Black/African American caregivers compared to their White counterparts, reported higher levels of pile-up of demands, formal social support, threat appraisal, passive avoidance coping, positive religious coping, negative religious coping, and lower levels of problem behaviors. See Table 4.

Family Adaptation in Black and White ASD Caregivers

The second aim of the study was to examine the levels of positive and negative adaptation outcomes in Black/African American caregivers of those with ASD and to compare outcomes between the two racial groups. Simple bivariate regression analyses were conducted first. Caregiver outcomes that were associated with race included anxiety [$R^2 = .15$, $F(1, 54) = 9.10$, $\beta = .38$, $p = .004$] and life satisfaction [$R^2 = .18$, $F(1, 54) = 11.89$, $\beta = -.43$, $p = .001$]. Specifically, Black/African American caregivers of individuals with ASD reported higher levels of anxiety ($M_{Black} = 11.08$, $SD_{Black} = 8.21$; $M_{White} = 5.29$, $SD_{White} = 6.03$) and lower levels of life satisfaction ($M_{Black} = 14.21$, $SD_{Black} = 6.72$; $M_{White} = 21.45$, $SD_{White} = 8.42$) than their White counterparts. In addition, Black caregivers reported greater levels of depression at a trend level ($M_{Black} = 13.17$, $SD_{Black} = 7.69$; $M_{White} = 7.23$, $SD_{White} = 8.98$; $R = .33$, $F(1, 54) = 6.69$, $\beta = .34$, $p = .012$).

The results indicated that caregiver strain [$R = .12$, $F (1, 53) = .74$, $p =.394$], caregiving satisfaction [$R = .09$, $F (1, 54) = .43$, $p =.516$], stress [$R = .21$, $F (1, 54) = 2.41$, $p =.126$], benefit finding [$R = .04$, $F (1, 54) = .10$, $p =.751$], family quality of life [$R = .03$, $F (1, 54) = .05$, $p =.824$], and marital quality [$R = .28$, $F (1, 33) = 2.63$, $p = .12$] were unrelated to race. That is, Black/African American and White ASD caregivers reported similar levels of caregiver strain ($M_{Black} = 2.35$, $SD_{Black} = .64$; $M_{White} = 2.17$, $SD_{White} = .78$), caregiving satisfaction ($M_{Black} = 18.25$, $SD_{Black} = 2.91$; $M_{White} = 18.87$, $SD_{White} = 3.88$), stress ($M_{Black} = 14.50$, $SD_{Black} = 8.11$; $M_{White} = 10.97$, $SD_{White} = 8.55$), benefit finding ($M_{Black} = 61.83$, $SD_{Black} = 10.15$; $M_{White} = 60.77$, $SD_{White} = 13.58$), family quality of life ($M_{Black} = 130.33$, $SD_{Black} = 21.38$; $M_{White} = 128.81$, $SD_{White} = 27.74$), and marital quality ($M_{Black} = 99.82$, $SD_{Black} = 23.01$; $M_{White} = 112.57$, $SD_{White} = 20.69$). See Table 5 for full listing of results.

As mentioned above, a second set of analyses were conducted to test whether potential explanatory elements of the ABC model, i.e., covariates, identified in aim 1, including pile-up of demands, formal social support, threat appraisal, passive-avoidance coping, positive and negative religious coping, and child problem behaviors could account for the obtained raw racial differences in outcomes. In addition, demographic variables significantly related to race (i.e., marital status) also were entered in the multiple regression analyses as covariates.

The results of multiple regression analyses with caregiver outcomes (e.g., caregiver strain, benefit finding) as DVs, race and the potential covariates as the IVs, indicated that race was no longer significantly related to any of the prior significantly different caregiver outcomes. Specifically, race was no longer associated with anxiety, life satisfaction, or depression. Instead, at a trend level, there was an association between depression and use of avoidance coping ($\beta = .42$, $p = .027$), between anxiety and greater formal social support ($\beta = .38$, $p = .027$), and between life satisfaction and decreased passive-avoidance coping ($\beta = -.37$, $p = .012$), negative religious coping ($\beta = -.28$, $p = .048$), and pile-up demands ($\beta = -.23$, $p = .040$), and greater use of positive religious coping ($\beta = .34$, $p = .01$).

Although not part of the original analyses aimed at understanding explanatory factors related to racial differences, we also tested whether race along with the covariates noted above were related to the other adaptational outcomes. None were related to race. However, at a trend level, stress was related to increased use of passive-avoidance coping ($\beta = .42$, $p = .04$). See details in Table 6. Based on the variance inflation factor (VIF), the multicollinearity was

moderate in all the models (VIF range: 1.1 - 2.6). The next aim focuses on findings related to caregiver strain.

The Relationship Between Caregiver Strain and General and Racial-Specific Factors in Black and White ASD Caregivers

The third aim of the study was to examine the association between caregiver strain and general and racial-specific ABC elements of the double ABCX model in Black/African American and White ASD caregivers respectively. As mentioned above, the analyses focused on caregiver strain as the outcome variable because it is the only variable that has been consistently examined in the literature. As previously noted, three sets of analyses were conducted. The first two examined the relationships between caregiver strain the ABC elements separately within the Black and White samples. Both bivariate (caregiver strain and each ABC element) and multivariate analyses were conducted. For the multiple regression analyses, caregiver strain was the DV. Variables that significantly correlated ($p<.05$) with caregiver strain were included as IVs. Finally, the analyses between caregiver strain and the ABC elements were repeated using the combined Black and White caregiver sample.

Bivariately, when the analyses were restricted to Black/African American caregivers, higher levels of caregiver strain were significantly related to lower levels of conscientiousness ($r = -.56$, $p = .006$). At trend levels, higher levels of caregiver strain were related to lower levels of extraversion ($r = -.48$, $p = .020$) and challenge appraisal ($r = -.46$, $p = .028$), higher levels of neuroticism ($r = .50$, $p = .016$), and greater use of positive religious coping ($r = -.46$, $p = .026$). See Table 7. In the follow-up multiple regression analysis with caregiver strain as the DV and the *ABC* variables as IVs, only conscientiousness ($\beta = -.56$, $p =.006$) was associated with caregiver strain, $R^2 = .31$, $F(1, 21) = 9.35$, $p = .006$. Specifically, lower levels of caregiver strain were related to higher levels of conscientiousness.

When restricting the analyses to White caregivers, bivariately, higher levels of caregiver strain were significantly related to higher levels of passive-avoidance coping ($r = .65$, $p = .000$), neuroticism ($r = .56$, $p = .001$), number of barriers identified to care ($r = .55$, $p = .001$), lower satisfaction with health care services ($r = -.53$, $p = .002$), greater use of threat appraisals ($r = .52$, $p = .003$), lower levels of parenting self-efficacy ($r =-.59$, $p = .001$), and total number of supports used ($r = .46$, $p = .009$). At a trend level, bivariately, higher levels of caregiver strain were

related to higher levels of autism symptom severity ($r = .38$, $p = .036$), greater use of negative religious coping ($r = .43$, $p = .017$), and lower levels of ease of using heath care services ($r = -.42$, $p = .020$) and conscientiousness ($r = -.45$, $p = .012$). See Table 7. In a follow-up multiple regression, when the above variables were included as IVs, increased use of passive-avoidance coping ($\beta = .49$, $p = .000$) and of number of formal supports ($\beta = .37$, $p = .001$), along with lower satisfaction with health care services ($\beta = -.30$, $p = .017$) were associated with increased caregiver strain, $R^2 = .74$, $F(4, 26) = 18.92$, $p = .000$. Based on the VIF, multicollinearity was in the moderate range (VIF range: 1.1 - 1.4).

The third analysis used the same procedures with the combined sample. Any predictor variables that were significantly related (i.e., barriers, satisfaction of health care services, neuroticism, conscientiousness, threat appraisal, passive-avoidance coping, and parenting self efficacy) or related at a trend level (i.e., symptom severity, ease of using health care services, formal social support, extraversion) were entered first as IVs into the model. Variables representing the interactions between those variables and race were also created and entered the model next. The results indicated no significant interactions, $R^2 = .73$, $F (22, 30) = 3.74$, $p < .001$. That is, racial group did not moderate the relationship between the predictor variables and caregiver strain.

Supplementary Analyses

One of the unanswered questions in the autism literature concerns potential differences in diagnostic presentation of Black and White children with ASD. Because the Cronbach's alpha for our measure of ASD symptomatology (i.e., SCQ) was somewhat low and within the Black caregiver group, some of the items showed negative or near zero correlations with the total scale, we ran additional exploratory analyses at the item level to examine potential group differences in symptom presentation between the two racial groups. We used the Fisher's Exact Test when frequency in at least one cell was less than five; otherwise, the Chi-Square test was used. The results identified four items on the Social Communication Questionnaire showing large significant group differences. Specifically, compared to Black caregivers (23.5%), White caregivers (76.5%) were more likely to endorse when reporting if the child ever uses social inappropriate questions or statement, $p < .001$, if the child has any complicated movements of his or her whole body (80% in White vs. 20% in Black), $p = .003$, or if the child has any particular

friends or a best friend (72.7% in White vs. 27.3% in Black), p = .005. In contrast, when asked if the child ever gets pronouns mixed up, more Black caregivers (61.7%) answered yes compared to White caregivers (39.3%), p = .019.

DISCUSSION

Few studies have examined the adaptational outcomes of Black caregivers of individuals with ASD. Using the framework of the double ABCX model of family adaptation (McCubbin & Patterson, 1983), the current study aimed at exploring family adaptational outcomes in Black caregivers, the relationships between caregiver strain and general and racial-specific factors in this group, and potential racial differences in potential predictors of adaptation between Black and White caregivers of individuals with ASD.

A total of 24 Black and 32 White ASD caregivers were recruited. The majority of the caregivers were mothers, which is consistent with most prior studies of caregiver strain and with the literature that mothers tend to be the primary caregivers of individuals with ASD (e.g., Keenan et al., 2016). As a first step, we compared demographic variables between Black and White caregiver samples—the only significant difference was that Black caregivers were more likely to be married. Of note, in contrast to some prior studies, we failed to find group differences in reported age of initial ASD diagnosis in our sample. For example, both Burkett and colleagues (2017) and Mandell et al. (2009) reported the age of first ASD diagnosis in Black children was significantly later than in White children. One possible reason is that we relied on parent report, not on an objective record. For example, the average age of first diagnosis for our sample was 5.2 (5.23 for the White children and 5.17 for the Black children), which is somewhat later than the national average (4.33 years; Maenner et al., 2020). It is possible that later age for parental report of first diagnosis was due to errors in retrospective recall. It also may indicate that the study sample has limited representativeness compared to other ASD caregivers in the US.

Race Differences in the General and Racial-specific Elements of the Double ABCX Model

Racial differences were found for both the general (e.g., social support, coping) and racial-specific factors (e.g., religious coping) of the model. Specifically, Black ASD caregivers reported higher levels of pile-up of demands, formal social support, threat appraisal, passive-avoidance coping, and positive and negative religious coping than White caregivers. The higher levels of pile-up of demands are consistent with the literature that Blacks report higher levels of daily stressors than their White counterparts (e.g., Jackson & Mustillo, 2001). In addition, Black

ASD caregivers tended to report greater use of threat appraisals and passive-avoidance coping than White counterparts. Both negative appraisal processes and avoidance coping have been consistently shown to be related to negative caregiver outcomes across several studies (Stuart & McGrew, 2009; Pakenham et al., 2005; McGrew & Keyes, 2014).

Black ASD caregivers also reported greater use of religious coping, both positive and negative, which is consistent with the general literature on coping styles. For example, Black mothers of individuals with intellectual disability were more likely to use religious coping than their White counterparts (Miltiades et al., 2002). Similarly, Black dementia caregivers reported higher levels of religious coping than their White counterparts (Haley et al., 2004; Pinquart & Sorensen, 2005). Ano and Vasconcelles (2005) found that positive and negative forms of religious coping are related to positive and negative psychological adjustment to stress, respectively. In partial replication, although decreased caregiver strain was related to positive religious coping in our sample ($r = -.46$, $p<.05$), negative religious coping was unrelated ($r = -.04$). However, further research will be needed to more fully understand these findings.

There also were differences in use of formal supports. To my knowledge, this is the first study to compare Black vs. White differences in formal social support among ASD caregivers. Somewhat curiously, Black caregivers reported higher levels of formal social support (e.g., community support groups, national and local autism organizations) than White caregivers. However, level of formal social support did not seem to provide the expected buffer against caregiver strain among Black caregivers although it was related to lower strain among White caregivers (aim3). It is difficult to understand these differences. For example, the top three formal social supports accessed by Black and White families were similar; both included occupational therapy and autism support groups. However, there were clear differences in the top three most helpful services, with Black caregivers identifying physical therapy, autism support groups, and social work, whereas White caregivers identified speech therapy, financial support from private or public organizations/sources, and occupational therapy as most helpful. However, despite these potential differences in helpfulness, there was no association between helpfulness and caregiver strain among Black caregivers. One possible explanation is that nearly all of the Black families were recruited from care providers (i.e., they were already connected to services), whereas, all but two of the White families were recruited using MTurk, and may or

may not have been as connected to services. Regardless, these results are worth exploring further in future studies about Black vs. White caregivers' perceptions of formal support.

Adaptation Outcomes in Black and White ASD Caregivers

Both White and Black caregivers reported moderate and approximately equal levels of caregiver strain, one of the most commonly used family adaptational outcomes used across studies of caregiver adjustment. However, we found significant differences in three other family adaptation outcomes. Specifically, compared to White caregivers, Black caregivers reported higher levels of anxiety and depression and lower levels of life satisfaction. The failure to find significant differences between the two racial groups for the other adaptational outcomes may be due to low statistical power (See Table 5 for effect sizes).

Although our results suggest that Black caregivers experience more negative adaptational outcomes, other authors have reported that Black caregivers experience similar levels of caregiver adaptational outcomes compared to their White counterparts. For example, in dementia caregivers, studies have found equal levels of depression and anxiety in Black caregivers compared to non-Black caregivers (Knight et al., 2000). Similarly, as suggested by some studies, Black caregivers may not report worse outcomes than their White counterparts, (e.g., Juster et al., 2010; Stronks et al., 2013) because they are more likely to use effective coping strategies (Pinquart & Sorensen, 2005), such as adaptive coping strategies.

These results also are in direct contrast to Bishop et al. (2007)'s finding that Black/African American ASD caregivers reported **lower** levels of negative caregiving outcomes than their White counterparts. In part, these differences in results may be due to differences in measurements. Bishop and colleagues (2007) used the Child and Adolescent Impact assessment to measure caregiver outcome, which was originally developed for caregivers of children with psychiatric disturbance and has been used less frequently in ASD caregivers. It is also possible that the sample of the two studies were different. Bishop et al. (2007) assessed caregiver outcomes when their children were approximately 9 years old, whereas this study had a wider age range. In addition, when we controlled for potential covariates suggested by the ABCX model (e.g., child problem behaviors, caregiver coping strategies, caregiver social support), the racial differences in outcomes were no longer significant. That is, our results suggest that the obtained racial differences in adaptation outcomes could be explained at least in part by the ABC

variables. Specifically, higher levels of depression were related to and largely "explained" by greater use of passive-avoidance coping ($p<.05$), higher levels of anxiety were explained by greater formal social support ($p<.05$), and higher levels of life satisfaction were explained by the greater use of positive religious coping, reduced use of passive-avoidance coping ($p<.05$) and negative religious coping ($p<.05$), and lower levels of pile-up of demands ($p<.05$). These findings are largely consistent with the prior literature on caregiver outcomes (e.g., increased avoidance coping has been consistently related to increased negative outcomes and decreased positive outcomes in prior studies of caregivers of ASD; Hastings et al., 2005; McGrew & Keyes, 2014; Paynter, Riley, Beamish, Davies, & Milford, 2013; Stuart & McGrew, 2009; pile-up demands has been related to worse adaptation in several studies; Pakenham et al., 2005). However, the finding that anxiety was explained by or related to greater formal social support was unexpected and, to my knowledge, has not been reported in the literature. One possible explanation is "reverse causation." That is, caregivers who are high in anxiety may be more likely to seek out formal social support and services.

Relationship Between Adaptational Outcomes and General and Racial-Specific Factors in Black and White Caregivers

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Relationship Between Adaptational Outcomes and General and Racial-Specific Factors in Black and White Caregivers

The results suggested that different factors were related to caregiver strain in the two racial groups. Specifically, in Black caregivers, only one factor was related to caregiver strain, conscientiousness. Black/African American caregivers of individuals with ASD, who reported higher levels of conscientiousness, reported lower levels of caregiver strain. That is, conscientiousness seemed to be a protective factor against caregiver strain for Black caregivers. However, there were additional findings at a trend level. Two additional personality factors (i.e., neuroticism, extraversion) as well as challenge appraisal and positive religious coping were related to caregiver strain ($p<.05$) with large or medium effect sizes. Specifically, Black ASD caregivers who reported lower levels of neuroticism, and higher levels of extraversion, challenge appraisal, and positive religious coping also reported lower levels of caregiver strain. No studies have examined the impact of the Big Five caregiver personality traits in Black caregivers of individuals with ASD. Further support for these findings on personality traits comes from the general literature that has shown that lower levels of neuroticism and higher levels of conscientiousness and extraversion in Black/African American adults are associated with lower levels of depressive symptoms (Clark et al., 2017). Similarly, the results with respect to challenge appraisal and positive religious coping echo those noted above for other adaptational outcomes, in that both are protective in increasing adaptation (Ano & Vasconcelles, 2005; Manning et al., 2011).

Multiple factors were related to caregiver strain for White caregivers. Specifically, higher levels of caregiver strain were related to greater use of passive-avoidance coping and threat appraisal, higher levels of neuroticism and barriers to care, and lower levels of satisfaction with services, parenting self-efficacy, and formal social support (e.g., support groups, autism organizations, respite care). These results are consistent with the extant ASD caregiver literature, which has focused primarily on White caregivers. For example, it has been shown that passive-avoidance coping and threat appraisal are strong maladaptive factors related to negative outcomes in parents of children with ASD and developmental disabilities (Hastings et al., 2005; McGrew & Keyes, 2014; Yu et al., 2018). In addition, higher levels of social support have been associated with reduced levels of both caregiver strain (Stuart & McGrew, 2009) and parenting stress (e.g., Bekhet et al., 2012). Similarly, parenting self-efficacy has been shown to be related

to increased parent well-being in caregivers of individuals with ASD (Giallo et al., 2013; Weiss et al., 2015). Also, neuroticism has been shown to have the strongest negative association with caregiver strain of the Big Five personality traits in primary caregivers of individuals with ASD and developmental disabilities, which was consistent with the results in this study as well (Jobe & Glidden, 2008; Yu et al., 2018). Finally, it is worth reiterating that consistent with the results above, one nearly universal finding is that denial or avoidance coping strategies and negative appraisal styles (threat appraisals, neuroticism) are related to poorer adaptation.

This was the first study to examine barriers to care and strain among ASD caregivers. As expected, caregiver strain was strongly related to barriers to care among White caregivers (r=.55), but unexpectedly, was unrelated to barriers to care among Black ASD caregivers (r= -.06). This was surprising. When barriers to care were then examined with respect to other caregiver outcomes, a similar pattern emerged. The results indicated that the number of barriers was unrelated to caregiver outcomes among Black caregivers (p>.01), and only related to higher levels of depression among White caregivers ($r = .48$, $p = .006$). In general, studies have shown that Black/African American parents reported barriers to entering or staying in mental health services (Owens et al., 2002). The thought is that such barriers interfere with receiving good care and thus should be associated with poorer child and parent outcomes. In the current study, 100% of the Black ASD caregivers identified more than one barrier vs. 81.2% of the White ASD caregivers, with 20% of White caregivers reporting no barriers to care and, compared to White caregivers, Black caregivers also identified a slightly higher number of barriers to care (5.33 vs. 4.81). That is, although there was clear evidence of barriers to care, the barriers to care only seemed to impact White caregivers. This will clearly require further study to understand why barriers impacted White but not Black caregiver strain.

Finally, as noted earlier, as an exploratory analysis, we also examined the patterns of autism symptom endorsement on the SCQ scale in the two racial groups. This was done in part because the internal consistencies for the SCQ scale were clearly lower among the Black caregiver group, which was further reflected in several items with low to zero item-total correlations. Clear racial differences emerged in item endorsements. Specifically, Black caregivers were less likely to endorse social concerns (e.g., use of socially inappropriate questions, friendships) and were more likely to endorse communication concerns (e.g., mixed pronouns) than their White counterparts. Studies have shown mixed results in parent-reported

racial differences in early developmental concerns. For example, studies have indicated fewer social concerns reported by Black parents of children with ASD than their White counterparts, using a variety of different measures (e.g., structured questionnaire, free-response questions; Donohue et al., 2019; Issarraras et al., 2019). Specifically, Donohue and colleagues (2019) found that Black parents of children with ASD reported fewer restricted and repetitive behavior concerns than White parents. In contrast, Issarraras and colleagues (2019) found no racial differences in communication, language/speech, and problem behaviors. No prior studies have examined racial differences in symptom endorsement using the SCQ. Additional studies are needed to explore if there are racial differences in ASD symptom endorsement perception, actual differences in ASD symptom presentation, or cultural problems with the language and use of the SCQ scale.

Limitations and Future Directions

This study is among a very few studies that have examined Black parents/primary caregivers of individuals with ASD. Nevertheless, it has several limitations. The internal consistency reliabilities were too low to be usable for some subscales/measures, which then had to be dropped from the analyses. The low reliabilities may be due to the small sample size (e.g., outliers in use of the scale) or few items in the subscales.

In addition, it is noteworthy that no Black participants reported incomes below $20,000 in this sample vs. about 19% of White caregivers with incomes below $20,000. Although there was no significant racial difference in income overall, this may indicate potential problems in the representativeness of the sample in this study, which is also consistent with the potential impact of the different recruitment sources for the Black (e.g., service providers) vs. White caregiver samples (e.g., MTurk).

Further, there were very significant difficulties recruiting Black ASD caregivers. Various ways of recruitment were attempted over an entire year. The recruitment was unlimited to geographic areas (except that participants had to live in the United States). Efforts were made specifically in two states due to the author's location (Indiana and South Carolina). It is possible that the recruitment information was less accessible to Black families, they were not interested in participating in the studies, or they did not trust the research process or research studies in general. The study survey was distributed online and required a certain literacy level. Thus, it is

also possible that literacy or lack of computer access/knowledge was a potential barrier to recruitment. Recently, Shaia et al. (2019) identified barriers to research involvement in Black families raising children with ASD, which included stigma, denial, shame, and or embarrassment, distrust of the research process, lack of interest and research material inaccessibility or literacy issues. Future studies may need to be creative in their recruitment strategies in this population.

One result of these problems was that the sample size for this study was relatively small, which provided limited power to run complex statistical models and examine more adaptational caregiver outcomes. Further, with the use of multiple tests, there is a high likelihood of Type I error. On the other hand, the small sample size also made the analyses underpowered and thus more prone to Type II error. Nevertheless, because very few studies have examined the characteristics of Black caregivers in individuals with ASD, we felt it was important to report the findings even at a trend significance level to provide information/data for future studies.

Even with the addition of the current study results, overall findings regarding Black ASD caregiver outcomes are still mixed in the literature, mostly due to small sample sizes and limited geographic sampling (Bishop et al., 2007; Carr & Lord, 2012). Therefore, more studies are needed examining racial differences with larger samples and exploring the relationship between the general and racial factors with other adaptational outcomes.

Because of the small sample size and multiple independent variables in the same regression models in this study, the analyses were potentially prone to multicollinearity. According to Hair et al. (2010), VIF values greater than 4.0 indicate a potential problem with multicollinearity. Our results indicated small to moderate multicollinearity that was less than 4. Nevertheless, the multivariate results should be taken with caution.

As already noted, although not intended, the sources of recruitment in the two racial groups were mostly different. Most of the White participants were from Amazon Mechanical Turk, and most of the Black ASD caregivers were from sources outside of MTurk. Although the recruitment source did not necessarily impact all of the results, it may have impacted some of them, and limited the representativeness of the sample and the generalizability of the results to other Black ASD caregivers.

Conclusion

Racial differences were found for both the general and racial-specific factors in the ABCX model. Black ASD caregivers reported higher levels of pile-up of demands, formal social support, threat appraisal, passive-avoidance coping, and positive and negative religious coping than White caregivers. Both White and Black caregivers reported moderate and approximately equal levels of caregiver strain, although, there were significant Black vs. White raw differences in other adaptational outcomes (i.e., anxiety, life satisfaction, depression). However, any racial differences in adaptation outcomes may be better explained in part by the ABC variables (e.g., passive-avoidance coping, religious coping). That is, the ABC model elements likely served as more proximal explanatory factors of any raw differences in the outcomes. The results also suggested that different factors were related to caregiver strain in the two racial groups. Conscientiousness seemed to be a protective factor against caregiver strain for Black caregivers, whereas higher levels of caregiver strain were related to greater use of passive-avoidance coping and threat appraisal, higher levels of neuroticism and barriers to care, and lower levels of satisfaction with services, parenting self-efficacy, and formal social support in White caregivers. These findings may be helpful in informing interventions and supports provided to Black caregivers of individuals with ASD.

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APPENDIX A

Table 1

Constructs and Measures in the Double ABCX Model

Double ABCX model		Constructs	Measures
A & aA	Stressors	Autism symptoms severity	SCQ
		Problem behaviors	PBRS
	Pile-up of demands	General life demands	SRRS
		Barriers to care	Barriers to care
		Ease of using health care services	A single-item question: "Thinking about the services [your child] needs, are those services organized in a way that makes them easy to use?"
		SES & Additional caregiving role	Demographic Questionnaire
B & bB	Family and caregiver resources	Informal social support	MSPSS
		Formal social support	Formal Social Support Checklist
		Personality traits	NEO-FFI-3
			AQ-10
		Racial identity	MIBI-Short
C & cC	Appraisals and Coping	Coping strategies	Brief-COPE
		Religious Coping	Brief-RCOPE
		Appraisals of caregiving	SAM
		Appraisals of health care services	A single-item question: "Thinking about [your child's] health needs and the service (he/ she) receives, how satisfied or dissatisfied are you with those services?"
		Self-efficacy	PSOC
X & xX	Caregiver Adaptation	Caregiver strain	CGSQ
		Depression, anxiety, and stress symptoms	DASS-21
		Caregiving Satisfaction	Caregiving Satisfaction
		Benefit Finding	BFS
		Life satisfaction	SWLS
		Family quality of life	FQOL
		Marital Adjustment	DAS

Note. SCQ: The Social Communication Questionnaire; PBRS: Problem Behavior Rating Scale; SRRS: Social Readjustment Rating Scale; MSPSS: Multidimensional Scale of Perceived Social Support; NEO-FFI: Neo Five Factor Index; AQ: Autism Quotient; MIBI-Short: Multidimensional Inventory of Black Identify; SAM: The Stress Appraisal Measure; PSOC: Parenting Sense of Competence; CGSQ: Caregiver Strain Questionnaire; DASS-21: Depression, Anxiety and Stress Scale; BFS: Benefit Finding Scale; SWLS: Satisfaction with Life Scale; FQOL: Family Quality of Life; DAS: Dyadic Adjustment Scale.

Table 2

Internal Consistency Reliability by Race

Measures	Black	White
SCQ	0.59	0.75
PBRS	0.84	0.88
SRRS	0.79	0.85
Barriers to care	0.34	0.83
MSPSS	0.96	0.96
FSS	0.71	0.64
NEO-FFI - Neuroticism	0.84	0.9
NEO-FFI - Extraversion	0.81	0.81
NEO-FFI - Openness	-0.92	0.5
NEO-FFI - Agreeableness	0.092	0.51
NEO-FFI - Conscientiousness	0.86	0.84
AQ	0.44	0.69
MIBI Centrality	0.51	
MIBI Private Regard	0.8	
MIBI Public Regard	0.88	
MIBI Assimilation	0.67	
MIBI Humanist	0.38	
MIBI Minority	0.46	
MIBI Nationalist	0.55	
SAM Threat Appraisal	0.71	0.87
SAM Challenge Appraisal	0.57	0.84
Brief COPE - Problem focused coping	0.85	0.78
Brief COPE - Emotion Coping	0.83	0.73
Brief COPE – Passive-avoidance Coping	0.81	0.78
Positive RCOPE	0.91	0.96
Negative RCOPE	0.93	0.9
PSOC - Self-efficacy	0.63	0.84
CGSQ	0.9	0.93
CGSAT	0.75	0.8
DASS-Depression	0.96	0.93
DASS - Anxiety	0.88	0.69
DASS - Stress	0.85	0.87
SWLS	0.75	0.95
BFS	0.88	0.93
FQOL	0.94	0.96
DAS	0.94	0.96

Note. SCQ: The Social Communication Questionnaire; PBRS: Problem Behavior Rating Scale; SRRS: Social Readjustment Rating Scale; MSPSS: Multidimensional Scale of Perceived Social Support; FSS: Formal Social Support Checklist; NEO-FFI: Neo Five Factor Index; AQ: Autism Quotient; MIBI: Multidimensional Inventory of Black Identify; SAM: The Stress Appraisal Measure; PSOC: Parenting Sense of Competence; CGSQ: Caregiver Strain Questionnaire; DASS: Depression, Anxiety and Stress Scale; BFS: Benefit Finding Scale; SWLS: Satisfaction with Life Scale; FQOL: Family Quality of Life; DAS: Dyadic Adjustment Scale.

Table 3

Participant Characteristics by Race

	Black (N = 24)	White (N = 32)	Cohen's d
Caregiver Characteristics			
Age [Mean (SD)]	40.21 (4.40)	41.94 (7.85)	.27
Gender (n)			
Female	21	28	
Male	3	3	
Education (%)			
Four year college degree or more	54.2	37.5	
Some college or less	45.8	62.5	
Income (%)			
Less than or equal to $20,000	0	15.6	
$20,000 - $40,000	16.7	18.8	
$40,001 - $60,000	20.8	18.8	
$60,001 - $80,000	37.5	18.8	
$80,001 - $100,000	20.8	15.6	
More than $100,000	4.2	12.5	
Marital Status (%)*			
Married or living with partner	91.7	68.8	
Single, widowed	8.3	31.3	
Child Characteristics Mean (SD)			
Age of diagnosis [Mean (SD)]	5.17 (2.49)	5.23 (2.86)	.02
Male (n)	10	28	
Symptom Severity	20.71 (4.35)	22.29 (5.64)	.31
Problem Behaviors	1.85 (.30)	2.10 (0.47)	.63

*Significant racial difference.

Table 4

General and Racial-Specific Elements of the Double ABCX Model in Black and White ASD Caregivers

ABC Factors	Black Mean (SD)	White Mean (SD)	F[1]	p[1]
Neuroticism	26.83 (7.22)	23.35 (10.18)	2.01	.162
Parenting Sense of Competence	58.29 (6.64)	60.16 (12.64)	.43	.514
Conscientiousness	32.25 (6.58)	33.19 (7.18)	.25	.618
Satisfaction with Health Care System	2.7 (0.64)	2.58 (1.03)	.23	.637
Threat Appraisal	3.19 (0.86)	2.16 (0.95)	17.07	**.000**
Barriers	5.33 (2.06)	4.74 (3.72)	.49	.488
Passive-Avoidance Coping	2.05 (0.52)	1.49 (0.39)	20.59	**.000**
Formal Social Support	8.78 (3.26)	5.84 (3.07)	12.31	**.001**
Extraversion	26.25 (6.73)	23.00 (7.54)	2.76	.103
Symptom Severity	20.71 (4.35)	22.29 (5.64)	1.29	.261
Ease of using health care services	2.42 (0.5)	2.23 (.72)	1.23	.273
Pile-up of Demands	30.83 (11.78)	19.80 (15.02)	8.75	**.005**
Problem Behavior	1.85 (0.3)	2.10 (0.47)	5.32	**.025**
Negative Religious Coping	2.13 (0.8)	1.15 (0.42)	34.50	**.000**
Informal Social Support	5.16 (1.27)	4.92 (1.52)	.38	.539
Emotion Coping	2.37 (0.61)	2.43 (0.51)	.13	.720
Challenge Appraisal	3.63 (0.57)	3.19 (1.03)	3.55	.065
Problem-focused Coping	2.51 (0.68)	2.78 (0.57)	2.57	.115
Helpfulness of Formal Social Support	2.78 (0.8)	3.07 (1.06)	1.06	.273
Positive Religious Coping	2.68 (0.73)	1.64 (0.78)	25.51	**.000**
Autism Quotient	3.29 (1.78)	2.84 (2.18)	.68	.412
MIBI Private Regard	5.54 (1.06)			
MIBI Public Regard	4.16 (1.6)			
MIBI Assimilation	5.49 (0.9)			

[1] Simple regression results with general and racial-specific elements of the double ABCX model as DVs and race as IV.

Table 5

Family Adaptational Outcomes in Black and White Caregivers

Family Adaptational Outcomes	Black Mean (SD)	White Mean (SD)	Cohen's d	F[1]	p[1]
Depression	13.17 (7.69)	7.23 (8.98)	.71	6.69	**.012**
Anxiety	11.08 (8.21)	5.29 (6.03)	.87	9.10	**.004**
Life Satisfaction	14.21 (6.72)	21.45 (8.42)	.95	11.89	**.001**
Marital Quality	99.82 (23.01)	112.57 (20.69)	.81	2.63	.12
Caregiver Strain	2.35 (.64)	2.17 (.78)	.58	.74	.394
Caregiving Satisfaction	18.25 (2.91)	18.87 (3.88)	.18	.43	.516
Stress	14.50 (8.11)	10.97 (8.55)	.42	2.41	.126
Benefit Finding	61.83 (10.15)	60.77 (13.58)	.09	.10	.751
Family Quality of Life	130.33 (21.38)	128.81 (27.74)	.06	.05	.824

[1]Simple bivariate regression results with family adaptation outcomes as DVs and race as IV.

Table 6

Multiple Regression Summary (Beta weights for final model) for Predicting Family Adaptational Outcomes

Predictors (ABC elements)	Outcomes (X)								
	Caregiver Strain	Depression	Anxiety	Stress	Life Satisfaction	Marital Quality	Caregiving Satisfaction	Benefit Finding	Family Quality of Life
Problem Behavior	0.15	0.06	-0.02	0.24	-0.11	0.07	0.01	0.08	-0.09
Pile-up of Demands	0.16	0.15	-0.07	0.29	-0.23$^+$	-0.11	-0.34	-0.25	-0.02
Formal Social Support	0.25	0.17	0.38$^+$	0.09	-0.13	-0.20	-0.02	-0.10	-0.06
Threat Appraisal	0.20	0.12	0.18	-0.01	-0.03	0.20	-0.18	-0.19	0.07
Passive-Avoidance Coping	0.23	0.42$^+$	0.10	0.42$^+$	-0.37$^+$	-0.36	0.04	-0.17	-0.39
Positive Religious Coping	-0.30	-0.19	-0.29	-0.17	0.34*	0.35	0.28	0.31	0.34
Negative Religious Coping	-0.13	-0.05	0.11	-0.22	-0.28$^+$	0.38	0.11	0.09	0.19
Relationship Status	-0.24	-0.09	-0.02	-0.03	0.17	0.46	-0.32	-.11	0.27
Race	0.10	0.11	0.19	0.16	-0.18	-0.61	-0.02	0.10	-0.18
R^2	0.39	0.43	0.38	0.36	0.66	0.41	0.26	0.22	0.24
F	2.99*	3.67*	2.94*	2.70*	9.53**	1.82	1.69	1.40	1.54

$^+p<.05$, $*p<.01$; $**p<.001$

Table 7

Correlations between Caregiver Strain and the ABC Factors in Both Racial Groups

	Caregiver Strain		
	Total Sample	**Black**	**White**
Neuroticism	.55**	0.50+	.56**
Parenting Self-efficacy	-.52**	-0.31	-0.59**
Conscientiousness	-.49**	-0.56**	-.45+
Satisfaction with Health Care System	-.46**	-0.32	-.53**
Threat Appraisal	.42**	0.24	.52**
Barriers	.40**	-0.06	.55**
Passive-Avoidance Coping	.38**	0.07	.65**
Formal Social Support	.32+	0.06	.46**
Extraversion	-.30+	-0.48+	-0.26
Symptom Severity	.29+	0.15	.38+
Ease of using health care services	-.28+	-0.02	-0.42+
Pile-up of Demands	0.26	-0.02	0.35
Problem Behavior	0.25	0.19	0.35
Relationship Status	-0.21	-0.02	-0.35
Negative Religious Coping	0.20	-0.04	.43+
Informal Social Support	-0.18	-0.11	-0.22
Emotion Coping	-0.17	-0.39	-0.01
Income	-0.16	-0.30	-0.11
Challenge Appraisal	-0.12	-0.46+	-0.05
Problem Focused Coping	-0.12	-0.31	0.06
Helpfulness of Formal Social Support	-0.11	-0.03	-0.12
Age	0.08	-0.11	0.15
Positive Religious Coping	-0.06	-0.46+	0.02
Autism Quotient	-0.04	-0.07	-0.05
Education	0.02	-0.25	0.15
Age of Diagnosis	0.00	-0.05	0.03
MIBI Private Regard		-0.06	
MIBI Public Regard		-0.15	
MIBI Assimilation		-0.21	

+$p<.05$, *$p<.01$; **$p<.001$

B & bB – Family Resources and Supports

A & aA – Stressors and Pile-up of Stressors

X & xX - Caregiver and Family Adaptation
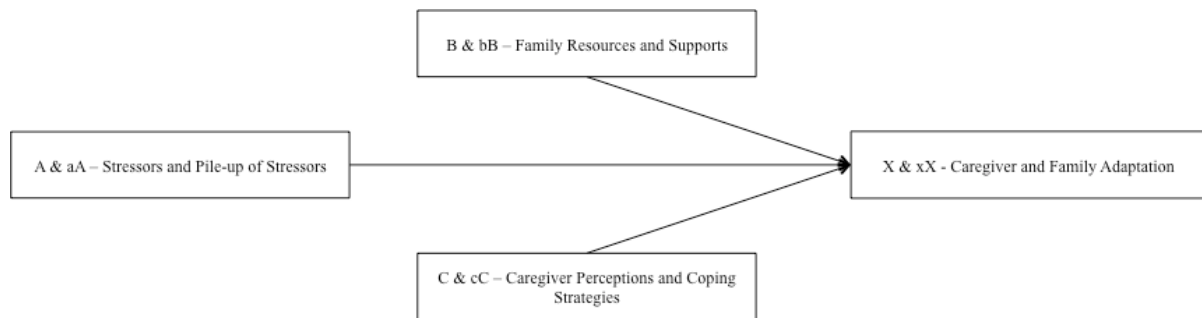
C & cC – Caregiver Perceptions and Coping Strategies

Figure 1. Double ABCX Model of Family Adaptation.