

PERCEPTIONS OF ADHD AMONG AFRICAN AMERICAN PARENTS
AND CAREGIVERS OF BOYS 5-14 YEARS OLD

by

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ABSTRACT

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The purpose of this study was to assess African American parents' and caregivers' perceptions about ADHD, diagnosis, treatment, and outcomes to determine if and/or how those views may affect diagnosis and treatment rates among African American youth. ADHD prevalence is increasing overall in the US across all races/ethnicities, but ADHD diagnosis and treatment rates are still low among African American youth compared to White youth. While African American youth may be more greatly affected by the disorder than White youth, there is a gap in understanding why some parents seek help for their child's ADHD related behaviors, while others do not. African American parents and primary caregivers of boys ages 5-14 who attended an afterschool program in Harlem, New York City, participated in a cross-sectional design interview study with 43 participants. Transcripts were audio-recorded, transcribed and analyzed using an inductive approach. Highlights of findings included parents' and caregivers' discomfort using medication to treat ADHD, concerns about labeling/stigma and misconceptions about ADHD, diagnosis, and treatment. Implications for practice included the need for: disseminating accurate and relevant information, improving understanding about proven and promising non-pharmacological treatment methods and addressing discriminatory practices in ADHD treatment. Recommendations for research include creating and evaluating culturally sensitive treatment approaches, exploring why certain families are misinformed about

ADHD, finding effective ways to correct misconceptions, and testing alternative ways to educate healthcare and education professionals on how best to work with African American and other underserved communities.

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A. E.

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Chapter I

INTRODUCTION

Attention-deficit hyperactivity disorder (ADHD) is characterized by inattention, hyperactivity, and impulsive behavior and, if left untreated, can lead to adverse outcomes such as lowered academic achievement, substance abuse, and involvement with the justice system (Akinbami, Liu, Pastor, & Reuben, 2011; Bussing, Zima, et al., 2012). In addition, ADHD has a profound effect on how children with the disorder interact with their family members and peers. The characteristic symptoms of ADHD can impede children's "social progress as well as strain family dynamics" (Ahmed, Borst, Yong, & Aslani, 2014, p. 661). Parents of children with ADHD often "have high levels of stress and depression, placing additional strain of family relationships" and "can find the condition emotionally taxing and time consuming" (p. 662).

The Centers for Disease Control and Prevention (CDC) reported that ADHD prevalence and medication use increased from 9.5% in 2007 to 11.0% in 2012 and 4.8% in 2007 to 6.1% in 2012, respectively (Visser, Blumberg, Danielson, Bitsko, & Kogan, 2013). In a state profile of New York, the CDC reported an ADHD prevalence of 7.7% in 2011 via parent report, but only 5.1% of children in New York were taking medication for ADHD (<http://www.cdc.gov/adhd>).

For reasons that are currently not well understood, African American children are diagnosed with ADHD less often than White children (Coker et al., 2016), and while recent studies seemed to indicate that the number of African American youth diagnosed

with ADHD is on the rise (Fairman, Peckham, & Sclar, 2017) and that geographic variation in prevalence and treatment exists (McDonald & Jalbert, 2013), when inattentive and hyperactive symptoms of undiagnosed symptoms of ADHD are paired with the risk factors associated with being an urban African American male, the chances of academic failure and punishment for disruptive school behavior increase dramatically (Angold et al., 2002).

Given the prevalence of ADHD and its adverse effects on academic achievement and overall life trajectories, it is important to understand how to identify children in the early stages of the disorder and ensure that they receive prompt treatment. A review of current knowledge indicates that there is a large gap in understanding why some parents seek diagnosis and treatment while others do not. The proposed study was intended to help fill the gap in current knowledge. This study was intended as a first step in improving rates of diagnosis and effective treatment among a population at high risk for this disorder and its harmful consequences.

Purpose, Research Questions, and Rationale

The purpose of this study was to assess the perceptions that African American parents and caregivers have about ADHD.

This study sought to address the following research questions:

1. What are African American parents' and caregivers' understanding of and perceptions about ADHD?
2. How, if at all, may those perceptions affect African American parents' and caregivers' willingness to have their child examined and treated for ADHD?

Parents' perceptions about ADHD may have a variety of implications and effects on rates of ADHD diagnosis and treatment for African American children. According to Pham, Carlson, and Kosciulek (2010), cultural beliefs about mental health, including

ADHD, may influence a family's willingness to seek help from health or education professionals. In a 2009 study conducted to "examine parents' early understanding of medication" for ADHD, dosReis et al. indicated that sociocultural factors can play a role in how and when parents seek help for their child's ADHD. Mental health issues are highly stigmatized, and individuals exhibiting symptoms of mental illness are often not diagnosed and treated appropriately (Tucker & Dixon, 2009). Stigma about mental health issues within the African American community is likely to impact diagnosis and treatment for mental health problems (Tucker & Dixon, 2009). Yet, there appears to be a lack of understanding about the specific negative perceptions toward ADHD and its diagnosis and treatment among African American parents and caregivers and how, if at all, those perceptions are linked to low ADHD diagnosis rates for African American youth (Ward, Wiltshire, Detry, & Brown, 2013).

The focus of this study centered on African American parents and caregivers of boys aged 5-14 years old, as the prevalence of ADHD is highest among low-income urban minority boys and the ages during which most children are diagnosed with ADHD are 6-12 years old (Basch, 2011; Tucker & Dixon, 2009). Compared with White children, African American children are diagnosed less often with ADHD, but there is little known about the factors that may lead to this disparity (Morgan, Hillemeier, Farkas, & Maczuga, 2014; Pham et al., 2010). One possible explanation is that parents' perceptions about ADHD may influence their willingness to have their child assessed by a health professional (Alvarado & Modesto-Lowe, 2017). But there is a large gap in understanding parents' perceptions, the feelings and thoughts underlying these perceptions, and how these perceptions may influence willingness to seek health care.

Olaniyan et al. (2007) explored perceptions of ADHD among a sample of African American parents and found that qualitative research methods were useful in learning about participants' attitudes, feelings, and beliefs regarding a sensitive subject such as behavior problems. They conducted 5 focus groups in inner-city Baltimore and

Washington, D.C., which included 31 self-identified African American primary caregivers recruited from primary care pediatric clinics. Several themes emerged from their focus groups: parents viewing ADHD as a label and doubting the legitimacy of the disorder; parents feeling that doctors may be too willing to medicate African American children; concerns about the effects of medication use; and thoughts that there is a lack of effectively trained teachers who are qualified to handle behavioral issues in the classroom. The authors indicated that the views expressed during the focus groups seemed to be linked to the specific injustices and inequalities experienced by African Americans in the U.S.

In 2012, Bussing, Koro-Ljungberg, et al. conducted a longitudinal, mixed-methods study to assess willingness to use ADHD treatments. The sample consisted of 148 adolescents (27% African American), 161 parents (28% African American), 138 health professionals (21% African American), and 122 teachers (28% African American). Their study included qualitative research methods, specifically the use of survey items that incorporated five vignettes, Likert-style responses, and open-ended questions, which was useful for understanding participants' concerns related to ADHD treatment options. They concluded that while their results indicated there were negative treatment perceptions and undesirable effect expectations, additional research was needed to better understand how racial and ethnic disparities translate to ADHD treatment willingness.

If African American parents and caregivers hold negative perceptions about ADHD, this may affect their willingness to have their child examined and may exclude a possible diagnosis. Therefore, a significant need exists to begin describing and improving understanding about the perceptions of ADHD within this community. This study was intended as a first step in improving understanding parents' perceptions of ADHD related to their willingness to seek diagnostic testing and, when indicated, appropriate treatment.

This study sought to help fill a gap in current knowledge about this topic since little is currently known. In addition, the choice to rely on open-ended questions and to

describe parents' perceptions in their own voices, rather than through closed response format questions, was intended to help improve educators' and healthcare providers' understanding of parents' perspectives. The longer-term goal of this work is to help reduce the burden of this prevalent, serious, and consequential behavioral health disorder that disproportionately affects low-income urban minority youth.

Chapter II

LITERATURE REVIEW

Epidemiology of ADHD

ADHD Description and Seriousness

Attention-Deficit Hyperactivity Disorder (ADHD), a childhood neurodevelopmental disorder, one of the most commonly diagnosed chronic childhood mental conditions, affects about 8% of children in the United States and has major implications for children's academic progress and social development (Bussing et al., 2016; Prudent, Johnson, Carroll, & Culpepper, 2005). Children with ADHD often face more academic-related problems than their peers without ADHD, which may have long-lasting effects (Bussing et al., 2016). Youth with ADHD are at great risk for low academic performance, including dropping out of high school, and are less likely to receive a post-secondary education (Bussing et al., 2016). Youth with ADHD are also at risk for poor health outcomes, poor peer relationships, and poor educational outcomes compared with youth without ADHD (Jimenez, Roy, Schwartz-Soicher, Lin, & Reichman, 2017). Jaber, Kirsh, Diamond, and Shuper (2015) estimated that between 40% and 80% of those affected during childhood also exhibit symptoms during adolescence and 49% to 66% continue to exhibit symptoms into adulthood.

The cause(s) of ADHD is unknown; however, research indicates that it may be linked to several biological and environmental factors. According to Bailey et al. (2010), ADHD is thought to involve genetic factors and dysfunction of the dopamine and norepinephrine neurotransmitter systems. Other hypotheses about the etiology of ADHD

include early exposure to air pollutants and environmental toxins and allergy sensitization (Bailey et al., 2010).

ADHD frequently co-occurs with disruptive behavior problems. These include defiance, aggression, anger, tantrums, and antisocial behavior, putting undiagnosed adolescents and adults at risk for experiencing police contact, arrest, and incarceration (Behnken et al., 2013; Miller, Nigg, & Miller, 2008). Thapar, Cooper, Eyre, and Langley (2012) found that ADHD also has a high comorbidity with alcohol and substance abuse and mood disorders, and certain psychiatric and behavioral disorders may develop later in life as a result of ADHD.

ADHD is increasing in the United States, and as many adults are also affected by ADHD, there is a great need to address the long-term consequences. Samuel et al. (1997) found that ADHD has a great financial impact on society and can lead to family stress, disruption in schools, and potentially to criminal behavior and substance abuse. A study conducted to assess the impact of ADHD on quality of life among a sample of 213 children that were diagnosed with ADHD found that the quality of life of children with ADHD was lower when compared to children without ADHD, and ADHD also negatively impacts the lives of parents/caregivers of children with ADHD (Coghill & Hodgkins, 2016). Hervey-Jumper, Douyon, and Franco (2006) stated that adults with ADHD have higher rates of employment difficulties and auto accidents, and that ADHD is associated with earlier onset of psychoactive substance use disorders.

ADHD affects poor children most often, and boys are more likely to be diagnosed than girls (Acri et al., 2016; Alvarado & Modesto-Lowe, 2017; Basch, 2011; Berry, Bloom, Foley, & Palfrey, 2010; Tucker & Dixon, 2009). Because compared with more affluent White children, low-income urban minority children are less likely to have access to quality healthcare and educational opportunities and more likely to be affected by environmental risk factors, they are at greatest risk for ADHD and its lifelong socio-emotional consequences.

ADHD Prevalence and Susceptibility

Davidovitch, Koren Fund Shrem, and Porath (2017) stated that parent-reported ADHD showed an increased prevalence in the disorder from 7.8% in 2003 to 9.5% for 2011-2013 in the United States and from 5.3% in 2007 to 7.2% worldwide in 2015. They acknowledged, however, that increased prevalence might be the result of changing attitudes toward ADHD and treatment and, therefore, an increased number of parents and teachers reporting of ADHD.

According to a report by Akinbami et al. (2011) in a National Center for Health Statistics brief, ADHD prevalence in the United States rose in the Midwest and South from 1998 through 2009. A 2014 study conducted by Wolraich et al. sought to describe the epidemiology of ADHD in communities in four school districts across two states (South Carolina and Oklahoma). They screened 4,606 children in South Carolina and 5,851 children in Oklahoma, all of whom met the criteria for the case definition for ADHD. It was reported that the percentage of children meeting the criteria for ADHD was higher in Oklahoma than in South Carolina; however, ADHD medication use was higher in South Carolina (46.7%) compared to Oklahoma (19.3%). The authors hypothesized that contributing factors included changes in access to care, increased awareness of the condition, changing socio-demographic patterns in the United States, and changes to state-based policy and screening program efforts. They concluded that the Oklahoma sample had a lower socioeconomic level than the South Carolina sample, which may have contributed to higher ADHD prevalence (Wolraich et al., 2014). Tucker and Dixon (2009) found that children with Medicaid were more likely to be diagnosed with ADHD than children without Medicaid coverage.

In 2013, Visser et al. used the National Survey of Children's Health to estimate U.S. ADHD medication rates for 2007, since medication is the single-most effective treatment for the treatment of ADHD symptoms. Via a telephone survey, parents reported if their child had been diagnosed with ADHD and if they were taking ADHD medication.

Of the 73,122 children in the sample, they found that the lowest state-based rates were in Nevada, California, Alaska, Hawaii, and New Mexico, and the highest state-based rates were in North Carolina, Louisiana, West Virginia, Arkansas, and Delaware. This supports a report from the National Center for Health Statistics by Akinbami et al. (2011), which indicated that in 1998-2000, ADHD prevalence was higher in the South region than in all other regions.

A study conducted by Singh, Yu, and Kogan (2013) aimed to examine the prevalence of ADHD and other chronic conditions among the children of U.S.-born and immigrant parents, using data from the 2007 National Survey of Children's Health. A parent-reported telephone survey was conducted between April 2007 and July 2008. The findings indicated that among a sample of 91,532 U.S.-born and immigrant children, immigrant children had a lower prevalence of ADHD than native-born children (2.86% vs 7.25%). These immigrant children also had lower exposure to environmental tobacco smoke, a pollutant that has been positively associated with symptoms of ADHD. Exposure to air pollution is a particular concern in densely populated areas where minority populations are at increased risk for adverse health and developmental outcomes (Perera et al., 2012).

Nature of the Problem

Disparity in ADHD Treatment

Research on disparities in ADHD treatment has been available for decades. LeFever, Dawson, and Morrow (1999) conducted a study during the 1995-1996 school year in two school districts in southeastern Virginia to assess the proportion of students receiving ADHD medication by the school nurse and to examine the association between ethnicity and ADHD medication use. The population included public school students in grades 2 through 5 in two cities (City A: n = 5,767; City B: n = 23,967). It was reported

that in City A, 8% of students sampled received medication for ADHD: 9% of Black boys compared with 16.8% of White boys. In City B, 10% of students received ADHD medication, with 8.9% of Black boys and 16.6% of White boys taking medication for ADHD. The authors concluded that, while ADHD may be more prevalent among minority and low-income communities, after controlling for household income and sex, ADHD medication was administered twice as often for White children than Black children.

Rowland et al. (2002) conducted a parent survey to determine ADHD treatment prevalence in 1st through 5th grade students who attended North Carolina public schools from 1997 through 1999. They were interested in the distribution of treatment rates across grades, sex, and race/ethnicity. Of the 6,099 parent responses, they found that 10% of children had been diagnosed with ADHD (15% of boys and 5% of girls), and within that subgroup, which included 4,437 White children and 1,208 Black children, African American children were less likely than White children to be diagnosed with ADHD. Treatment for ADHD was highest among White children in all grades except 2nd; 8% of White children were treated for ADHD compared to 5% Black children. The authors concluded that cultural factors might have contributed to the disparity in treatment rates, specifically the use of medication, although barriers to treatment, such as access to medical providers, may also have had an impact on diagnosis and treatment rates among the community.

Many studies suggest that Black children are less likely to be treated for mental health issues than White children, perhaps due to varied parental help-seeking behavior (Coker et al., 2009). In a 2009 study, Coker et al. hypothesized that there were significant racial/ethnic disparities in mental health service use, especially for children with ADHD. They used data from Healthy Passages, a longitudinal cohort study of 5th graders and their parents that assesses preadolescent health and behavior, to recruit from public schools in Birmingham, Alabama, Los Angeles, California, and Houston, Texas. A total

of 5,147 primary caregivers were interviewed. The authors found significant differences in parent-reported ADHD symptoms and that Black children used ADHD services less than White children. They stated that an effective way to reduce this disparity may be to educate primary caregivers about ADHD and its treatment options and to conduct additional research on how caregivers' culture influences their help-seeking preferences.

In 2012, Alegria et al. conducted a study to investigate racial and ethnic differences in identification/encouragement of parents to seek treatment for their child's ADHD. Data came from the National Comorbidity Survey Replication Adolescent Supplement, which was carried out from 2001 through 2004 in households and schools of youth ages 13-17 years. Parents of these youth were asked to complete questionnaires about their child's use of mental health service history. The results, which included data from 6,112 adolescent-parent/caregiver dyads, found that Black youth were less likely than White youth to use services (47.9% versus 72.1%). The authors suggested that more research is needed on differences of behavioral expectations across races and ethnicities.

School-aged minority children are less likely than White children to be diagnosed with ADHD (Morgan et al., 2014). To determine if and to what extent racial and ethnic disparities in ADHD diagnosis exists by kindergarten entry, Morgan et al. used data from a longitudinal cohort study representative of children born in the U.S. in 2001. The sample included 6,550 children who were developmentally assessed at 9, 24, 48, and 60 months of age. They found that at 60 months, 150 children had ADHD, and 30% of African Americans were taking medication compared to 40% of White children. In addition, Black children had lower ADHD rates than White children, although they had higher displays of ADHD symptoms. Morgan et al. indicated that possible explanations for the disparity might be a decreased willingness of parents to seek treatment, varied attitudes about ADHD among different racial/ethnic groups, or a reluctance to seek medical treatment because of unfavorable attitudes about mental health.

In 2016, Coker et al. conducted interviews to determine if the disparity in ADHD diagnosis and treatment rates between African American and White children was due to an under-diagnosis of African American children or an over-diagnosis of White children. They interviewed 4,297 student-parent dyads from 2004 through 2011 within 10 school districts in Alabama, California, and Texas. Of the 118 schools, their sample included 1,497 African American children and 1,039 White children. At baseline, 12% of African American children and 7% of White children exhibited ADHD symptoms; however, only 9% of African American children were diagnosed with ADHD, compared with 16% of White children. There was also a disparity in treatment rates: 14% of White children were treated, while only 9% of African American children received treatment. Their findings revealed that African American children were significantly less likely to “have a parental report of ever receiving an ADHD diagnosis” (p. 6) or to have taken “ADHD medication in the past year” (p. 5).

Minority youth often do not receive the behavioral health services they need, perhaps because of their parents’ beliefs about seeking treatment (Locke et al., 2017). In a study that sought to compare in-school and out-of-school behavioral service use among ethnic minority youth, which included services for ADHD, Locke et al. sampled 23,601 Medicaid-enrolled youth ages 5-17 years old who used behavioral health services in Philadelphia between October 2008 and September 2009. They found that 50.5% of the African American youth in their sample had been diagnosed with ADHD, but they were 58% less likely than White youth to use out of school services. There were also disparities in the in-school service use for youth with ADHD between African American and White youth. The authors recommend an increase in cultural awareness and culturally appropriate assessments to reduce disparities in diagnosis and treatment.

Flowers and McDougale (2010) conducted a MEDLINE search of peer-reviewed literature, which included titles from 1970 through 2009. Their focus was limited to the diagnosis of African American children to assess the appropriateness of diagnostic

instruments for African American youth. As a result of their search, they discovered that few assessments were effective in determining “behavior abnormalities across cultures” (p. 372). They found, however, of the tools used to evaluate African American youth, the Terry and Vanderbilt ADHD assessments were appropriate in diagnosing ADHD. These authors recommend that additional studies be conducted to develop culturally sensitive diagnostic instruments for African American youth.

Jones et al. (2010) conducted a study to determine whether cultural differences in parenting styles had an effect on ADHD-related behavior among a sample of White ($n = 348$), Black ($n = 113$), and Latino ($n = 47$) children. They found that parenting styles of the African American parents in their sample, which they described as more authoritarian, resulted in more positive behavior from their children than the White families, whose children exhibited more negative behaviors, although the African American children exhibited more negative behavior at the start of the study. The authors concluded that delivering ADHD treatment options to African American families, which may include parenting strategy suggestions, should be culturally appropriate and responsible, building on the parenting strategies already present among the African American community.

Alvarado and Modesto-Lowe (2017) discussed barriers to diagnosis and treatment for African American families. They stated that parents must first identify their child’s behavior and indicate that there is a problem, which may be influenced by “knowledge about ADHD and their cultural attitudes about behaviors” (p. 172). The authors stated that minority parents may have “limited knowledge and misperceptions about ADHD” (p. 172), thinking that the child will grow out of the behavior. They added that African American parents may have more authoritarian parenting styles, in which they are more likely to tell their children what to do, whereas White parents may give their children decision-making ability, which may account for a difference in the recognition of symptoms. The authors recommend the development of culturally sensitive interventions

that might allow parents and practitioners to discuss the child's needs in a way that is relevant and appropriate.

Paidipati, Brawner, Eiraldi, and Deatrick (2017) conducted an integrative review of 32 articles to “explore parent and family processes” related to ADHD management, specifically for “racially and ethnically diverse youth” (p. 1). The authors acknowledged a gap in the knowledge on parents' treatment preferences especially for minority families and stated that children rely on their families to recognize symptoms. The results of this integrative review indicate that racially and ethnically diverse parents prefer “psychosocial interventions or behavior therapy” rather than medication (p. 11), and the authors recommend the development of evaluation tools for minority children.

Ji, Druss, Lally, and Cummings (2018) examined discontinuous ADHD medication use among Medicaid-insured racial and ethnic groups within a sample of 102,669 children. The authors used Medicaid claim data from nine states “to identify racial-ethnic differences in patterns of ADHD medication treatment” between 2008 and 2010 (pp. 322-323). They found that Black children were 25% more likely to have medication use discontinuity and recommended that further research be conducted to examine reasons for the “gaps to inform interventions to improve ADHD treatment continuity” (p. 322).

ADHD screenings generally rely on parental report of symptoms, and while family members are often the first individuals to express concern about the child's behavior, attention, or performance, levels of parental awareness of ADHD differ by race and ethnicity (Visser, Zablotsky, Holbrook, Danielson, & Bitsko, 2015). The Health Belief Model suggests that an individual's likelihood of seeking health care is determined by the perception of susceptibility to and seriousness of a health condition (Bussing et al., 2015). Additionally, treatment-seeking behavior depends on an individual's knowledge and awareness of a condition and its treatment (Bussing, Koro-Ljungberg, et al., 2012).

Cultural Differences in Beliefs, Opinions, Stigma, and ADHD Diagnosis and Treatment

In 2010, Pham et al. sought to “explore the differences in parental beliefs about the causes and treatment of ADHD” (p. 585) and whether those perceptions affected parents’ preferred method of treatment for ADHD. They surveyed 119 parents, 55% of whom were African American and Latino, recruited from educational, community, and healthcare facilities in mid-Michigan. Parents responded to 36 Likert-style items and 2 open-ended questions, which were designed for participants to share their beliefs about the causes of ADHD and their treatment preferences. They found that ethnic minority families may be more informed about the causes of ADHD than in the past but they have different views about the various treatment options. Black and Hispanic parents favored behavioral intervention treatment methods for ADHD over pharmacological methods when compared to White parents, and their preferred method of treatment was based on their perceptions and/or views about ADHD treatment. The authors highlighted the need for practitioners to acknowledge and respect cultural differences among ethnic minority families of children that have ADHD, as those cultural beliefs may affect parents’ preferred method of treatment. Pham et al. also highlighted the importance of learning about ADHD-related views of African American parents and caregivers, as it is essential for the development of programs designed to address the needs of families supporting a child with ADHD.

Olfson, Gameroff, Marcus, and Jensen (2003) studied trends in ADHD treatment rates during 1987 and 1997 among a sample that included children who were 3 to 18 years old. In each sample, 8,367 and 8,771 participants were interviewed in 1987 and 1997, respectively, in 165 geographic regions in the United States. They found that ADHD treatment rates for Black children increased from 0.3% in 1987 to 1.5% in 1997 but fell behind treatment rates for White children, which were 1.1% in 1987 and 4.4% in 1997. They concluded that African American children were less likely to receive

pharmacological treatment compared to White children, which may be due to cultural factors and was not likely attributable to low socioeconomic status among African American families.

In a case study, Livingston (1999) illustrated the varied behavioral expectations for youth of different racial and ethnic groups, which may account for differences in ADHD diagnosis and treatment rates within minority communities. The study included an 8-year-old African American 3rd grade student whose mother initially doubted the severity of behavioral issues expressed by the child's teacher. The mother found the issues to be normal and attributed it to the usual "boys will be boys" behavior. Livingston suggested that multicultural approaches to addressing behavioral issues are needed to account for racial and ethnic differences in perceptions of ADHD symptoms.

Hazel-Fernandez, Klorman, Wallace, and Cook (2006) conducted a small study to determine the effects of ADHD medication on executive functioning (EF), which is known to be deficient in children with ADHD. EF skills are needed for self-regulation and goal-directed behavior. They recruited 19 African American children from a mental health center and pediatric clinic, all taking medication for ADHD. Their results indicated that medication was an effective form of treatment for the African American children in this sample. They recommended more research on the role of cultural factors in shaping attitudes toward medication as a form of treatment for ADHD, and finding ways to increase access within certain communities to resources needed for the management of ADHD.

Miller et al. (2008) conducted a review of literature on ADHD in African American children in the United States from 1990 to 2007. They reviewed 73 articles on ADHD in African American children, 6 of which focused on parents' perceptions of ADHD. As a result of their literature review, they found that African American children were diagnosed two-thirds as often as White children and treatment rates for African American children were lower than those for White children. They also discovered that African

American parents had different perceptions of ADHD, which translated into lower rates of treatment seeking for children. They posited that the lack of response to ADHD symptoms among African American youth may be because those “symptoms do not have the same disabling meaning” (p. 84) to African American parents and caregivers. A lack of response to ADHD symptoms may also represent an unwillingness to seek professional help. Their findings, which were consistent with other researchers’ data, showed that African American children were diagnosed less often than White children, which may be the result of parental beliefs about ADHD. The authors suggested that there was a need for research on parental beliefs around ADHD diagnosis and treatment, as those beliefs may be directly impacting diagnosis and treatment rates of African American youth.

Hillemeir, Foster, Heinrich, Heier, and the Conduct Problems Prevention Research Group (2007) conducted a study to examine the differences among African American and White children with respect to ADHD measurement using a parental report instrument. They collected data from the Fast Track Project, a longitudinal study of emotional and behavioral problems in predominantly low-income African American and White children in North Carolina, Tennessee, Pennsylvania, and Washington. The sample included 1,070 children: 541 African American children and 529 White children. The results suggested that perceptions of ADHD-related symptoms among African American parents differ from those of White parents, which may affect willingness to seek a diagnosis for ADHD and to comply with recommended treatment. They stated that a critical next step would be to examine and improve diagnostic instruments and treatment methods among different racial and ethnic groups. They indicated that future research and practice should include an assessment of parents’ knowledge of and feelings about an ADHD diagnosis.

Olaniyan et al. (2007) explored parents’ perceptions of childhood behavior problems and attention-deficit hyperactivity disorder among a sample of African American parents. They recruited participants from primary care pediatric clinics, and

only African American primary caregivers with children under the age of 17 were eligible for the study. They conducted five focus groups in the Baltimore-Washington Metro area from 2003 to 2005 and obtained data from 31 participants. Most parents attributed behavioral difficulties to poor parenting. Their results showed that some parents felt that ADHD was a label and expressed concern over children being damaged, while others viewed an ADHD diagnosis as a form of social control, questioning its legitimacy as a diagnosis, and some of the families preferred to handle their child's behavioral issues through parenting practices rather than seeking professional help. The researchers concluded that African American cultures and beliefs can greatly influence parents' views on ADHD treatment methods, and those cultures and beliefs must be acknowledged by medical and school professionals when assessing children for the disorder. They confirmed that some families have varied understandings regarding what constitutes a behavior problem and there needs to be an increased awareness of parental perceptions of ADHD among providers who treat behavioral problems, as it might help explain the difference in ADHD diagnosis and treatment rates for African American youth.

In a commentary on racial and ethnic disparities in diagnosis and treatment of ADHD, Eiraldi, Mazzuca, Clarke, and Power (2006) stated that parental attitudes toward ADHD might significantly impact their willingness to seek help. They indicated that fear of stigmatization may have a major impact on parental decisions to seek help for ADHD. Additionally, White parents are more likely than African American parents to rely on an ADHD diagnosis to explain their child's behavior, and African American parents expressed increased negative expectations about mental health services. The authors hypothesized that low ADHD diagnosis and treatment rates for African American children may be due to parents' perceptions toward ADHD and their unwillingness to seek services.

Johnson, Seipp, Hommersen, Hoza, and Fine (2005) stated that little is known about parents' views of ADHD and how that relates to children's treatment. They sought to examine the relationship between parental beliefs and attitudes and ADHD treatment and recruited 73 parents of boys with ADHD living in British Columbia. Participants completed questionnaires measuring beliefs about ADHD. The authors found that parents' beliefs predicted their treatment choices; however, additional research is needed on how ethnic minority parents' views and beliefs can affect how they perceive symptoms and subsequent courses of treatment.

Guevara, Feudtner, and Romer (2005) conducted a study to identify causes for fragmented ADHD care among inner-city minority youth. They recruited primary care physicians, mental health therapists, and school staff serving inner-city Black youth with ADHD for a focus group study. They also recruited the parents of children with ADHD from the same sites. There were 13 focus groups conducted, which included 4 to 10 participants each, with the goal of identifying perceptions of how care was provided and coordinated for children with ADHD and to learn about how African American families view behavioral problems in their children. Guevara et al. found that among this sample, minority parents were less likely to view ADHD as legitimate, which may have an effect on their willingness to seek care.

In 2005, Prudent et al. conducted a case study of a Haitian American boy to highlight cultural differences regarding ADHD treatment. Their case study sought to describe cultural issues faced by the family that affected the child's ADHD care. The authors identified five barriers to care for Haitian immigrants with ADHD, one of which was the stigma of ADHD in their community. They reported that while there were limited studies detailing how ADHD symptoms are perceived by different cultures, African American parents, like the Haitian American families described in this study, may have alternative, less traditional methods for coping with children that exhibit ADHD symptoms and often seek help from those in their community, rather than that of

healthcare professionals. According to Prudent et al., among this sample of Haitian Americans, parents' or caregivers' perceptions of ADHD may influence their acceptance of a physician's diagnosis and treatment options.

In 2017, Thurston et al. sought to examine factors that contributed to parents' intentions to seek help for their child's ADHD by assessing their willingness to seek help. They hypothesized that Black families would be willing to seek help from informal sources over formal sources. Their sample included 251 parents, 51% of whom were White and 49% of whom were Black, which were recruited from a community event and organizations. Parents read vignettes that described ADHD and then were asked to respond to 18 questions about potential barriers when seeking professional help for their child's mental health. The authors found that Black parents seemed more willing to seek help from religious officials (informal sources) than White parents. This study highlights the important role the church plays for some individuals in the Black community and should therefore be used as a resource, providing parents with encouragement and reassurance to seek help from professionals for their child's mental health.

Santiago and Miranda (2014) also conducted a review of data collected from clinical trials that took place between 2001 and 2011 and a workgroup of research staff with affiliations to various healthcare organizations to assess mental health workplace diversity. They indicated that ethnic minorities might seek mental health services more readily from providers who share their ethnicities and cited evidence that ethnic minorities are likely to stay in treatment longer when their provider is an ethnic match. They focused their search on trials for adults with bipolar disorder, schizophrenia, major depression, and ADHD among adults and children. The authors found that while there have been increases in the number of racial and ethnic minorities in mental health professions, it is a very small number and this group is still poorly represented. They indicated that in 2006, African American psychologists were only 2.5% of the African American population in the United States. It was recommended that additional studies

focus on racial and ethnic minorities in a way that is sensitive to the possibility of a lack of trust in the healthcare system as a result of the historical mistreatment of ethnic minorities.

Siegel, Laska, Wanderling, Hernandez, and Levenson (2016) drew data from a 2011 New York State Public Mental Health System survey to estimate the proportion of Black and White children ages 3-17 years old who were receiving services for ADHD and treatment rates. They found that there were inconsistencies between national diagnosis rates for Black children and those in NYS and suggested that there was a “misunderstanding of cultural differences” on the part of the healthcare professionals (p. 204). The authors suggested that racial and ethnic children would “benefit from more nuanced cultural based diagnostic assessments” (p. 204).

DuPaul et al. (2016) conducted a study to assess the use of an 18-symptom-item ADHD behavior rating scale used by parents and teachers in the evaluation and diagnosis of ADHD and to determine if symptom report was a function of teacher race/ethnicity and student race/ethnicity. The sample included parents (n = 2079; 64.1% White) and teachers (n = 1070; 87.3% White) who reported on ADHD symptoms among children (13.1% Black) and student (12% Black) ADHD symptoms, respectively. They found that the teachers rated Black students higher for inattentive and hyperactive symptoms, while parents rated White children higher for inattentive symptoms. The authors suggested that more research is needed to determine why teachers are rating Black children higher than White children for certain ADHD symptoms when, in this study, Black children comprised only 12% of their total number of students. The results also indicated that perceptions of symptom severity differ by parents’ culture in that there are “culturally influenced thresholds for differentiating” behaviors (p. 223) and that cultural factors influence teachers’ ratings of ADHD symptoms.

In 2018, Walls, Allen, Cabral, Kazis, and Bair-Merritt sought to examine the association between family characteristics and ADHD treatment options and whether

there were disparities for non-pharmacological therapy use, especially for minority families, as “minority parents express hesitancy and distrust toward ADHD medications” (p. 257) and minority parents may be more willing to explore non-pharmacological treatment options. The authors stated that pediatricians recommended medications as a first-line treatment, which may not align with the values and/or beliefs of families, particularly minority families. They used data from a 2014 National Survey of the Diagnosis and Treatment of ADHD and Tourette’s Syndrome, which included children 8-17 years old (n = 2401; 14.3% Black) who had an ADHD diagnosis. They found that there were “disparities in medication use for minorities and low-income school-age children” (p. 262) and recommended additional research to examine the differences for minority children and ADHD management interventions.

Stigma Related to ADHD

While reported prevalence of ADHD among school-aged children is increasing, research on the existence and impact of stigma, beliefs, and opinions about ADHD is lacking (Mueller, Fuermaier, Koerts, & Tucha, 2012). Mueller et al. reviewed empirical research from 1994 through 2011 focusing on stigma associated with ADHD. Using the key terms ‘ADHD’ and ‘stigma,’ they identified 33 results. They expanded the search to include the key terms ‘rejection’ and ‘perception,’ which yielded 5 additional articles. Based on their review, they found that an individual’s culture might affect the level of stigmatization associated with ADHD. Mueller et al. found that stigma related to ADHD may have a profound negative effect on the treatment of the disorder and that future studies should focus on learning more about those attitudes toward individuals with ADHD.

In a 2002 commentary, which focused on ADHD-related issues among people of different ethnicities, Kendall and Hatton (2002) reported that ADHD-related stigma appeared to have an effect on the number of African American families seeking help for

the disorder. They indicated that African American families are more likely to be stereotyped and stigmatized because of a child's behavioral problems, which may contribute to reservations about seeking help for ADHD-related symptoms. They also stated that African American families were likely to negatively associate ADHD with other mental health disorders or related behavioral characteristics, such as oppositional or violent behavior, possibly resulting in an unwillingness to consult with medical professionals.

In a study that was specifically designed to assess ADHD stigma using the ADHD Stigma Questionnaire (ASQ), Kellison, Bussing, Bell, and Garvan (2010) included a sample of African Americans. They recruited participants from a longitudinal study designed to create a representative sample of youth at high and low risk for ADHD, following them in waves from 1998 and 2008 for four years. Parents and children were interviewed, and it was found that of the 301 youth, 192 were at high risk for ADHD and 109 were at low risk for ADHD. The results indicated that some African Americans, 32% of the sample, expressed concern about public attitudes regarding ADHD. Cultural differences may also contribute to beliefs about diagnosis and treatment for the disorder. The authors recommended that additional research should examine the impact of cultural background on ADHD stigma, since "children and adolescents are dependent on their parents" for diagnosis and treatment (p. 9).

Zito, Safer, dosReis, Magder, and Riddle (1997) conducted a retrospective analysis to compare methylphenidate patterns according to race using 1991 Medicaid prescription drug reimbursement claims for children ages 5-14 years old in Maryland. They suggested that the disparity in diagnosis and treatment rates for African American children may be due to cultural differences in the ways that African American and White families respond to hyperactivity. They indicated that these differences might be attributed to many factors, including concerns about the labeling of children with ADHD.

African American parents may view ADHD-related behavior as normal or as behavior that their child will outgrow (Davison & Ford, 2001). Davison and Ford recruited 25 participants from a large African American community, in a qualitative study that sought to understand perceptions and attitudes of African American parents that may affect their willingness to seek medical attention for a child's ADHD symptoms. As a result of their interviews, they found that African American parents resisted identification of their child's ADHD-related behavior because they were concerned with the child being labeled "crazy." The authors suggested that professionals be trained in how to work with African American families and be aware of how cultural differences and perceptions can impact help-seeking behavior.

In a 2015 study, Mikami, Chong, Saporito, and Na sought to assess parental stigma about their child's ADHD symptoms. They recruited parent and child dyads from pediatricians, schools, and clinics, resulting in 63 pairs. All of the children met DSM-IV-TR criteria for ADHD. The sample was made up of 81% White children and 9% African American children, and 40 children in the sample were taking psychotropic medication. Parents completed questionnaires about ADHD stigma and their child's social functioning. Results indicated that parents who exhibit negativity toward their child with ADHD, as a result of ADHD stigma, may "exacerbate or fail to improve their child's poor social functioning" (p. 3). Additionally, parents that have negative views about ADHD may be less likely to seek help or support for their child's ADHD symptoms. The authors recommended research on parents' perceptions of ADHD and the effect of those perceptions on the child with ADHD.

In 2013, Ohan, Visser, Moss, and Allen conducted a study to evaluate parental stigmas concerning ADHD and depression and found that parents "held high levels of stigma towards children with ADHD" (p. 1272). They recruited 225 parents via school newsletters, billboards, and word of mouth. Participants were asked to read vignettes that described children with various developmental behaviors and respond to measures of

stigma. The authors reported prejudice and social distance toward a child that has ADHD compared to a child with depression (p. 1272). According to Ohan et al., parents are often fearful that a diagnosis will label their child and result in stigmatization. They added that seeking help from professionals, which will provide treatment options and validation, might reduce stigmas or labels associated with diagnosis.

In a 2009 commentary, Tucker and Dixon discussed the challenges African American male youth face, specifically those that exhibit ADHD symptoms in addition to other mental health issues. They found that the disparity in diagnosis and treatment rates among African American youth may be due to several factors, one of which is parents' unwillingness to seek help for ADHD-related symptoms and behavior due to their perceptions of ADHD. The authors identified a need for culturally sensitive and appropriate assessment and diagnosis procedures and acknowledged that there are "cultural differences in perceptions to children's behavior" (p. 311) among the African American community that might affect parents' willingness to seek help from healthcare professionals.

Bussing, Gary, Mills, and Garvan (2003) conducted a study to examine if parents' understanding of ADHD contributes to cultural variation in help-seeking steps. They recruited 182 parents of children at risk for ADHD from school district registration records in North Central Florida. Interviews were conducted between May 1999 and July 2000, and the sample included 41% African Americans. Their results indicated that African American families might prefer to seek help for mental health matters (including ADHD) privately with assistance from family or other trusted individuals and that stigmatization and a lack of perceived severity may prevent African American families from seeking help for their child's ADHD-related behavior. There are three takeaways from this research: a high rating of ADHD symptoms in African American children may be an indication of a difference in manifestation of the disorder; African American male youth may benefit from more accurate ADHD assessment procedures; and there are

barriers to mental health care, which include cultural biases/stigmas, for African American children that need to be addressed. The authors recommended that health professionals take into account racial, ethnic, and cultural backgrounds and beliefs of their patients, as those factors will likely influence their willingness to seek help and adhere to treatment.

Bailey, Jaquez-Gutierrez, and Madhoo (2014) reviewed sociocultural factors that may affect African American families' ability to seek help for a child with ADHD. They conducted a literature review in April 2012 and September 2012 on ADHD and its problems among African American minorities. They highlighted that parental attitudes and beliefs, such as viewing ADHD as a weakness or source of shame, can complicate the diagnosis and treatment of ADHD, in that African American parents of children with ADHD may decline professional help because of their "understanding of and attitudes towards ADHD" (p. 5). They reported that parents might have fear about their child being labeled as a result of an ADHD diagnosis and be concerned with the use of medication for ADHD treatment, which may discourage parents from seeking ADHD treatment. According to Bailey et al., how ADHD symptoms are perceived can vary across cultures and parents may feel uncomfortable discussing a sensitive topic, such as a child who is exhibiting symptoms of ADHD, with healthcare professionals.

Additional research is needed on how ethnicity influences parental intentions to seek help for mental health, as parental attitudes can promote or hinder help-seeking behavior (Turner, Jensen-Doss, & Heffer, 2015). In a 2015 study, Turner et al. hypothesized that European American parents would have more positive attitudes toward mental health services than African American parents. They recruited primary caregivers from urban Head Start programs and community public schools in Texas, Louisiana, and Mississippi, resulting in a sample of 238 parents, 48% European American and 35% African American. Parents completed a demographic questionnaire and the Parental Attitudes Toward Psychological Services Inventory, which is a 21-item Likert-type

assessment. They found that African American parents reported less positive attitudes and higher stigma than European American parents. The authors indicated that future studies should explore the effects that religious beliefs and ethnic identities have on parental help-seeking behavior.

Aciri et al. (2016) sought to identify barriers to mental health service implementation among minority youth. According to their findings, mental health service utilization is low among minority youth, including for ADHD symptom identification and management, possibly resulting in those youth not being diagnosed and treated appropriately. The authors found that while primary care is the main method for ADHD symptom support, primary care physicians indicated feeling that they had inadequate training to deal with such mental health issues. This might exacerbate minority families' apprehension about seeking help for a child's behavior and may be a barrier to mental health service use.

Summary

Based on current knowledge, several conclusions seem clear. First, ADHD is a prevalent cognitive-behavioral disorder that seriously affects a person's ability to succeed academically, socially, and more generally in life. Second, estimating prevalence is complex because of the intricacies of diagnosis. There is agreement that ADHD is more prevalent among males than females. Furthermore, based on the fact that ADHD appears to be more prevalent among single-head-of-household and low-income families, African American youth are at considerably high risk. Third, African American youth appear to be under-diagnosed and under-treated for ADHD. Fourth, there seem to be cultural differences that influence not only the ways in which boys' behaviors are interpreted, but also the likelihood of seeking psychological or medical consultation related to diagnosis and treatment. Collectively, this synthesis of current knowledge indicates a gap in

understanding about how to address disparities in diagnosis and treatment. The current study is intended as a step toward filling this gap by identifying and describing the views of African American parents and caregivers regarding the etiology, diagnosis, and treatment of ADHD.

Chapter III

METHODS

Rationale and Design

African American children are affected with ADHD as often as White children but are diagnosed and treated at lower rates. The factors that may contribute to this difference in diagnosis and treatment rates are unclear, as research on the subject is limited. The perceptions that African American parents and caregivers have about ADHD may significantly affect their willingness to having their child examined and, if appropriate, treated.

This study's aim was to understand the perceptions of ADHD among African American parents and caregivers using qualitative research methods. In keeping with the goal of gaining insight into the perceptions of parents and caregivers, face-to-face, semi-structured interviews were conducted. This method of data collected allowed participants to express their views in their own words and did not restrict responses to categories that may not have reflected their opinions and feelings. As interviewing is a meaning-making process and can be a way for a researcher to understand the culture of the participants and their level of (mis)information, (Seidman, 1991), it was the primary data collection method for this study. A survey approach was also used solely to collect the same information from all participants in a standardized way to describe the sample.

The study design was cross-sectional. Participants were enrolled and interviewed at a single conceptual point in time. The study was delimited in scope in this respect, since

participants' perceptions about ADHD may change over time. All interviews were conducted by the Researcher, and all participants were recruited from a single after-school program in New York City. Only some questions were asked. Collectively, these aspects of the design delimit the scope of the study.

Setting and Participants

The setting for this study was a community center that houses an after-school program. It is located in Central Harlem, New York City, and serves approximately 175 school-aged young people (ages 5-14 years old). Participants who attend the after-school program are able to receive all available services free of charge, as the program is fully funded by the City of New York's Department of Youth and Community Development (DYCD). A majority of participants are eligible for free or reduced price lunch. During school hours, these participants attend public, charter, private, and Catholic schools, many of which are within walking distance of the community center, and are in grades kindergarten through 8th. From 3 p.m. to 6 p.m., they attend the after-school program. About half of the total young people attending the program are male, and over 90% identify as African American. The after-school program targets the areas in which many disadvantaged children struggle: academically, socially/emotionally, and physically. Each day, program participants receive structured activities to help address and support areas of deficiency.

The program is staffed by 21 individuals, including 12 group leaders that facilitate various activities with the program participants, 5 specialists who provide targeted academic (literacy and STEM) and physical fitness interventions, and 2 Program Directors who are supervised by the Center Director. This site was selected because it provides direct access to the target population, with whom the Researcher has been working for five years as one of the afterschool Program Directors.

The target population of this study includes African American parents and caregivers of 5- to 14-year-old boys that attend the aforementioned after-school program. Stevens, Harman, and Kelleher (2005) indicated that children ages 7-12 are more likely to be diagnosed with ADHD compared with children in other age groups. Recruiting from this age range was intended to create a sample who are likely to be affected by ADHD. Parents and caregivers of boys with and without an ADHD diagnosis were included in this study. One of the ultimate goals of the study was to learn about what African American parents and caregivers perceive as barriers to diagnosis and treatment of ADHD. Learning about the experiences of families who have gone through that very difficult process may help shed some light on the reasons why African American children are diagnosed and treated less often than White children. Including parents and caregivers whose children did not appear to be affected by ADHD may improve understanding about how ADHD diagnosis and treatment are perceived in the community. While many of the studies in the literature included White and African American families in the samples, this study was unique in that it focused solely on African American families, providing information that will be relevant to the African American community and to educators, researchers, and policymakers. The intent was to complete interviews with 50 participants.

Inclusion and Exclusion Criteria

In this study, a caregiver was defined as any individual that was older than 18 years and that has been identified as a legal guardian for a child, such as grandparent, aunts/uncle, foster parent, godparent, or sibling. Parents and caregivers had to identify as African American and be the parent or caregiver of an African American boy between 5 and 14 years old. Only individuals who were English language-proficient and who provided informed consent were invited to participate in the study. Another inclusion criterion was willingness to provide written consent for participation and for audio-

recording the interview. The number of individuals who were excluded was documented along with the reasons for exclusion.

Delimiting the study to African American parents and caregivers was essential for gaining a deep understanding of their perspectives relative to this topic. As mentioned above, very few studies have focused on the views of African American families and how those beliefs may impact the diagnosis and treatment rates of ADHD among African American youth. A limitation of this approach is that only the comparison between the views expressed by study participants and other groups of parents and caregivers was based on previously published literature.

Recruitment

The Researcher has worked to support the academic and social-emotional needs of the after school participants for over 5 years and therefore has established a relationship with many of the families that is built on trust and acceptance, which is valuable given that the study participants were asked to share their personal views and experiences, including their interactions with school administration and teachers and perceptions of their children. When conducting face-to-face interviews, it is essential to develop a strong rapport with the interviewees, and such a rapport was already in place with many of the parents and caregivers that were eligible to participate in the study.

Participants were recruited by flyers posted in the community center (see Appendix A). The flyer described the intent and purpose of the study and the eligibility criteria. The flyer also informed prospective participants about the dates that the data collection would begin and the ways in which they would be compensated for their time. Other approaches to recruitment involved contacting prospective participants directly via email, telephone (see Appendix B for script), and in person and assessing their willingness to participate, at which point they were also informed of the dates that data

collection would begin and the ways in which they would be compensated for completion of the study. Each participant received a VISA gift card in the amount of \$25 and a Metrocard with one round-trip fare for transportation to and from the interview site, a private room at the after-school program site. Parents and caregivers who expressed interest in participating in the study were contacted via email and/or telephone to assess eligibility and to schedule the date and time they would be available for interviewing.

There were 43 participants interviewed for this study. Of those who expressed interest, 6 were unable to participate due to scheduling conflicts. One individual who expressed interest in participating did not meet the eligibility criteria because they did not identify as an African American parent or caregiver, and 5 individuals did not respond to outreach. Overall, outreach was made to 55 total parents or caregivers, yielding a 91% response rate.

Data Collection

There were two instruments used for data collection. One was a semi-structured interview guide developed by the Researcher for the study. A second, also developed by the Researcher, was intended to collect data from participants in a closed-response format to describe characteristics of the study sample.

Semi-Structured Interviews

The Researcher used an interview guide that she developed for the study (see Appendix D). Some interview questions were semi-structured, and others were open-ended. This allowed participants to share their experiences not only as African Americans living in an urban community but also as the parents/caregivers of African American school-aged boys. Questions were developed using the ADHD Stigma Questionnaire (ASQ) as a guide and aligned with the Health Belief Model. The ASQ was designed to

focus “on the assessment of public stigma perceptions” for ADHD, as there was “no specific assessment instruments available to evaluate stigmas associated with ADHD (Kellison et al., 2010).

The interview guide consisted of 21 questions, which were divided into 6 categories. The first category targeted each participant’s general knowledge of ADHD, such as causes of ADHD and symptoms or signs of the disorder. The questions that followed the General Knowledge items were based on the Health Belief Model categories of Perceived Susceptibility, Perceived Severity, Perceived Benefits and Barriers, and Efficacy of Treatment, which asked participants to share how they think youth are affected across genders, ages, and races; the consequences and effects of ADHD on the youth and their family; potential benefits and barriers of being diagnosed with and treated for ADHD; and various methods for treating ADHD and their perceptions of those methods. The closing questions, which were developed by the Researcher, addressed certain views that parents and caregivers may have about ADHD, such fear of self-rejection, lack of trust in the healthcare system, and possible over-diagnosis of youth with ADHD.

Face-to-face interviews enabled the researcher to give those from a disadvantaged community a voice that would otherwise not be heard and assessed each participant’s perceptions about ADHD. Interviews were audio-recorded and transcribed, and interview notes were recorded by the Researcher at the completion of each interview. The transcriptions and notes were the raw data used for analysis. Pseudonyms were assigned to each participant when reporting results to ensure that participants’ identities remained confidential.

Demographic Survey

Participants completed a survey at the end of the interview session (see Appendix E). The demographic survey asked participants to share information about their

age range, gender, and marital status. In addition, items ascertained category of parent or caregiver and information about their child's school. These data were used to describe the study sample. Such data enabled description of the entire sample, as well as providing context when describing particular cases.

Consent Procedures

Written informed consent for each participant was obtained. Participants were provided with information regarding the study's purpose, benefits, and associated risks. Participants were also informed that the study was completely voluntary, that they could withdraw from the study or end the interview at any time, and that their identity and responses would remain confidential and only be used for purposes of this study. All of the data collected from surveys, interviews notes, audio-recordings, and transcriptions were coded to protect each participant's confidentiality. Prior to the start of each interview, participants were assigned a pseudonym and code (e.g., 01, 02, 03, etc.), which was stored separately from any data collected via the surveys or interviews. During each interview, the pseudonym and code assigned to a particular was documented on the survey, interview notes, and the audio-recording transcriptions. Signed consent forms were kept by the Researcher in a locked file. This study was approved by the Teachers College, Columbia University Institutional Review Board.

Pilot Study

Prior to conducting the main study, a pilot study was conducted to evaluate the practicality of the recruitment and interview protocol and to enable the Researcher to practice the methods. After obtaining approval from the Teachers College, Columbia University Institutional Review Board, the Researcher recruited three parents who met

the criteria and reviewed the consent form and intent of the study. Participants received a \$25 VISA gift card and a Metrocard with one round-trip fare at the end of the interview. Each interview was audio-recorded, transcribed by a professional, reviewed, and two coding schemes were designed: In vivo codes were used to maintain the quality, accuracy, and authenticity of participants' responses; and concept coding was used to help develop deeper meanings of the responses. For the pilot study, analytic categories were selected using the Health Belief Model (HBM) as a guide. The HBM is an intrapersonal theory that may determine whether and under which conditions an individual will adopt a course of behavior. According to the HBM, health behavior is determined by personal beliefs or perceptions about a disease (or disorder) and the strategies available to decrease its occurrence (Hochbaum, 1958). It includes four categories: Perceived Susceptibility, Perceived Severity, Perceived Benefits, and Barriers. The category Efficacy of Treatment, as used in this study, is a modification of an additional HBM category, Self-Efficacy, in that treatment of ADHD is essential for the effective management of the disorder. Individuals who do not believe that there are effective treatment methods or who are concerned about the available treatment options for ADHD may be resistant to having their child examined for and diagnosed with ADHD.

Presented in Appendices F and G are the data from the surveys collected and interviews conducted, including the research questions, analytic categories, and coding schemes.

Data Analysis

Seidman (1991) recommended that researchers “come to the transcripts with an open attitude and see what [themes] emerge” (p. 89). Therefore, even though HBM was used to develop the interview guide for this study, an inductive approach to analyzing the data was used, as the goal was to learn about the participants' perspectives on ADHD and

understand if/how those perspectives might influence their willingness to have a child examined for a possible diagnosis of ADHD.

Written notes were taken during each interview, during which the Researcher highlighted significant points. The Researcher reviewed the audio-recordings of each interview and made note of non-verbal communication, such as when participants paused or moments where participants hesitated to respond. Audio-recordings were transcribed by a professional and then reviewed for accuracy and coded by the Researcher.

For the first review of transcribed data, in vivo codes were developed, which involved capturing exact language of individual participants in response to question prompts. Themes/categories were created that retained the voice of the participant. During the second review of data, concept coding was used to create descriptive categories of data. This facilitated the development of larger concepts that may highlight underlying perceptions and/or concerns of the target population (Saldana, 2016).

Following the second review of data, the Researcher reviewed all codes to make connections with various characteristics of each participant. For example, participants who shared their beliefs that ADHD had environmental causes and, specifically, that it was linked to vaccinations were mothers of children who had not been diagnosed with ADHD. Since current literature does not yet suggest a link between ADHD and childhood vaccinations, it was unclear where these beliefs stemmed from. Therefore, that association among this demographic was likely due to misinformation. Participants in most demographics in this study expressed fear of their child being medicated should they be diagnosed with ADHD, which might prevent them from seeking help for a child's ADHD-related behaviors. Participants' occupations also were reviewed, which provided insight into their access to ADHD information. For example, several participants worked in the education or social services field and seemed to have considerably more knowledge about the various methods for treating ADHD compared to participants who did not work in such fields. Additionally, many participants who were teachers or who

worked in educational settings indicated a need for their peers to be more adequately trained, specifically on how to engage low-income urban youth with respect to their culture. The Researcher also analyzed the types of schools that participants' children attended, as charter, public, private, and Catholic schools. Each have varied services available for students with ADHD and other learning differences. In this study, those who had been diagnosed with ADHD attended either charter, public, or private schools, the latter of which was designed to support students who had specific academic needs.

All codes were cross-referenced with the research questions to determine the possible outcomes of participants' perceptions about ADHD, as this study sought to identify a potential connection between parents' and caregivers' perceptions about ADHD and their willingness to have a child evaluated.

Chapter IV

RESULTS

The results are presented in six sections. The first section describes selected characteristics of the sample, including age, marital status, and income. In addition, other data describing the sample include their role (mother, father, caregiver), whether their child had an ADHD diagnosis, and the kind of school their child attends. The substantive research topics are organized into five categories that describe the respondents' perceptions about ADHD with respect to aspects of epidemiology; treatment options and side effects; labeling and/or stigma; diagnosis and treatment disparities; and benefits of diagnosis and treatment.

Sample

The sample included 43 African American parents or caregivers of school-aged boys 5-14 years old who attended an after-school program in Central Harlem, New York City. The majority of participants (n = 31) identified as mothers of boys in the program, followed by 8 participants who identified as fathers. The majority (n = 26) were in the age group that ranged from 30 to 39 years old, while 11 were 40 to 49 years old. Approximately two-thirds of the respondents indicated that they did not have a child with ADHD. When asked to provide information about the type of school their child attended, 20 reported a charter school, 13 reported a public school, and 9 reported a private or Catholic school. Two of the boys were reportedly homeschooled. Participants who were

single made up approximately one-half of the sample, while those who were married comprised just over 25%. Participants' reports of their total household income indicated that 17 reported household income greater than \$50,000; 10 reported household income between \$30,000 and \$50,000; and 7 reported household income between \$15,000 and \$30,000 (see Table 1).

Table 1. Selected Characteristics of Respondents Participating in Interviews about ADHD, Harlem, New York City, 2018 (n = 43)

Parent/Caregiver	n	%
Mother	31	72.10
Father	8	18.60
Caregiver	2	4.65
No Response	2	4.65
Has a child with ADHD		
Yes	13	30.23
No	29	67.44
No Response	1	2.33
Age Range		
18-29	2	4.65
30-39	26	60.47
40-49	11	25.58
50-59	4	9.30
60-69	0	0.00
70-79	0	0.00
School Child Attends		
Private or Catholic	9	20.93
Public	13	30.23
Charter	20	46.51
Homeschool	2	4.65

Table 1 (continued)

Parent/Caregiver	n	%
Relationship Status		
Married	11	25.58
Single	22	51.16
BF/GF Living together	3	6.98
BF/GF Not living together	2	4.65
Divorced	0	0.00
Widowed	0	0.00
No Response	5	11.63
Total Annual Household Income		
Less than \$15K	0	0.00
\$15-\$30	7	16.28
\$30-\$50	10	23.26
More than \$50K	17	39.54
No Response	9	20.93

Perceptions Related to Causes of ADHD

Participants were asked if they had learned about the causes of ADHD, and while the exact causes are unknown, participants' responses on the potential causes of ADHD varied between genetics, prenatal care, vaccinations, and diet.

When asked what he had learned about the causes of ADHD, Harvey, a father of two children who have not been diagnosed with ADHD and who has expressed distrust in the healthcare system in the United States, stated:

Harvey: The causes, I think I hear a lot about this in the news ... I think it could be family related or DNA or genetically ... so probably it must be either in the family.... I think that people are born with it.

Interviewer: Why do you think some kids are affected with it and some are not?

Harvey: I think it could be environmental, where they're exposed to it ... it could be in the house.... I think they may be born differently.

Carolyn, who when asked about the causes of ADHD stated that kids with ADHD are provided "pills," which "definitely changed the mood of the kids," thought that ADHD might be caused by multiple factors, including vaccines:

Carolyn: I'm thinking just probably maybe genetics.

Interviewer: Maybe genetics?

Carolyn: Yeah, probably. I've heard people link some of the vaccines possibly to it.

Interviewer: Why do you think some children are affected with it and others aren't?

Carolyn: I have no idea.... Things that happen in the womb....

Katherine, a mother who works in a school setting with youth ages 9 to 11 years old and whose child has not been diagnosed with ADHD but does receive related services at her private school, shared:

I think it's from birth. Maybe their parents [were] on drugs or something.... It all depends on when they're pregnant what they eat, or what medication they are on, I guess.... Some blame it on the vaccine.... Because certain things I'm not giving my child like the flu shot and that stuff ... some people believe whatever medication they give them during pregnancy or when they take their child to get vaccinated, it [ADHD] could probably come from that or the foods that have a lot of chemicals.

Helen is a mother who has considered having both of her children evaluated for ADHD. She also has a friend whose two adult children were diagnosed with ADHD during childhood.

Interviewer: Have you learned about the causes of ADHD?

Helen: I've heard that the immunization shots sometimes can be causes of certain things, and then also children of drug addict parents. That causes it at times.... I do believe that the drugs cause it and I've seen it firsthand unfortunately. The children have ADHD.

Jasmine, a mother of three children, one of whom was adopted, also believed that ADHD might be related to many factors: "... some of it is inherited. Some of it is drugs ... environmental ... I mean I consider drugs environmental...." Jasmine went on to discuss that, during pregnancy, her adopted child's birth mother had used drugs. Jasmine thought it was possible that since the child was diagnosed with ADHD, the birth mother's prenatal drug use was the cause.

Clarissa, the mother of a child who attends a public school and is in a special education class setting, has a friend with a child who was diagnosed with ADHD. According to Clarissa, her friend's family had a history of ADHD. She shared that she believed drug use during pregnancy was linked to ADHD:

Clarissa: Sometimes it could be genetic. It can also be, how can I say it, like developmental. Some people may have something with them while they're pregnant....

Interviewer: Something during pregnancy?

Clarissa: Yeah, something from pregnancy. Or some people might make a mistake and take a pill or a drug ... alcohol ... or their environment where they're living. Say if they're under construction.

Jody, a participant who has worked for a number of years in a school setting with children, some of whom had been diagnosed with ADHD and were taking medication agreed that prenatal care was related to ADHD.

Jody: I think smoking and possibly drinking while you're pregnant because I've had some parents tell me, "I used to smoke a lot. I used to drink a lot." ... I work in an inner-city school and a lot of parents did that, and we have quite a few kids who some were diagnosed ... drinking [during pregnancy].

Interviewer: Smoking and drinking during pregnancy?

Jody: Drinking.

Ruby's elementary age child was diagnosed with ADHD and Ruby advocated for her child during the evaluation process, and the child received the services needed to be successful in the classroom.

Interviewer: What have you learned are the causes of ADHD?

Ruby: It could be genetics. It could also be dieting.

Interviewer: Diet? What do you mean?

Ruby: Like what they're eating.

Interviewer: Certain food?

Ruby: Mm hmm, or pretty much it could just be the makeup of the characteristics of that child.... Maybe it was the food that we fed them because that can have an effect on why they are the way they are ... our food is made up differently now.... They say it's organic, but how do we know it's organic?

Marcy, an educator who works with students in grades kindergarten through 8th, acknowledged that she tries to keep up with the information about ADHD. She shared that her thoughts on the causes of ADHD were linked to SES but admitted the possibility of it being linked to the people's diet and a lack of access to high-quality food. She also indicated that vaccines may be linked to ADHD prevalence. Marcy has two close friends who have children who have been diagnosed with ADHD. They each treat it differently (one with medication and the other with therapy), and Marcy shared that both families seem "happy."

Interviewer: Do you know anything about the causes?

Marcy: Food and some vaccinations I do think have a big cause with it. But mainly food ... the ones that don't have better resources, especially when it comes to food, organic stuff....

Natalie a mother of two children who are under the age of 12, has two cousins who have been diagnosed with ADHD and shared that the evaluation process and treatment

was rough for the parent, who tried different treatment methods, but ultimately felt compelled to put the child on medication.

Interviewer: What have you learned are the causes?

Natalie: I've heard it could be sometimes vaccines.

Interviewer: Okay.

Natalie: It could be vaccines, the children or the person's eating habits, their intake. Hereditary thing.

Interviewer: Hereditary.

Natalie: Maybe hereditary ... Or maybe the environment....

Overall, the findings show that the respondents have a variety of ideas about the causes of ADHD. Among the topics that were mentioned, exposure to drugs or alcohol during pregnancy, vaccines, and diet were mentioned frequently. Other hypothesized causes were genetic factors.

Perceptions Related to ADHD Treatment Options and Side Effects

Many participants expressed concern about the use of medication to treat ADHD because of the associated side effects. Some thought that while medication may actually be effective in treating the symptoms of ADHD, the risk of side effects did not outweigh the benefits. Some felt as though medications changed the child's personality, others thought that using medication for ADHD did not address the root cause of the disorder, and others feared that it might lead to chemical dependence, addiction, and the use of illicit drugs later on in the child's life.

When asked about effective treatments for ADHD and if there were any concerns about the use of medication for ADHD, Adele, a mother of an 11-year-old child who struggled academically and who was retained in the 2nd grade, stated, "If there are not tested studies and future side effects ... because now you hear many medications just for

regular ailments like you may have these odd side effects.” She went on to ask, “What are the effects when they become adults?”

Another participant, Eliana, a mother of two children who have not been diagnosed with ADHD, shared that she preferred homeopathic methods for treatment:

Interviewer: Are there any effective treatments for ADHD that you know of, other than medications?

Eliana: I don't do meds, I do natural herbs ... I'm not at all into Western medication that if you take it you might die.

Interviewer: Okay.

Eliana: So let me do some natural, holistic things to do ... all these chemicals [in medications] ... I would go holistic first before I do anything ... I have to do my own research

Samantha, a primary caregiver who works in a pre-school with several children who have already been diagnosed with ADHD, had similar concerns about the use of medications to treat ADHD:

Interviewer: What do you think about medications [to treat ADHD]? Do you have any concerns about it?

Samantha: ... with the medication, you first don't get the right dose. The child will come in. You can tell that he's on drugs because he is very quiet and he goes to sleep for half of the day.

Interviewer: You have issues with the dosing?

Samantha: Yeah. I think they should just find a better way to treat the kids instead of putting them on medication. It's just too young ... I teach from three to five-year olds ... imagine having your child on medication and coming in all drugged up.

Jack, a parent who was diagnosed with ADHD when he was younger and had some involvement with the juvenile justice system, shared that he was put on medication to treat the symptoms of ADHD.

Jack: I was diagnosed with [ADHD].... I was put in a group home ... I was taking medication.... There were other ways that I

felt like I [could] can handle it, but I was taking medication and I felt like it made me slow and sluggish.

Interviewer: Did you think medication was helpful [for you]?

Jack: I don't think [medication] is helpful because I didn't like the way it made me feel, and plus [it has] bad side effects behind it.... The medication throws you off, [it] put[s] weight on you, give[s] you water weight. To get off that medicine, you got to wean yourself off if it.

Interviewer: Really?

Jack: Yeah, I was having blackouts.

Zara, who is a health professional who does not have a child who has been diagnosed with ADHD but whose sibling was diagnosed with the disorder, shared that they were prescribed medication, which her mother, a homeopath, did not support, because of the way the medication caused them to behave. Zara described the behavior as zombie-like and stated that they had a limited appetite, which she attributed to the medication. Her mother then stopped giving the medication, and as a result, their teacher refused to allow them in the classroom unless they were medicated. They were then referred to a facility in Central Harlem that is designed to provide youth who have various mental health issues with behavior management strategies and therapy to help them succeed.

Zara: Because [the sibling] went there ... [the sibling] got support ... they were able to refer [the sibling] to a good school and good doctors ... [the sibling] doesn't have any issues now.

Interviewer: Because [the sibling] got the help they needed?

Zara: Yeah, definitely. I do think that sometimes medication is overused. I don't think all children with ADHD need to be medicated.... I sometimes see that as soon as child is diagnosed the first thing they want to do is put them on medication. That's unfortunate because, like I said, I don't think every case is the same so you shouldn't treat every case the same ... medications, they have so many side effects and then it's kind of a hit and miss. You can prescribe this medication to Johnny for example, and then prescribe the same medication to David and David may have a totally different reaction to it or it affects him in a very different way.

Amelia, a single mother whose son was diagnosed with ADHD, shared that the experience was very challenging and, as a result, struggled with depression. She was not only concerned with the effects of medication in the short term; she also expressed concern about the long-term effects of the medication.

Interviewer: Do you have concerns about medication?

Amelia: Medication is not for everyone ... I have a lot of concerns about medication ... what is that medication going to do for them long term ... are they then more likely or more susceptible to drug use ... Substance abuse. Because all of the drugs ... all of the medications, rather, for ADHD are controlled substances. I have chosen to have my child on medication with a combination of therapy because I did want him to have the kinds of best education experiences possible. But ... I think you have to choose what's best for you and your family and I know that [using medications] is not something that we're going to do long-term.

Evelyn, a mother of two children who have not been diagnosed with ADHD, shared concerns about the use of medication to treat ADHD:

Interviewer: What do you think about medication? Do you have any concerns?

Evelyn: Yes, I do. Absolutely the side effects. I wouldn't want my child or any other child to become addictive to medication.

Interviewer: Okay, side effects and addiction?

Evelyn: Yes.

Estelle, who has a young child, expressed a distrust in the health care system as a result of her labor and delivery experience, stating that she thought ADHD medication might only not be effective but may also be dangerous:

Interviewer: What do you know about ADHD?

Estelle: ... it's a mental disorder and it's diagnosed in children at a young age. Usually they try to prescribe medication to help with it. Sometimes the medication is known to cause suicidal thoughts and threatening or hurting others around you ... pop some pill and I get cancer ... they act out based off the

treatments that they're getting, the medications that they're being prescribed. Maybe it's not treating. Maybe it's hurting the condition even more.

Jay, Layla, and Vera shared the view that medications used to treat ADHD might not be helpful and may be causing other issues for the child. Jay, a primary caregiver, works with Black male youth who have been involved with the criminal justice system.

Interviewer: Do you think [medication] is effective?

Jay: No.

Interviewer: Okay, why not?

Jay: It slows them down. It's not treating the problem, it's just masking the problem.... I feel like in treating a problem, for example if I break my arm, you set it [in a cast]. But when you constantly stay on the medication, you're just masking the problem ... what are the side effects ... if you're putting a chemical in your body, you [have] got to have some sort of chemical imbalance ... they [youth who are in juvenile centers/prisons] [have] psychiatric problems ... the problem is stemming from the side effects of these drugs.

Layla's oldest son was diagnosed with ADHD when he was in elementary school.

Interviewer: Do you have any concerns about [medications]?

Layla: You always have concerns ... because no medication is really what they say it's for. Everything is experimental ... you never know what you're giving your kid. You could be giving them psychotic medication ... maybe it could hurt them. You just don't know, so I didn't take that risk.

Vera, whose son has been diagnosed with ADHD, shared her frustrations with navigating the school system, and she tried to find the most appropriate academic setting for her child.

Interviewer: Are there effective treatments?

Vera: I'm not sure ... I'm not sure about medication because I never went that route.

Interviewer: You're not sure if it works or you're not sure about using it?

Vera: Yes, I'm not sure if that work because I haven't tried it firsthand. I was offered it [for her kids] but I don't want them to take medication.

Interviewer: Why is that?

Vera: Because I don't feel that they're in that state where they need something that's going to induce ... I don't know what the medication is going to do, so the medication is trial and error. You're going to give them something that's going to make them worse.... I'd rather get them counseling and get them the services they need instead of trying to alter them by drugs.

Faith works with adults who have mental disabilities and shared similar concerns about the use of medications and the possible side effects:

Interviewer: Are there any effective treatments for ADHD?

Faith: I think besides medications ... I don't think there is a permanent solution ... Medications have side effects ... your child becomes a zombie.

Interviewer: You mentioned the side effects. Do you have any concerns about medication for ADHD?

Faith: Yeah. I feel like eventually ... because I think the majority of the meds are to loosely control the child if they are hyper, who's to say that after a long period of time it won't just kind of dim that light in little "Bobby"... it's like now little "Bobby" is a little former shell of himself.

Nia indicated that parents will need to decide about the trade-offs to treating their child's ADHD symptoms with medication:

Interviewer: What do you think about medication used for ADHD?

Nia: The little bit that I do know or heard through the media and stuff like that ... it seems to make the children sluggish. I know a lot of parents, even if their child does have [ADHD], they're not usually too happy about necessarily medicating their children to the point where they're kind of zombie-ish.... It's kind of the decision that the parent would make whether or not they think their child really needs it and if the side effects are worth the benefits of the medication.

Elizabeth has three sons. The eldest has had some problems in school. She has friends, some of whose children have been diagnosed with ADHD. She shared that she thought medications would interfere with the child's development:

Elizabeth: ... I don't really believe in children taking medication until after they have passed puberty.

Interviewer: Why is that?

Elizabeth: Because I believe it affects the body and brain chemical that children develop ... you're also altering development of the children when they have to take the medication before that time ... because the medications that they do have to take for dyslexia or ADHD sometimes do have side effects ... then how is it going to affect my child's health for his future?

Some participants had strong responses to medication use for ADHD and indicated that they would likely seek out alternative measures to treat ADHD symptoms; others expressed that should their child be diagnosed with ADHD, they would consent to medication use as a final measure, only after exhausting all other non-pharmacological treatment options.

Zara: I don't think every child needs medication. I think that other alternatives should be explored first....

Interviewer: It sounds like [you're saying] it should be used as a last resort?

Zara: Right ... you're diagnosed with a medical condition and then your first option is "I've got to have surgery." ... You see what less invasive things you could try first.

Overall, most participants shared various concerns about the effects an ADHD diagnosis had on the child and their family, and many agreed that if a child were exhibiting symptoms of ADHD, having the child evaluated was the responsible course of action. However, some expressed an unwillingness to subject their child to medication to treat the disorder, which in some participants' eyes, the child could outgrow. The response to treating ADHD with medication appeared to be the greatest motivating factor

in determining willingness to having a child diagnosed. For most participants, their main concern for having a child diagnosed with ADHD was the use of medication to treat ADHD and the risk for side effects. While other participants shared that concern, some expressed fear of the child being labeled as an additional concern due to a risk of the diagnosis and associated label hindering the child's academic, social, and emotional growth.

Perceptions Related to Labeling and/or Stigma

Participants were asked to share reasons why they thought parents might avoid having a child diagnosed with ADHD. While many expressed concerns about the child being labeled and embarrassment or stigma that could result from an ADHD diagnosis, others shared that parents may just be in denial or afraid that their child would have to be medicated.

Trevor is a father of multiple children.

Interviewer: Can you think of any reasons why a parent might not want to have their child diagnosed?

Trevor: ... Maybe they don't want their kids to be on meds and not really being himself ... just being drowsy on medications and you're slow dragging your day, and you're just not feeling good and stuff.

Annmarie's son was referred for an evaluation, but she did not feel it was warranted.

Interviewer: Can you think of any reasons why someone would avoid having their child diagnosed?

Annmarie: Yes, because of medication ... some parents don't agree with it. So it's a lot of controversy with giving a child medicine or not.

Interviewer: What do you mean "some parents don't agree with it"?

Annmarie: It just may not be normal, you may not want your child to be on medication all the time, and the medications also do have side effects.

Annmarie also shared her views on whether a child would be treated differently in the classroom once they are diagnosed:

White kids, I feel like have more privilege where they are going to different schools [that can support students with ADHD], compared to a black child who has to be in a school but they don't have the special privileges where you can go to a private school to study and everything.

Her reluctance to have her son evaluated seemed to stem from the fear that he would be treated differently in his school as a result of an ADHD diagnosis.

Daisy, a mother of two school-aged sons, shared that one of her sons was recently diagnosed with a mental health disorder. He faced considerable struggles academically despite various academic interventions provided during the school day and in his after-school program. She thought parents might avoid having their child diagnosed due the fear of a stigma and apprehension about medication, as she could relate to those feelings.

Daisy: They don't want to be labeled.

Interviewer: Anything else?

Daisy: They don't want the stereotype. The first thing parents assume is they're going to put their child on medication, so a lot of parents are totally against that.

She shared that while initially she resisted having her son evaluated and used to be "totally against it," she looks forward to getting him the help he needs.

Interviewer: Why were you against it?

Daisy: Just the stereotype because I wasn't educated about it. But after speaking to [a friend whose son was diagnosed with ADHD], I've been learning that you have to do what's best for your child.

Keenan, the father of a pre-pubescent child, works with some youth who have had a variety of mental health diagnosis His child attends who attends a local school and has not had any academic challenges.

Interviewer: Can you think of a reason why a parent would not want to have their child diagnosed?

Keenan: It could be denial. My main reason would be denial ... it affects their [the parent's] life because now they're not dealing with a "normal" child.

Maya, a teacher who has experience working with students who have been diagnosed with a variety of mental health issues and is the mother of multiple children, shared her reasons why a parent might avoid having their child diagnosed with ADHD.

Maya: I guess there's a stigma behind it. A lot of parents, they don't want their child to be stigmatized by it ... they're resistant to having them evaluated or having them tested because of the stigma. They don't necessarily think anything is wrong with the child.... I would think the labeling and the stigma, taboo. A lot of times parents will just be in denial.... I probably wouldn't want my child labeled....

Interviewer: You think diagnosing them give them a label?

Maya: It does. It gives them a label, and then the general public at-large associates negative in their head with ADHD, as "he's a problem."

Brenda's son is under 10 years old. He was diagnosed with ADHD and struggled with behavioral issues in his school and in his after-school program. Brenda shared that she was against using medication to treat her son's ADHD symptoms, but realized that it might be necessary for her son's academic success. She shared that fear may prevent parents from having their child diagnosed.

The fear. The fear of knowing something could possibly be wrong with your child. The fear of having to sit down with people you don't know and them telling you that this is what your son has.... They don't want their child to be judged, but they fail to realize not getting that help for that child, they're [the parents] being judged.

Maria has a son over 10-year-old who attends a public school and shared her reasons for why a parent might not want to have their child diagnosed:

... because they don't want them to get put in a box, in a category, given restrictions or limitations. People assume that they can't accomplish things ...

I would imagine it's hard for them to get out of a category, once they're in there. Especially in Special Education ... they're branded in a population.

Tamia, a mother of two school-aged children and whose friend has a child who was diagnosed with ADHD, thought parents might avoid having their child diagnosed for several reasons but acknowledged the cultural resistance to discussing such matters with medical professionals outside of the community:

... probably denial. Especially in the culture that I grew up in, you don't talk your business outside the household ... that's not happening. And if you go see a therapist of psychiatrist or psychologist, for what? Momma is your psychiatrist or psychologist. It's that. Embarrassment.

Sharon, a mother who works in an educational/social services field, indicated that she has ADHD and that her son was also diagnosed with ADHD . She shared:

Sharon: They are afraid to face the truth and are fearful of the stigma that comes along with having ADHD. Because people don't want to deal with that stigma, and I think a lot of people will be embarrassed. I used to be embarrassed, but there's really nothing to be embarrassed about ... people just don't want to live with that stigma ... a lot of parents don't want their child on medication along with people possibly judging their child because of this issue.

Interviewer: You said that you have a child who's been diagnosed with ADHD ... can you share a little about what that was like?

Sharon: ... I can say the best thing I did for my child was having him evaluated. I knew he had some type of mental illness.... Yes, it's hard to deal with a child with such [a] diagnosis, but there are medications and therapy that can help.

Madeline, who has a son who was diagnosed with ADHD, cited embarrassment as a reason why parents might avoid having their child diagnosed. She emphasized the importance of having a pediatrician who worked well with her family:

Interviewer: Can you think of any reasons why a parent would avoid having their child diagnosed?

Madeline: Embarrassed ... embarrassed because some people prefer to say, "This child is perfect ... it's this, that" ... being embarrassed ... being labeled ... a child being labeled ... for fourth grade you have a teacher and he [the child's teacher]

already has a perception of your child ... the first thing they want to do it throw you in special education. But they're just not educated enough, honestly. You have to have a good doctor. My children have an excellent pediatrician ... I know her (their pediatrician) since I was a child ... she was my pediatrician now my children have her.

Reflecting on her experience having her child evaluated and diagnosed:

Madeline The first thing the teacher will do is say, "He has a problem." ... the district's only resources is trying to throw you in special ed[ucation] ... when the district tested [the child] it's a waste of time ... and they throw your kid away.

Interviewer: You've got three kids.

Madeline: Two boys and a girl.

Interviewer: What was that experience like for you?

Madeline: ...I didn't know much about it.... I was able to get him tested ... and we have a good pediatrician ... first line, educate yourself.... There will be no medication until I see the different things that we can do.

Amelia, a single mother whose son has been diagnosed with ADHD, also thought that a fear of labeling might prevent a parent from having their child diagnosed. She works in the education/social services field and admitted that she was concerned people would question her ability to deal with her child's needs:

Interviewer: You mentioned your personal feelings of being judged and blaming yourself. Can you think of any reasons why a parent might not want to have their child diagnosed?

Amelia: Yeah, for fear. Fear of that child being labeled, fear of that child being ostracized in school and kind of not being able to have a normal experience in school. Then again, kind of shame that comes or the blame that comes with you didn't do something right as a parent. This is your fault because ADHD shows up as a child who doesn't listen.... It's different if you have a child with autism. People say, "Okay, that was genetic. There's nothing you can do about that." But your kids won't sit down in the classroom? Your child can't take directions. Your child can't remember to bring their book, backpack, their homework packet. That's your fault. You're not disciplining them enough. You're giving them too much. You

need to take things away ... this was something I only shared with my sister because I didn't want the judgment.

Participants were asked to share their perceptions on the main consequences of boys that have ADHD. While most thought they would be disciplined more often at home and in the classroom, a few participants thought boys with ADHD were at risk for ending up in the justice system. Brenda, the mother of a child who has been diagnosed with ADHD, shared:

Brenda: If [the ADHD] is not handled at a young age, once they hit 13 [years old] they're going to be targets because they're "men."

Interviewer: Targets for who?

Brenda: For the law. If you don't get the child the help they need, they're [society] not going to see a child with ADHD. They're going to see predominantly minorities, a disgruntled Black man ... and the first thing they want to do is lock you up and close the record for you ... without getting them help now so that when they hit those ages that if they need medication or they need therapy to help them work through it, they're just going to be thrown to the system.

Eliana, who works in the social services system, shared that jail is a likely consequence for boys with ADHD: "...because [jail] is where they send them, straight there to jail. There is detention. There's suspension. There's juvenile halls leading right up to jail because we have a pipeline to prison."

Amelia, whose son was diagnosed with ADHD, also discussed the prison pipeline:

...for young people of color ... the consequences and response to [ADHD-related] behaviors go on [their] record. I've done a lot of research on the schools to prison pipeline. A lot of young people began to be diagnosed with ADHD around the third grade, and that is also, research shows, that is the grade and the age range where states start to look at the number of young people of color in the third grade to determine jails.

Harvey works with youth: "I'd see a lot of [youth with ADHD] resulting to illegal activity. Which you think about the prison industrial complex which is a multi-billion dollar business ... so many Blacks and minorities are the ones that populate these prisons."

Overall, the findings presented in this section highlight participants' fears of being judged and/or stigmatized by their family, friends, and community. Participants who have children who were diagnosed with ADHD shared some of the challenges they faced during the evaluation process and thereafter, many of which included the idea that their child would then be treated differently by teachers and peers. Some participants shared concerns about how others would view them if they decided to medicate their child.

Perceptions Related to ADHD Diagnosis and Treatment Disparities

Participants were asked to share their opinions on ADHD diagnosis and/or treatment disparities. These views varied greatly; some participants thought that Black children were diagnosed more often than White children; others believed that diagnosis rates were equal for Black and White children but treatment rates differed.

When asked if she believed ADHD affects Black and White youth equally, Amy, who has worked with underserved youth for a long time and whose child attends a non-public school, shared:

Amy: I believe that the environment and socio-economic background can play a part ... ADHD affects children that live in highly impoverished neighborhoods or where there are fewer resources for medical and educational materials ... I believe that children of color are over diagnosed.

Interviewer: Children of color?

Amy: Yes ... I believe that parents of color may feel that they do not receive the same type of care and are being judged.

Lucy was encouraged by her son's teachers at his charter school to have him evaluated. She indicated that he was not diagnosed with ADHD, even though certain symptoms were present, and thought diagnosis and treatment rates were linked to resource accessibility.

It's not only just African Americans, but Caucasians as well, they experience [ADHD] a great deal. I know their methods of resources. It seems like automatic ... like the swimmer athlete Michael Phelps. I understand that he suffered from ADHD, but his parents channeled it through sports ... and I believe they used other resources as well.

Lucas has multiple children; one of his sons has been diagnosed with ADHD. The child, who has attended multiple schools in the past years, is frequently disciplined for his behavior. The family is struggling to find the best setting for the child, and while they have tried medication in the past to manage the symptoms, they feel it is not the best treatment method for their family. Lucas expressed the following when asked if he believed ADHD affects Black and White youth equally: "Yes ... I think White people have better knowledge and materials to deal with ADHD better.... Black people get medication as a form of treatment, and that's it."

Maliah, who works in the medical profession and whose child attends a charter school and has not been diagnosed with ADHD, questions whether healthcare professionals are accurate in their diagnoses.

Maliah: Only because I'm African American, it might seem more percentage rates of it, but ... but not to sound racist or anything, their [Caucasian] kids might have more of the issues because a lot of times African American, they come from one-family homes. But wealthy Caucasian people, they have nannies a lot. And just seeing those [Caucasian] kids sometimes with these nannies, I'm like that's not normal ... African Americans, for sure are diagnosed more ... because in life, there are less educated African American teachers in the school systems ... they're quick to diagnose African American kids or [say] this has a problem because you're not more like [non-African American] children.

Interviewer: Is there a group that you think is diagnosed more often?

Maliah: African Americans for sure.

Interviewer: Why is that?

Maliah: Because there were less educated African American teachers in the school systems ... now in your community you see more Black teachers ...but before they were quick to

diagnose African American kids because they were not like [a White child].

Faith, a mother whose children attend Catholic school and have not been diagnosed with ADHD, shared a similar perspective.

Interviewer: Do you think that ADHD affects Black and White youth equally?

Faith: I do ... I feel like everything has the potential to affect different races equally. I feel like it may not be talked about in urban communities more just because we tend to not always go get our kids tested for things unless someone brings it to our attention or because we were raised...thinking they'll grow out of it.... I feel like in other cultures, they test more. It's like they have such a strict standard from birth of how their kid should be ... I think a lot of times it gets overlooked in urban communities.

Paul, a father whose child does not attend a public school, indicated that he believes race does not matter and that diagnosis and treatment disparities may be linked to socioeconomic status.

Interviewer: Do you think that ADHD affects Black youth and White youth equally?

Paul: You put a White kid in an environment that he's not, I guess, comfortable in, hey, you're going to see a little bit of restrain ... that's just any kid though. Black, White ... kids are kids ... I understand it as a disease ... it's recently become more popular. I was just reading that some people have been using it to get their kids in a way around tests and stuff like that ... they use that to maybe get their kids more time on tests.

Interviewer: Extended time on tests?

Paul: Something to that effect ... it's like you know that's not going on in the lower class. They don't have that much pull.

Aaron, a father whose son was diagnosed with ADHD, stated:

Aaron: I don't think it affects White kids at all ... of course you can't say that for every single White child. But for the most part, I think [ADHD] is significantly higher in the Black community.

Interviewer: Why do you think that?

Aaron: ... just the lack of resources from the food that we eat, the parental guidance, the moral support.

When asked if Black and White children were equally affected with ADHD, Eliana, a mother whose child attends a public school and has not been diagnosed with ADHD, shared:

Yeah, but it's labeled differently ... I think we're easily labeled ... even for mental health ... there's always a reason why [a White child] is having a bad day opposed to [a Black child] having a bad day ... where they have more patience for [a White child], but not [a Black child]. And they could be diagnosed with the same thing, same teacher and she doesn't have patience for the minority child.

Samantha, a caretaker, works mostly with minority children.

Interviewer: Do you believe that ADHD affects Black and White youth equally?"

Samantha: Because most of the kids ... I'm teaching, it's mostly Hispanic or African American children [who are affected with ADHD], a very small amount of White [children]. It's very small.

Jack, the father of a school-aged child, also thought the Black and White children were diagnosed and treated at different rates for ADHD.

Interviewer: Do you think that ADHD affects Black and White youth equally?"

Jack: Yes, I do. I just think that the minority groups get diagnosed more often with it. Like Blacks [sic], Latinos [sic] ... we get diagnosed because our doctors ... they are quick to diagnose you, put you one medication. To me, I feel like it's a way to control that person.

Elizabeth, who expressed that the school in her community did not support her academic needs and whose son has been struggling academically in multiple school settings, shared a personal experience with disparity in schools.

Elizabeth: Once I went out of my community to a school in a White community that had children that were actually commercials and stuff like that, having dyslexia and ADHD was the norm in these schools and I was treated differently. I was actually

shown things that helped me throughout life ... the teacher, she said ... she was telling me I was dyslexic.

Interviewer: Do you think that if you had gone to a school in ... the Black community you would have been...?

Elizabeth: ... maybe I wouldn't have graduated from junior or high school ... in my schools and my community that was missed.

Interviewer: The schools in the White communities, it sounds like you're saying they offered you more resources?

Elizabeth: Yes ... people who was diagnosed with dyslexia, they were diagnosed with ADHD. It was all types of programs there....

Nia, a mother who works in the education field, indicated that since she believed ADHD might be caused by genetic factors and/or prenatal drug use, Black and White youth are equally affected.

Interviewer: Do you think that Black and White youth are affected equally with ADHD?

Nia: If I'm going to base it on the fact that it's something that's biological or something that can be brought on because the mother may have been using drugs, I feel like Black and White people, they both fall into that category.... I would assume it's about the same rate ... but sometimes I feel like the school system doesn't take the time to dig a little deeper to figure out what other things could it be besides just wanting to label the child ... it could be emotional things ... we live in an urban community ... people who are dying around us ... you have an attitude and you're lashing out. Does that mean that you have ADHD? ... I think it's a possibility that there's some over-diagnosis, but ... it could be that they were being under-diagnosed ... years ago we didn't know what mental illness was ... now you get more accurate diagnosis ... we are doing a little bit more work and research.

Overall, this section highlights participants' perceptions about the disparity in ADHD diagnosis and treatment rates for African American youth. Participants believed that access to resources needed to diagnose and treat ADHD affected diagnosis and treatment rates and certain factors such as socio-economic statuses and race/ethnicity determined such access. Some thought that while Black children might be diagnosed

more often than White children, it was White children who had greater access to treatment resources and therefore would be better equipped to manage ADHD symptoms and behaviors.

Perceptions Related to the Benefits of ADHD Diagnosis and Treatment

While some families seemed to have various reservations about having a child evaluated for ADHD, mostly due to the potential for the child being put on medication or labeled, most respondents saw value in having a child diagnosed, as a diagnosis would then provide resources for ADHD treatment.

Layla, a mother whose oldest son was diagnosed with ADHD, shared that the benefits for her and her son have been mostly academic:

Interviewer: Would there be any benefits to having a child diagnosed?

Layla: The benefit with that is that it comes in academically ... they're given the extra time, a little more attention if the school is doing what they have to do.

Faith, who does not have a child with ADHD, thought there were benefits to having a child diagnosed.

Interviewer: Would there be any benefits to having a child diagnosed?

Faith: Yes. Because ... hopefully it'll give you a better understanding or it'll help you kind of ... there's a reason why. I mean too many times you may be a parent sitting at home crying because this kid is exhibiting these symptoms these symptoms that you don't know why your kid is acting out ... then when you finally get that kid tested or somebody recommends it's like, "Oh, finally I understand" ... I think it makes it better when you do know there's finally something.

Jody, who has worked with students that have been diagnosed with ADHD but who does not have a child with ADHD, believed there were benefits to having a child diagnosed.

Interviewer: Would there be any benefits to having a child diagnosed with ADHD?

Jody: ... if the child [has] ADHD and they are diagnosed and they have the proper treatment in their control, I think it makes them function better in class. I think they'll achieve more because then they're a little bit calmer. They can focus a little bit more and sometimes they even excel.

Interviewer: That's a result of being evaluated and diagnosed?

Jody: Yes, properly treated.

Marcy, a mother who works in the education field, indicated that having a child diagnosed with ADHD might come with benefits, as well as disadvantages.

Interviewer: Would there be any benefits to having a child diagnosed with [ADHD]?

Marcy: There are benefits since you know what the issues are. But at the same token, sometimes teachers can also be biased to someone with ADHD ... they'll treat them a certain way....

Clarissa, the mother of a pre-pubescent child who attends public school, indicated that a diagnosis might provide the child and their families with social support:

Interviewer: Would there be any benefits to having a child diagnosed with ADHD?

Clarissa: If ... along with you getting a diagnosis, the person who's doing the diagnosis gives you resources like counseling, therapy. Also, associating with other parents who have a child with ADHD.

Interviewer: A support group?

Clarissa: Yes.

Ruby, whose child has been diagnosed with ADHD and attends a private school, identified a major benefit to having a child evaluated and diagnosed.

Interviewer: Would there be any benefits to having a child diagnosed with ADHD?

Ruby: Yeah, because then you get the services, it doesn't have to be medication.... Because I feel like cognitive therapy, other

strategies and techniques, things that excite them or they're interested in will keep their focus.

Interviewer: Getting services is the main benefit?

Ruby: Other related services is the key factor.... Don't let a school dictate what [the child] shouldn't have ... [her child's pervious school] didn't even address ADHD.

Carolyn, a mother whose child attends a private school, thought that a benefit to diagnosis was increased knowledge.

Interviewer: Would there be any benefits to having a child diagnosed?

Carolyn: Yes ... because then you learn how to ... you learn what triggers the child. You learn what type of environment that child might need to be in, if they need a special classroom or education services that might not fit a "normal" classroom. There's definitely a lot of benefits to that.

Aaron shared that having his son diagnosed helped him understand a little more about the disorder:

Interviewer: Would there be any benefits to having a child diagnosed?"

Aaron: Absolutely, right.

Interviewer: Like what?

Aaron: You can't change something that you don't know about. Where I'm still unclear is exactly the causes of it. I would rather know that there's some type of challenge with my child, some type of issue. Now we can take the necessary steps from there to improve.

Annamarie, who has experience working with youth who have been diagnosed with ADHD, expressed that she sees a benefit in having a child diagnosed: "The benefits of having them diagnosed ... because now, especially if you don't know what's going on with him, you can't help your child, but now that you know that this is what it is, now you can figure out what plans can work for my child better."

Keenan shared that a lack of diagnosis may lead to the child getting into trouble because of their behavior:

Keenan: There are some benefits to a child being diagnosed ... if you're able as a parent to get your child tested ... just getting help ... if a child is not diagnosed with ADHD, he may go outside and behave in a certain manner.

Interviewer: Certain manner?

Keenan: ... he's not diagnosed; he may get into trouble faster than someone [who] is diagnosed. They [parents whose children have been diagnosed] have more understanding of the situation. Yeah, I think it's helpful ... and to get the child the best ... that he or she deserves.

Sharon, whose son attends a private school and was diagnosed with ADHD, values the resources that accompany a mental health diagnosis:

I want to say yeah, because there's a lot of help out there. They have therapists. He sees a therapist ... we have a psychiatrist. Once you're diagnosed, you know what you can do. Whereas if you're not diagnosed, you're walking around all [unaware] and you're not getting the help that you need. People are just saying, "Oh, this kid's bad."

Overall, participants believed there were benefits to having a child diagnosed and treated, but their concerns indicated a fear that the effects of a disorder diagnosed during childhood would affect their lives long term, whether it was physically due to side effects of medication use, or socially and emotionally as a result of being singled out or ostracized by teachers and peers, and since ADHD frequently co-occurs with disruptive behavior, the potential to end up in the justice system. Many participants emphasized that they wanted to make the best decision(s) for their child and support their needs; however, they were unsure as to what was the best option for their family should they be faced with treating this disorder.

Summary

These findings indicate participants' understanding that ADHD is a serious disorder, with effects that can last beyond childhood. Many acknowledged that if their child were to exhibit ADHD-related behaviors, it would be best for the child to be

evaluated, diagnosed, and treated, but major concerns about the outcome of that diagnosis and subsequent treatment methods were discussed. Highlighted in Figures 1 through 5 are the frequency of participants' responses to the following concepts, respectively: labeling and stigma; nonpharmacological methods to treat ADHD; perceptions about medication use; disparity in diagnosis and treatment; and causes of ADHD.

Participants more frequently shared concerns about labeling, in addition to those related to their child being treated negatively or differently (see Figure 1). Perceptions of non-pharmacological ADHD treatment methods were discussed (see Figure 2). The most frequently reported non-pharmacological treatment methods were yoga and swimming, followed by dietary changes, specifically decreasing the amount of sugar in the child's diet and meditation. Captured in Figure 3 is the frequency of responses to items regarding the use of medication. Participants cited concerns about side effects most frequently, followed by general concerns about the use of medication and concerns about addiction. While discussing overall diagnosis and treatment disparities, participants most frequently indicated that the evaluation and diagnosis process and various treatment methods could be challenging for parents and caregivers (see Figure 4). Lastly, when focusing on the factors that participants believed caused ADHD, genetic causes were more frequently reported (see Figure 5). Participants also indicated that dietary causes potentially caused ADHD, followed by environmental factors and pre/postnatal care.

Overall, participants had major reservations about ADHD as a disorder and its diagnosis and treatment methods, some of which result from a lack of information, in addition to misinformation and long-held stigmas about mental health among the African American community. However, despite those reservations, participants offered their recommendations for addressing the diagnosis and treatment disparity for African American youth, which are discussed in the next chapter.

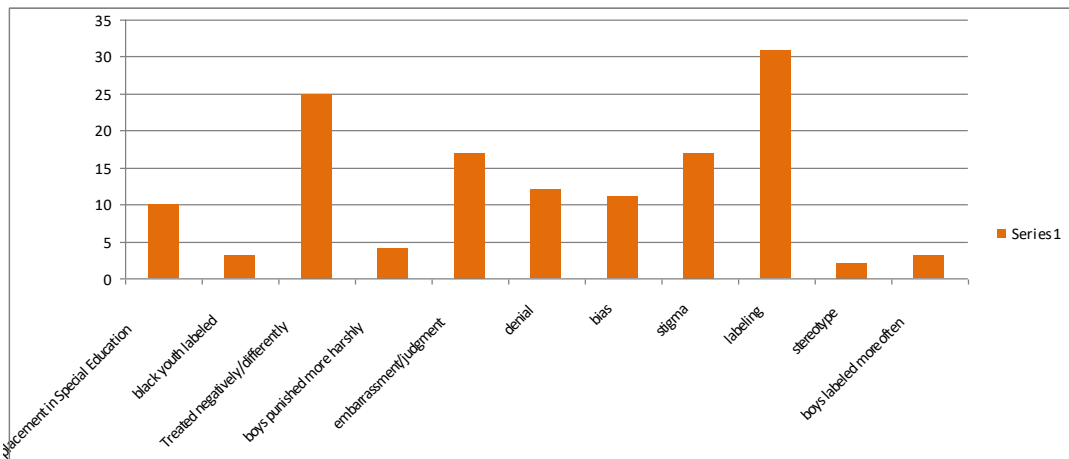


Figure 1. Labeling and Stigma

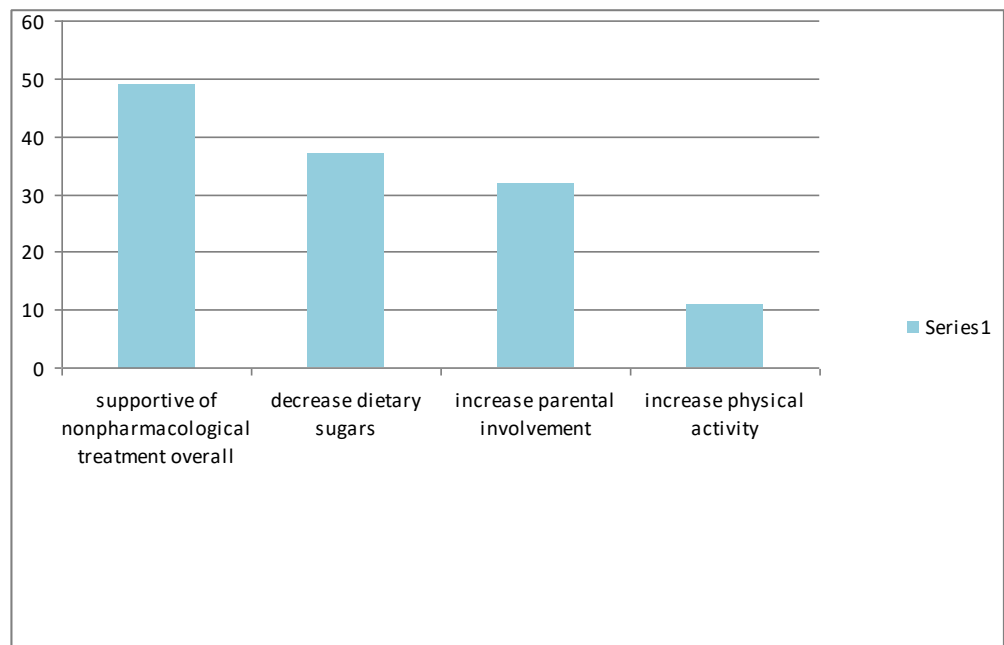


Figure 2. Non-pharmacological Treatment Methods

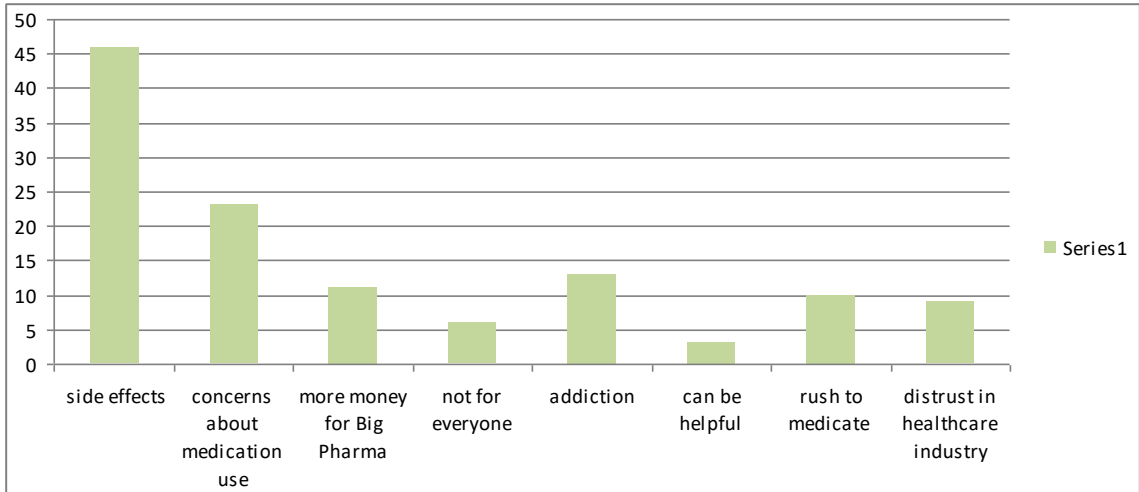


Figure 3. Medication Use

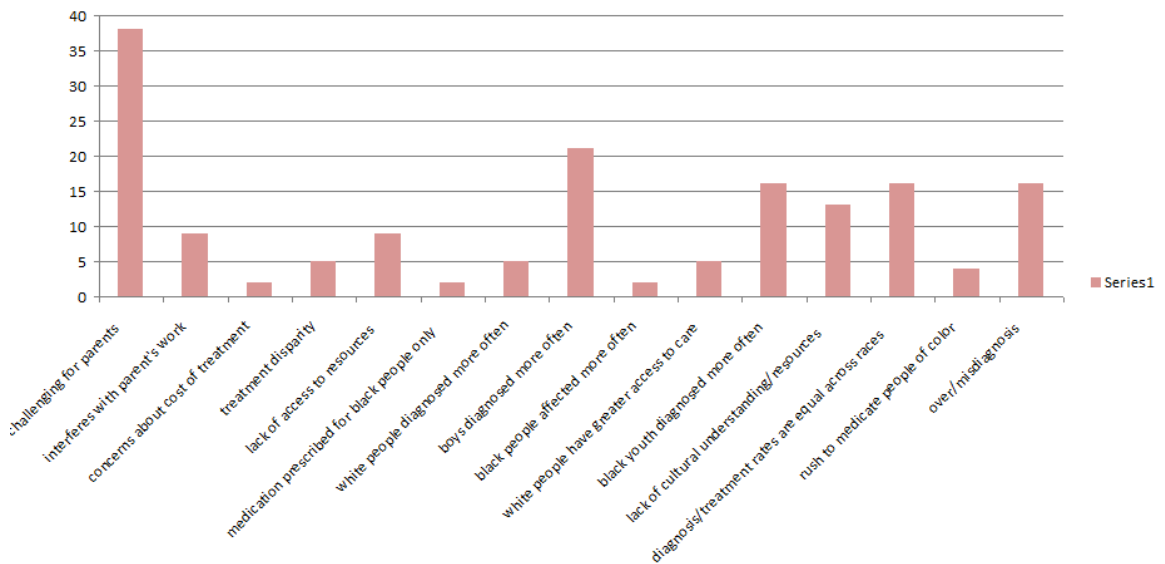


Figure 4. Disparity in Diagnosis and Treatment

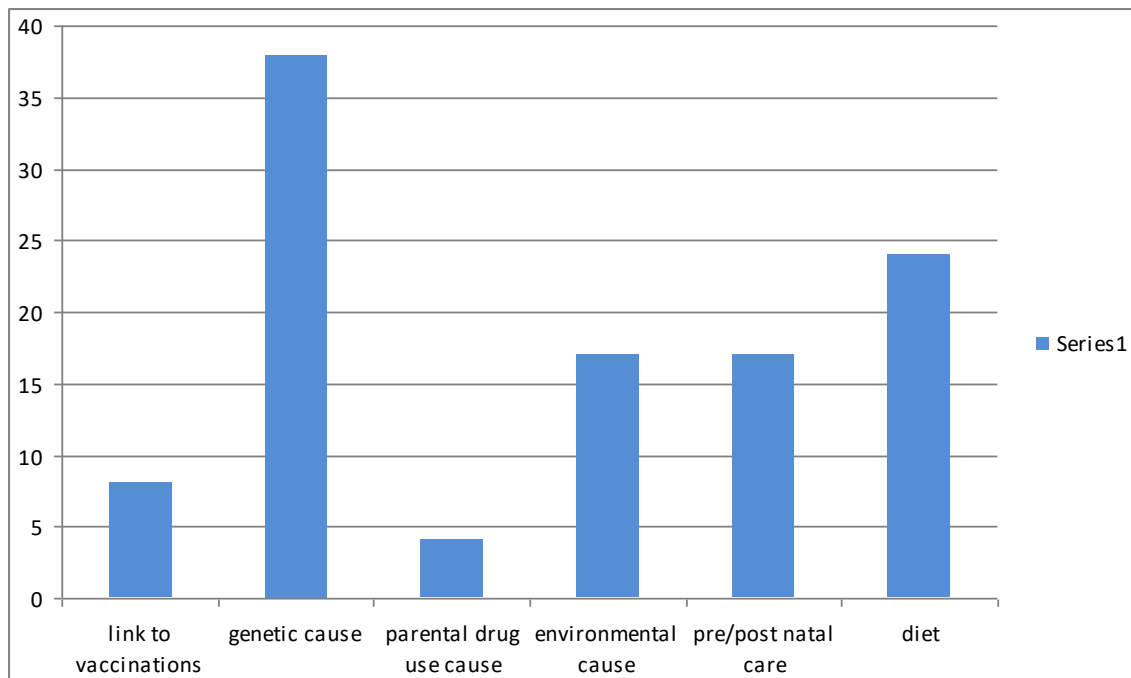


Figure 5. Causes of ADHD

Chapter V

CONCLUSIONS AND IMPLICATIONS

Main Conclusions

The purpose of this study was to explore African American parents' and caregivers' perceptions about Attention-Deficit Hyperactivity Disorder (ADHD) and to assess how, if at all, those perceptions may affect their willingness to have their child evaluated, diagnosed, and treated for ADHD. The study was intended as a first step in addressing the disparity in ADHD diagnosis and treatment for African American youth. The qualitative findings presented in this study highlighted participants' perceived susceptibility and risk of ADHD, including who is perceived to be at risk for developing the disorder. Perceived effects of a disparity in diagnosis and/or treatment were also discussed. Participants had major concerns about popular treatment methods for ADHD symptoms, most notably, the associated side effects of medications. Participants also expressed concern about being judged for their child's ADHD diagnosis and/or their child being labeled or faced with stigma resulting from an ADHD diagnosis. Perceived benefits of having a child diagnosed with ADHD were also discussed.

Many participants acknowledged that having a child with ADHD would be extremely challenging for myriad reasons, including frequent calls from the school, having to leave work early because of their child's behavior issues at school, and the possibility of lost wages or termination from employment. These findings are aligned with those of Coghill and Hodgkins (2016) that ADHD negatively affects the lives of

parents/caregivers. Despite these potentially negative life-altering outcomes, some participants seemed ambivalent about ADHD as a diagnosis, which may be related to their views about how ADHD develops, and as Morgan et al. (2014) indicated, there may be varied views about ADHD among different racial and ethnic groups. Many participants believed that the symptoms of ADHD were related to parenting methods; some shared that children with ADHD “just needed a beating,” which was a common method for discipline among some individuals in this sample. This perception indicates that parents believe they have control over their child’s ADHD-related behaviors and, therefore, no need to seek professional help for the disorder. However, this method of handling ADHD is not effective in addressing the child’s academic needs, ultimately delays the child’s academic progress, and contributes to the growing diagnosis and treatment disparity between African American and White children.

As mentioned Chapter IV, participants had varied responses when asked about the causes of ADHD, and some perceived that ADHD susceptibility was out of their control, stating that ADHD was caused by genetics and that it “ran in families.” Similar to Bailey et al. (2010), other participants believed that ADHD was related to the presence of environmental toxins, such as pollutants in apartment buildings and from construction sites or chemicals/preservatives in their food, a factor that some participants attributed to socioeconomic status in that access to higher-quality food is usually neighborhood-dependent, a perception that also indicates that whether children develop ADHD may be out of parents’ control.

There were also many participants who believed that ADHD prevalence was related to pre- and post-natal care, including vaccinations and the use of drugs and alcohol during pregnancy, which implied that ADHD is preventable and may explain parents’ reluctance to evaluating their child for ADHD. If ADHD does have genetic roots (Bailey et al., 2010), adults with ADHD may be more likely to use alcohol during pregnancy, which, according to Thapar et al. (2012), has a high comorbidity with alcohol

and substance abuse, possibly leading to ADHD in their children. The perception that ADHD is caused by prenatal alcohol use is aligned with the findings from a longitudinal study conducted by Pagnin, Zamboni Grecco, and Furtado (2018) that “low-moderate alcohol use during pregnancy was associated with increased odds” of ADHD in children (p. 1). Therefore, parents may doubt their child’s susceptibility for developing ADHD if they did not use alcohol during pregnancy and may then question education and healthcare professionals’ recommendations for evaluation. If the child were to exhibit symptoms of ADHD, symptoms that African American parents might view as “normal” childhood behavior, they may not seek help, which may likely account for the disparity in ADHD diagnosis rates among African American youth.

When discussing ADHD causes and susceptibility, some participants appeared unsure about many of the factors that may lead to the disorder, suggesting that they have different ideas for how ADHD develops, which may affect their willingness for having their child evaluated. In alignment with the Health Belief Model, Perceived Susceptibility appeared to be a factor that affected participants’ motivation to consult with a professional if their child exhibited certain behaviors indicative of ADHD. According to the Health Belief Model (Hochbaum, 1958), if individuals believe they are at greater risk or have a higher susceptibility for a disorder, they are more likely to seek help if their child displays ADHD-related symptoms or behaviors. However, the parents/caregivers who believed that ADHD is caused by environmental factors such as drug or alcohol use during pregnancy may not think their child is susceptible to ADHD. If certain ADHD-related behaviors appear during the child’s later school-age years, parents and caregivers may not view the behavior as a cause for concern and, therefore, may not express a willingness to have their child evaluated.

Participants who attributed ADHD to environmental toxins in the home, such as lead paint or cigarette smoke, which according to Singh et al. (2013) is positively associated with symptoms of ADHD, expressed helplessness when discussing this

disorder. They understood that ADHD was a serious disorder and would likely have long-lasting effects on the child and family but did not express a sense of urgency about the disorder that might be expected from parents and caregivers of school-aged youth. This could be the result of generational despair due to certain historical atrocities that have plagued the African American community, many of which some individuals still experience, and according to Kennedy, Mathis, and Woods (2007), it is “the combination of both historical and modern day experiences” (p. 59) that has led to the distrust in the healthcare system.

African Americans are underrepresented at clinical trials, which may be attributed to past medical experimentation and poor medical treatment (Otado et al., 2015). The beliefs regarding their participation in clinical trials likely carry over to other medical/healthcare interactions, including the evaluation of a child for ADHD, and as reported by Kennedy et al. (2007), “the perception of mistrust from the African American community is in large caused by their previous experiences with the health care system” (p. 57). Kennedy et al. referenced the Tuskegee Syphilis Study, a research study exclusive to African American males that took place in Alabama from 1932 to 1972 and sought to “study how the disease progressed” (p. 56) while withholding treatment from participants. Such experiments are possibly a major reason why African Americans distrust the healthcare system.

Maria, a single mother whose child attends public school and does not have ADHD, shared the following:

Interviewer: Do you think there are some people who may lack trust in the healthcare and/or education system, or feel it wasn't designed for people of color?

Maria: Yes.

Interviewer: Can you say a little bit more?

Maria: (long pause) I just think from people's experiences they develop a lack of trust because the school system sometimes doesn't produce in the children what they're supposed to ... the course of action taken against certain demographic of students shows there's a lack of care for those students.... In healthcare, I've just read enough to know that it's based on bad experiences with healthcare, disparity in healthcare, unequal access to care, and then just so many studies show that people don't get the same treatment based on where you live and what demographic that clinic or hospital serves.

There are many African American adults alive today who are only one generation removed from those who suffered from the horrific effects (both direct and indirect) of the Tuskegee Study, and according to Kennedy et al. (2007), there is documented proof that African Americans "still receive decreased access and treatment to care compared to their white counterparts" (p. 57). Participants believed various diagnoses, including ADHD, by health care professionals should be questioned, which is in accordance with the findings of Berger-Jenkins, McKay, Newcorn, Bannon, and Laraque (2012) that certain ethnic groups do not receive the same access to and quality of care; their distrust in the health care system is apparent.

The participants in this study are part of a larger African American community who, in the brief history of this country, were subjected to inhumane treatment from medical professionals, those who had been entrusted with the well-being of individuals in extremely vulnerable conditions. According to Kennedy et al. (2007), many African Americans feel like the act of receiving health care is "often a degrading and humiliating experience" (p. 57). As a result of those experiences, a deep distrust in the healthcare system still exists among this community, which likely accounts for their perceptions about ADHD.

Many participants recognized that medication is the most widely used and likely an effective treatment method for ADHD. However, of the 43 participants who were interviewed, about two-thirds ($n = 29$) indicated at least once that they were concerned about the potential side effects of the medications. It was the concept that appeared most

significant to participants when discussing the use of medication to treat ADHD, and there are many factors that may contribute to such perceptions.

Many participants felt there was a lack of information about the chemicals and/or ingredients found in the medications, and there was very little research on the short- and long-term effects, especially for pre-pubescent youth. Some expressed concern about the potential for long-term health effects of using medication for ADHD, including addiction and dependency and the possibility of it leading to the use of illicit drugs. For example, Maliah shared:

...a drug is a drug ... once they don't have it, because of the insurance [costs], they can't afford it. Their system is already accustomed to it, and without it ... that's why you see some people walk around streets ... they can't get their medication, so that why a lot of them harm and hurting and killing ... it's because of the medication.

Participants' apprehension about having their child diagnosed with ADHD for fear that medication would be the sole recommended form of treatment was evident in the conversations about medication use, and some indicated that if they had a child who was taking medication for ADHD, they would worry about the effects of the medications on the child's neurological development. It is possible they seemed uncomfortable with sharing these fears with their child's doctors, because they felt their concerns would not be taken seriously or that the medical professionals would placate them in the moment without considering the basis and outcomes of those fears, which is likely connected to their seeming distrust in the healthcare system.

Many participants believed that non-pharmacological treatment methods, such as changes in diet and exercise, and various behavior management strategies could be just as effective as medication, and although those methods may not be as fast-acting, they should be explored and a recommended first option. This finding is consistent with the study by Pham et al. (2010), whose results indicated that compared to White parents, Black and Hispanic parents favored behavioral intervention treatment methods for

ADHD over pharmacological methods. Several participants shared their belief that medical professionals are “quick to prescribe” medication to Black children, whereas, when assessing White children, they may be more willing to recommend alternative, non-pharmacological options. This finding supports Walls et al. (2018), who found that using medications as a first line of treatment may not align with African American families’ values and beliefs and indicates a lack of trust in the ability of their healthcare practitioners to provide high-quality and equitable care. Therefore, it is possible that they would be reluctant to divulge concerns about their child’s behavior to healthcare professionals.

Annmarie: ... doctors may just want to give medication to the people of color ... [they] say, “okay, well let’s medicate him on this.”

Jack: ... the first thing the doctor wants to do is put you on medication.

Madeline: ... that’s the first thing they want you to do is give them a pill. First thing.

Tamia: [referring to a friend whose child was evaluated] was aggravating because it felt like ... it seemed like the doctors or the people that were involved, their immediate thing was medication.

Vera: ... that’s the first thing they say before they say anything. They’re quick to say, “Oh, your child has ADHD. They need medication.”

Those who acknowledged the severity of ADHD and the need to treat the disorder and were not comfortable treating ADHD with medication were more engaged when the conversation shifted to non-pharmacological treatment options, highlighting their preferred treatment methods.

Interviewer: What do you think you about decreasing the intake of high sugar foods?

Ruby: Don’t give them any sugar!

Interviewer: No sugar?

- Ruby: If they're hyper, why would you hype them more? No sugar. If you can avoid sugar.
- Interviewer: What do you think you about decreasing the intake of high sugar foods?
- Marcy: Absolutely. I've actually seen a classroom teacher get her middle school kids to stop eating so much sugar, and it really worked for her ... especially for her boys, the overactive ones.
- Interviewer: What do you think you about decreasing the intake of high sugar foods?
- Elizabeth: Yes.
- Interviewer: What about other dietary changes?
- Elizabeth: I'm not sure ... but I know I have coworkers that have children with ADHD.... They do remove a lot of things out of their diet. They basically give their children organic diets, a lot of fruit, no fried foods, gluten-free food, and they say that it helps.
- Interviewer: What do you think you about decreasing the intake of high sugar foods?
- Jack: Cut out the sweets. They need carbs because they're going to be running and trying to burn off that energy. We didn't have medication [when he was growing up]. We didn't have Xbox and video games. We get diagnoses because our doctors they figure, "Okay, he's got ADHD." But I tell parents [of the children on the team that he coaches], "You've got to release that energy. Play."
- Interviewer: What do you think you about decreasing the intake of high sugar foods?
- Tamia: See, I've read so much about pros and cons. It's back and forth. But I would say yes because it's a situation where they're hyperactive.

Overall, treating ADHD with medication was not an option for many of the families. This supports the findings of Walls et al. (2018), which concluded that Black and Hispanic youth were less likely than White youth to receive pharmacological treatment. These findings highlight that participants prefer methods of treatment that they

could control; diet changes, including decreased sugar intake and increased physical activity can all be managed at home under the parent's care and without having to consult with healthcare professionals.

Some participants expressed willingness to having their child diagnosed and/or treated for ADHD; however, many shared concerns about that process as it might result in their child being medicated, which supports a 2012 longitudinal cohort study conducted by Bergen-Jenkins et al. (2012) that found minority families were reluctant to seek help for a child's ADHD due to concerns about medication use. Many indicated that, while medication may be useful in treating ADHD-related symptoms, they were not sure if the benefits of the medication outweighed the risk of side effects. In alignment with a variation on the Health Belief Model's category of Self-Efficacy (Hochbaum, 1958) referred to in this study as Efficacy of Treatment, if individuals are concerned about the treatment options available to them, they may be resistant to having their child evaluated for and diagnosed with ADHD.

A common non-pharmacological treatment option for ADHD is the daily report card, which sets clear expectations for children with ADHD, allows parents and teachers to work together targeting certain ADHD-related behavior, and involves the development of goals for which the child is accountable throughout the school day. Each goal that is accomplished is recognized and rewarded by the child's teachers and parents, encouraging more frequent, appropriate behavior. This method of treatment, while effective, requires parents and teachers to be consistent with its implementation, which may time-consuming.

Other non-pharmacological treatment methods include behavior therapy and skills training and self-management, which Richardson et al. (2015) reviewed in a report for the National Institute of Health. Merrill et al. (2016) found behavioral therapy to be more effective at improving academic performance, specifically on homework completion and accuracy. Catalá-López et al. (2017) compared the efficacy of pharmacological ADHD

treatment options with non-pharmacological treatment options, such as dietary changes, homeopathic treatment, and increased physical activity and behavior therapy. The authors found that behavior therapy, especially when given by parents with child and teacher involvement, was the most beneficial non-pharmacological treatment method.

About two-thirds of participants in this study were familiar with the daily report card and/or behavioral therapy. This highlights that knowledge of non-pharmacological treatment options is available; however, perhaps those options are not offered to families or that the treatment method did not fit in with their family's lifestyle, as those methods can be time-consuming. One mother whose son had been diagnosed with ADHD and was taking medication to treat the disorder shared that she had tried non-pharmacological treatment methods, but they did not work. Another mother, whose son was also diagnosed with ADHD, commented on how tedious behavior therapy was, although she admitted that it was effective when implemented correctly. ADHD treatment methods, whether pharmacological or non-pharmacological, must be practical with each family's daily routine and align with their values; otherwise they are likely to discontinue treatment, which is highlighted by the findings in this study.

When participants were asked to share any reason(s) why a parent or caregiver might not want to have their child diagnosed for ADHD, 24 of the 43 participants cited fear of labeling and/or stigma. This may be a major barrier to treatment, a finding that is consistent with Olaniyan et al. (2007), who reported that some parents felt ADHD was also a label and shared the concern over children being damaged. This was a recurring theme: fear of a child being labeled because of an ADHD diagnosis. African American parents likely feel their children, especially male children, have so many obstacles stacked against them from birth that they fear another hardship might further hinder their academic and social progress.

According to the Health Belief Model, individuals who believe the effects of a course of treatment could be more harmful than the disorder itself are unlikely to seek

help (Hochbaum, 1958). Some participants also expressed that their peers might ridicule or judge them for medicating their child to treat ADHD-related symptoms. Others worried that their parenting skills might be called into question and that they would be subjected to harsh judgment and criticism by peers, family, and even healthcare and educational professionals. Social circles are extremely significant to the African American community; therefore, concerns about whether they will be judged by family and friends may likely deter parents and caregivers from seeking help if a child exhibits symptoms of ADHD. Alternatively, and in accordance with the findings of Thurston et al. (2017), African American parents and caregivers are likely to seek help from those in their community and not from healthcare practitioners when concerned with their child's behavior.

Interviewer: You have a child who has been diagnosed with ADHD. What was that experience like for you?

Amelia: It was very challenging. For me, being in the field [of social work] and having to go home and do the same thing for my child.... I've always been a person that family and friends have come to but ... now I was the one that was needing the services ... and sometime that also, too was showing up in those spaces and in [healthcare] offices, and they're like "Well, wait. You have this degree and you've been doing this work, and your child is having this experience, and you haven't been able to manage that?"

Interviewer: Do you think ADHD affects Black and White children equally?

Andrea: I don't think it's equally, but I know it's affecting everybody. Black, White, Indian, anybody.... Then you have the Black people who are looking scared because they're going to get an ACS [Administration for Children's Services] case because someone is going to say they did something to their kid [in an effort to discipline them for ADHD related behaviors].

Some parents expressed fear of their child being treated differently in the classroom, "ostracized in school" and by society because of negative associations with ADHD. They viewed an ADHD diagnosis as a life-long label, one that may affect the

child's ability to be successful throughout adolescence and into adulthood. The findings of Bailey et al. (2014) support the finding in this study: African American parents may fear their child being labeled due to an ADHD diagnosis. Similarly, Ohan et al. (2013) reported that parents are often fearful that an ADHD diagnosis will label their child and result in stigmatization. Some participants indicated that a diagnosis of ADHD increased the risk of the child being put into Special Education, an outcome that many participants found extremely concerning. They expressed that some children in Special Education classes, especially children of color, have significantly less access to the resources they need to succeed academically, which makes their academic progress even more challenging.

Ultimately, participants were fearful of their child being "different." While many understood that children with ADHD might go on to be successful, thriving adults, they acknowledged that an ADHD diagnosis creates an additional hurdle. Unfortunately for African American youth, who are already at a disadvantage by the time they first step into a classroom, one additional hurdle could mean the difference between being academically successful and potentially being involved with the justice system.

A few participants saw a caveat with having a child diagnosed with ADHD. One participant in particular expressed that, while she saw some value in having a child diagnosed with ADHD, she thought the diagnosis might come with biases from teachers and other school staff, and while the child may have access to additional services that could allow them opportunities for academic success, school staff might begin to treat the child "a certain way." Similarly, some participants expressed that a lack of qualified teachers was part of the reason they felt African American children, including those who may have had an ADHD diagnosis, are "singled out" and appear more likely to get into trouble in school compared with White children, implying a lack of trust in the ability of teachers and other school staff to treat all students fairly.

This information is invaluable, as it focuses on the views expressed by African American parents and caregivers about a topic that has not been widely discussed. The studies referenced in Chapter II highlighted the need for addressing low diagnosis and treatment rates for African American youth. Participants expressed that some individuals in the African American community may be embarrassed to discuss their child's behavior with family and friends as ADHD and other mental illnesses are highly stigmatized in the African American community. Kendall and Hatton (2002) found that African American families were actually more likely to be stereotyped and stigmatized due to a child's negative behavior. Therefore, participants' fear of stigma is valid and is likely a cause for resistance to treating this disorder and may account for the disparity in ADHD diagnosis and treatment rates for African American youth.

Responses regarding participants' belief that ADHD affects Black and White children equally varied widely. Some participants believed that socioeconomic status affected diagnosis and treatment rates. Clarissa (reflecting on the difference in the quality of schools in a low-income neighborhood, such as her child's school, compared to one in a more affluent neighborhood):

Clarissa: I think that, for example a charter school setting, they give their all into the children's education. Even schools, say [in a more affluent part of New York City], a public school in that area, even though it's not charter, I think they give their all into the children's education. The parents are also involved; it's like teamwork.

Interviewer: Do you mean compared to other schools?

Clarissa: More urban neighborhoods ... [children] will wind up in first grade, second grades, third grade and not know, sitting in a general education class not knowing how to read and write properly.

These findings highlight the view that individuals who had greater access to resources would be diagnosed and treated more often than individuals who did not have such access, which may be dependent on race/ethnicity or socioeconomic status.

Unfortunately, in their communities, there is a lack of resources specifically for African American families. Therefore, African American youth are at increased risk for being adversely affected by the disorder. The results of Hazel-Fernandez et al. (2006) correspond with these conclusions, and they recommended increasing access to resources for the management of ADHD. The term “greatly affected” indicates the belief that ADHD has a larger adverse impact on African American children compared with White children, such as being treated differently in classrooms by teachers and peers or by limiting their ability to succeed through transitions from adolescence into adulthood.

Interviewer: Do you think that ADHD affects Black and White children equally?

Jody (a teacher): That’s a good question. Probably Black people, but then maybe also it depends on their socioeconomic status ... when the parents, they can’t afford to send their child to get treated, they tend to miss out on a lot, so it probably affects them more than those who are able to afford to go to the doctor.

Harvey: I would say no, based on the social economical and culture heritage of the country. Things are not proportional ... people [have] lack of access to care, as you know ... we don’t have access to the same quality education. We don’t have access to the same quality hospital based on the color of skin or where you live.

Natalie: No, I don’t think so.... Because I think Caucasians ... if they are eating healthier would change the person’s behavior. They’re able to do that maybe because they have more money or maybe they just have more knowledge....

Annmarie: Once they are diagnosed, they are treated differently.... Because a lot of times, White kids, ... have a little bit more privilege, where they’re going to different schools, compared to a Black child who has to be in a school, but they don’t have the special privileges, where you can go to a private school to study and everything.

Ruby: No. I would say that [a white child] could have ADHD and get all the resources and techniques that he needs to progress and to be successful, but then [a Black child], on the other hand, won’t get anything or he’ll get put out of the classroom.

Others indicated that African American youth have higher rates of ADHD compared with White youth for several reasons, including educator and healthcare professional bias, highlighting participants' distrust in educators and healthcare professionals. Some participants believed that Black youth were diagnosed and treated at higher rates than White youth because education and medical professionals are more likely to identify certain behaviors of an African American child as ADHD-related behavior, a concept that is likely due to a lack of understanding about the African American community. This view is aligned with the work of DuPaul et al. (2016), who found that symptom report was a function of teacher race/ethnicity and student race/ethnicity. Participants believed that certain education and medical professionals may view specific behavior exhibited by Black children, as behaviors that would indicate that the child should be evaluated for ADHD and that those professionals might not view the same behaviors exhibited by White children in the same way, highlighting potential discrimination by education and healthcare professionals. Individuals in the African American community might view "negative" behaviors exhibited by African American children as normal, which supports Davison and Ford (2001), who reported that African American parents may view ADHD-related behavior as normal or as behavior their child will outgrow. One participant believed that if a Black child and a White child exhibited the same behavior, teachers might be more patient with the White child while choosing to discipline the Black child.

Interviewer: Do you feel like Black and White children are equally affected with ADHD?

Tamia: I feel like Black kids are misunderstood. The ones that are referring the Black kids are not from the same ethnicity, race and it's a lack of understanding there of the child and the culture or the environment that the child is growing up in.

Amelia: No, I don't. I think that young children of color are definitely at a disproportionate rate for being diagnosed with ADHD. Definitely the impact is greater on children of color ... the

consequences and responses to those behaviors go on record. I've done a lot of research on the school-to-prison pipeline.

Madeline: I just think that [teachers] are quicker to label a Black child than they are a White child ... I think that from what I've seen, the first thing that they equate anything with a behavior or anything ... is ADHD ... I think they equate it more with black and Hispanic children.

Similarly, others indicated that cultural differences might affect diagnosis and treatment rates in that “[ADHD] may not be talked about in urban communities.”

Amelia: I think understanding that specifically for young people of color, you have to take in culture. You have to take in environment and those things when thinking about diagnosing and thinking about treatment.

While the research indicates that African American youth are diagnosed and treated less often than White children (Pham et al., 2010), there are perceptions among the African American community that African American youth are actually diagnosed more often than White children, which is supported by Fairman et al. (2017), who found that ADHD diagnosis was 24% more likely in Black youth compared with White youth in 2013. Danielson et al. (2018) indicated that the “proportion of black children who have received an ADHD diagnosis was higher than for white children” (p. 209). This perception, while inconsistent with Coker et al. (2016), who found that African American youth had “lower odds” of having ADHD compared to White youth, may prevent African American parents and caregivers from seeking help if their child is exhibiting ADHD-related symptoms and may be the result of a lack of culturally relevant information about the disorder, a concept that, when addressed according to Locke et al. (2017), might reduce ADHD diagnosis and treatment rates for African American youth. Those perceptions may also be due to families’ long held beliefs about medical professionals; several participants referenced the Tuskegee experiment as a reason not to trust healthcare practitioners.

Interviewer: Do you think that there are some individuals that may lack trust in the system (health-care and education), feel that it was

not designed for people of color or that it has marginalized them? What are your thoughts about those views?

Lucy: Yeah. My take is you're not being looked at as ... you're looked at as "Okay, you told me you have certain symptoms. We're going to give you this and then we're going to send you on your way." Instead of getting to the root of or getting down to what's really going on ... you load me up on a prescription and ... I'm walking out and I'm not well.

Estelle: I don't trust any healthcare system ... the reason why I say that is because they have done the tests on women, children, men for years.... Nobody cared about them.... They say Black people can't feel pain ... they used to perform a test on them and not give them any kind of medication to help with the pain ... because they didn't care.

Paul: If you're the lower class, you get whatever is made available to you. A lot of people don't take advantage of what's available to the lower class, but skepticism passed on over generations.

African American families may not view certain behaviors, such as unsolicited movement in class, as problematic and therefore not seek help, thinking the child will "just grow out of it." Alvarado and Modesto-Lowe (2017) found similar results in their study and discussed barriers to diagnosis and treatment for African American families. Many of the participants in this study described the behavior of boys as "rambunctious," a belief that African American boys have a predisposition to behaviors that may seem characteristic of ADHD, particularly in comparison to individuals of other racial and ethnic groups, but are considered normal in African American homes. However, those behaviors may be compounded as the child grows, widening the achievement gap between them and their peers. It is important to note that education and healthcare professionals must be made aware of these distinctions, as they likely influence the opinions on the behavior of African American youth.

There were some individuals who viewed an ADHD diagnosis as a way to get academic support in the form of testing accommodations such as extra time, an action they didn't view as appropriate in that their child would be given an unnecessary and

potentially hindering label. Overall, participants acknowledged the disparity in diagnosis and treatment rates for African American children compared with White children and the difference in the ways the disorder affected each community, but they indicated that there were many factors that may contribute to the disparity.

In the Health Belief Model, the construct Perceived Benefits states that individuals will likely take a specific course of action only if they recognize the benefit of such action. . The construct can be applied to this study: if parents and caregivers perceive that the outcome of having their child diagnosed will benefit the child and family, then they may be more likely to seek help if they are concerned about their child's behavior. As previously mentioned, although most participants shared various concerns about a child being diagnosed with ADHD and they acknowledged that a diagnosis would likely provide numerous academic, behavioral, and emotional supports, services, and resources for the child and their family, they still expressed apprehension about having their child evaluated, which likely was attributed to a general distrust in the evaluation process.

Some participants expressed that if their child were to be diagnosed with ADHD, they would have the comfort of knowing how best to support the child and how to treat the disorder. For others, it was likely that individuals who interact with their child on a daily basis, such as teachers and peers, might show more compassion and treat the child more kindly and with more patience. Participants believed that an ADHD diagnosis might prevent the child from getting into trouble, as the child would likely be provided with resources and strategies to manage their ADHD symptoms and would also likely be placed in the appropriate setting for their academic needs.

Some participants, including those who had had children diagnosed with ADHD, thought that a diagnosis might provide access to support groups for parents and caregivers and an ability to connect with individuals who would likely share the struggles of having a child with ADHD. These participants saw great value in having a social

support system, as many acknowledged that having a child with ADHD might create a huge “burden” for the parent or caregiver.

Interviewer: Are there any benefits to having a child diagnosed with ADHD?

Clarissa: Yes. If you ... along with getting a diagnosis, the [doctor] gives you resources like counseling, therapy. Also ... associating with other parents who have a child with ADHD.

Interviewer: So like a support group?

Clarissa: Yes!

Jasmine, whose 13-year-old adopted child had been diagnosed with ADHD at 11 years old and who works nights, had begun meeting her child at school in the morning and in the afternoon to ensure that they were taking the prescribed medication. She admitted that it was a major sacrifice but one that is absolutely necessary in order for her child to be successful.

It’s demanding. [ADHD] affects them in school, [parents] are running back and forth to school for disciplinary problems ... [medication] works, if they take it consistently ... [after work] I’ll be sitting at the school in the morning time because I get off at 8:00 [in the morning].

While most participants recognized that if a child exhibited symptoms of ADHD it would be best for the child to be evaluated, diagnosed, and treated, there are valid concerns about the effects an ADHD diagnosis has on the child, including various neurological and other physical effects from medication use, along with the social and emotional effects that may accompany such a diagnosis, especially for African American male youth. These concerns must be acknowledged by education and healthcare professionals, who must then work with African American families to develop strategies for managing childhood ADHD that align with the values and beliefs of the community.

Participants who did not have a child diagnosed with ADHD empathized with such families and recognized that making decisions to determine the best course of treatment for the child must be difficult. Those who have had a child diagnosed with ADHD were

frustrated and shared associated challenges but expressed gratitude for the resources that became available post-diagnosis. It was extremely difficult coming to terms with their child's diagnosis and determining the appropriate methods for treating the disorder, but they ultimately managed those feelings with support from their community and from doctors, whom they trusted.

For the participants who decided to medicate their child as a form of treatment, it was not an easy decision and they believed it was necessary at the time, but they also wished there were alternative treatment options available that were as effective as medications. Participants who shared thoughts on their child's academic progress since being diagnosed indicated that while they were consistently concerned about the effects of medications, they felt conflicted as their child's academic gains were significant.

Interviewer: How do you feel about medication? Do you have any concerns?

Brenda (son has been diagnosed with ADHD and anxiety): In the beginning, I was very against it. He's not going on medicine. [I thought] you're going to ruin him, you're going to mess up his life.... I had to step back and actually take a look at the bigger picture. When we had that final situation when he was going to end up in Bellevue, I had to realize that I'm not helping him ... when we started the medicine, so much changed for him ... he's doing a lot better in school. He's focusing ... he's much happier.

Ultimately, distrust in the healthcare system due to discrimination by healthcare and education professionals was the overarching theme. Participants' concern about the side effects of ADHD medications was connected to their distrust in the ability of healthcare professionals to provide them with safe and effective treatment options. While the benefits of treating ADHD with medication seemed evident, participants were still very conflicted over its use. Individuals are exposed to pharmaceutical commercials promoting medications purporting to treat various debilitating disorders, which come with a long list of side effects likely intensifying participants' feelings of distrust in their

doctors' prognoses. For those who do their research and learn that ADHD can be successfully treated without the use of medication to then be prescribed medication by their child's doctor, even after they have shared their concerns about the potential side effects, they are very likely to have doubts about the intentions of healthcare providers. Many individuals in the African American community feel their concerns and fears are not validated by those in the medical community, feelings that are exacerbated by healthcare practitioners who do not take their patients' opinions and values into account when deciding on appropriate courses of action.

Implications for Practice

The findings from this study highlight the importance of taking steps to eliminate the discrimination African American parents and caregivers may face when seeking help from healthcare and education professionals. This should include improving healthcare practices such that African American families are allowed to be more involved in the evaluation, diagnosis, and treatment of ADHD and educating health and education professionals on the perceptions of African American families related to ADHD diagnosis and treatment. Many participants believed that medications were either the only option for treating ADHD or the only option available for them, as some felt that medical professionals only prescribe medication to African American children and that White children who present similar symptoms are offered non-pharmacological treatment options. Others felt helpless in the diagnosis and treatment process, powerless to the disorder, and unsure how to best support their child. It is possible that by including parents and caregivers from the start and throughout the many steps of the evaluation, diagnosis, and treatment process, they will feel empowered, less apprehensive, and, as a result, more willing to address ADHD-related symptoms as soon as they present to ensure the child receives services and supports as early as possible. This is supported by a

Berger-Jenkins et al. (2012) recommendation that parents and caregivers be a part of the discussion from the very beginning and be educated about various treatment options. Families who feel left out of their child's health evaluations, perhaps due to discriminatory healthcare practices, may find comfort in seeking medical assistance if future practices are inclusive of their values and beliefs. Turner et al. (2015) suggested that "mistrust of providers and fear of coercive treatment" may lead to disparities and that mental health practitioners who were "more culturally competent and acknowledge societal racism" were more effective with minority families (p. 616).

Participants in this study had a lack of information about and felt excluded from ADHD evaluation, diagnosis, and treatment processes; therefore, the following implications for practice should be considered: a need for additional ADHD-related information for parents and caregivers; an increased availability of non-pharmacological treatment options; and elimination of discrimination in treatment and improving culturally appropriate practices.

Additional ADHD-Related Information

Participants, including some who had had a child diagnosed with ADHD, did not know much about the disorder. Coker et al. (2009) indicated that one way to increase the number of African American youth with ADHD who are appropriately diagnosed and treated would be to educate African American families about ADHD and its treatment options.

Interviewer: What information or facts do you know about ADHD?

Nia: Not that much. That it's a disorder and it's usually, I guess, people who aren't able to focus well, so they are diagnosed with that disorder. That's all I know about it.

Maria: Very little ... it's just an assumption when I see it ... some of them [children with ADHD] are restless, they can't sit down.

Adele: I don't have any real information regarding ADHD. Any facts, hard facts? More like assumptions ... that many children suffer from ADHD, meaning they aren't able to focus or children receive medication for not being able to focus in a classroom setting or just large crowds.

Many knew it was a disorder that affected an individual's ability to focus or concentrate on certain tasks; others thought it was a reason why children were hyper in the classroom, and some indicated that it may cause various behavioral and academic issues for the individual with the disorder. Overall, many of the general knowledge responses on ADHD highlighted participants' uncertainty and varied misconceptions about this disorder, which supports the findings of Hillemeir et al. (2007), who suggested an assessment of parents' knowledge and feelings about ADHD.

Interviewer: Have you learned about any of the causes of ADHD?

Helen: I don't know if it's actual. I've heard that the immunization shots sometimes can be causes of certain things....

Estelle (earlier in the interview acknowledged that ADHD was not the same as autism): I don't know the cause, but my theory is maybe the vaccinations that ... we're giving our kids at a young age...it's a full-blown virus being injected inside of you, I guess they call it a lower dose of it, it's still the virus ... I feel like it probably causes the ADHD, probably does something to the wiring of their brains.

Layla: I don't know, but I just know it's like a chemical imbalance in the brain in the sensory area.

Elizabeth: I think now they're saying that it could come from the father where-and I'm not sure, but this was a few years back that I had done the research- the father smoking marijuana and stuff like that.

Tamia: ... the research I've seen and I read up on, some were trying to tie it to the DNA of the father.

Some participants in this study lacked relevant knowledge about ADHD, perhaps simply because they did not have a need for such knowledge; 67% of the sample did not have a child who was diagnosed with ADHD. However for the 13 participants who have

a child diagnosed with ADHD, many felt they were on their own to research the disorder because their practitioners did not provide them with adequate, relevant information. Overall, participants did not have access to enough information. Therefore, increasing the amount of and accessibility to ADHD-related information is essential for African American parents and caregivers.

Interviewer: You said that you have a child who's been diagnosed with ADHD.

Aaron: Right.

Interviewer: Can you share a little about what that was like for you?

Aaron: It was just a lot of uncertainty. What is this about ... I've never gotten one specific explanation as to what it is. It's always like it can be triggered by this or it could be caused by that ... I'm just a little confused by the whole thing.

It is pivotal that all African American parents be informed of the consequences of their children having undiagnosed ADHD, not just those who have children with ADHD, as those consequences may have long-lasting effects on the child's life. What is not known is whether African American parents and caregivers are even aware of those negative outcomes. Therefore, it is essential to educate all African American parents and caregivers on ADHD diagnosis and treatment (Coker et al., 2009), focusing on non-medicinal forms of treatment, and the outcomes for children who are not diagnosed may help reduce the ADHD diagnosis and treatment disparity among this community. Such information should be disseminated in spaces where families feel comfortable discussing their child's behavior and/or academic progress, especially for those who have a child with ADHD—for example, at a community center or other local facility and ideally delivered by individuals who are recognized, considered staples in and have experience working with the community. The goal is not only just sharing this important information with the community, but it being well-received, which is more likely if the

individual delivering the information is part of the community. There is great value in giving back and empowering one's own community.

Non-Pharmacological Treatment Options

Many participants were concerned about the side effects of using medication to treat ADHD and may be more willing to seek help if they were confident that medication would not be “pushed” as the only form of treatment. Similar to a review of literature conducted by Paidipati et al. (2017), there is a gap in the knowledge of minority families' treatment preferences, and minority parents prefer that non-pharmacological treatment methods are presented as an option. This study begins to fill in that gap in knowledge and supports the findings of Paidipati et al. Cummings, Ji, Allen, Lally, and Druss (2017) also indicated that approaches must acknowledge the treatment preferences of minority families, as Black children are more likely than White children to discontinue medication use (Ji et al., 2018). Most participants shared the methods that, in their view, might be helpful for treating ADHD and their views on the use of medication, as that is the most popular method of treatment. Some participants were not aware of alternative methods for treating ADHD, such as the use of behavior management interventions, counseling, or therapy, which, according to Catalá-López et al. (2017), has been found to be the most beneficial non-pharmacological treatment option, with parent and teacher involvement. However, participants who were aware of those methods acknowledged that while they might be effective in managing ADHD, they were time-consuming and required a great commitment on the parts of the parent and the child.

Richardson et al. (2015) conducted a comprehensive review of non-pharmacological treatment interventions for ADHD, and while the authors recommend further research, several methods were found to be effective: the Daily Report Card; behavioral interventions, which include Behavior Parent Training (BPT); social skills training, specifically if implemented at a young age; and peer-tutoring and self-

regulation. However, of the non-pharmacological interventions reviewed, only the Daily Report Card “recorded consistently positive reviews from educators” (p. xxix).

Many participants supported the idea of managing ADHD through diet changes or behavioral interventions, but they did not feel as though such options were available for them. Participants who had a child diagnosed with ADHD felt that medication was their only choice if they wanted to successfully treat their child’s disorder, which led many of those families to distrust the recommendations of their healthcare professionals. Walls et al. (2017) agreed in their report that minority families distrust ADHD medication and might be willing to explore non-pharmacological treatment options. Some of the participants in this study even began to research alternative ADHD treatment methods for their child, a process that was successful for a few families. If African American parents and caregivers are aware of treatment options that do not include medication, which corroborates Pham et al. (2010). who found that minority parents favored non-pharmacological treatment methods, they may be more likely to take action and have their child evaluated and diagnosed. In contrast, their concerns about the side effects of ADHD treatment medications may prevent them from seeking help early on, if at all, which could lead to the child falling behind academically and socially.

Many participants believed that diet plays a role in the treatment of ADHD and thought that by changing a child’s diet, such as decreasing sugar consumption, symptoms of ADHD could be managed. However, the research does not corroborate those perceptions. Cagigal, Silva, Jesus, and Silva (2018) reviewed current treatments for ADHD and found that dietary interventions may not positively affect ADHD symptoms. for ADHD treatment. The results of a birth cohort study by Del-Ponte et al. (2018) suggested no association between sugar consumption and ADHD. The findings of these studies, which contrast the perceptions of the participants in this study, also highlight the need for additional ADHD-related information, specifically about effective non-pharmacological treatment methods.

Discrimination in Treatment and Culturally Appropriate Practices

Many participants felt discriminated against by healthcare and education professionals and that recommended methods for treatment were based on racial and/or ethnic differences. Healthcare and education professionals who share their patients' and students' culture can offer a familiarity that is crucial when working with the African American community, similar to the rapport that was present between the Researcher and this study's participants. Overcoming the inherent distrust for healthcare and education professionals is essential in addressing diagnosis and treatment rate disparities.

Many participants felt that practitioners only prescribe Black children medication, but for White children, practitioners are willing to explore non-pharmacological treatment options, and similar to the findings of Santiago and Miranda (2014), ethnic minorities may be more willing to seek care from providers who share their culture. Additionally, Siegel et al. (2016) found misunderstandings of cultural differences of healthcare professionals, which may affect the diagnosis and treatment of African American youth. Healthcare professionals unaware of the perceptions that some African American families have about the diagnosis process and recommended treatment options may intensify the apprehension of those families. Therefore, minority healthcare and education professionals have a duty to contribute to the knowledge of ADHD, diagnosis, and treatment options in ways that are relevant to their communities so that the information disseminated is well-received. African American parents and caregivers may then feel empowered and willing to seek help for their child's ADHD-related behaviors.

The findings from this study, which are aligned with the findings of Morgan et al. (2013), indicate a need for culturally appropriate practices when evaluating, diagnosing, and treating African American youth considering that participants felt certain education and medical professionals did not understand them. Therefore, African American parents and caregivers would benefit from the development of culturally appropriate evaluation and diagnosis procedures, particularly those that include non-pharmacological treatment

options. There are various cultural nuances that may be misunderstood by non-African American healthcare and education professionals, which can contribute to distrust. For this reason, culturally appropriate practices should be developed, ideally by individuals who are from minority communities that would capture the cultural norms and beliefs of the African American community, which could then be used to inform healthcare and education professionals. This recommendation is supported by Davison and Ford (2001), who agreed that professionals should be trained on how to work with the African American community. Emdin (2011) also recommended that educators learn how to engage African American youth in science classes, a finding that can be applied to other content areas. The author suggested that training involve teachers learning about their students' unique cultures to become "connected to realities of the urban youth experience" (p. 292), which may include traumas that some African American youth are forced to deal with daily and yet expected to suppress while in the classroom. African American students are often expected to behave in accordance with various norms created by non-African American adults who have little experience working with the African American community; however, African American youth carry many different life experiences with them to the classroom, many of which are exclusive to the African American community.

Schools in predominantly African American communities should continue to recruit teachers who reflect their school's demographic. Parents and caregivers may feel that teachers who do not share the culture of their students can misinterpret certain culturally specific behavior exhibited in the class. For example, participants felt that their child's teachers, many of whom do not share their culture, would be more understanding toward a White child exhibiting ADHD-related behavior but not the Black child. Some believed that Black children were more likely to be disciplined for certain behavior and White children would not, a disparity they attributed to cultural differences. This may instill fear in parents and caregivers, who may then not have conversations with their

child's teachers concerning behavior. However, parents may feel that teachers who share their child's culture are more trustworthy, meaning that if teachers disciplined students' inappropriate behavior, parents would not likely attribute that to cultural differences and they may be willing to address some of those behaviors. Additionally, teachers who share their students' cultures are less likely to view certain behaviors as problematic, understanding the implicit cultural norms of the African American community, which might assuage parents and caregivers' feelings of being misunderstood. These feelings are corroborated by DuPaul et al. (2016), who found that in their study, White teachers rated Black students as exhibiting ADHD behaviors more often than White students—although Black students only comprised 12% of the total number of students—and that cultural factors influence teacher rating of ADHD symptoms. By recruiting teachers who reflect the students in certain communities, parents and caregivers may feel less reluctant to discuss concerns about their child's behavior with teachers and other school staff.

Similarly, if practitioners in African American communities were representative of the community, parents and caregivers may be less apprehensive to consult with their healthcare professionals about their child's behavior. It is also essential that healthcare and education professionals who are not representative of the communities they serve receive training on working with African American communities, ideally by individuals who are from such communities, so that they can be made aware of cultural differences and perceptions (Davison & Ford, 2001) and acknowledge and respect their cultural differences (Olaniyan et al., 2007; Pham et al., 2010) and how those difference may affect their practice. It is crucial that healthcare and education professionals be educated by individuals from African American communities on how cultural differences manifest in the classroom. DuPaul et al. (2016) found that cultural factors influence teacher ratings of ADHD; therefore, education on cultural differences may prevent certain behaviors from being misinterpreted as behavior that might warrant an ADHD evaluation.

Implications for Future Research

ADHD diagnosis and treatment rates for African American youth are lower than those of White youth. The research indicates that there may be many factors contributing to the disparity, including perceptions of African American families. This study sought to highlight those perceptions among a sample of African American parents and caregivers with the goal of learning how those perceptions might affect willingness to have a child evaluated, diagnosed, and treated for ADHD. Most participants were concerned about the use of medication to treat ADHD, and that fear of being prescribed medication might prevent them from seeking help. Others did not trust education and healthcare professionals—a distrust that is likely attributed to their perception that only Black children are prescribed medication. Overall, participants were aware of the discrimination that exists in the healthcare and education systems, which also likely affects their willingness to seek help for concerns about their child's behavior.

To further this research, emphasized in this section are key questions, aligned with this study's research questions of learning about the perceptions of African American families and understanding how those perceptions might affect their willingness to have their child diagnosed and treated for ADHD.

First, and most notably, this study highlighted African American families' perceptions about the use of medication to treat ADHD and their concerns with the associated side effects. Future research would benefit from focusing on how to treat African American youth who have been diagnosed with ADHD while respecting the beliefs and values of their parents and caregivers. Addressing and treating ADHD among African American youth is a nuanced process with many contributing factors.

While research indicates that medication is effective in treating ADHD among African American youth (Hazel-Fernandez et al., 2006), African American youth experience medication discontinuity, which Ji et al. (2018) describe as when patients

have inconsistent medication use. This study highlighted African American parents' and caregivers' discomfort with that form of treatment. Therefore, future research should focus on which types of evaluation interventions can be developed, specifically on non-pharmacological treatment methods for African American youth, as this may be a useful strategy in addressing the ADHD diagnosis and treatment disparity.

There was an overall lack of information about ADHD and treatment options among the sample, and participants did not have adequate access to relevant information and/or resources about ADHD, its diagnosis, and treatment. Such information is available; however, the dissemination of relevant and accurate information about ADHD is lacking. An understanding of why this information is not reaching its intended audiences is a major step in addressing ADHD diagnosis and treatment disparities for this community and, therefore, should be a focus for future studies. Improving the dissemination of ADHD-related information may also help reduce the stigma, a perception that was prominent in this study and that exists among the African American community, not only for ADHD but for other mental health illnesses as well. Additional information is needed for African American parents, especially for those who have children with ADHD; therefore, increasing such access within this community is essential in addressing these disparities.

The participants in this study had various misconceptions about ADHD, specifically that ADHD is diagnosed more often in Black children compared with White children; however, it is unclear from where those perceptions arose. Parents and caregivers who believe that African American youth are diagnosed more often are unlikely to seek help for concerns about their child's behavior. Thus, additional research is needed to examine the sources of misinformation and develop resources to provide African American families with accurate knowledge about the disorder.

Second, this study highlights a main factor that may affect African American parents' and caregivers' willingness to have their child diagnosed and treated for ADHD:

discrimination in healthcare and education systems. To address the discrimination that exists and likely affects willingness to seek help, future research would benefit from the following: creating culturally appropriate ADHD diagnostic procedures, and educating healthcare and education professionals on the perceptions of African American families, specifically on the preferred ADHD treatment methods of African American families and on how cultural differences manifest in the classroom.

Participants were uncertain about ADHD and the evaluation, diagnostic, and treatment processes and indicated that the referral procedures may not be sensitive to the cultural differences and norms of their families. Future research would benefit from exploring the source of those uncertainties, as they likely contribute to ADHD diagnosis and treatment disparities for African American youth. Additionally, creating evaluation tools for minority youth (Paidipati et al., 2017), culturally sensitive diagnostic instruments, assessments, and interventions (Alvarado & Lowe, 2017; Flowers & McDougle, 2010; Siegel et al., 2016), culturally appropriate ADHD assessments and treatment options (Jones et al., 2010; Locke et al., 2017), and a system for sharing might help alleviate some of the apprehension African American families feel about the ADHD diagnosis process.

Participants in this study felt that healthcare and education professionals were not aware of the cultural norms of African American families and, at times, felt that their lack of knowledge on those cultural differences resulted in African American youth being unnecessarily referred for ADHD evaluation. For this reason, future studies should investigate the extent to which healthcare and education professionals are educated on how best to work with the African American community and how that translates to ADHD referrals for African American youth.

Finally, this study should be replicated to assess generalizability among the African American community. The results of this study are informative and highlight the perceptions that African American parents and caregivers have about ADHD, which

likely affect their willingness to have a child evaluated and diagnosed with this disorder. Since ADHD screenings depend on the report of symptoms by parents and caregivers, if African American parents are not reporting on their child's ADHD-related behavior for fear of the recommended treatment options, then that child will likely go undiagnosed. The ramifications of not being diagnosed with ADHD for an African American child, especially an African American male, are serious and potentially life-threatening.

Limitations of the Study

As with many studies, this study had several limitations, which included the sample, the Researcher, the reliance on self-report, and the design. Each is discussed briefly below.

The sample was limited to parents and caregivers of boys who attended one after-school program in Central Harlem. Therefore, the results of this study are not meant to generalize and are specific to the study's sample. While the results from this sample may not be generalizable, this sample was drawn from a population that has not been widely studied, yet is greatly affected by ADHD.

A second limitation is the effect of the Researcher on the participants. The Researcher has worked with the children of the participants for over five years, as the children attended the after-school program for which the Researcher was the Program Director. While having worked with the participants and their children for five years has allowed the Researcher to develop a strong rapport with the participants, participants may have experienced ingratiation desirability bias and felt compelled "to provide the right answers" during interviewing. While this may be viewed as a limitation, it was also a potential advantage. The Researcher has worked as an educator with primarily African American youth for over 15 years and is also the child of an African American father. There were many experiences expressed by the participants in this study that the

Researcher could relate to, and her ability to establish rapport with respondents most likely contributed to their willingness to openly share their opinions.

Additionally, this study had a single interviewer, the Researcher, who conducted all of the interviews, collected all of the data, distributed and collected the demographic surveys. This Researcher also conducted all of the data analysis and coding. It is possible that had there been another individual collecting and reviewing data and coding transcripts that alternative perspectives and themes could have emerged.

Nevertheless, the Researcher's connection to the participants and data offered a unique perspective, a major advantage, one that might not have been achieved with a third party who did not have such a rapport with each participant. As mentioned above, the Researcher has interacted with the participants' children for over five year and developed a strong relationship with them through supporting their children's academic progress. Her shared racial and ethnic background also had advantages for the study. It allowed participants the space to share sensitive information and feelings about their family with an individual who understood their personal experiences. This receptivity may not have been accomplished by a researcher who did not share those experiences and/or background or who had not developed their trust over the years. That level of comfort is invaluable.

A third limitation is that all the results were based on self-report. No attempt was made to verify the information provided in the interviews or the demographic data form. This limitation is inherent in the kind of research conducted.

A fourth limitation is that the design was cross-sectional. The data collected reflect participants' responses at one point in time. It is possible that, if the respondents were interviewed over time, the results may have been different.

Final Comments

While ADHD is becoming increasingly prevalent, the number of African American youth who are being diagnosed and treated still falls behind the number of White youth who are diagnosed and treated for this disorder. However, for African American youth who are undiagnosed, ADHD can have long-term impacts, well beyond the child's class and academic performance. African American youth who have ADHD may be more likely to be disciplined by their teachers for disruptive behavior, and those who are not diagnosed may be subjected to even harsher consequences and, as they struggle with behavior management, may be seen as trouble-makers or labeled as "aggressive." Too often African American males are viewed as criminals, views that often begin in their early academic years. African American youth with undiagnosed ADHD may drop out of school and/or end up in the juvenile justice system, at which point social and academic interventions are harder to implement. For the youth who have had unresolved behavior issues since childhood, the trajectory is grim.

It is imperative that steps be taken to address this disparity, so that African American youth can be diagnosed with ADHD and receive the treatment needed for their academic success. As parents and caregivers are usually the first lines of defense in identifying and reporting behavioral concerns to teachers and/or physicians, it is essential that they be included in all stages of the evaluation, diagnosis, and treatment process. However, African American families must feel valued and respected and seen as equals by healthcare and education professionals. Unfortunately, the current study highlights their feelings of uncertainty and struggles with self-doubt, which are likely intensified by discriminatory views and practices.

It is also essential that African American families receive accurate, up-to-date information about ADHD, specifically about the number of African American youth who are diagnosed with the disorder and how those numbers compare to White youth. Their

misconceptions about the rates of ADHD among African American youth are alarming, surprising, and appear baseless, which is especially concerning, as those views likely affect their willingness to have a child evaluated. The participants in this study are hard-working parents and caregivers who truly want to the best for their children, but they need to be given the opportunity to make informed decisions, which cannot happen if accurate, relevant ADHD-related information is not presented thoughtfully. Changes must be made regarding who delivers this information to families. Community members who have developed strong rapport with families will likely be more successful and well-received. Spaces must be created which allow families to discuss their concerns without fear of embarrassment, judgment, or discrimination.

Unfortunately, policy changes alone will not affect disparity rates for African American youth. While Healthy People 2020 aims to increase the number of youth who are treated for ADHD, unless steps are taken to address the discriminatory practices in healthcare described by participants in this study, families will continue to feel apprehensive about seeking help. African American parents and caregivers need educators and practitioners who are representative of the communities in which they live and who can relate to the experiences and struggles of their families.

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Appendix A
Recruitment Flyer



Parents/Caregivers, Participate in a Study about ADHD!

Purpose: We'd like to learn about the opinions of Attention-Deficit Hyperactivity Disorder (ADHD) among African American parents and caregivers of school-age boys.

Compensation: You will receive a \$25.00 VISA gift card and a Metrocard with one round trip ride for completing this study.

Contact Info: Adrienne Evans ae2447@tc.columbia.edu 917-822-7414

Location: Community Center in Harlem, NY

Eligibility: To be able to participate in this study, you must be

- African American
- the parent or caregiver of a boy who is 5-14 years old
- over 18 years old
- able to speak and read English

Activity: You will be asked to

- complete a short survey, that should take approximately 10 minutes to complete, about you, your child and their school
- participate in an interview, that will last about 30 minutes, where you will be asked questions related to ADHD so that we can learn about your opinions.

Start/End Dates: Interviews will begin in (tbd) and will run through (tbd)

*Please note: Participation in this study is voluntary. If you choose not to participate, it will NOT affect any after school or summer camp services that your child receives.

Appendix B

Recruitment Email

Good Morning (Afternoon, or Evening).

Thank you for your expressed interest in our study about parental and caregiver perceptions on Attention-Deficit Hyperactivity Disorder (ADHD).

The interviews for this study will begin approximately on (date) and will end on (date). I'd like to schedule a date and time to conduct your interview.

What is your availability for the week of (date) between 5pm and 7pm?

Thank you so much for your willing to participate in this study and for your contribution to raising the academic achievement of our youth.

Best,

Adrienne Evans
Principal Researcher
Teachers College, Columbia University

Appendix C

Consent Form

Protocol Title: Perceptions of Attention-Deficit Hyperactivity Disorder (ADHD) among African American Parents and Caregivers of Boys Ages 5-14 Years Old
Study Consent

Principal Investigator: Adrienne Evans, Teachers College
917-822-7414 ae2447@tc.columbia.edu

INTRODUCTION

You are being invited to participate in this research study called “Perceptions of ADHD among African American Parents or Caregivers of Boys Ages 5-14 Years Old”. You may qualify to take part in this research study because you are over 18 years old, the parent or caregiver of a male youth aged 5-14, identify as African American and are a native English speaker. Approximately 6 people will participate in this study and it will take about 1 hour of your time to complete (5-10 minutes to complete the demographic survey and 50-55 minutes to complete the interview). Audio recording is an essential part of this research study so that I am able to accurately capture your responses. You can choose whether to give permission to be recorded, however, if you decide that you don’t want to be recorded, you will not be able to participate in this research study.

WHY IS THIS STUDY BEING DONE?

This study is being done to learn about the understanding and opinions of Attention-Deficit Hyperactivity Disorder (ADHD) among African American parents and caregivers of school-age boys.

WHAT WILL I BE ASKED TO DO IF I AGREE TO TAKE PART IN THIS STUDY?

If you decide to participate, you will be interviewed by the principal investigator and will be asked to share your opinions on ADHD. If there are any uncomfortable or personal questions, please mention them. This interview will be audio-recorded and noted. The audio-recording will then be written down (transcribed) and the recording will be deleted. If you do not wish to be audio-recorded, you will not be able to participate. The interview will take approximately 45 minutes. You will be given a de-identified code in order to keep your identity confidential. You will then be asked to complete a questionnaire, which will take about 15 minutes. Both the interview and the questionnaire will take place at the Dunlevy Milbank Center, at a time that is convenient to you.

WHAT POSSIBLE RISKS OR DISCOMFORTS CAN I EXPECT FROM TAKING PART IN THIS STUDY?

This is a minimal risk study, which means the harms or discomforts that you may experience are not greater than you would ordinarily encounter in daily life while taking routine physical or psychological examinations or tests. You may feel embarrassed answering some of the questions or from being recorded. However, you do not have to

answer any questions or divulge anything you don't want to talk about. You can stop participating in the study at any time without penalty. The principal investigator will take precautions to keep your information confidential and prevent anyone from discovering or guessing your identity, such as using a pseudonym instead of your name and keeping all information on a password protected computer and locked in a file drawer.

WHAT POSSIBLE BENEFITS CAN I EXPECT FROM TAKING PART IN THIS STUDY?

There is no direct benefit to you for participating in this study. Participation may benefit the field of education to create culturally appropriate programs and services for examining, diagnosing and working with African American youth who exhibit symptoms of ADHD. Additionally, participation may benefit parents and caregivers of youth exhibiting symptoms of ADHD.

WILL I BE PAID FOR BEING IN THIS STUDY?

You will receive a VISA gift card in the amount of \$25.00 and one Metrocard with one round trip fare for your participation after the survey and interview are both completed. There are no costs to you for taking part in this study.

WHEN IS THE STUDY OVER? CAN I LEAVE THE STUDY BEFORE IT ENDS?

The study is over when you have completed the interview and filled out the survey. You can leave the study at any time even if you haven't finished, however, you will not receive the \$25.00 VISA gift card or the Metrocard.

PROTECTION OF YOUR CONFIDENTIALITY

The investigator will keep all written materials locked in a desk drawer in a locked office. Any electronic or digital information (including audio recordings) will be stored on a computer that is password protected. What is on the audio-recording will be transcribed using a professional transcriptionist and the audio-recording will then be destroyed. There will be no record matching your real name with your pseudonym.

HOW WILL THE RESULTS BE USED?

The results of this study will be published in journals and presented at academic conferences. Your name or any identifying information about you will not be published. This study is being conducted as part of the dissertation of the principal investigator.

CONSENT FOR AUDIO RECORDING

Audio recording is part of this research study. The audio data for this study will be professionally transcribed by a 3rd party. The transcriptionist will be required to sign a nondisclosure agreement form, wherein they agree not to share any information from the study. You can choose whether to give permission to be recorded. If you decide that you don't wish to be recorded, you will not be able to participate in this research study. The risk associated with audio recording may include embarrassment. Should you feel embarrassed while being audio recorded, you may request that the interview be stopped.

_____ I give my consent to be recorded

Signature

_____ I **do not** consent to be recorded

Signature

WHO MAY VIEW MY PARTICIPATION IN THIS STUDY?

I consent to allow written and audio taped materials viewed at an educational setting or at a conference outside of Teachers College

Signature

WHO CAN ANSWER MY QUESTIONS ABOUT THIS STUDY?

If you have any questions about taking part in this research study, you should contact the principal investigator. If you have questions or concerns about your rights as a research subject, you should contact the Institutional Review Board (IRB) (the human research ethics committee) at 212-678-4105 or email IRB@tc.edu. Or you can write to the IRB at Teachers College, Columbia University, 525 W. 120th Street, New York, NY 1002. The IRB is the committee that oversees human research protection for Teachers College, Columbia University.

PARTICIPANT'S RIGHTS

- I have read and discussed the informed consent with the researcher. I have had ample opportunity to ask questions about the purposes, procedures, risks and benefits regarding this research study.
- I understand that my participation is voluntary. I may refuse to participate or withdraw participation at any time without penalty to future services that I would otherwise receive.
- The researcher may withdraw me from the research at his or her professional discretion. For example, if it is determined that I am not being truthful in my responses.
- If, during the course of the study, significant new information that has been developed becomes available which may relate to my willingness to continue my participation, the investigator will provide this information to me.
- Any information derived from the research study that personally identifies me will not be voluntarily released or disclosed without my separate consent, except as specifically required by law.
- I should receive a copy of the Informed Consent document.

My signature means that I agree to participate in this study

Print name: _____

Date: _____

Signature: _____

Appendix D

Interview Guide

Introduction

We will be having a conversation about Attention-Deficit Hyperactivity Disorder (ADHD) among school-aged boys (ages 5-14) and about your experiences as an African American parent or caregiver of a school-aged boy. The goal of our conversation is to learn about your understanding of and opinions on ADHD. I will be taking notes and to ensure accuracy of our conversation I will also be recording this conversation. All of your responses will remain strictly confidential, any information shared today will be used only for the purposes outlined in this study and will not include names or other identifying information.

General ADHD Knowledge

I'd first like to get a sense of what you already know about ADHD.

1. What information or facts do you know about ADHD?
2. What have you learned are the causes of ADHD?
3. Why do you think that some youth are affected with ADHD while others are not affected with it?
4. What are some behaviors or signs that might suggest a child has ADHD?

Perceived Susceptibility:

5. Do you think girls and boys are equally affected with ADHD?
If no, why are some more affected?
6. Do you believe ADHD affects black and white youth equally?
Probe: Why do you think that is so?
7. Do you think ADHD affects youth from different ages equally?
Probe: Which age groups are more/less likely to be affected by ADHD?

Perceived Severity:

8. What do you think are the main consequences for boys that have ADHD? For the family?
9. Do you think youth with ADHD are sometimes treated differently in the classroom?
If yes, in what ways?
10. In what ways does having a child with ADHD affect the life of a parent?

Perceived Benefits and Barriers:

11. Are there benefits of having a child diagnosed with ADHD?
12. Are there any reasons why you think people would avoid getting their child diagnosed?
13. Do you think children who have been diagnosed with ADHD will do better than those who do not get a diagnosis?
Probe: Do you think or believe there are any negative consequences of getting a diagnosis?

Efficacy of treatment

14. Are there effective treatments for ADHD?
Probe: If yes, what are they?
15. What you think about medicine for ADHD?
Do you have any concerns about this?
16. Do you believe that any of the the following would be helpful for youth with ADHD?
Please answer yes or no.
 - Yoga?
 - Meditation?
 - Swimming?
 - Increased daily physical activity?
 - Decreased intake of high sugar foods?
 - Other dietary changes?
 - Medication?
17. Have you ever heard of:
 - Daily Report Card?
 - Cognitive Behavioral Therapy?
 - Homeopathic Treatment?

Closing

18. Some individuals may express concern that once their child is diagnosed with ADHD that they will use the diagnosis as an excuse or a crutch for inappropriate behavior. What do you think about that?
19. Do you think parents of a child with ADHD may have fears of self-rejection i.e. worrying that ADHD is linked to biological (hereditary) factors or that something they did caused their child's ADHD? What are your thoughts about such factors?
20. Do you think that there are some individuals that may lack trust in the system (health-care and education), feel that it was not designed for people of color or that it has marginalized them? What are your thoughts about those views?
21. ADHD has become more common today than in recent years. It has been discussed that health/educational professionals may be over diagnosing youth with ADHD. What

do you think about that? Do you think there may be one group that is overdiagnosed more often than another?

Thank you so much for your time and for sharing your thoughts on a very sensitive topic.

Is there anything else that you would like to share, or that you wished I had asked?

Appendix E

Demographic Survey Items

The following questions are for the purposes of this study only and are intended to collect information in a standardized way. You may skip any question that you do not feel comfortable answering. Your responses will remain confidential.

1. Please indicate which of the following best describes your relationship to the African American male child (or children) aged 5-14 years old:
 - a. Mother
 - b. Father
 - c. Caregiver i.e grandparent, aunt, uncle, foster-parent, sibling, other relative or legal guardian
2. Are you the parent or caregiver of a child who has been diagnosed with ADHD?
 - a. Yes
 - b. No
3. Please select your age range.
 - a. 18-29
 - b. 30-39
 - c. 40-49
 - d. 50-59
 - e. 60-69
 - f. 70-79
4. Which type of school does your child (or children) attend?
 - a. Private or Catholic
 - b. Public
 - c. Charter
 - d. Homeschool
5. Does your child's school provide academic services or support outside of classroom instruction, such as tutoring?
 - a. Yes, there are services or supports outside of classroom instruction
 - b. No, there aren't any services or supports outside of classroom instruction
 - c. I'm not sure
6. How satisfied are you with the experiences you've had with your child's school?
 - a. Very Satisfied
 - b. Satisfied
 - c. Not Satisfied

7. Have you had any conversations with your child's teacher(s) about their academic work or behavior?
- a. Yes
 - i. Have those conversations been helpful?
 - 1. Yes
 - 2. No
 - b. No
8. Has your child's teacher(s) ever recommended ways for you or anyone else to provide your child with academic support?
- a. Yes
 - b. No
9. How many people live in your household that are over 18 years old? Do not include yourself.
- _____ people over 18 years old
10. How many children under the age of 14 years old live in your household?
- _____ children under 14 years old
11. What is your current relationship status?
- a. Married
 - b. Single
 - c. Boyfriend/girlfriend, living together
 - d. Boyfriend/girlfriend, not living together
 - e. Divorced
 - f. Widowed
12. Which best represents your total annual household income?
- a. Less than \$15,000
 - b. \$15,000-\$30,000
 - c. \$30,000-\$50,000
 - d. More than \$50,000

Appendix F

Pilot Survey Data

Survey Question	Participant 1	Participant 2	Participant 3
Mother, father or caregiver	Mother	Mother	Mother
Parent/caregiver of child with ADHD	No	No	Yes
Age range of parent	30-39	18-29	30-39
Years lived in NYC	More than 10	More than 10	More than 10
Languages spoken other than English	No	Yes (Spanish)	No
Type of school child attends	Charter	Public	Private or Catholic
Child's school provides academic support outside of classroom?	Yes	No	Yes
Very satisfied, satisfied, not satisfied with child's school	Not satisfied	Satisfied	Satisfied
Spoken with child's teacher about child's academic work or behavior? Was it helpful?	Yes; No	Yes; Yes	Yes; Yes
Child's teacher suggested methods for academic support	No	No	Yes

Appendix G

Pilot Coding Schemes and Data

Research Question	Analytic Categories (based on HBM)	Concept Codes	Invivo Codes
What are African American parents' and caregivers' understanding of and perceptions on ADHD?	Knowledge	<ul style="list-style-type: none"> -Problematic in classroom -Need resources -Boys over diagnosed 	<ul style="list-style-type: none"> -Big issue in schools -Special way of learning -New diagnosis of ADHD -Different types of ADHD -Genetics causes [ADHD]
	Perceived Susceptibility	<ul style="list-style-type: none"> -Disparity in treatment due to race/ethnicity -Disparity in resources between races/ethnicities -Affected equally across races/ethnicities 	<ul style="list-style-type: none"> -Tend to diagnose boys more -[black kids] treated differently -[white kids] more privileged -No group is singled out -African American boys are treated differently -Consequences are not equal [for all children] -Boys get disciplined more harshly [than girls] -Boys show more symptoms
How, if at all, do those perceptions affects African American parents' and caregivers' willingness to have their child examined for a possible diagnosis with ADHD?	Perceived Severity	<ul style="list-style-type: none"> -Lack of school resources/support -Labeling of boys -Inconvenience/disruption for parents and caregivers -Kids with ADHD not receiving proper services 	<ul style="list-style-type: none"> -[parents must] go [outside of the school] for resources -Parents must decide which child to focus on -Parents may feel guilty

Research Question	Analytic Categories (based on HBM)	Concept Codes	Invivo Codes
	Perceived Benefits & Barriers	<ul style="list-style-type: none"> -Appropriate services, resources, supports -Disputes over using medication as treatment -Diagnosis can mean support 	<ul style="list-style-type: none"> -Parents [must] be extra involved -No diagnosis means not getting the help
What is the basis for the resistance, given parents and caregivers are apprehensive about having their child examined for and diagnosed with ADHD?		<ul style="list-style-type: none"> -Side effects -Addiction -Diagnosis can mean labeling -loss of money due to losing hours at work 	<ul style="list-style-type: none"> -Parents must be more involved -Concerns over how [parent] can help [child] -Parents don't agree with [medication] -It's better [to get diagnosed] It's challenging and hard -Stigma/embarrassing -Parents are in denial; don't see it as a problem -Difference in treatment by therapists

Research Question	Analytic Categories (based on HBM)	Concept Codes	Invivo Codes
	Efficacy of Treatment	<ul style="list-style-type: none"> -Treatment options should be case by case -Self-blame -Certain ethnic groups are offered only certain treatment options -Availability of resources linked to race -Lack of appropriate schools -Different response to similar behavior due to gender -Strain on family -Fear of stigma -Non-traditional learning environment is needed -Mixed feelings about use of medication -Concern that high sugar leads to ADHD -Thoughts of genetics being a cause 	<ul style="list-style-type: none"> -Would like to have [services for ADHD] inside the school -Medication isn't effective all the time -[medication use] takes a toll on the child -People blame the parents first -Doctors may just want to medicate kids of color -Kids of color have a disadvantage -Difficult -Hands-on approach needed for in classroom -Medications can be problematic -Parents shouldn't feel bad