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## Factors Associated with Medication Decision Making in African American Families of Children with ADHD: A Mixed Methods Study

Amy Glasofer

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FACTORS ASSOCIATED WITH MEDICATION DECISION MAKING IN LOW-INCOME  
AFRICAN AMERICAN CAREGIVERS OF CHILDREN WITH ATTENTION-  
DEFICIT/HYPERACTIVITY DISORDER: A MIXED METHODS STUDY

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## **Abstract**

Attention-deficit/hyperactivity disorder (ADHD) is the most common neurobehavioral pediatric disorder in the United States. Pharmacotherapy is a recommended component of treatment for ADHD. While medication treatment of ADHD is not optimized overall, minority groups experience medication treatment disparities. The persistently lower rates of medication treatment in minority groups may have culturally specific origins which cannot be generalized across minorities. The purpose of this dissertation was to assess and extend knowledge regarding medication decision making (MDM) in African American caregivers of children with ADHD. To assess the state of the science on ADHD disparities, a review of 41 descriptive studies exploring the relationship between ADHD diagnosis and/or treatment and race was conducted. The review concluded that despite a trend toward reduction in ADHD diagnostic disparities over time for African American children, medication treatment disparities persist. Next, a literature review was conducted to synthesize what is known about the beliefs of African Americans regarding ADHD diagnosis and treatment, and their experiences of MDM for children with ADHD. Findings from the fourteen articles yielded a preliminary framework describing factors influencing African American caregiver decision making. Factors included fundamental perspectives of ADHD and cultural norms for childhood behavior, the impact of fundamental perspectives on MDM, and ADHD as a form of social control. Subsequently, a sequential exploratory mixed method study was conducted to identify factors associated with MDM in low-income African American families of children with ADHD. Phase 1 comprised a case study of seven low-income African American caregivers of children with ADHD. Phase 2 aimed at validating the qualitative findings through secondary analysis of data from a survey of low-income African American families of children with ADHD. Qualitative themes included child safety and volatility,

caregiver aggravation, caregiver mental health, sole caregiver status, receipt of shared decision making (SDM) and family centered care (FCC), and school involvement. After conducting univariate and multivariate logistic regression analyses, previous receipt of special education services, and receipt of FCC and SDM were independently associated with receiving a medication for ADHD. These findings indicate that clinicians and educators can intervene to improve health equity for children with ADHD.

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## **Dedication**

I dedicate this dissertation to my family- I am here today because of you. Adam, 16 years ago we vowed to “share in each other’s aspirations and empower each other to fulfill our goals and pursue our physical, intellectual, and spiritual potential and dreams”. You have never wavered in your commitment to this promise, seeing in me more potential than I see in myself, stoking the fire of every dream so that I burn brighter. You remain all I need. Mya, I never imagined I would find one of my truest friends in my teenage daughter. Loving you and being loved by you is everything. You make me want to do better and be more, to inspire you to continue charting your own brilliant path, and everyday step into the sun. And Sam, I will forever wonder at the many miracles that made me your mom. You have changed me more than I knew one person could, giving my life new purpose and meaning. You can’t imagine how much you are loved, just as you are. Don’t stop believing!

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## **Chapter 1: Introduction**

This research was conducted to explore and verify factors associated with medication decision making (MDM) among low-income African American caregivers of children with Attention-Deficit/Hyperactivity Disorder (ADHD). The rationale for research, gaps in the literature, aims of the dissertation, and descriptions of the manuscripts are included in this chapter.

### **Rationale for Research**

Healthy People 2020 set the goal to improve mental health by ensuring access to appropriate, quality mental health services (Office of Disease Prevention and Health Promotion [ODPHP], 2019). Specific objectives of this goal are to increase the proportion of children with mental health problems who receive treatment, and to reduce mental health disparities (ODPHP, 2019). Attention-deficit/hyperactivity disorder (ADHD) is one pediatric mental health diagnosis in which both ethnic and socio-economic treatment disparities exist (Cummings et al., 2017). Children from families whose income is less than 100% of the poverty threshold are least likely to receive mental health treatment (ODPHP, 2019). Additionally, though African Americans have similar rates of mental illness compared to the general population, they often receive poorer care and lack access to culturally competent care (American Psychiatric Association [APA], 2017). To date, there is insufficient evidence to inform culturally competent care that can facilitate health equity for African American children with ADHD.

### **ADHD Outcomes**

ADHD is the most common neurobehavioral pediatric disorder in the United States (US). Approximately 9.4% of US children receive the diagnosis, and 8.4% have a current diagnosis (Danielson et al., 2018a). The symptoms of ADHD, primarily inattention, hyperactivity, and

impulsivity, result in significant morbidity for both the child and family. Children with ADHD are 1.3 times more likely to sustain an injury than those without, (Dalsgaard et al., 2015a) and have more than double the risk of death (Dalsgaard et al., 2015b).

Aside from threats to safety, ADHD impacts social and academic achievement outcomes. Compared to typical children, those with ADHD perform significantly lower in overall school functioning including reading and standardized test scores, and have increased absenteeism and grade retention, and lower high-school graduation rates (Barbaresi et al., 2007; Birchwood & Daly, 2012; Wu & Gau, 2013). As children with ADHD progress to adulthood, they experience continued underachievement. They are less likely to enroll in a 4-year college, and more likely to work in entry level occupations, experience long-term work disability, and incur lower lifetime earnings with greater financial dependence on family and the welfare system (Altszuler et al., 2016; Fredriksen et al., 2014; Kuriyan et al., 2013; Voigt et al., 2017). Other related outcomes include increased risk of unintended pregnancy, substance use disorders, criminal convictions, and incarceration (Groenman et al., 2017; Mohr-Jensen & Steinhausen, 2016; Ostergaard et al., 2017).

The child's symptoms also have implications for the family. Parental and family strain are increased, contributing to nearly double the risk for divorce (Laugesen et al, 2016; Wymbs et al., 2008). Furthermore, parents of children with ADHD experience greater healthcare costs, employment absenteeism and turnover, as well as decreased psychological and physical wellness (Kleinman et al., 2009; Lovell et al., 2015).

### **Pharmacotherapy for ADHD**

Guidelines for the treatment of ADHD recommend a combination of behavioral and medication therapies (Wolraich et al., 2019). Behavioral therapies are interventions directed at

changing behaviors, including contingency management, behavior therapy, and cognitive behavior therapy (Catala-Lopez et al., 2017). However, behavioral therapies alone are inferior to pharmacotherapy or combined behavioral and pharmacotherapy (Catala-Lopez et al., 2017; MTA Cooperative Group, 1999). Thus, pharmacotherapy is strongly recommended as a component of treatment for children with ADHD (Wolraich et al., 2019).

Medications for ADHD work primarily by increasing synaptic availability of dopamine and norepinephrine (Faraone, 2018). Approved medications for ADHD are typically categorized as stimulants or non-stimulants. Stimulants include methylphenidate and amphetamines. A variety of medications are available for both classes, offering different preparations such as tablet or liquid, and different formulations such as immediate release, extended release, or combined. In children, both methylphenidate and amphetamines have demonstrated superiority in core symptom relief over placebo based on clinician and child rating, and teacher ratings also support methylphenidate over placebo (Cortese et al., 2018). There is an absence of head-to-head trials; however, meta-analyses demonstrate that amphetamines may be more effective than methylphenidate (Cortese et al., 2018; Padhila, et al., 2018). Still, methylphenidate (long- or short-acting) remains the first-line therapy for treatment of ADHD (National Institute for Health and Care Excellence [NICE], 2018).

### **Pharmacotherapy and ADHD Outcomes**

There is a large body of evidence demonstrating outcomes in support of medication treatment for ADHD. Medication therapy has a protective effect from injury in children diagnosed with ADHD (Ruiz-Goikoetxea et al., 2018). Additionally, academic coursework completion, classroom behavior, on-task behavior, performance on standardized achievement tests and higher education entrance exams improve when individuals with ADHD use

medications (Langberg & Becker, 2012; Lu et al., 2017; Prasad et al., 2013; Scheffler et al., 2009; Shaw et al., 2012). Appropriate stimulant use can also have immediate and long-term protective effects against substance abuse (Chang et al., 2014; Quinn et al., 2017; Shaw et al., 2012), and improved occupational outcomes (Shaw et al., 2012). The child's medication treatment is associated with decreased parental report of child symptoms, and decreased parental occupational absenteeism (Fridman et al., 2017a; MTA Cooperative Group, 1999).

Despite evidence in support of medication treatment for ADHD, only about 62% of children with a current diagnosis of ADHD receive medication (Danielson et al., 2018a). Reasons for caregiver hesitancy to adopt medication treatment for children with ADHD include factors such as a non-physiologic explanation of ADHD symptoms, influence of friends and family, influence of media and other informal information sources, negative experiences of stigma, concerns for side effects, and fears of addiction and abuse (Gajria et al., 2014; Rashid et al., 2018; Ross et al., 2018b; Taylor & Antshel, 2021).

### **ADHD Medication Treatment Disparities**

While medication treatment of ADHD is not optimized overall, African American, Hispanic, and other minority groups experience medication treatment disparities (Bax et al., 2019; Danielson et al., 2018a). There are several points in the medication treatment process at which children can experience disparities. The first events are provider driven and include determination that the individual is a candidate for the drug therapy of interest followed by writing a prescription (Raebel et al., 2013). As for receipt of a prescription, children from ethnic minorities with a diagnosis or symptoms of ADHD are two to five times less likely to be prescribed a medication than their White counterparts (Coker et al., 2016). Subsequent to receiving a prescription, medication receipt becomes family and child driven, expressed as “how,

when, and how much patients take prescribed medications, regardless of how they are prescribed” (Alsalman & Smith, 2013, p. 118). The terms most often used to describe these behaviors include initiation, adherence, persistence, and discontinuation. Initiation is the point at which a patient takes the first dose of medication, adherence is the extent to which a patient’s actual dosing corresponds to the prescribed dosing regimen, discontinuation occurs when the patient stops taking the prescribed medication, and persistence is the length of time between initiation and discontinuation (Vrijens et al., 2012). Concerning these child and family driven outcomes, African American children are more likely to demonstrate low adherence with ADHD medication regimens and gaps in treatment than white children (Faraone et al., 2007; Ji et al., 2018; Palli et al., 2012) and are more likely to discontinue medication within a 300 day period (Cummings et al., 2017, Ji et al., 2018).

The persistently lower rates of medication treatment in minority groups may have culturally specific origins which cannot be generalized across minorities. For example, the role of the male in the household is a uniquely significant factor for Hispanic children (Leslie et al., 2007). Additionally, children from homes where Spanish is the primary language are less likely to receive medication for ADHD than those where English is spoken (Danielson et al., 2018a). This is likely to be a greater factor in treatment disparities for Hispanic children than African American.

The sources for ADHD treatment disparities among African Americans are diverse and relate to social determinants of health (SDOH) and experiences of structural and cultural racism and discrimination. SDOH include individual culture and beliefs along with social, economic, and environmental conditions that can influence an individual’s level of health (National Academies of Sciences, Engineering, and Medicine [NASEM], 2019). Structural racism exists

where laws, policies, and societal practices favor one group while oppressing another (Williams et al., 2019). Cultural racism refers to the larger society's ideology of inferiority and unstated assumptions toward a minority group which manifest as stereotyping, implicit bias, and persistent negative imagery (Williams et al., 2019). Finally, discrimination is where individuals are treated differently resulting in inequitable access, or demonstrate altered physiologic and health behaviors that result from the negative emotions of experiencing discrimination (Williams et al., 2019)

The connections between SDOH or structural racism and ADHD treatment are simpler to illustrate than cultural racism and discrimination. As evidence, children coming from affluent households are 20% more likely to receive medication for ADHD than poor children (Pastor & Reuben, 2005). This intersects with ethnicity, as the average income of an African American household is less than 2/3rds that of non-Hispanic White (White), and African American families are 2.4 times more likely to be living below poverty (Fontenot et al., 2018). Income disparities are multifactorial, likely relating to family composition and education attainment. Based on family composition, African American households are more likely to have a single-income, and African American adults are less likely to obtain advanced degrees (Rostain et al., 2015; United States Census Bureau, 2017). These inequities result from years of structures including policies and laws that serve to oppress African Americans (NASEM, 2021).

Insurance and provider availability are important examples of SDOH driving ADHD treatment disparities. Children without insurance are significantly less likely to receive medication for ADHD than those with public or private insurance (Danielson et al., 2018b). Again, this converges with ethnic disparities as 10.6% of African Americans are uninsured, compared to 6.3% of Whites, and a staggering 26.8% of African American children living in



poverty are uninsured (Fontenot et al. 2018). Finally, culture exerts an influence on the attitudes of African American's towards medical treatment of ADHD. These beliefs are founded in a deep history of mistrust that result in underutilization of healthcare, and specifically mental health services (Rostain et al., 2015). Additionally, only 4% of the psychology workforce is African American (APA, 2018). Mistrust is important, as positive prior experiences with physicians is one of the most significant factors contributing to positive attitudes toward ADHD treatment (Taylor & Anstheil, 2019). Experiences of cultural racism and discrimination will be a focus of this research.

### **Gaps in the Literature**

This dissertation addresses several gaps noted in the literature. First, there is a paucity of research on how to address ADHD treatment disparities. This is because the reasons for ADHD treatment disparities beyond the most evident SDOHs, such as issues of access or health insurance coverage, are poorly understood (Glasofer et al., 2021). The exploration of how cultural racism and discrimination shape the experiences, beliefs and behaviors of African Americans pursuing treatment for their children with ADHD is essential to ensuring ADHD treatment equity. Secondly, the literature has treated African American children as a homogenous group. This approach fails to recognize how the intersection of SDOHs, like race and socioeconomic status together, converge to impact outcomes in ADHD treatment. Moreover, understanding differences between individuals of a similar background who do and do not select medication treatment for their children with ADHD will yield information on barriers and facilitators to MDM. Finally, the literature largely treats MDM as a distinct event with a binary outcome- a child is either on or not on medication for ADHD. Little attention has been paid to the dynamic process of MDM, whereby a prescription is written with a number of decisions that

must follow and may be revisited as a child's ADHD medication treatment status fluctuates over time. Qualitative research is needed to explore MDM as a process in order to measure and promote engagement and family centered care throughout treatment, rather than simply measure treatment initiation. A focus on MDM as a process transcends the traditional view of ADHD medication treatment as a finish line to consideration of ADHD treatment quality. Long-term (> 2 years) and consistent treatment of ADHD reduces the negative impact of ADHD on life functioning (Shaw et al., 2012). Research is needed to better quantify disparities in ADHD treatment adherence and persistence, and test interventions aimed at addressing these disparities and promoting improved treatment quality and duration in minority children.

### **Aim of the Dissertation Project**

The aim of this dissertation was to assess and extend knowledge regarding MDM in African American caregivers of children with ADHD. This aim has three components: a literature review establishing disparities in ADHD medication treatment for African American children with ADHD; a literature review identifying gaps in understanding MDM in African American caregivers of children with ADHD; and the conduct of a mixed-method study to explore and validate factors associated with MDM in low-income African American families of children with ADHD. The implications of identifying factors associated with MDM in this population include providing the knowledge necessary for interventions to achieve health equity for African American children with ADHD.

### **Manuscript Selection**

This dissertation is comprised of three manuscripts focused on ADHD disparities and MDM in low-income African American caregivers of children with ADHD. The first manuscript offers an in-depth review of literature and state of the science on ADHD diagnostic and

treatment disparities. The second manuscript provides a review and synthesis of existing literature on MDM in low-income African American caregivers of children with ADHD. The third manuscript provides a data-based report of the dissertation study that explores experiences of MDM in low-income African American caregivers of ADHD and tests associations resulting from the exploratory inquiry. Therefore, the first manuscripts establish the existence of persistent ADHD treatment disparities in African American children, the second describes current gaps in understanding these disparities, and the final manuscript describes an investigation that addresses the identified gaps.

**Manuscript 1.** The first manuscript is a literature review of ADHD diagnosis and treatment disparities in African American children with ADHD. Though research describing ADHD disparities has been ongoing since the 1990s, no published review of the relevant research was identified. A total of 41 studies were included in this review. Of these studies, 38 were cross-sectional, and three were longitudinal in design. The studies were descriptive in nature, examining the relationship between ADHD diagnosis and/or treatment and various demographic and socio-economic variables. The review concluded that despite a trend toward reduction in ADHD diagnostic disparities over time, medication treatment disparities persist. Identifying the inequity in treatment for African American children with ADHD demands further exploration and development of strategies to address disparities.

**Manuscript 2.** The second manuscript focuses on synthesizing what is known about the beliefs of African Americans regarding the diagnosis and treatment of ADHD, and experiences of MDM in African American caregivers of children with ADHD. Only articles with a primary focus on African American caregivers' perspectives of ADHD medication treatment in children were retained for analysis. The final fourteen articles included seven observational studies, four

qualitative studies, and three mixed methods studies. The manuscript provides a preliminary framework describing known factors influencing African American caregiver decision making. These include fundamental perspectives of ADHD and cultural norms for childhood behavior, the impact of fundamental perspectives on MDM, and ADHD as a form of social control. Critical gaps in understanding these MDM experiences in African American caregivers were identified, mainly understanding MDM as a process, and how experiences contribute to decision making. The manuscripts provide evidence-based recommendations for practice, specifically the provision of family centered care, and approaching medication treatment as an ongoing process. Finally, research priorities include development of culturally sensitive ADHD diagnostic tools, further exploration of the relationship between internalized racism and ADHD MDM, and interventions to overcome mistrust in healthcare providers among African Americans caring for children with ADHD.

**Manuscript 3.** The final manuscript is an exploratory sequential mixed method study of MDM in low-income African American children with ADHD and their caregivers. Phase 1 utilized qualitative methods to conduct a case-study identifying factors associated with a MDM in a sample of low-income African American caregivers of children with ADHD. Phase 2 sought to validate these findings through secondary data analysis of related demographic, health, social, and educational measures in a sample of African American children with ADHD using data from the National Survey of Children's Health (NSCH). The NSCH is a mail- or internet-based survey conducted by the U.S. Census Bureau within the U.S. Department of Health and Human Services covering the 50 states and the District of Columbia. The survey collects information on key indicators of health and well-being for children ages 0-17. Data from the 2016-2019 surveys were utilized. The qualitative themes included child safety and volatility, caregiver aggravation,

caregiver mental health, sole caregiver status, receipt of shared decision making (SDM) and family centered care (FCC), and school involvement. After conducting univariate and multivariate logistic regression analyses, previous receipt of special education services, and receipt of FCC and SDM were independently associated with receiving a medication for ADHD. Findings from this study offer guidance to clinicians and educators interfacing with low-income African American families of children with ADHD, and establish directions for future research in working to achieve health equity for children with ADHD.

## Chapter 2: Manuscript 1

Diagnostic and medication treatment disparities in African American children with ADHD: A literature review

The first manuscript is a review of the literature on diagnostic and medication treatment disparities in African American children with ADHD. This review includes 41 observational studies exploring the relationship between ADHD diagnosis and/or treatment and race. The majority of studies reviewed concluded that African American children were less likely than White children to be diagnosed with ADHD, and African American children with ADHD were less likely to receive a medication. When looking at trends, diagnostic disparities improved over time while medication treatment disparities persisted. The findings indicate that despite more than twenty years of research describing ADHD treatment disparities, interventions have been insufficient to assure health equity for African American children with ADHD.

In September, 2021 this manuscript was published online in the *Journal of Racial and Ethnic Health Disparities*, the leading peer-reviewed journal dedicated to examining and eliminating racial and ethnic health disparities (Springer, 2021). Copyright permission was obtained from the publisher to include this manuscript in this dissertation (Appendix A). Written permission was obtained from the coauthor to include this manuscript in the dissertation (Appendix B).

Glasofer, A. & Dingley, C. Diagnostic and medication treatment disparities in African American children with ADHD: A literature review. *Journal of Racial and Ethnic Health Disparities*. September 14, 2021. DOI: 10.1007/s40615-021-01142-0. Springer Nature.

## **Abstract**

Background: Despite a national focus on achieving health equity, limited attention has been paid to behavioral and pediatric health disparities. As the most common pediatric neurobehavioral disorder, Attention-Deficit/Hyperactivity Disorder (ADHD) provides an opportunity to assess the status of pediatric behavior health disparities. The purpose of this literature review is to provide a synthesis of existing research on ADHD diagnostic and treatment disparities between African American and White children. Methods: Studies were systematically identified through searches in Pubmed, CINAHL, and APA PsycInfo using the terms Attention-deficit/hyperactivity disorder, disparity, race, ethnicity, diagnosis, medication, and treatment. Summary calculations were conducted to report the proportions of studies with statistically significant differences in ADHD diagnosis and treatment between White and African American children, and to describe trends in disparities over time. Results: Forty-one studies were included in this review. The majority of studies identified significant disparities in ADHD diagnosis and medication treatment between African American and White children. While diagnostic disparities show a trend toward reduction over time, a similar trend was not observed in medication treatment disparities. This synthesis provides a critique of the existing literature, and recommendations for practice and future research.

## Introduction

Racial and ethnic health disparities have received considerable attention since the turn of the 21<sup>st</sup> century (Agency for Healthcare Research and Quality [AHRQ], 2003). While Healthy People 2000 initially aimed to reduce health disparities, Healthy People 2020 expanded the goal to “achieve health equity, eliminate disparities, and improve the health of all groups” (HealthyPeople.gov, 2021). As Meyers et al. (2021) wrote, “a lack of health equity underlies these disparities and continues to result in unconscionable differences in patient outcomes” (para. 2). However, limited attention has been paid to behavioral and pediatric health disparities (American Psychological Association [APA], 2017; Flores et al., 2010). Accordingly, the American Academy of Pediatrics (AAP) prioritized advancing both the equity agenda and mental health care for children in 2021 (Hegland, 2021). Similarly, the National Institute of Mental Health’s (NIMH) most recent strategic plan for research includes addressing mental health equity (National Institute for Mental Health [NIMH], 2020). The Institute of Medicine (IOM) (2003) recommended research should explore sources of racial and ethnic disparities, and monitor progress toward elimination of these disparities. Perhaps the best lens through which to view the status of disparity research at the intersection of pediatric and behavior health is attention-deficit hyperactivity disorder (ADHD).

ADHD is the most common neurobehavioral pediatric disorder in the United States (US). Approximately 9.4% of US children receive the diagnosis in their lifetime, and 8.4% report a current diagnosis (Danielson et al., 2018a). The symptoms of ADHD, primarily inattention, hyperactivity, and impulsivity, result in significant morbidity for both the child and family. Shaw and colleagues (2012) reviewed 351 studies, grouping the outcomes of ADHD into categories including academic, antisocial behavior, driving, substance abuse, occupation, service use,



obesity, self-esteem, and social function. They found that 74%, or 244 of these studies reported poorer outcomes in untreated participants with ADHD compared to non-ADHD participants (Shaw et al., 2012). Specifically, individuals with ADHD have more than double the risk of death than those without (Dalsgaard et al., 2015a). Additionally, children with ADHD are two times more likely to sustain an injury (Amiri et al., 2017). Excess mortality and injury rates among individuals with ADHD are driven by accidents and substance abuse (Dalsgaard et al., 2015b).

Regarding academic performance, children with ADHD perform significantly lower in overall school functioning than typical children, including reading and standardized test scores (Barbarese et al., 2007; Birchwood & Daley, 2012; Wu & Gau, 2013). Among children with ADHD, the odds are increased for failure to complete high school (OR = 3.7), expulsion (OR = 3.9), grade retention (OR = 3.64), and suspension (OR = 6.31) (Erskine et al., 2016). As children with ADHD progress to adulthood, they experience continued underachievement. Individuals without ADHD are more likely to enroll in a 4-year college (OR = 6.47), while those with ADHD are more likely to work in entry level occupations, experience long-term work disability, be fired (OR = 3.92), experience unemployment (OR = 1.97) and incur lower lifetime earnings with greater financial dependence on family and the welfare system (Altzuler et al., 2016; Fredriksen et al., 2014; Kuriyan et al., 2013; Voigt et al., 2017).

Social outcomes are impacted as well. The prevalence of ADHD among detained children is estimated to be 41.1%, a five-fold increase compared to the general population (Baggio et al., 2018). There is a two-fold risk for arrest, and three-fold for conviction and incarceration (Mohr-Jensen & Steinhausen, 2016). Childhood ADHD is associated with future substance abuse (Groenman et al., 2017). There are increased odds for substance use disorder

(OR = 1.73), illicit drug use (OR = 2.24) and illicit drug use disorder (OR = 2.57), alcohol abuse (OR = 1.29) and alcohol use disorder (OR = 1.60), and tobacco dependence (OR = 2.41) (Erskine et al., 2016). Finally, compared to others, children with ADHD are significantly more likely to become parents by the age of 16, with nearly a three-fold risk of early pregnancy (Erskine et al., 2016; Ostergaard et al., 2017).

The child's symptoms also have implications for the family. Parental and family strain are increased, including negative experiences of guilt, blame, stigmatization, and exhaustion (Laugesen et al., 2016). This impacts health, psychological, marital, and occupational functioning (Corcoran et al., 2017). Caregivers of young children with ADHD are nearly twice as likely to become divorced (Wymbs et al., 2008). Employed caregivers of children with ADHD have significantly greater healthcare costs, health related absence days, and termination rates than those of children without ADHD (Kleinman et al., 2009). The economic burden also includes costs of accidents and injuries, criminality, healthcare including prescriptions and appointments, replacement of lost items, and prolonged financial dependence (Usami, 2016). Furthermore, parents of children with ADHD experience decreased psychological and physical wellness (Lovell et al., 2015).

Guidelines for the treatment of ADHD recommend a combination of behavioral and medication therapies (Wolraich et al., 2019). Behavioral therapies are interventions directed at changing behaviors, including contingency management, behavior therapy, and cognitive behavior therapy (Catala-Lopez et al., 2017). However, behavioral therapies alone are inferior to pharmacotherapy or combined behavioral and pharmacotherapy (Catala-Lopez et al., 2017; MTA Cooperative Group, 1999). Thus, pharmacotherapy is strongly recommended as a component of treatment for children with ADHD (Wolraich et al., 2019). Medications for ADHD work

primarily by increasing synaptic availability of dopamine and norepinephrine (Faraone et al., 2007). Approved medications for ADHD are typically categorized as stimulants or non-stimulants. Stimulants include methylphenidate and amphetamines (Dupar & Dodson, 2018). A variety of medications are available for both classes, offering different preparations such as tablet, capsule, or liquid, and different formulations such as immediate release, extended release, or combined (Dupar & Dodson, 2018). While treatment recommendations for ADHD include both behavior and pharmacotherapy, this review is focused on medication treatment. Thus, the term treatment will further refer specifically to medication treatment.

There is a large body of evidence demonstrating positive outcomes to support pharmacotherapy for ADHD. In their review, Shaw et al. (2010) found that across all categories of studied outcomes, 72% reported benefits related to pharmacotherapy. With regard to safety, medication therapy has a protective effect from injury in children with ADHD (Ruiz-Goikoetxea et al., 2018). Pharmacological treatment of childhood ADHD corresponds to a 31.5-43.5% reduction in injuries, a 28.2-45.7% reduction in emergency department visits, and a significant reduction in overall hospital contact (Dalsgaard et al., 2015a; Dalsgaard et al., 2014). There is a 38-42% reduction in risk of motor vehicle collision with medication use (Chang et al., 2017). Likewise, pharmacotherapy for ADHD can benefit academic outcomes. Academic coursework completion, classroom behavior, on-task behavior, grade point average, performance on standardized achievement tests and higher education entrance exams improve when individuals with ADHD use medications (Keilow et al., 2018; Langberg & Becker, 2012; Lu et al., 2017; Prasad et al., 2013; Scheffler et al., 2009; Shaw et al., 2012).

Treatment is associated with improved social and family outcomes as well. The odds of substance abuse during treatment for ADHD, and for two- to three-years following treatment, are

significantly reduced with stimulant use (Chang et al., 2014; Goksoyr & Nottestad, 2008; Quinn et al., 2017). Pharmacotherapy also decreases risk for criminality, including police interaction and arrest (Dalsgaard et al., 2014; Goksoyr & Nottestad, 2008). Regarding family function, the majority of parents with children receiving medication for their ADHD were satisfied with symptom control, which was subsequently highly correlated with medication satisfaction (Fridman et al., 2017a). Parental employment absenteeism is reduced when the child is medicated, as is family strain (Fridman et al., 2017b; Silva et al., 2015; Gajria et al., 2014).

Given the evidence in support of pharmacotherapy for ADHD, it follows that a significant body of research has been dedicated to describing the prevalence of ADHD diagnosis, treatment, and patient experiences with treatment. Gajria et al. (2014) conducted a review of medication taking experiences for individuals with ADHD, including 41 studies with reasons for ADHD medication discontinuation, switching, and nonadherence. Rashid et al. (2018b) followed with an updated review of 30 additional studies, and related research continues (Flood et al., 2019; Ross et al., 2018; Taylor & Antshel, 2021). However, no review examined the literature on ADHD prevalence or treatment related to ethnic and racial disparities. This is significant as such a review would allow for a synthesis of the state of the science regarding disparities in ADHD diagnosis and treatment. Moreover, a review could provide necessary guidance for clinical practice and future research. Finally, a review may serve as a proxy for monitoring progress toward eliminating pediatric behavioral health disparities.

ADHD medication and treatment disparities exist across racial and ethnic subgroups; however, causes for disparities vary between races (Bax et al., 2019). For example, Latino children are significantly less likely to be diagnosed with or treated for ADHD than non-Latino (Danielson et al., 2018a). Children from homes where Spanish is the primary language are also

significantly less likely to be diagnosed with or treated for ADHD (Danielson et al., 2018a). Thus, it may be that language spoken at home is a driver of disparities for Latino children, though this would be less significant for African American children. The sources for ADHD treatment disparities among African Americans are diverse (Rostain et al., 2015). Attitudes of African American's towards medical treatment of ADHD symptoms are founded in a deep history of mistrust that result in underutilization of healthcare, and specifically mental health services (Rostain et al., 2015). Additionally, only 4% of the psychology workforce is African American (APA, 2018). Mistrust is important, as positive prior experiences with physicians is one of the most significant factors contributing to positive attitudes toward ADHD treatment (Taylor & Antshel, 2021). Cultural and historical factors render African American children vulnerable to ADHD diagnostic and treatment disparities unique from other minority groups (Bax et al., 2019). Thus, the purpose of this literature review is to provide a synthesis of existing research on ADHD diagnostic and treatment disparities between African American and White children. The objectives of this review are threefold: (a) to summarize the evidence describing diagnostic and medication treatment disparities between African American and White children; (b) to explore potential causes for variations in findings; and (c) to view the reporting of disparities over time as a report on the progress of eliminating ADHD disparities.

## **Methods**

### **Study Search, Retrieval, and Selection**

Studies were systematically identified through searches in Pubmed, CINAHL, and APA PsycInfo. Relevant articles referenced in studies identified through database searches meeting the inclusion criteria were also reviewed. Search terms included Attention-deficit/hyperactivity disorder, disparity, race, ethnicity, diagnosis, medication, and treatment. Database searches were

limited to research published prior to March, 2021. Studies were included or excluded based on the following criteria:

Inclusion Criteria:

1. Published in English
2. Published in a peer-reviewed journal
3. Participants limited to children as defined by each publication.
4. Quantitatively reported ADHD diagnostic or medication treatment disparities between White and African American children and included a measure of statistical significance
5. Could be retrieved through university library services

Exclusion Criteria:

1. Published in a foreign language
2. Non-peer reviewed papers
3. Qualitative research or secondary sources
4. Epidemiological reports racial disparities in ADHD diagnosis or treatment without a measure of statistical significance

The initial search, based on the stated search terms, yielded a significant number of articles (3563) and was reduced to 1466 once duplicates were removed, including duplicate descriptions that were clearly the same study. Those records were then further screened for relevance based on the inclusion and exclusion criteria, resulting in 77 articles. After a more detailed review of the 77 articles, 36 were excluded as they did not include sufficient race comparisons, lacked a focus on ADHD prevalence/treatment, combined ADHD with other diagnoses so that it was

indistinguishable, and lacked a measure of statistical significance. The final composite of articles (41) was included in this literature synthesis. (Figure 1).

### **Data Extraction and Summary Measures**

The main findings and outcomes were compared across studies. Summary calculations were conducted to report the proportions of studies with statistically significant differences in ADHD diagnosis and treatment between White and African American children. The authors conducted group discussions to draw inferences from the data regarding the overall results of the synthesis, trends that could possibly explain variations in individual study findings, and trends in disparities over time. Discussion and review of the primary sources continued until consensus was reached and the findings of the review were confirmed. Data extracted from each study included sample and setting, measure of ADHD diagnosis and medication treatment, difference in diagnosis or medication treatment between White and African American subjects. Odds ratios (OR), adjusted odds ratios (AOR), prevalence ratios (PR), and p values are reported to summarize the association and significance between race, and diagnosis or treatment.

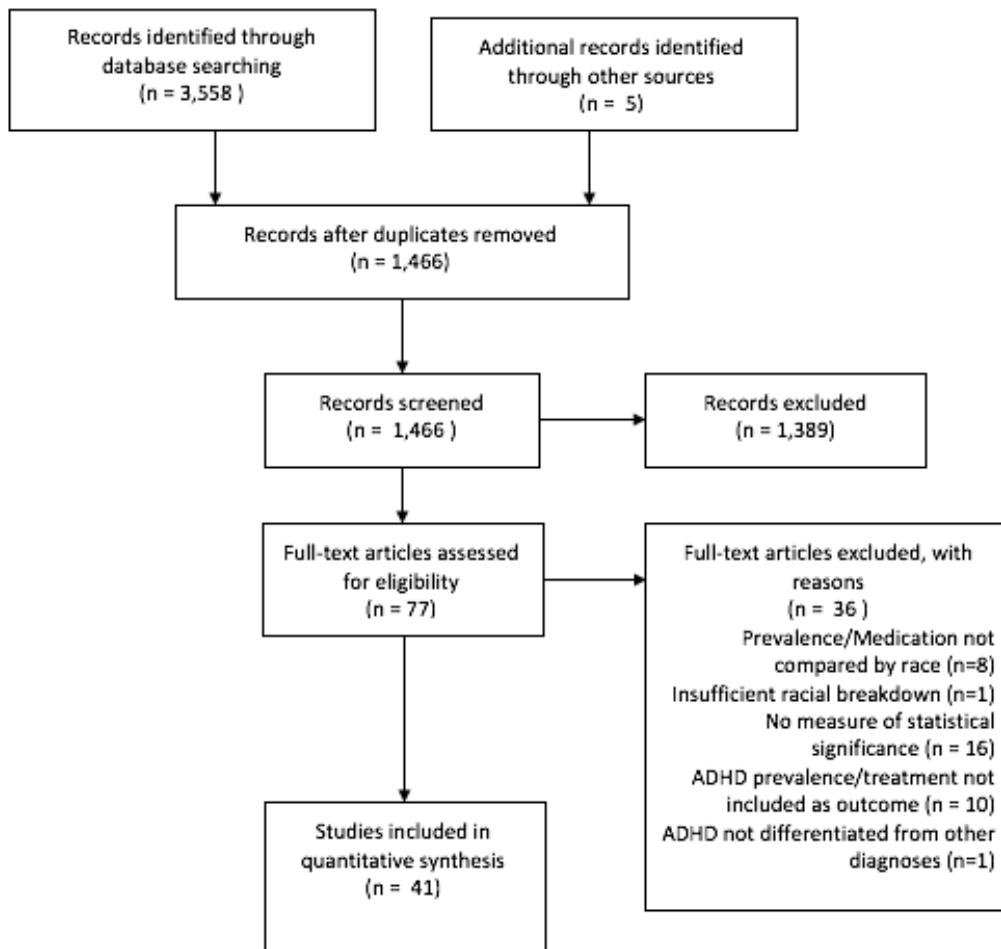
### **Results**

A total of 41 studies were included in this review (Figure 1). Of these studies, 38 were cross-sectional (Table 1), and three were longitudinal in design. The studies were descriptive in nature, examining the relationship between ADHD diagnosis and/or treatment and various demographic and socio-economic variables. For the purposes of this review, independent variable data extraction was limited to race (African American and White). Sample sizes ranged from 242 children to 304,951, with some studies providing annualized and population estimates. Participants ranged in age from 0-22, with 18 (44%) studies limited to children between the ages of 6 and 18. Most studies (24, 59%) included nationally representative samples, while six (15%)

represented single or multi-state level data and 11 (26%) drew local or regional samples. Among the studies reporting racial breakdown of the sample (n = 32), thirteen (41%) approximated similar proportions of African American and White children compared to 2019 national data (Annie E. Casey foundation, 2019). African Americans were overrepresented by at least 10% in eleven (34%) samples and underrepresented by at least 5% in two (6%) samples. White children were overrepresented by at least 20% in 6 (19%) samples and underrepresented by at least 20% in 4 (13%) samples.

**Figure 1**

*Search Flow Diagram*





**Table 1***Diagnostic and Medication Disparities between White and African American Children with ADHD*

Source	Sample/ Setting	Measures	Prevalence Findings	Medications Findings
Anderson et al. (2015)	Children age 2-21 N = 1,778 60.7% White, 18.4% African American, 20.9% Hispanic Nationally representative data from the Medical Expenditure Panel Survey (MEPS) from 2008-2011.	Parent report of child with outpatient visit for ADHD Parent report of stimulant or alpha-2 agonist for child		No significant association between medication receipt and race/ethnicity
Baumgardner et al. (2010) [2005] <sup>\$</sup>	Children age 5-17 N = 50,463 28.5% White, 4.5% African American, 3.1% Hispanic, 1.7% Other, 62.3% Unknown Primary care clinics from a system serving eastern Wisconsin from 2004-2006	ICD-9 Diagnosis of ADHD	African American children were less likely than White children to be diagnosed with ADHD (10.6 vs. 17.3%)*** (OR 0.55)	
Bax et al. (2019)	Children age 4-12 N = 1,068 children 51.3% White, 28.6% African American, 10.4% Hispanic, 9.6% Other One school district in South Carolina and 6 school districts in Oklahoma	Vanderbilt ADHD Diagnostic Teacher Rating Scale Parent report of child with ADHD diagnosis or medication Parent interview	African American children were less likely than White children to be diagnosed with ADHD (OR 0.47)*. No significant differences	African American children were less likely to be receiving a medication for ADHD (OR 0.43)*

Source	Sample/ Setting	Measures	Prevalence Findings	Medications Findings
			in ADHD prevalence between races based on teacher ratings.	
Coker et al. (2009)	Children in 5 <sup>th</sup> grade N = 5,147 3 urban areas in the US Baseline data from longitudinal study	Parental report of child with ADHD symptoms based on Diagnostic Interview for Children Predictive Scales Parent report of child mental health care utilization	African American parents were more likely to report symptoms of ADHD for their children than White parents (14% vs. 10%) (OR 1.4)** African American children with ADHD symptoms were less likely to use mental health care than White children (49% vs. 20%) (OR 0.3)***	
Coker et al. (2016) [2005 <sup>S#</sup> , 2007 <sup>#</sup> , 2010 <sup>S#</sup> ]	Children in 5 <sup>th</sup> grade N = 4,297 22.1% White, 29.1% African American, 44.4% Latino, 4.4% Other 3 timepoints (5 <sup>th</sup> , 7 <sup>th</sup> , and 10 <sup>th</sup> grade) from 3 urban areas in the US.	Parent report of child with ADHD symptoms based on Diagnostic Interview for Children Predictive Scales Parental report of child with physician diagnosis of ADHD. Parent report of child taking medication for overactivity, hyperactivity, or difficulty paying attention.	African American parents more likely to report child with ADHD symptoms at all time points (5 <sup>th</sup> grade 12% vs. 7%, 7 <sup>th</sup> grade 11% vs. 6%, 10 <sup>th</sup> grade 13% vs. 9%). African American children less likely to be diagnosed with ADHD in 5 <sup>th</sup> grade (OR 0.54)*** and 10 <sup>th</sup> grade (OR 0.46)***	African American children with a diagnosis/symptoms of ADHD were less likely than White children to receive medication for ADHD at all time points (5 <sup>th</sup> grade AOR 0.43***, 7 <sup>th</sup> grade AOR .41***, 10 <sup>th</sup> grade AOR 0.44***)
Collins & Clearly (2016)	Children age 5-17 N = 190,409	Parent report of child with	African American children	

Source	Sample/ Setting	Measures	Prevalence Findings	Medications Findings
[2011] <sup>\$</sup>	58.2% White, 14.2% African American, 18.9% Hispanic, 8.3% other Nationally representative data from National Surveys of Children's Health (NSCH) from 3 years (2003, 2007, 2011)	physician diagnosis of ADHD.	were less likely than White children to be diagnosed with ADHD (AOR 0.62)*	
Cuffe, et al. (2005)	Children age 4-17 N = 10,255 64.5% White, 15.1% African American, 16% Hispanic, 4.5% other Nationally representative data from the 2001 National Health Interview Survey (NHIS)	Parent report of child with ADHD symptoms based on the Strengths and Difficulties Questionnaire	African American parents were more likely than White parents to report clinically significant symptoms of ADHD, though the difference was not statistically significant (5.65% vs. 4.33%)	
Cummings, et al. (2017)	Nationally representative sample of children age 6-12 N = 172,322 47.9% White, 30.9% African American, 14.4% Hispanic, 1% Other, 5.9% Unknown Medicaid data from 2008-2011	ICD-9-CM diagnosis of ADHD on 2 distinct visits Prescription for ADHD medication filled Medication discontinuation-medication fills for <210 of 300 days		African American children were more likely to discontinue medication compared to White children (72.7% vs. 49.8%)***
Danielson et al. (2018a) [2016] <sup>\$#</sup>	Children age 2-17 N = 45,736 77.6% White, 6.2% African American, 16.3% Other	Parent report of child with healthcare provider current and lifetime diagnosis of ADHD	In weighted prevalence estimate, African American children were more likely than White	No statistically significant difference in a medication for ADHD between African

Source	Sample/ Setting	Measures	Prevalence Findings	Medications Findings
	Weighted national prevalence based on data from 2016 NSCH	Parent report of child currently taking medication for ADHD	children to have a current (PR 1.27)* or lifetime (PR 1.27)* diagnosis of ADHD	American and White children (PR 0.98)
Danielson, et al. (2018b) [2014] <sup>#</sup>	Children aged 4-17 N = 2,495 71.7% White, 16.2% African American, 12.1% Other Data from 2011-2012 National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome study	Parental report of child with physician diagnosis of ADHD. Parental report of child's lifetime and current medication treatment for ADHD		No significant difference in percent of children currently receiving medication for ADHD (69.2% of White, 61.6 of African American children) (OR .89) More White children had received medication in their lifetime compared to African American children (93.3 vs. 83.3%)* (OR .89)
Davis et al. (2020) [2017] <sup>\$</sup>	Children age 2-5 N = 2,397 76.1% White, 10.5% African American, 3% Hispanic, 10.3 other or missing Kentucky Medicaid claims from 2017	ICD-10 diagnosis of ADHD National drug code (NDC) for treatment with alpha-2 agonist or stimulant	African American children were less likely to be diagnosed with ADHD than White children (OR 0.76)***	There was no difference in receipt of stimulant medication (OR .8), or combination of stimulant plus alpha-2 agonist (OR .71) African American children were less likely to receive an alpha-2 agonist alone (OR 0.36)***
Davis et al. (2021) [2017] <sup>\$\$</sup>	Children age 6-17 N = 304,951 76% White, 14.2% African	ICD-10 diagnosis of ADHD NDC for treatment with stimulant	After accounting for confounding variables, African American children were less likely	African American children were less likely to receive a stimulant

Source	Sample/ Setting	Measures	Prevalence Findings	Medications Findings
	American, 6.7% Hispanic, 3.1% other Kentucky Medicaid claims from 2017		to be diagnosed with ADHD than White children (AOR 0.71)*	than White children (AOR 0.68)*
Froelich, et al. (2007) [2003] <sup>\$\$</sup>	Children age 8-15 N = 3,082 29.4% White, 33.3% African American, 30.1% Mexican American, 7.2% Other National Health and Nutrition Examination Survey 2001-2004	DSM-IV ADHD diagnosis Parent report of child with ADHD symptoms and medication use based on Diagnostic Interview Schedule for Children- IV (DISC-IV)	African American children were less likely than White children to be diagnosed with ADHD in the past year (AOR 0.7)*, and less likely to be diagnosed with inattentive type (AOR 0.4)*, or hyperactive- impulsive type (AOR 0.6)*. No statistically significant difference between groups in diagnosis with ADHD combined type (OR 1.6). Overall African American children were less likely than White children to be diagnosed with ADHD (OR 0.8)	African American children were less likely to receive ADHD medication treatment in the past year (OR 0.7)* There was no significant difference between groups in taking medication for most of the past year.
Hudson et al. (2007) [2001] <sup>\$\$</sup>	Children aged 5-17 N = 19,115 person-years 48.2% White, 18.8% African American, 32.9% Hispanic Nationally representative data from MEPS from 2000-2002	Parent report of child with ADHD diagnosis Parent report of medication purchases for child Pharmacy component of MEPS including NCD data.	African American children were less likely than White children to be diagnosed with ADHD (2.8% vs. 5.8%)* (OR 0.48)	African American children were less likely than White children to receive stimulants (2.8% vs. 5.1%)* (OR .55)

Source	Sample/ Setting	Measures	Prevalence Findings	Medications Findings
Ji et al. (2018)	Children age 6-12 N = 102,669 47.8% White, 32.1% African American, 13.7% Hispanic, 6.5% other/unknown Medicaid claims from 9 states from 2008 to 2010	Medicaid records with ICD-9-CM diagnosis of ADHD on 2 distinct dates Prescription fill for ADHD medication Patterns of medication treatment: continuous = fills for at least 210 medication days/300, early termination, or medication gaps of at least 14 days with reinitiation		Compared to White children, African American were less likely to receive continuous medication treatment (27% vs. 49.6%)***, and more likely to experience early termination (14.6% vs. 11.6%)***, 2 gaps in treatment (22.3% vs. 15.6%)*** and 3 or more gaps in treatment (32% vs. 18.9%)***
Johansen et al. (2015) [2008]#	Children age 12-17 N = 11,343 58.2% White, 15.1%, African American, 18.9% Hispanic, 8.5% Other MEPS data from 2003-2012	Participant report of amphetamine, methylphenidate or atomoxetine prescription followed by pharmacy confirmation		African American children were less likely than White children to be taking a medication for ADHD (OR 0.53)***
Jonas et al. (2013) [2008]#	Children age 12-19 Population based estimate Nationally representative data from National Health and Nutrition Examination Survey data from 2005-2010	Participant report of medication used in previous month classified as treatment for ADHD by NDC		African American children were less likely than White children to receive medication for ADHD (2.2% vs 4%)* (OR .55)
Kamimura-Nishimura et al. (2019)	Children in grades 1-5 N = 577 patients 62% White, 38% non-White	ADHD medication prescribed within one year of ADHD-related contact		Child race was not significantly associated with ADHD medication prescription

Source	Sample/ Setting	Measures	Prevalence Findings	Medications Findings
	Children referred for ADHD symptoms from 50 pediatric practices in central and northern Ohio			
Karnik et al. (2010) [1999] <sup>\$</sup>	Youths age 13-22 N = 790 17% White, 28% African American, 47% Hispanic, 8% other Juveniles admitted to California Division of Juvenile Justice October 1997 – June 1999	Diagnostic Interview for Children and Adolescents (DICA)	No statistically significant difference in ADHD between African American and White boys (6% vs. 13%) (OR 0.46) African American girls were significantly less likely than White girls to be diagnosed with ADHD (10% vs. 34%)** (OR 0.29) Overall African American children were less likely than White children to be diagnosed with ADHD (OR 0.36)	
LeFever, et al. (1999) [1996] <sup>#</sup>	Children in grades 2-5 N = 27,910 66.2% White, 33.8% African American Children enrolled in two public school districts in southeastern Virginia	ADHD medication administration by school nurse during school hours		African American children were less likely than White children to receive medication for ADHD (OR 0.45-0.48***)

Source	Sample/ Setting	Measures	Prevalence Findings	Medications Findings
Lingineni et al. (2012) [2008] <sup>§#</sup>	Children age 5-17 N = 68,634 56.8% White, 14.9% African American, 19.8% Hispanic, 8.5% Other Weighted national prevalence based on data from NSCH 2007-2008	Parent report of child with healthcare provider diagnosis of ADHD Parent report of child taking medication for ADHD	African American children were less likely than White children to be diagnosed with ADHD (OR 0.72)*	African American children with ADHD were less likely to receive a medication for ADHD than White children but the difference was not statistically significant (OR 0.74)
Lipkin et al. (2005)	Children age 4-19 N = 242 44.6 White, 52.9% African American, 2.5% other Children from an urban referral center on a stable dose of stimulant for at least 6 months	Medical record review for prescription information		African American children with Medicaid received significantly lower stimulant doses than non-African American children with Medicaid (30mg/day vs. 39.9mg/day)*** African American children with private insurance received significantly higher stimulant doses than non-African American children with private insurance (35.6mg/day vs. 30.1mg/day)**
Merikangas et al. (2011) [2003] <sup>§</sup>	Children age 13-18 N = 10,148 65.6% White, 15.1% African American, 14.4% Hispanic, 4.9% other Nationally representative	Interview conducted using World Health Organization Composite International Diagnostic Interview 3.0, based on	African American children were less likely than White children to be diagnosed with ADHD (AOR 0.58)*	



Source	Sample/ Setting	Measures	Prevalence Findings	Medications Findings
	data from National Comorbidity Survey-Adolescent	DSM-IV criteria for ADHD		
Morgan et al. (2014) [2006] <sup>\$#</sup>	Children age 5 N = 6,550 53.7% White, 13.9% African American, 25.1% Hispanic, 7.2% Other Nationally representative data from the Early Childhood Longitudinal Study- Birth Cohort	Parent report of child with physician diagnosis of ADHD Parent report of child taking medication for ADHD	African American children were less likely than otherwise similar white children to receive ADHD diagnosis (OR 0.30**-0.72 depending on model covariates). No differences between teacher rating of behaviors displayed across races.	African American children were less likely to be taking stimulants than White children, but the difference was not statistically significant (30% vs. 40%) (OR 0.75)
Morgan et al. (2013) [2003] <sup>\$#</sup>	Children followed from kindergarten to 8 <sup>th</sup> grade N = 17,100 57.3% White, 15.7% African American, 19.3% Hispanic, 7.6% Other Nationally representative data from the Early Childhood Longitudinal Study- Kindergarten cohort	Parental report of child with diagnosis of ADD, ADHD, or hyperactivity Parental report of child taking medication for ADD or ADHD or hyperactivity	African American children were less likely to be diagnosed with ADHD (OR 0.31-0.64 depending on model)***.	African American children were less likely than White children to receive a medication for ADHD (OR 0.35)***
Palli et al. (2012)	Children age 6-19 N = 46,135 Medicaid claims data from 4 states for 2003-2005	At least one visit with ICD 9 Clinical Modification (ICD-9 CM) code for ADHD Initiation of stimulant therapy during study period		Persistence across 3 types of stimulants was significantly lower among African American children compared to White

Source	Sample/ Setting	Measures	Prevalence Findings	Medications Findings
		Persistence = consecutive stimulant refills without a 30 day gap in treatment Analyzed by stimulant action: short-acting stimulant (SAS); intermediate-acting stimulant (IAS); long-acting stimulant (LAS)		children (SAS 17%, IAS 12%, LAS, 15%)*
Pastor & Reuben. (2005) [1999] <sup>\$</sup>	Children age 6-11 N = 20,401 55.3% White, 17.5% African American, 27.2% Hispanic National Health Interview Survey 1997-2001	Parental report of diagnosis of ADHD or ADD with or without a learning disability (LD)	African American children were less likely than White children to have diagnosis of ADHD without learning disability (LD) (OR 0.40). No significant difference in ADHD with LD between African American and White children (4% vs. 3%). Overall African American children were less likely than White children to be diagnosed with ADHD (OR 0.82)	
Rowland et al. (2002) [1998] <sup>\$\$</sup>	Children in grades 1-5 N = 6,099 72.7% White, 19.8%	Parent report of child with ADHD diagnosis Parent report of child	No significant difference in ADHD diagnosis between White and	African American children were less likely than White children to

Source	Sample/ Setting	Measures	Prevalence Findings	Medications Findings
	African American, 6.2% Hispanic, 1.3% other 17 public elementary schools from single county in North Carolina	taking medication to treat ADHD symptoms	African American children (OR 0.9)	be receiving medication for ADHD (OR 0.7)***
Saloner et al. (2013)	Children age 3-17 N = 33,099 (1996); N = 63,276 (2004) 1996: 48% White, 31% African American, 21% Hispanic; 2004: 40% White, 24% African American, 36% Hispanic Florida ADHD related Medicaid claims	Medicaid records with ICD-9 diagnosis of ADHD on 2 distinct dates within one year Prescription fill for at least one ADHD medication		White children were more likely to receive medication than African American children in both time periods ***
Siegel et al. (2016) [2011] <sup>\$</sup>	Children age 3-17 N = 133,091 annualized estimate based on 32,047 records 41.2% White, 24.1% African American, 34.7% Hispanic 2011 New York State (NYS) Office of Mental Health biennial one-week Patient Characteristics Survey- children receiving care in the NYS public mental health system	Medical record with DSM-IV-TR diagnosis of ADHD	African American females were more likely than White females to be diagnosed with ADHD (aOR 1.2)***, as were males (aOR 1.17)*** Overall African American children were more likely than White children to be diagnosed with ADHD (OR 1.14)	

Source	Sample/ Setting	Measures	Prevalence Findings	Medications Findings
Stein et al. (2012)	Children age 6-12 N = 2,077 48% White, 32% African American, 20% other Claims from a Medicaid managed behavioral health organization in a mid-Atlantic state for children beginning ADHD medication treatment between October 2006 and December 2007	Pharmacy data indicating treatment with an ADHD medication Receipt of community-based mental health services for ADHD		African American children were more likely to initiate psychosocial treatment alone than medication treatment alone compared to White children (AOR 1.80)***
Stevens et al. (2004) [1998]§#	Children age 3-11 N = 26,441 76% White, 12% African American, 12% White Nationally representative sample of primary care visits from 1995-2000	Physician diagnosis of ADHD using International Classification of Diseases, 9 <sup>th</sup> Revision Prescription of a stimulant medication	African American children were less likely to receive a diagnosis of ADHD (OR 0.62); however, this difference was not statistically significant	African American children were less likely to be prescribed a stimulant (OR 0.69); however, this difference was not statistically significant
Stevens et al. (2005a) [1999]§#	Children age 3-18 N = 27,802 67.4% White, 16.5% African American, 16.1% Hispanic 1997-2000 MEPS data	Outpatient visit for ADHD Number of children reported ever taking a stimulant Annualized number of stimulant prescriptions for children taking a stimulant at least once	African American children were less likely than White children to be diagnosed with ADHD (2.1% vs. 5.1)* (OR 0.41)	African American children with ADHD were less likely to receive at least one stimulant prescription than White children with ADHD (60.5 vs. 76.5)* (OR 0.79)
Stevens et al. (2005b)	Children age 3-18 N = 15,167 2000-2001 MEPS data	Parent report of short-acting vs. long-acting stimulant medication		There were no differences between groups in taking a short-acting vs. long-acting stimulant

Source	Sample/ Setting	Measures	Prevalence Findings	Medications Findings
Visser et al. (2007) [2003] <sup>§#</sup>	Children age 4-17 Weighted national prevalence based on data from NSCH 2011	Parent report of child with current ADHD diagnosis Parent report of child ever having ADHD diagnosis Parent report of child taking medication for ADHD	No significant difference in current or lifetime diagnosis of ADHD between African American and White children (OR 0.98)	African American children with ADHD were less than White children likely to receive a medication (OR 0.8)*
Walls et al. (2018) [2014] <sup>#</sup>	Children age 8-17 N = 2401 63.1% White, 14.3% African American, 15.5% Hispanic, 7.1% other National representative data from 2014 National Survey of the Diagnosis and Treatment of Attention Deficit/Hyperactivity Disorder and Tourette Syndrome	Parent report of child taking medication for ADHD		No significant difference in current receipt of medication for treatment of ADHD between African American and White children (OR 0.65). African American children were less likely to report ever taking a medication for ADHD (OR 0.3)*.
Wasserman, et al. (1999)	Children age 4-15 N = 22,059 401 pediatric practices from 44 states, Puerto Rico, and 4 Canadian provinces	Physician report of child with attention deficit/hyperactivity problems via post-visit questionnaire	There was no difference in physician report of attention deficit/hyperactivity problems between White and African American children	
Xu, et al. (2018) [2016] <sup>§</sup>	Children age 4-17 N = 186,457 49% White, 15.5% African	Parent report of child with physician diagnosis of ADHD	In 2016, African American children were more likely than White children to be diagnosed	

Source	Sample/ Setting	Measures	Prevalence Findings	Medications Findings
	American, 27.5% Hispanic, 8% other Nationally representative data from National Health Interview Survey 1997-2016		with ADHD, however the difference was not significant (12.8% vs. 12%) (OR 1.07).	
Zablotsky, et al. (2019)  [2013] <sup>\$</sup>	Children age 3-17 N = 88,530 National Health Interview Survey 2009-2017	Parent report of ADHD	African American children were less likely than White children to be diagnosed with ADHD (9.85% vs. 10.74%)* (OR 0.92)	
Zuvekas & Vitiello. (2012)  [2007] <sup>#</sup>	Children age 0-18, analysis based on children age 5- 17 N = 27,969 42% White, 20% African American, 33% Hispanic, 5% Other 1996-2008 MEPS Data, analysis based on 2007 year	Parent report of child taking a stimulant with pharmacy verification		African American children were less likely than White children to be taking a stimulant (OR 0.64)***
Zuvekas et al. (2006)  [2000] <sup>#</sup>	Children age 0-18, analysis based on children age 5- 17 N = 53,511 1997-2002 MEPS Data	Parent report of child taking a stimulant with pharmacy verification		African American children were less likely than White children to be taking a stimulant (OR 0.49)***

*Note.* Data years are presented in brackets. OR = Odds Ratio; AOR = Adjusted Odds Ratio; PR = Prevalence Ratio; \$ = Summary statistic included in diagnostic disparity trend analysis; # = Summary statistic included in medication treatment disparity trend analysis  
\*p<.05; \*\*p<.01; \*\*\*p<.001

## **Diagnostic Disparities**

Twenty-one of the included studies reported ADHD prevalence by race. Current ADHD diagnoses were reported from multiple data sources including parent report of child with a diagnosis of ADHD (n=12), medical record documentation of an ADHD diagnosis (n=3), diagnostic exam or interview for ADHD (n=3), Medicaid record with claim for ADHD (n=2), or physician report of ADHD diagnosis (n=1). Within this sample of studies, ADHD prevalence was significantly lower in African American children compared to white children in 14 (66.7%) studies, while 5 studies (23.8%) reported no significant difference, and 2 studies (9.5%) reported a significantly greater prevalence of ADHD among African American children than White children. Incidence was reported in two studies, one which found a significant disparity for African American children when measuring parent report of lifetime diagnosis of ADHD (Danielson et al., 2018a), and one which found no difference (Visser et al., 2007).

ADHD prevalence disparities were also reported in the context of other variables. One study (Froelich et al., 2007) reported prevalence by ADHD type, finding that African American children were less likely than White children to be diagnosed with inattentive and hyperactive types of ADHD, but no difference was noted in diagnosis of combined type ADHD. Two studies explored the intersection of race, gender, and ADHD. Karnik et al. (2010) reported that African American girls were less likely than White girls to be diagnosed with ADHD, though there was no significant difference between races for boys. Conversely, Siegel et al. (2016) found that both African American boys and girls were more likely than White children to be diagnosed with ADHD. Pastor & Reuben (2005) explored the intersection of race with ADHD and learning disabilities, finding that African American children were less likely than White children to have

a diagnosis of ADHD without a learning disability, but there was no difference between races in diagnosis of ADHD with a learning disability.

Aside from prevalence and incidence, diagnostic-type disparities were captured through parent and teacher ratings of child symptoms. Three studies (Bax et al., 2019; Coker et al., 2016; Cuffe et al., 2005) found African American parents were more likely to report children with ADHD symptoms than White parents, however the difference was not statistically significant in Cuffe et al.'s (2005) study. Bax et al. (2019) and Morgan et al. (2013) found no difference in teacher ratings of ADHD behaviors between African American and White children.

### **Medication Treatment Disparities**

Like ADHD diagnosis, medication treatment was measured in multiple ways. Receipt of a medication was operationalized in different ways, inconsistently across studies. First, treatment was defined as the presence or absence of medication treatment measured via parent report of child taking an ADHD medication or taking a medication for symptoms of ADHD (n=19), Medicaid claim for treatment with an ADHD medication (n=2), medical record showing prescription of a medication for ADHD (n=1), or school record showing administration of a medication for ADHD (n=1). In these cases, medication treatment included stimulant monotherapy, alpha-2 agonists monotherapy, a combination of stimulant and alpha-2 agonist, or any psychoactive medication, depending on the study. In this sample of 23 studies, fifteen (65%) found that African American children with ADHD were significantly less likely than White children with ADHD to be receiving a medication, while eight (35%) found no significant difference between the groups. There were no studies finding that African American children with ADHD were more likely than White children to receive medication treatment. Studies exploring incidence of medication disparities reported fewer African American caregivers



reported their children had ever received a medication for ADHD in their lifetime than White caregivers of children with ADHD (Danielson et al., 2018b; Walls et al., 2018).

Treatment disparities were also quantified in terms of medication adherence and discontinuation in three studies. Results of these studies consistently reported treatment quality to be poorer among African American children compared to White children. Cummings et al. (2017) found African American children were more likely than White children (OR 1.46) to discontinue medication without reinitiation within a 300 day time period. Ji et al. (2018) also found African American children were more likely to discontinue medication in a 300 day period. Moreover, they concluded that African American children were less likely to receive continuous medication treatment, and more likely to experience two or more gaps in treatment during which a prescription was not filled for at least 14 days. Similarly, Palli et al. (2012) found that gaps of 30 days in treatment were more common among African American children.

Four of the studies explored treatment disparities on more granular levels, such as medication type. Davis et al. (2021) found that while there was no difference in treatment with stimulants alone or in combination with alpha-2 agonists between groups, African American children were less likely than White children to receive an alpha-2 agonist alone. Stevens et al. (2005b) found that there was no difference in selection of a short-acting versus long-acting stimulant between races. Lipkin et al. (2005) reported on dosing disparities by race and insurance type, finding that African American children on Medicaid received significantly lower doses of stimulants compared to other children, while those with private insurance received significantly higher doses. Finally, Stein et al. (2012) looked at disparities in medication treatment versus psychosocial treatment, concluding that African American children were more likely than White children to initiate psychosocial treatment alone than medication treatment alone.

## **Disparities over Time**

The studies included in this review were published beginning in the late 1990s through 2021. However, when considering trends in disparities over time, the year of the data collection was more valuable than publication date. Therefore, for this analysis, studies were included if they reported the data year. For studies with data covering multiple years, the median year was utilized. If there was an even number of years, the year greater than the median was used. This analysis was also limited to studies that reported disparities in with a summary statistic (OR, AOR, PR) or provided percentages that could be converted to an odds ratio.

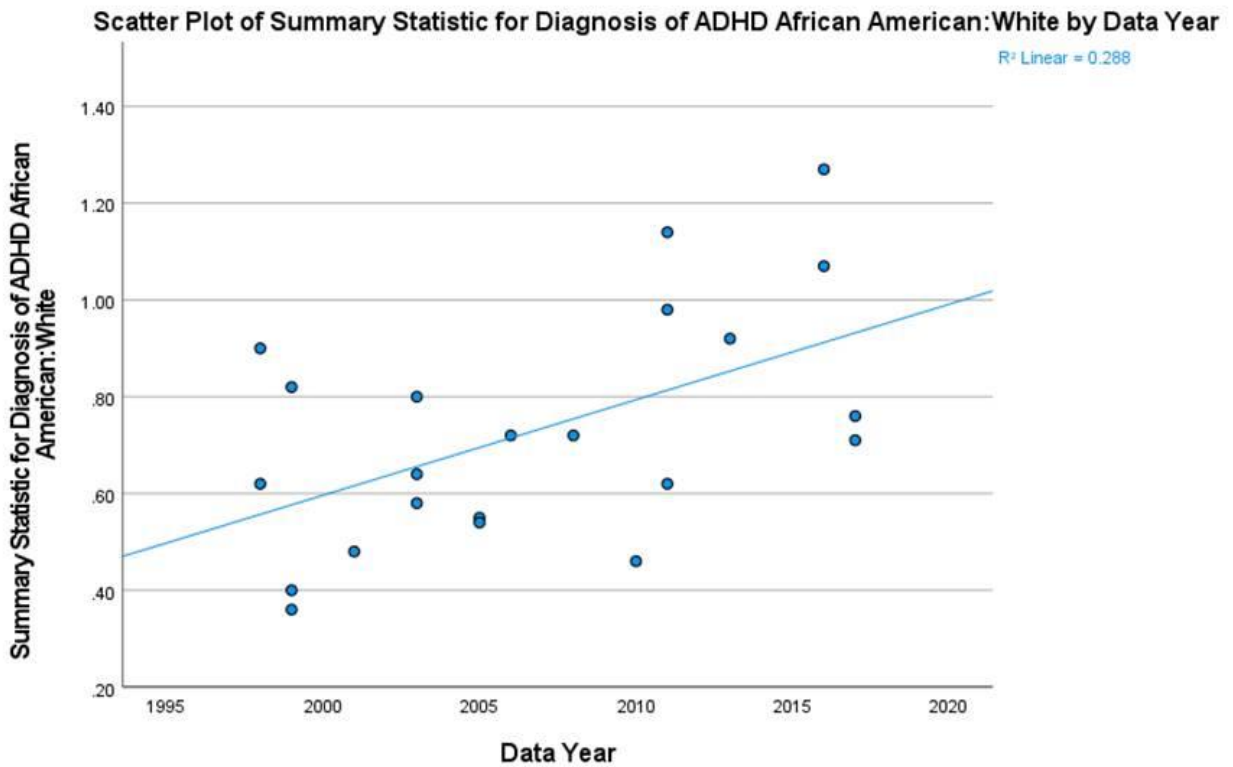
There were 22 studies meeting the criteria to be analyzed for diagnostic prevalence disparities over time. The data for these studies were collected over a 19 year period, between 1998 and 2017. Figure 2 shows the reported summary statistic of an ADHD diagnosis for African American children compared to White children plotted against the data year. A regression line has been fit to the data. The regression line represents the line of best fit, or the line that can be drawn with the least amount of distance from the data points (Field, 2009). The closer the data points are to the line, the stronger the relationship between the variables (Field, 2009). In Figure 2, the regression line has a positive slope over time, with the earliest data points grouped around 0.5 and final data points grouped around 0.9. Overall, the data points cluster near the trend line, indicating that there is likely some degree of association between time and a reduction in reported ADHD prevalence disparities.

There were 19 studies meeting criteria to be analyzed for medication treatment disparities over time. The data for these studies were collected over a 21 year period from 1996 through 2017. Figure 3 shows the reported odds ratios of medication treatment for ADHD for African American children compared to White children plotted against the data year. The trend line has a

positive slope over time, with the earliest data points grouped around 0.5 and final data points grouped around 0.75. The data points in Figure 2 are spread further from the trend line, indicating that there is likely no association between time and ADHD treatment disparities.

**Figure 2**

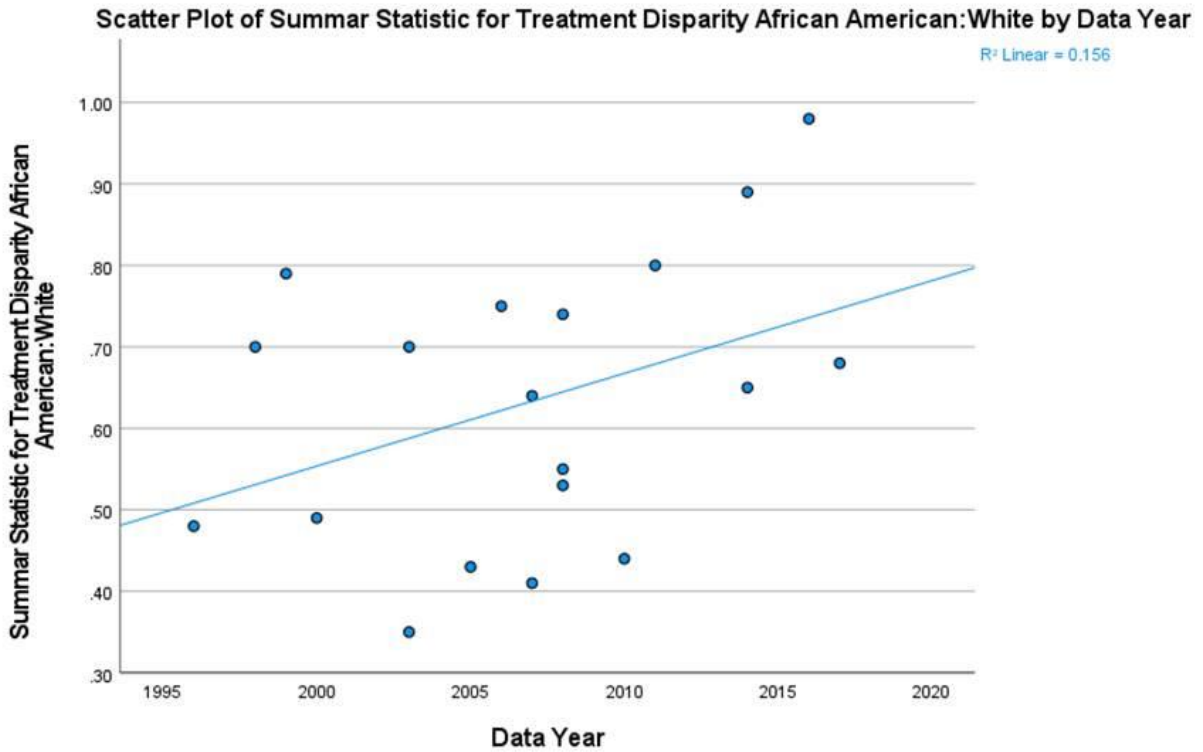
*Diagnostic Disparity Summary Statistic by Year*



*Note.* Each data points reflect the summary statistic (OR, AOR, or PR) from a discrete published study.

**Figure 3**

*Medication Disparity Summary Statistic by Year*



*Note.* Each data points reflect the summary statistic (OR, AOR, or PR) from a discrete published study.

### **Discussion**

Overall, this synthesis indicates that disparities exist in ADHD diagnosis and treatment between African American and White children. Though studies including direct observation of child behavior indicate African American children are equally if not more likely to present with symptoms of ADHD (Bax et al., 2019; Coker et al., 2016; Cuffe et al., 2005; Morgan et al., 2014), the majority of studies reviewed found they are less likely than White children to be diagnosed with ADHD. Similarly, though African American children with ADHD are likely to

benefit from medication treatment (Starr & Kemner, 2005), most studies found they are less likely than White children to receive a medication. A number of socio-demographic characteristics were analyzed in the studies reviewed in relation to both prevalence and medication disparities. These characteristics include insurance status, continuity of insurance coverage, household income, family composition, primary language spoken, region of the country, urban or rural location, population density, physician density, parent highest education, neighborhood safety, and neighborhood resources. Findings between studies conflicted on the degree to which any one or combination of socio-economic factors explain ADHD prevalence or treatment disparities.

The absence of consistent explanatory factors for disparities is consistent with the IOM (2003) definition of disparity as differences in healthcare quality that are not due to access related factors. According to Coker et al. (2016), ADHD disparities exist independent of socio-demographics and mental health needs. For example, Assari & Caldwell (2019) concluded that health gains associated with family income are smaller for African American families than White. Thus, other factors must be considered. Provider bias has been suggested as a source of ADHD disparities (Fadus et al., 2020), though observational studies suggest this may not be a significant contributor (Garland et al., 2015; Sabin & Greenwald, 2012). Still, the inherent bias of tools available to clinicians diagnosing children with ADHD may contribute to diagnostic disparities and downstream treatment disparities. Diagnostic tools relying on parent report of symptoms may be limited by culturally-based differences in parent ratings of ADHD symptoms (Glasofer et al., 2021). In fact, culture likely exerts influence on ADHD disparities through multiple channels. In a review of African American caregiver experiences of medication treatment for children with ADHD, Glasofer et al. (2021) concluded that African American

parental perspectives of ADHD and norms for child behavior differ from those of White parents, and impact how they access care and make decisions about treating children with ADHD.

Moreover, experiences of ADHD as a form of social control among African American parents impacts decision making and is likely reflected in prevalence and treatment disparities (Olaniyan et al., 2007).

### **Disparities over Time**

Based on this review, it appears there is a trend toward reduction in ADHD diagnostic disparities over time. This is consistent with literature finding that ADHD prevalence has increased in African American children at a greater rate than White children (Collins & Cleary, 2016; Xu et al., 2018). However, there does not appear to be a similar trend toward reduction in ADHD medication treatment disparities. The increase in the use of stimulant medications over time is more pronounced in White children than African Americans (Johansen et al., 2015; Zuvekas & Vitiello, 2012). Moreover, this review indicates there are persistent disparities in treatment quality for African American children with ADHD. Taken together, these findings indicate that while there may be increased access to care and shifting perspectives of ADHD in African American communities, significant gaps remain in ensuring equitable care for African American children with ADHD.

### **Inconsistencies in Findings**

**Studies identifying greater ADHD diagnosis in African American children.** While the majority of studies indicated African American children were less likely to be diagnosed with or treated for ADHD than White children, several notable inconsistencies were found among studies. Nearly 25% of prevalence studies and 35% of treatment studies found equivalence between groups. and two studies found that ADHD was diagnosed more commonly in African

American children. Danielson (2018a) and Siegel et al. (2016) found that African American children were more likely than White children to be diagnosed with ADHD. Both of these studies were published within the past five years, thus it is tempting to conclude that the trend toward reduced disparities in recent history explains this outcome; however, Siegel et al. (2016) used data from five years prior to publication, and most of the studies using data since 2011 did not reach this conclusion. In fact, these two studies have little in common that can provide insight into their unique findings. Of note, Siegel et al. (2016) was the only group who specifically sampled from the medical records of a public mental health system. Thus, their finding likely reflects that African American individuals are more likely to access psychiatric care in a public health system as opposed to private practice psychiatric or primary care practitioners compared to White children, who are also more likely to be covered by private insurance (Siegel et al., 2016). Conversely, Danielson et al. (2018a), was one of seven studies utilizing three nationally representative databases to measure parent report of a child with an ADHD diagnosis in a community based sample, but was the only one of these to report African American children were more likely than White children to have a diagnosis of ADHD. Of the remaining six similar studies, five found African American children to be less likely than White children to have a diagnosis of ADHD. Xu et al. (2018) reported no difference by race. Danielson et al. (2018a) suggest their finding could have resulted from a methodological change from previous versions of the National Surveys of Children's Health (internet and mail collected survey responses vs. phone). Of note, Danielson et al.'s (2018a) sample was the only one of this group to overrepresent White children and underrepresent African American children, thus the racial composition may have impacted study findings. Additionally, given that Danielson et al.

(2018a) and Xu et al. (2018) utilized data from 2016, the findings may reflect a trend toward the recent reduction in diagnostic disparities.

**Studies identifying equivalence in ADHD diagnosis between groups.** Five studies reported no difference in ADHD diagnoses between African American and White children. Remarkably, four of the five used data from 1999 or earlier, thus these studies are not temporally related to the trend toward reduction in disparities over time. Otherwise these studies are heterogeneous in methodology. The samples were drawn from a single juvenile justice setting, elementary schools in a single county, two nationally representative samplings of primary care records, and one nationally representative community based survey. ADHD diagnosis was measured through direct interview of the child, parent report of physician diagnosis, medical record with physician diagnosis, and physician survey. The methodologies may have resulted in samples that limit generalizability of study findings. For example, Karnik et al.'s (2010) sample was composed of only 17% White children while African American children represented 28% of the sample. White children were overrepresented in Rowland et al. (2002), Stevens et al. (2004), and Wasserman et al.'s (1999) samples compared to national data (Anne E. Casey Foundation, 2019). Only Xu et al. (2018) included a representative sample. Moreover, samples ranged in size from 790 children (Karnik et al., 2010) to nearly 200,000 (Xu et al., 2018). Aside from Xu et al.'s study (2018), it seems an absence of significant findings amid a majority of studies that identified significant disparities in ADHD diagnosis between African American and White children may result from the heterogeneity and limitations of methodologies.

**Inconsistencies in treatment disparity findings.** Again, the majority of studies exploring disparities in medication treatment found African American children were less likely than White children to receive a medication. There were eight studies that did not detect a



significant difference in receipt of a medication for ADHD between African American and White children. Of these, six studies reported summary statistics, and all found African American children were less likely to receive a medication though the difference was not statistically significant. The data trend toward reduction in medication disparities over time was not as notable as the prevalence trend. In parallel with this, there was no trend in findings of equivalence over time, with study data years spread from 1998 through 2016. The data sources, outcomes measured, and sample sizes between those studies reporting a significant disparity or equivalence varied similarly. White children were overrepresented in half of the studies reporting equivalence compared to 1/3<sup>rd</sup> of studies reporting disparities in medication treatment. African American children were overrepresented in 42% of studies reporting significant disparities but none of the studies reporting equivalence. These differences in sampling indicate that sample racial composition may influence study findings. Also, of note, six of the eight studies reporting equivalent findings included children younger than age six, while only four of the 12 studies reporting significant disparities included children this young. This is significant as the American Academy of Pediatrics (Wolraich et al., 2019) recommends behavioral interventions prior to medication treatment in children younger than six. Thus, it may be that inclusion of preschool age children (5 years old and under) along with school age (6-11 years old) and adolescent subjects (12-18 years old) skews data on ADHD medication disparities. Of the studies that included individuals age 18 and over, three consistently found African American children were less likely to be diagnosed with ADHD than White children, and three of four found African American children were less likely receive treatment than White children. Thus, it does not seem the inclusion of individuals who would not typically be considered children, and who would be able to make decisions independently skewed study findings.

## **Limitations of the studies**

Generalization of the findings from this literature may be impacted by several limitations. Methodologies were heterogenous in key aspects of sampling, data collection, and measurement. In regard to sampling, fewer than half of the studies included representative samples. While oversampling of minorities may be necessary to recruit sample sizes sufficient for analysis (Chen et al., 2020), studies in which African American children were underrepresented or White children were overrepresented may cause an over or underestimation in the degree of disparities. Additionally, there is evidence that disparities differ by geographic region (Danielson et al., 2018a), thus local, regional, and state-based samples may not provide an accurate depiction of disparities across the US.

Data collection methods may also contribute to limitations in findings. Data collected from medical interfaces, such as Medicaid claims and medical records may miss individuals who were not accessing healthcare. Access issues confound findings related to disparities. Individuals who are uninsured or underinsured are less likely to receive care (Healthy People 2030, ND). Therefore, relying on insurance claims or medical records disproportionately excludes individuals most vulnerable to health inequities. Community-based samples may provide a more generalizable reflection of the population; however, surveys utilizing parent responses are relying on individuals for accuracy of information, and a willingness to participate in research which is reduced in African Americans (Branson et al., 2007).

There was a lack of standard tools or instruments for measures of prevalence or treatment. Issues with the measurement of ADHD in African American populations limits the validity of prevalence findings. Studies have found that African American parents' ratings of child behavior differ significantly from White parents in ways that yield different results on

ADHD screening instruments, such that children with similar underlying needs may be treated differently (Harvey et al., 2013; Hillemeier et al., 2007; Wiesner et al., 2015). This issue will persist until there is a more culturally competent approach to diagnosis of ADHD in African Americans (Miller et al., 2009). Studies of medication treatment presented unique limitations. Inconsistencies in the operationalization of medication treatment limit the validity of treatment related findings and the ability to compare results between studies. Most studies captured the prescription of a medication or fill of a prescription, either as documented in the medical record or insurance claim. These data sources do not reflect if a child is taking the medication. Where parents were surveyed on medication receipt, the question was framed as a binary response, and did not capture disparities in treatment type, dosing, persistence, or discontinuity. Thus, it is still not possible to determine if African American children with ADHD are receiving equitable care. The few studies that did explore measure of treatment quality also utilized inconsistent measures for outcomes such as treatment discontinuation and medication gaps. In addition, no data was collected regarding reasons for treatment decisions, rendering it difficult to assess the science. However, the studies of treatment quality indicate there are significant disparities in medication dosing practices and medication taking outcomes (Cummings et al., 2017; Ji et al., 2018; Palli et al., 2012). This small set of studies is important in identifying the future direction for ADHD disparity research.

### **Limitations of the review**

This review is also not without limitations. First, only peer reviewed studies were included which limits the chances that null and negative findings were represented in this review. However, a number of included studies did report null and negative findings. Additionally, this review assumed a position that disparities reflect underdiagnosis or treatment in African

Americans rather than exploring the possibility that they reflect overdiagnosis or treatment in White children. Finally, this review was limited to disparities between African American and White children. The findings of this review cannot be generalized to other minorities. Disparities in other groups may result from different factors such as primary language, different cultural beliefs and expectations related to behavioral health, and different experiences of discrimination and racism. Moreover, through the exclusion of qualitative studies, it does not explore reasons for disparities or heterogeneity of experiences within African Americans. Despite these limitations, this review provides a rigorous and robust synthesis of the existing research on diagnostic and medication treatment disparities between African American and White children in the US.

### **Recommendations for Practice and Future Research**

The findings of this review suggest that policy and practice changes are working to reduce disparities in ADHD diagnosis. Programs such as Healthy People 2020 have prioritized the health of children and adolescents, have established objectives, and provided resources in order to achieve equitable health in this population (HealthyPeople.gov, 2021). For example, Healthy People 2020 includes an objective to increase the percent of adolescents who've had a wellness checkup in the past year from 68.7% to 75.6% (HealthyPeople.gov, 2021). This objective has already been exceeded among African American children. As most pediatric ADHD diagnoses are made and treated by primary care physicians (Patel et al., 2017), programs like Healthy People 2020 indirectly impact ADHD disparities.

However, persistent disparities are complex and will not be eliminated solely by equalizing socio-economic status and access. Based on the National Institute of Minority Health and Health Disparities (NIMHD) research framework, existing inequities result from the

influence of biological, behavioral, physical environment, sociocultural environment, and the health care system including family, community, and social norms (NIMDH, 2017). The work of clinicians and policy makers moving forward must be to reduce the impact of bias, mistrust, and historical trauma on ADHD disparities without assuming a paternalistic approach. Rather, attention must be given to eliminating structural racism, bias, and discrimination, and supporting African American families to leverage socio-economic status to improve health (Assari & Caldwell, 2019).

Continued research on diagnostic and medication treatment disparities in ADHD should further evaluate trends moving forward, should address the limitations identified in this review, and should be informed by a synthesis of the literature on disparities in other minority groups. Research on medication treatment disparities will require greater attention. A much deeper assessment of prescription practices and medication-taking behaviors is required to determine the status of health equity for children with ADHD, and what steps will need to be taken to address persistent disparities. Interventions to reduce the impact of clinician bias will need to be tested, as well as studies to explore how experiences of racism impact medication decision making, and how to restore relationships between the African American and medical communities. Interventions are required to increase minority representation among ADHD clinicians and researchers. Finally, there is a need to conceptualize race beyond a set of unchangeable biological characteristics (Sen & Waslow, 2016). Sen and Waslow (2016) assert that future research should better connect race and causation by exploring within-group variation. Lipkin et al. (2005) illustrated this by identifying an interaction between race and insurance type. Future research should explore within group variations to identify factors contributing to medication decision making among African Americans.

## **Conclusion**

This review found that there are diagnostic and medication treatment disparities between African American and White children with ADHD. Interestingly, it seems that diagnostic disparities are improving over time. Despite the increase in diagnosis of ADHD among African American children, treatment disparities persist. This review demonstrates that further research is required to fully describe and intervene on ADHD treatment disparities. Though progress has been made since research on ADHD disparities began more than 20 years ago, this review indicates there is work to be done to ensure equitable healthcare for children with behavior health needs.

## Chapter 3: Manuscript 2

### Medication Decision Making among African American Caregivers of Children with ADHD: A Review of the Literature

Building on findings from Manuscript 1, the second manuscript synthesizes fourteen studies on African American caregiver experiences of MDM for their children with ADHD. This review resulted in three main themes including (a) fundamental perspectives of ADHD, and cultural norms for child behavior; (b) the impact of fundamental perspectives on MDM in ADHD; and (c) ADHD diagnosis and treatment as forms of social control. The manuscript provides recommendations for practice including provision of patient centered care, exploration of ADHD knowledge and explanatory models, and efforts to increase diversity in mental health professionals. Future research should include development of culturally sensitive ADHD rating scales, exploration of ADHD MDM as a process rather than an outcome, and identification of within group variations in factors associated with MDM.

In October, 2021 this manuscript was published in the *Journal of Attention Disorders*, a peer-reviewed journal focused on basic and applied research related to attention disorders (Sage, 2021). Copyright permission was obtained from the publisher to include this manuscript in this dissertation (Appendix C). Written permission was obtained from the coauthors to include this manuscript in the dissertation (Appendix B & Appendix D).

Glasofer, A., Dingley, C., & Reyes, A. T. (2021). Medication decision making among African American caregivers of children with ADHD. *Journal of Attention Disorders*, 25(12), 1687-1698. DOI: [10.1177/1087054720930783](https://doi.org/10.1177/1087054720930783)

## **Abstract**

*Background:* Significant pharmacotherapy disparities exist among children from ethnic minorities with ADHD. *Objective:* The purpose of this review is to synthesize existing evidence on African American caregiver medication decision making (MDM) for children with ADHD. *Method:* Databases queried for this review included the Cumulative Index of Nursing and Allied Health Literature (CINAHL), PsychINFO, PubMed, and Education Resources Information Center (ERIC). Information regarding the unique culturally specific barriers and supports to MDM were examined through the relevant literature search. *Results:* Fourteen articles were included in this review (7 observational studies, 4 qualitative studies, 3 mixed methods studies). Three main themes were identified which include (a) fundamental perspectives of ADHD, and cultural norms for child behavior; (b) the impact of fundamental perspectives on MDM in ADHD; and (c) ADHD diagnosis and treatment as forms of social control. *Conclusions:* Evidence-based recommendations for clinicians are provided, along with direction for future research.



## **Introduction**

Attention-Deficit/Hyperactivity Disorder (ADHD) is the most common pediatric neurobehavioral disorder in the United States, resulting in significant morbidity for children and families (Wolraich et al., 2019). An estimated 6.1 million U.S. children have a current or prior diagnosis of ADHD (Danielson et al., 2018a). Prevalence data indicate that ADHD is diagnosed less frequently in African American children than White children, with odds of an ADHD diagnosis for African American compared to White children ranging from 0.30 to 0.62 (Collins & Cleary, 2016; Morgan et al., 2014).

While African American children are less likely to receive a diagnosis of ADHD than White children, this does not indicate they are less likely to express symptoms of the disorder. Observational studies of childhood behavior indicate that symptoms of ADHD are expressed equally across ethnicities (Bax et al., 2019; Morgan et al., 2014). One meta-analysis concluded that African American youth had more symptoms than White children (Miller et al., 2009). It does not appear that confounding variables, such as birth weight, income, insurance coverage, or learning disability account for diagnostic differences (Miller et al., 2009). One potential explanation is the validity of standardized ADHD rating scales in African American children. Factor structure and individual item performance of standardized instruments may not measure ADHD severity equally across races (Hillemeier et al., 2007; Miller et al., 2009, Wiesner et al., 2015). For example, differences in cultural processes behind parental and teacher ratings of behaviors may yield differing thresholds for acceptability of “argued or talked back” on a scale (Wiesner et al., 2015).

In addition, specific factors such as differences in parental perceptions of ADHD symptoms between African American parents and White parents and teachers have shown to be

associated with lower rates of ADHD diagnoses among African American children (Bax et al., 2019; Morgan et al., 2013; Hillemeier et al., 2007; Kang & Harvey, 2020). For example, perceptions of hyperactivity in African American children are not necessarily perceived as problematic by African American parents but rather encouraged as part of the child's expressiveness (Boykin & Bailey, 2000; Kang & Harvey, 2020). African American parents rate their knowledge of ADHD lower compared to their White counterparts (Bailey & Owens, 2005; Turner et al., 2015). Additionally, lower levels of trust in medical providers, and difficulty accessing medical care and information among African American caregivers serve to further disparities in receipt of an ADHD diagnosis (Bax et al., 2019). This literature review will provide an in-depth exploration of potential explanations for differing perceptions of African American caregivers on ADHD related behaviors.

Access to care is another factor that may result in diagnostic disparities. Siegel et al. (2016) found that children from ethnic minorities were actually more likely to be diagnosed with ADHD. Their sample was drawn from a publicly funded mental health service (Siegal et al., 2016), as opposed to results from other studies that draw from primary care clinics in which White children are more likely to be diagnosed with ADHD (Bax et al., 2019; Coker et al., 2016). Moreover, children living below the poverty level, who lack health insurance, who live with a stepparent, and who live in unsafe neighborhoods are less likely to have a parent report of ADHD, regardless of ethnicity (Collins & Cleary, 2016). Thus, reporting disparities may be a reflection of socioeconomic status and access to care rather than a primary function of ethnicity.

Pharmacotherapy is one element of a comprehensive treatment plan for ADHD (Wolraich et al., 2019). Pharmacological treatment of ADHD is associated with positive health, safety, academic, occupational, social, and family outcomes (Fridman et al., 2017a; Prasad et al., 2013;

Quinn et al., 2017; Ruiz-Goikoetxea et al., 2018; Shaw et al., 2012; Silva et al., 2015). There are multiple components of pharmacotherapy that require caregiver decision-making related to medication initiation, persistence, adherence, and discontinuation. For the purposes of this discussion, these terms are defined as follows: medication initiation- the first fill of a prescription and provision of the first dose, medication persistence- the period of time between medication initiation and discontinuation, medication adherence- the extent to which actual dosing corresponds to prescribed dosing, and medication discontinuation- the final dosing of a medication (Raebel et al., 2013; Schmittdiel, et al., 2013; Vrijens et al., 2012). Regarding medication initiation, an estimated 62% of children with a current diagnosis of ADHD are taking medication for their ADHD (Danielson et al., 2018a). In terms of treatment persistence and adherence, treatment duration for ADHD averages 136 days, and non-adherence estimates range between 15 and 83% (Atzori et al., 2009; Spencer et al., 2011; Usala, et al., 2009). These numbers likely do not reflect sufficient treatment (Wolraich, 2019). Moreover, children with ADHD from ethnic minorities are significantly less likely to receive pharmacotherapy than their White counterparts (Coker et al., 2016). The odds of taking a medication for ADHD in African American children compared to White children range from 0.35-0.65 (Morgan et al., Staff, et al., 2013; Walls et al., 2018). In addition, African American children are more likely to demonstrate low adherence and early discontinuation of ADHD medication regimens than their White and Hispanic counterparts (Cummings et al., 2017; Ji et al., 2018; Saloner et al., 2013).

While literature on medication taking experiences in ADHD exists, it has not specifically examined the unique perspective of African American caregivers (Gajria et al., 2014; Rashid et al., 2018b). A recent integrative review examined 32 studies focused on family processes including identification, care-seeking, treatment preferences, and engagement with services

among ethnically diverse youth with ADHD (Paidipati et al., 2017). While their review is comprehensive, it generalizes across ethnic minorities and does not specifically explore medication decision making (Paidipati et al., 2017). Given the evidence supporting the existence of pharmacotherapy disparities between African American and White children with ADHD, a specific review of the literature exploring perspectives of African American caregivers of children with ADHD is needed to better describe what is currently known, and to identify gaps in knowledge. In order to address ADHD pharmacotherapy disparities, the unique experiences and perspectives of ethnic minorities must be understood.

While disparities exist across multiple ethnicities, there are cultural and historical factors for ADHD medication disparities exclusive to African American individuals. In explaining these factors, Suite et al. (2007) reference an 1840 U.S. census report that falsely claimed insanity rates among African Americans increased the further north they lived. Suite et al. (2007) describe the medicalization of typical behavior among African Americans that did not suit White Americans, such as developing a diagnosis for the desire to escape slavery. Thus, the fear of using medical diagnoses to achieve control of African American's has historical precedence. A lack of trust in healthcare professionals, in the diagnoses they render, and in the treatments, they recommend contributes to pharmacotherapy disparities for ADHD (Suite et al., 2007). Inadequate knowledge and understanding of these barriers hinder mental health treatment of African American children with ADHD (Rostain et al., 2015). Moreover, caregivers are predominantly the ones to make medication decisions for children with ADHD (Berger et al., 2008). Therefore, the purpose of this review is to synthesize existing evidence on African American caregiver medication decision making (MDM) for their children with ADHD.

## Methods

The following inclusion criteria were applied to the literature search: (a) articles written in English; (b) peer-reviewed or clinical practice guidelines from professional associations; (c) research or theoretical reports on African American caregiver experiences with children with ADHD; and (d) focused on ADHD medication. Databases queried included the Cumulative Index of Nursing and Allied Health Literature (CINAHL), PsychINFO, PubMed, and Education Resources Information Center (ERIC). Keywords used in the search included the terms *attention-deficit/hyperactivity disorder, ADD, and ADHD* along with each of the following terms: *diagnosis, prevalence, medication, stimulant, treatment, outcome, adherence, minority, disparity, African American, and caregiver*. No year limits were placed on articles, however literature that was published up through 2019 were included. Titles and abstracts were screened for relevance prior to full review for inclusion. Manual searches from the reference lists of articles that met the above criteria were also conducted for relevant works. In total, 14 out of 915 articles met the inclusion criteria for full text review and were synthesized in this paper. After removing duplicates, 824 records were excluded because they lacked a primary focus on ADHD medication in children from the perspective of African American caregivers.

The 14 articles underwent an extensive comprehensive data extraction and evaluation process. Data extracted from each study included: study aim, design and methods, sample and setting, and main findings and outcomes. The categories of data were analyzed through iterative comparisons across primary sources. The main findings and outcomes were compared across studies and similar data grouped together as categories that were compared and further synthesized. The authors conducted group discussions to draw inferences from the data, using a narrative approach. Discussion of the preliminary categories and thematic analysis continued,

until consensus was reached, and the findings of the review were confirmed. The final 14 articles included 7 non-experimental quantitative studies, 4 qualitative studies, and 3 studies utilizing mixed methods (Table 2).

**Table 2**

*Table of Evidence*

Authors	Main Aim	Study Design and Methods	Sample and Setting	Main Findings and Outcomes
Berger-Jenkins et al. (2012)	Explore minority parents' knowledge and perceptions of ADHD	Quantitative- prospective cohort	Parents of children with ADHD diagnosis not using medication or psychological treatment N = 70 57.1% Hispanic, 34.3% African American Primary care and mental health specialty clinics at New York City hospital	Parents were hesitant to start a medication based on what they heard about Ritalin Parents who were hesitant to start Ritalin were 2.4 times less likely to attend follow-up appointments
Bussing et al. (2003a)	Describe whether parents' understanding or explanatory models contribute to gender and cultural variations in help-seeking for children with ADHD.	Mixed methods	Parents of elementary school students at high risk for ADHD N = 182 41% African American, 59% White Single elementary school district in Florida	African American parents were less likely to use medical labels for child's condition (OR 0.26)*** African American parents were more likely to say they did not know the cause of child's condition (OR 2.7)**

Authors	Main Aim	Study Design and Methods	Sample and Setting	Main Findings and Outcomes
Bussing et al. (2007)	Explore cultural variance in parental health beliefs, knowledge, and information sources related to ADHD.	Quantitative- cross sectional	Parents of children with and without ADHD N = 1,615 41% African American, 59% White Single elementary school district in Florida	<p>African American parents were less likely to request medication (OR .26)*** treatment or school intervention (OR .39)**.</p> <p>African American parents were less likely to endorse that ADHD can be treated by medications (OR .7)*</p> <p>African American parents were less likely to denounce sugar as cause for ADHD symptoms (OR .3)***</p> <p>African American parents were less likely to report knowing a lot about ADHD (OR .4)***, ever hearing about ADHD (OR .1)***, or recently hearing about ADHD (OR .5)***</p> <p>African American parents were less likely to report a diagnosis of ADHD for themselves (OR .2)***, family members (OR .7)*, or others (OR .4)***</p>

Authors	Main Aim	Study Design and Methods	Sample and Setting	Main Findings and Outcomes
				Fewer concerned African American parents received information on ADHD from written materials*, hospitals or clinics**, public health departments***, friends*, teachers and schools**, and the internet**.
Bussing et al. (1998)	Describe variations in ADHD knowledge, information sources, and explanatory model by ethnicity and socioeconomic status	Mixed Methods	African American and White caregivers of 2 <sup>nd</sup> -4 <sup>th</sup> grade children with learning disabilities Phase 1 n = 499, Phase 2 n = 139 46% African American, 54% White Single school district	African American caregivers were less likely to have exposure to individuals with ADHD or information about ADHD***, and rated ADHD knowledge lower than White parents*** African American caregivers were more likely to attribute sugar as a cause of ADHD***, less likely to indicate a genetic cause* or use a medical label for ADHD (OR 0.24)***, and more likely to label the child as “bad”*** African American caregivers were



Authors	Main Aim	Study Design and Methods	Sample and Setting	Main Findings and Outcomes
				less likely to endorse medication as a treatment for ADHD*** Fewer African American parents received information from physicians**, library***, medical journals ***, and newspapers***. More African Americans received information from public health departments**
Bussing et al. (2003b)	Describe help-seeking and explore variations in help-seeking for ADHD by sociodemographic variables, and describe barriers from parents who have not engaged in treatment	Mixed Methods	Phase 1: African American or White K-5 <sup>th</sup> grade children at high risk or diagnosed with ADHD, Phase 2: African American or White children with ADHD not receiving services. Phase 1: N = 389, Phase 2: N = 91 Phase 1: 52% African American, 48% White; Phase 2: 50% African American, 50% White Single school district in Florida.	African American children were less likely to have ADHD symptoms recognized*, evaluated***, diagnosed***, or treated***. Having a negative expectation* was the only significantly different barrier between African American and White parents of children with ADHD not receiving services.
Bussing et al. (2012)	Explore how ADHD knowledge,	Quantitative- cross-	Adolescents classified as high (56%) and low (44%) risk for ADHD and	White parents were more likely

Authors	Main Aim	Study Design and Methods	Sample and Setting	Main Findings and Outcomes
	perceptions, and cues to action vary by sociodemographic characteristics	sectional design using data from longitudinal study	their parents selected from longitudinal cohort study of access to care for ADHD. N = 347 36% African American, 64% White Single school district in Florida	to have heard of ADHD OR 6.4)***, know some or a lot about ADHD (OR 2.8)***, and know someone with ADHD (OR 5.7)** White parents were less likely to endorse sugar as a cause for ADHD (OR .5)**
dosReis et al. (2006)	Explore caregiver attitudes, satisfaction, knowledge, and medication experiences of stimulant medications for ADHD	Quantitative- cross-sectional	African American caregivers of children with ADHD who had received a medication for ADHD within the past 12 months. N = 48 Urban academic primary care clinic in Baltimore, Maryland	Caregivers believed stimulants would improve ADHD symptoms (88%), were safe if recommended by a physician (90%), and would recommend stimulant medication for a child with ADHD (63%). Majority were hesitant to initiate medication (71%), and would prefer counseling over medication (54%). Negative perceptions included concern for drug abuse (17%), side effects (21%), and overprescribing of medications (22%).
dosReis et al. (2007)	Develop a theory of coming to terms with ADHD diagnosis among	Qualitative- Grounded theory	African American caregivers of children newly diagnosed with ADHD	Parents who viewed behaviors as ADHD symptoms with a medical or biological cause

Authors	Main Aim	Study Design and Methods	Sample and Setting	Main Findings and Outcomes
	urban African American caregivers of children with ADHD.		N = 26 Clinics associated with an urban academic medical center in Baltimore, Maryland.	engaged in medical interventions. Parents who attributed behaviors as atypical but not symptoms of ADHD focused on religious beliefs or discipline to manage behaviors. Some parents sought medical treatment as a result of 3 <sup>rd</sup> party intervention but did not perceive behaviors as problematic.
Graves. (2017)	Develop a theory of help-seeking processes among African American single mothers living in poverty seeking mental health services for their children.	Qualitative- Grounded theory	African American impoverished single mothers seeking mental health services for their children with ADHD or anxiety and comorbid personality disorder, autism, or Tourette syndrome N = 11 mothers, 12 children (ADHD = 11, anxiety = 1) Public housing authority in urban area.	Medication decision-making was influenced by perceptions, beliefs, and personal experiences with medication; the mother's relationship with the mental health provider; competence in managing the child's behavior; and informal support system. Participants expressed reservations about medications and a belief in discipline over medication.

Authors	Main Aim	Study Design and Methods	Sample and Setting	Main Findings and Outcomes
				<p>Medication was chosen from a need to manage behaviors, observations of progress of others on medication and other personal experiences, or pressure from a third party.</p> <p>Influences on remaining on treatment included finding the right medication, relationship with the mental health provider/school/pediatrician, and informal supports.</p> <p>Mothers were concerned with side effects and lack of follow-up with providers.</p> <p>Continued treatment was influenced by perceived improvement in symptoms and future orientation or third party pressure.</p>
Hillemeier et al. (2007)	Item Response Theory was used to determine whether differential item function (DIF) existed between African American	Quantitative- cross-sectional design using data from longitudinal study	Parents of children enrolled in longitudinal study of children at risk for emotional/behavioral problems N = 1070 51% African American, 49% White	At the same level of hyperactivity, White parents were more likely to endorse hyperactivity items than African American. Except for concentration, each

Authors	Main Aim	Study Design and Methods	Sample and Setting	Main Findings and Outcomes
	and white respondents on the DISC assessment of ADHD symptoms.		Elementary schools in 4 states in the US.	<p>subscale contained one item that demonstrated DIF, such as excessive talking at home.</p> <p>Removing items exhibiting DIF in the hyperactivity scale reduced racial difference in means and differences were no longer significant.</p> <p>Medication disparities were reduced when items exhibiting DIF were deleted.</p>
Krain, Kendall, & Power. (2005).	Explore treatment acceptability and parent report of treatment pursuit at 3-4 months after diagnosis and treatment recommendation.	Quantitative- prospective cohort	<p>Caregivers of children newly diagnosed with ADHD and no prior treatment</p> <p>N = 55</p> <p>75% White, 20% African American, 5% other</p> <p>ADHD center at a large metropolitan pediatric hospital.</p>	<p>White parents rated treatment acceptability of medication significantly higher than non-White, primarily African American, parents.**</p> <p>White children were significantly more likely to pursue medication therapy than non-White children.**</p> <p>Parental rating of acceptability of medication accurately predicted pursuit of medication at 3-4 months in 83.7% of cases.</p>

Authors	Main Aim	Study Design and Methods	Sample and Setting	Main Findings and Outcomes
McLeod et al. (2007)	Explore general public knowledge, beliefs, and treatment preferences for ADHD, and identify variations by sociodemographic characteristics.	Quantitative- cross-sectional	Nationally representative sample of community-based adults N = 1,139 Participants in the National Stigma Study- Children	African American were less likely to be aware of ADHD (OR .50)* African Americans were less likely than white respondents to say that ADHD is real (OR .58)*. Treatment preferences were strongly associated with belief about whether ADHD is real or not.
Mychailyszyn et al. (2008)	Develop a theory about how African American mothers conceptualize their child's ADHD and how this relates to treatment	Qualitative- grounded theory	African American caregivers of children with ADHD N = 34 Outpatient offices in an inner-city community.	Parents who viewed ADHD as a medical illness endorsed a biological explanation of behavior, and utilized medication Parents who viewed behaviors as a normal stage of development expected the behaviors to be cured or outgrown without treatment
Olaniyan et al. (2007)	Describe how African American parents view behavior problems and	Qualitative	African American parents N = 31 Primary care pediatric clinics in the Baltimore-Washington Metropolitan area.	Most parents attributed behavioral problems to poor parenting, such as a lack of attention or appropriate discipline.

Authors	Main Aim	Study Design and Methods	Sample and Setting	Main Findings and Outcomes
	their management in children.			<p>Views of an ADHD diagnosis were mixed, with some feeling that ADHD was not sufficiently diagnosed and others that it is not a real diagnosis.</p> <p>Racial concerns existed about the stigma of ADHD, and that medicalization of behaviors is a form of social control with historical routes.</p> <p>Participants expressed distrust of physicians and pharmaceutical companies.</p> <p>Negative opinions of medication were prevalent, with concerns for sedation and addiction.</p> <p>Medication was viewed as a last resort and a short-term solution.</p> <p>Medication was seen as a way to control classroom behavior for ineffective teachers and</p>

Authors	Main Aim	Study Design and Methods	Sample and Setting	Main Findings and Outcomes
Pham et al. (2010)	Explore cultural differences in parental beliefs of causes and treatment of ADHD, and the relationship between beliefs and treatment preferences	Quantitative- cross-sectional	Parents of children with and without ADHD N = 119 54% White, 28% African American, 18 % other. Mid-Michigan community.	school systems, and to make the teacher's job easier. No significant differences between ethnic groups regarding beliefs of causes of ADHD or medication treatment. Significant relationship between belief in a biological/genetic cause for ADHD and preference for a medication only treatment plan*.

*Note.* OR = Odds Ratio

\*p<.05; \*\*p<.01; \*\*\*p<.001

## Results

Based on the results of our literature search and review, we observed that African American caregiver decision making regarding pharmacotherapy for children with ADHD is largely based on caregivers' inadequate scientific knowledge of ADHD, personal stigmatized beliefs about medication treatment, and public stigma of ADHD diagnosis and treatment. To this end, the focus and findings of the literature in this review was synthesized into three overarching themes that describe the evidence related to medication decision making in African American caregivers: (a) fundamental perspectives of ADHD, and cultural norms for child behavior; (b) the impact of fundamental perspectives on MDM in ADHD; and (c) ADHD diagnosis and treatment as forms of social



control. These three overarching themes demonstrate factors that contribute to medication decision making and potential pharmacotherapy disparities. Additionally, these three themes concur with findings about key factors affecting increased help-seeking behaviors of ethnic minority children and caregivers with ADHD treatment and mental health services (Eiraldi et al., 2006).

More particularly, the quantitative studies in our literature review used cross-sectional methods to assess beliefs about ADHD and medications in minority caregivers, and contrast them to their White counterparts (Bussing et al., 1998; Pham et al., 2010). Qualitative studies focused on specific experiences of African American families and communities related to ADHD (dosReis et al., 2007; Olaniyan et al., 2007).

#### Fundamental Perspectives of ADHD *and Cultural Norms for Child Behavior*

*Fundamental perspectives of ADHD and cultural norms for child behavior* was the first overarching theme that emerged from our analysis of the literature synthesis and accounts for the caregivers' perceptions about ADHD. This theme is comprised of three sub-themes: (1) ADHD knowledge: pertains to the caregivers' level of scientific knowledge of ADHD and exposure to medical information about ADHD; (2) explanatory models of ADHD: pertains to the caregivers' health beliefs about ADHD and seeking medical care related to ADHD; and (3) cultural differences in perceptions of ADHD: pertains to the differences in perspectives about ADHD between African American caregivers and other racial groups.

ADHD knowledge. The majority of empirical evidence of parental knowledge of ADHD among African Americans is based on the works of Bussing and colleagues (Bussing et al., 1998, 2003a, 2003b, 2007, 2012). McLeod and colleagues (2007) were the only other team to assess

racial differences in ADHD knowledge. However, their study was limited to investigating whether participants had ADHD knowledge or not. (McLeod et al., 2007).

In many quantitative studies, knowledge level of ADHD among different racial groups was measured by parent or investigator ratings, reports of exposure to ADHD information and information source, or exposure to others with ADHD (Table 2, Bussing et al., 1998, 2003a, 2007, 2012; McLeod et al., 2007). Findings from these studies demonstrated that African American parents had lower ADHD knowledge, less exposure to ADHD information, and less frequent interactions with individuals with ADHD than their White counterparts (Table 2, Bussing et al., 1998; 2003a; 2007; 2012; McLeod et al., 2007). White parents were more often exposed to information about ADHD from physicians, medical journals, newspapers, other written materials, hospitals and clinics, friends, teachers and schools, and the internet (Bussing et al., 1998, 2007). Additionally, Bussing and colleagues (1998, 2007) found that African Americans were more likely to receive information from the public health departments than White parents (Table 2). These findings are important to MDM as individuals who know more about ADHD may be more likely to have exposure to information about pharmacotherapy options (Bussing et al., 1998).

Explanatory models of ADHD. Explanatory models of illness pertain to the individual's beliefs about the illness, the meaning of the illness, and the notions about the expected treatments (Kleinman, 1980). Explanatory models of illness explore the perceptions of the cause of the illness, how the illness started, how the illness affects the person, the severity of the illness, and the type of treatment one should receive (Hark & DeLisser, 2009). In our literature review and synthesis, the majority of the evidence on explanatory models of ADHD are based on the works of Bussing and colleagues (Bussing et al., 1998, 2003a, 2007, 2012). Additionally, dosReis et al.,

(2007), Graves (2017), Mychailyszyn et al. (2008), and Olaniyan et al. (2007) conducted qualitative studies in which themes of explanatory model emerged. African American parents, some of whom were caregivers to children with ADHD and some who were not, attributed ADHD-like behaviors to origins other than medical or biological causes. Explanations of ADHD-like behaviors included poor parenting, lack of attention, insufficient discipline, or a normal stage of development that would be outgrown (Table 2, Bussing et al., 1998, 2003a, 2007, 2012; dosReis et al. 2007; Graves, 2017; Mychailszyn et al., 2008; Olaniyan et al., 2007). Moreover, these beliefs were more common among African American than White parents. In Bussing et al.'s (1998) study, African American caregivers were twice as likely to indicate that ADHD is caused by eating too much sugar compared to White caregivers and more likely to label their child as bad, while they were significantly less likely to attribute ADHD to genetic origins, or apply a medical label (Table 2). Bussing and colleagues reported similar findings in their subsequent studies (Bussing et al., 2003a, 2007, 2012). Some African American parents expressed the belief that the diagnosis of ADHD was not real (Olaniyan, 2007). McLeod et al. (2007) found that the odds ratio of endorsing ADHD as a real disorder among African Americans was 0.52 ( $p < .05$ ) compared to Whites.

Cultural differences in perceptions of ADHD. In their study, Bussing et al., (2003b) found that White children had twice the odds of African American children to receive an evaluation, diagnosis, or treatment for ADHD, despite the fact that there were no differences in rates of recognition of ADHD symptoms (Table 2). They concluded that there may be cultural differences in the threshold that determines when a parent seeks help for ADHD symptoms (Bussing et al., 2003a). This notion has been supported in other studies. For example, participants in Olaniyan et al.'s (2007) study expressed concern that ADHD represents a

medicalization of typical behavior. Hillemeier et al. (2007) administered a commonly used parent-rated ADHD diagnostic instrument to African American and White caregivers of children with ADHD. They found that White caregivers reported more symptoms of hyperactivity than their African American counterparts despite comparable levels of hyperactivity as rated by teachers (Hillemeier et al., 2007). This indicates that hyperactivity is perceived differently according to race. Their findings imply that children with similar underlying needs may receive different medical treatment based on parent report of symptoms utilizing instruments that function differently across populations (Hillemeier et al., 2007).

#### The Impact of Fundamental Perspectives on MDM in ADHD

Fundamental perspectives of ADHD, including knowledge, explanatory model, and cultural norms, impact different areas in MDM. One area which is impacted is parental beliefs of efficacy and effectiveness of ADHD medications. Bussing et al. (1998, 2007) reported that significantly fewer African American parents believed medications can be effective in treating ADHD than White parents (Table 2). The odds of an African American endorsing medication as a treatment were 0.7 ( $p < .05$ ) compared to White parents (Bussing et al., 2007). Bussing et al. (2003b) found the only significant difference in barriers to care between groups was that African American caregivers indicated they had a negative expectation for treatment, such as they thought the treatment could not help, compared to Whites (Table 2). Similarly, Krain et al. (2005) developed an instrument to assess treatment acceptability which pertains to the attitude toward pharmacological treatment, and pursuit which refers to the choice to receive pharmacological treatment. The instrument was administered to caregivers of children with ADHD who had not been previously treated. They found that White caregivers rated medication acceptability significantly higher than minority caregivers, and that 78.9% of White children

went on to receive medication therapy, while only 27.3% of minority children did (Krain et al., 2005).

The difference in certainty of efficacy of medical treatment may be due to differing explanatory models. Preferences for medical treatment of ADHD are associated with a biological explanatory model (Bussing et al., 1998, McLeod et al., 2007; Pham et al., 2010). Pham et al., (2010) assessed differences in parental beliefs about causes of ADHD among 119 ethnically diverse parents of children with and without ADHD through their researcher-developed instrument. They found that both beliefs of biological and behavioral causes of ADHD significantly predicted medication treatment preferences (Pham et al., 2010). Endorsing a biological cause for ADHD was associated with a preference for medication only treatment ( $p = .037$ , Pham et al., 2010). Pham et al.'s (2010) conclusion was supported by dosReis et al.(2007), McLeod et al.(2007), and Mychailyszyn et al. (2008). These findings demonstrate how important perceptions of medication and explanatory model are to subsequent treatment decisions.

The second area in which fundamental perspectives of ADHD impact on MDM is an amplified concern for side-effects of medications and addiction among African Americans. African American individuals express greater concern for side effects of psychiatric medications ( $p < .01$ , Schnittker, 2003). In ethnic minority samples, concerns for drug abuse, addiction, sedation, and weight loss result in reserving medication as a last resort or refusing it entirely for the treatment of ADHD (Berger-Jenkins et al., 2012; dosReis et al., 2006; Graves, 2017; Olaniyan et al., 2010). dosReis et al. (2006) developed a survey based on existing evidence to assess attitudes of African American caregivers whose children had recently taken a medication for ADHD – about 17% were concerned about abusing the medication and 21% about unwanted side-effects. Berger-Jenkins et al. (2012) and Graves (2017) identified concerns specific to

Ritalin in minority parents of children with ADHD. Concerns included sedating side effects, weight loss, and addiction and were sufficient enough that respondents reserved medication as a last resort or refused entirely (Graves, 2017; Olaniyan et al., 2010). In their sample of 70 caregivers of minority children with ADHD, Berger-Jenkins et al. (2012) found that parents who expressed concerns (i.e. weight loss and addiction) about medications were 2.5 times less likely to use treatment at follow-up.

Finally, African American caregivers' fundamental perspective of ADHD directly impacts parental tolerance and perception of ADHD behaviors and symptoms. Studies revealed that African American caregivers perceived ADHD behaviors and symptoms as typical childhood behaviors, or that a child was "just bad" (Mychailyszyn et al., 2008). Similarly, Bussing et al. (2003b) found that African American caregivers were less likely to recognize ADHD behavioral symptoms as problematic or impairing compared to their White counterparts. This may result in a decreased likelihood that African Americans will present to medical professionals for a diagnosis of ADHD. Bussing et al. (2007) supported this notion, finding that African American caregivers were less likely to have a child evaluated compared to their White counterparts (51% vs. 28%). Moreover, variations in tolerance of ADHD symptoms based on cultural norms may mean that children with similar underlying symptoms receive disparate medical treatment due to utilization of instruments that are based on parental report of symptoms. Hillemeier et al. (2007) demonstrated that standardized instruments perform differently across ethnicities. For example, at the same level of hyperactivity, African American caregivers are less likely to endorse items measuring hyperactivity than White parents (Hillemeier et al., 2007). Thus, medications may not be offered to minority children based on differences in caregiver report of symptoms. Furthermore, removing items from a standardized

assessment of ADHD that perform differently between races can reduce medication disparities (Hillemeier et al., 2007).

#### ADHD as a Form of Social Control

A final unique and important factor to ADHD MDM among African Americans is the belief that ADHD diagnosis and treatment are attempts at social control. In a study of African American parent perspectives of ADHD, Olaniyan et al. (2007) noted that participants felt the diagnosis of ADHD represented a form of social control, as did use of medications to control behaviors. ADHD was described as “something the medical people came up with to handle kids” (Olaniyan et al., 2007, p. 228), so they “just sit there like zombies” (Table 2, Olaniyan et al., 2007, p. 229). Participants in other studies indicated that they selected medication treatment only as a result of pressure from a third party, typically the school system (Graves, 2017; dosReis et al., 2007). Rather than using the term social control, dosReis et al., (2007) called this “coerced conformance,” a phase of parental decision making with their children’s care in which they do not see their children’s behaviors are problematic but yet are compelled to yield to their children’s school coercion to opt for treatment.

Medications were viewed by African American parents as a mechanism to propagate addiction (Table 2, Olaniyan et al., 2007). One participant’s quote clearly represents this theme: “Because of addictions past and present and how much it really hurts the black community. I think that’s another reason why we don’t like to consider using drugs” (Olaniyan et al., 2007, p. 229). Physicians were also perceived as colluding with pharmaceutical companies (Bussing et al., 2003b). A lack of trust in healthcare professionals, in the diagnoses they render, and in the treatments, they recommend contribute to MDM and subsequent pharmacotherapy disparities for ADHD.

## **Discussion**

This literature synthesis demonstrates that culture exerts a strong influence on MDM in African American caregivers of children with ADHD. Multiple factors converge to produce persistent disparities in ADHD treatment. These include African American caregivers' perspectives on typical childhood behavior and explanations for behavioral issues, the validity of ADHD as a diagnosis, concerns about efficacy and safety of stimulant medications, mistrust in physicians and the pharmaceutical industry, and views of ADHD diagnosis and treatment as forms of social control, along with culturally biased ADHD screening tools. Moreover, a blending of historical, structural, and political influences result in a preponderance of African American families in lower socioeconomic status, and therefore vulnerable to disparities related to access to care and segregation (Paidipati et al., 2017; Saloner et al., 2013). These findings must be integrated into practice and research agendas to ensure equity in treatment of ADHD for all children.

### **Implications for Practice**

Clinicians can address culturally based ADHD treatment disparities by adopting a patient-centered approach to ADHD management. Clinicians should explore beliefs, knowledge, and misgivings regarding both the diagnosis and treatment of ADHD, in order to better provide patient education, pursue acceptable forms of treatment, and promote shared decision-making (Paidipati et al., 2013). Additionally, clinicians must be aware that initiation of a medication is not a sufficient hallmark of treatment adoption. Continued relationships, assessment, and support of African American children with ADHD and their caregivers are required to address disparities in medication adherence and persistence. Finally, clinicians can use instruments that have been



validated in diverse populations when screening for ADHD, such as the Terry and the Vanderbilt ADHD scales (Flowers & McDougle, 2010).

In addition to individual clinician efforts, healthcare infrastructure and policy must adjust to address ADHD treatment disparities. Establishing long-term partnerships in culturally relevant community-based contexts may allow mental health establishments to build trust with the African American community and identify and partner with highly-regarded change agents (Jemmott, et al., 2017). Furthermore, education establishments will need to address barriers that perpetuate the underrepresentation of African American physicians and members of the psychology workforce (Lin et al., 2015; Prince & Williams, 2017). The work of policymakers will be to ensure that neither race nor socioeconomic status, or their convergence, impede children from receiving equitable treatment for ADHD.

#### Implications for Research

Though much has been published documenting disparities in ADHD treatment, our literature synthesis demonstrates that gaps persist in knowledge needed to address medication disparities. Further research is needed to explore how assessment and diagnostic tools for ADHD are culturally sensitive and how established ADHD diagnostic rating scales are used and administered in culturally diverse communities. Additionally, participatory research is needed to determine if community-based interventions can overcome African American caregiver mistrust in the medication establishment, and specific concerns related to ADHD as a form of social control. The social control aspect specifically deserves greater attention from the medical community as only Olaniyan et al., (2007) drew attention to it, though it is a deeply-rooted tenet with hundreds of years of historical foundation (Johnson, 2013). Qualitative research exploring perspectives of African American's who have experienced the diagnosis and treatment of ADHD

as a means to subjugate African American children is needed in order to understand the contributions of social control to medication disparities, and potentially address them. Finally, research to date has not sufficiently explored the complex processes that African American families navigate when making decisions about medications for their children with ADHD. Families continually make and revisit decisions as they attempt to gain knowledge, balance behavior management with side-effects, and weigh other concerns related to ADHD medications (Rashid et al., 2018a). Decision making does not happen only once as a medication is started, or just once more as the medication is discontinued, but it is an ongoing process, particularly when caregivers have to deal with medication-related decisions on a daily basis. How African American families move through these medication decisions as a process is largely unknown. Additionally, there has been very little description of what is supportive to MDM for African American caregivers. MDM is a complex process that warrants further investigation as current research has not addressed the nuances of the African American culture. MDM is a complex process that warrants further research.

## Conclusion

The purpose of this literature review was to elaborate the current understanding of African American caregivers' experiences of MDM for their children with ADHD. More work is needed to understand MDM in African American caregivers of children with ADHD. Gaps persist in understanding how African American caregivers' perspectives on ADHD contribute to decisions regarding medication treatment at each point in the process of MDM. Failure on the part of the medical community to better understand and address the decisions of African American's related to ADHD treatment further perpetuates healthcare disparities. These

disparities must be addressed to ensure that all children with ADHD receive comprehensive treatment to succeed through their adolescence.

### **Chapter 4: Manuscript 3**

#### **Medication Decision Making in African American Families of Children with ADHD: A Mixed Methods Study**

The final manuscript, a sequential exploratory mixed method study exploring factors associated with MDM in low-income African American families of children with ADHD, addresses gaps identified in Manuscript 2. During the first phase, seven low-income African American caregivers of children with ADHD participated in semi-structured interviews focused on their experiences with MDM. Qualitative analysis resulted in seven themes including child safety and volatility, caregiver aggravation, caregiver mental health, sole caregiver status, receipt of family centered care (FCC) and shared decision making (SDM), and school involvement. These themes were validated through secondary analysis of data from a national sample of low-income African American children with ADHD who participated in the National Survey of Children's Health (NSCH). Receipt of FCC, SDM and previous receipt of special education services were independently associated with receipt of a medication for ADHD. Findings of this study indicate that clinicians practicing FCC and SDM can impact health equity for African American children with ADHD. Study results suggest that future research should focus on development of interventions to promote FCC and SDM, and the evaluation of intervention efficacy in achieving health equity.

Written permission was obtained from the manuscript co-authors to include this manuscript in the dissertation (Appendix B & Appendix E). Furthermore, this manuscript is currently under-review with the Journal of the American Academy of Child and Adolescent Psychiatry (Appendix F), the leading peer reviewed journal focused on child and adolescent psychiatry (Elsevier, 2021).

Glasofer, A., Dingley, C., Kim, J., Colosimo, R., & Gordon, H. R. D. Medication decision making in African American families of children with ADHD: A mixed methods study. Manuscript in Preparation, School of Nursing, University of Nevada, Las Vegas.

## **Abstract**

Objective: Significant pharmacotherapy disparities exist for African American children with attention-deficit/hyperactivity disorder (ADHD). Research on the factors contributing to medication decision making among African American families of children with ADHD has not been sufficient to inform interventions effective in reducing ADHD disparities. The purpose of this study was to explore how and why some low-income African American caregivers seek medical treatment for their children with ADHD. Method: This study utilized a sequential exploratory mixed method. A preliminary qualitative phase (Phase 1) designed to identify important variables to ADHD medication decision making was followed by a quantitative phase (Phase 2) to validate the emergent framework and extract findings to a larger population. Phase 1 comprised a case study of seven low-income African American caregivers of children receiving medication for ADHD who participated in semi-structured interviews. Phase 2 involved a secondary analysis of data on African American uninsured or publicly insured children age 6-17 with ADHD (n = 450) from the National Survey of Children's Health (NSCH). Results: Themes identified through qualitative analysis included child safety and volatility, caregiver mental health, caregiver aggravation, family centered care (FCC), shared decision making (SDM), sole caregiver status, and school involvement. After adjusting for ADHD severity, previous receipt of special education services and experiences of FCC and SDM were independently associated with receipt of a medication for ADHD. Conclusion: Clinicians and school personnel can intervene to decrease disparities in the treatment of ADHD.

## **Introduction**

Attention-deficit/hyperactivity disorder (ADHD) is the most common pediatric neurobehavioral disorder in the United States (US), with approximately 8.4% of children reporting a current diagnosis, and 9.4% reporting a diagnosis during their lifetime (Danielson et al., 2018a). The core symptoms of ADHD include hyperactivity, impulsivity, and inattention. These symptoms have negative impacts on academic, occupational, social, safety, and family outcomes for individuals with ADHD (Laugesen et al, 2016; Shaw et al., 2012). Fortunately, the core symptoms of ADHD are responsive to medication treatment (Wolraich et al., 2019). Pharmacotherapy for ADHD is associated with improvements across ADHD outcomes (Shaw et al., 2012). However, only about 62% of children with a current diagnosis of ADHD receive medication (Danielson et al., 2018a). Caregiver hesitancy to adopt medication treatment for children with ADHD has been related to non-physiologic explanation of ADHD symptoms, influence of friends and family, influence of media and other informal information sources, negative experiences of stigma, concerns for side effects, and fears of addiction and abuse (Gajria et al., 2014; Rashid et al., 2018a; Ross et al., 2018; Taylor & Antshel, 2021).

While medication treatment of ADHD is not optimized overall, African American, Hispanic, and other minority groups are significantly less likely to receive medication than White children (Danielson et al., 2018a; Bax et al., 2019). While trends indicate diagnostic disparities in African American children have reduced over time, medication treatment disparities have not (Glasofer & Dingley, 2021). The persistently lower rates of medication treatment in minority groups may have culturally specific origins which cannot be generalized across minorities. A recent review identified unique considerations among African American caregivers including fundamental perspectives of ADHD, norms for childhood behavior, and concerns that ADHD

treatment is a form of social control (Glasofer et al., 2021). Furthermore, attention-deficit/hyperactivity disorder (ADHD) is one pediatric mental health diagnosis in which both ethnic and socio-economic treatment disparities exist (Cummings et al., 2017). There is a need to explore within group variation in order to better connect race, socioeconomic status, and ADHD medication treatment decisions among low-income African Americans and improve equity in ADHD outcomes (Glasofer & Dingley, 2021; Sen & Waslow, 2016). Thus, the purpose of this study was to explore how and why some low-income African American caregivers seek medical treatment for their children with ADHD while others do not.

## **Methods**

### **Design**

This study utilized a sequential exploratory mixed method design (Creswell & Clark, 2011). In the current study, the key variables to measure regarding how and why some low-income African American caregivers select medication for their children with ADHD were initially unknown. Thus, a mixed method design with a preliminary qualitative phase (Phase 1) designed to identify important variables to ADHD medication decision making was followed by a quantitative phase (Phase 2) to validate the emergent framework and extract findings to a larger population (Creswell & Clark, 2011). The qualitative phase utilized a multiple case study of low-income African American caregivers of children receiving medication for ADHD following Yin's (2018) framework and resulted in thematic findings related to medication selection. Phase 2 involved a secondary analysis of a large public data set aimed to validate the relationships between the themes described in the qualitative phase and medication selection among low-income African American children with ADHD.

### **Sample and Data Source**



Participants for the qualitative phase of the study were recruited from an outpatient pediatric behavioral health clinic in an urban setting in New Jersey. Caregivers were invited to participate if they met the following inclusion criteria: (a) identified as African American , (b) identified as a caregiver of a child age 6-17 with ADHD, (c) participated in decision making regarding the medical ADHD treatment of the child, (d) the child was currently receiving a medication for ADHD, and (e) the child was uninsured or on government insurance only

After completing Phase 1, existing databases were reviewed for alignment with the themes resulting from the qualitative analysis. The National Survey of Children's Health (NSCH) was selected for triangulation of qualitative findings as most themes were represented in selected items. The NSCH is a mail- or internet-based survey conducted by the U.S. Census Bureau within the U.S. Department of Health and Human Services covering the 50 states and the District of Columbia (Child and Adolescent Health Measurement Initiative, ND). The full NSCH dataset, methodology, and procedures are publicly available at <https://www.childhealthdata.org/learn-about-the-nsch/NSCH>. The survey collects information on key indicators of health and well-being for children ages 0-17. The sample size required for this phase of the study was 276 at a power level of 0.80 and alpha = 0.05. The NSCH datasets collected from 2016-2017 and 2018-2019 were utilized. The analytical sample includes African American children age 6-17 with a current diagnosis of ADHD who were uninsured or receiving government subsidized insurance only. To compare children receiving a medication to those who were not, children were included regardless of their ADHD medication status in Phase 2.

### **Data Collection and Measurement**

After receiving institutional review board approval (Appendix G) to conduct the study, the qualitative phase commenced. One investigator (AG) approached caregivers in the clinic

waiting room and distributed fliers. After providing informed consent, each interview was preceded by collection of demographic data. Caregivers then participated in a semi-structured interview with the purpose of understanding medication decision making for their children with ADHD. Interviews were recorded, lasted approximately 1 hour, and were conducted in a private location. A small gift certificate was provided to participants. All interviews were conducted by the same investigator (AG). Interviews were conducted from February to March 2020.

For the quantitative phase, select items of the NSCH were utilized. The descriptive variables included gender, age, insurance status (public insurance or uninsured), and ADHD severity (mild, moderate, or severe). The analytical sample included only those who had responded uninsured or public insured only. The dependent variable for this study was whether currently receiving a medication for ADHD. For this variable, participants were only included in the analytical sample if they had endorsed a current diagnosis of ADHD.

For independent variables, each qualitative theme was mapped to NSCH items that best operationalized the theme. The investigators reviewed the themes, potential items, item scoring, and hypotheses until there was agreement on item selection and scoring. Ultimately, the independent variables included neighborhood safety, school safety, child volatility, a safety and volatility composite score, caregiver aggravation, caregiver mental health, family centered care (FCC), shared-decision making (SDM), receipt of special education services, and contact by the school for problems at school. Table 3 presents each theme and the associated NSCH items as well as information regarding item scoring. Volatility was an author derived composite including items that reflected behaviors that Phase 1 participants described potentially leading to unsafe situations. The child safety and volatility composite, also author derived, added parent perception of child safety in the neighborhood and school to the volatility composite. Caregiver mental

health was assessed for both the caregiver responding to the survey (Caregiver 1), and an author derived composite of combined caregiver 1 and 2 mental health. The composite scores for parent aggravation, FCC, and SDM are original to the NSCH scoring system. All other variables consist of individual items from the NSCH.

**Table 3**

*Phase 1 Qualitative Themes with Corresponding Phase 2 NSCH Database Items*

Theme	Variable Name	NSCH Items	2016-2017 Scoring	2018-2019 Scoring	Transformations	Final Scoring
Child Safety & Volatility	Neighborhood Safety	This child is safe in our neighborhood	4-Point scale from definitely agree to definitely disagree			
	School Safety	This child is safe at school	Point scale from definitely agree to definitely disagree			
	Volatility Composite	This child stays calm and in control when faced with a challenge  This child argues too much	3-point scale from not true to definitely true  3-point scale	4-point scale from never to always  4-point scale	2018-2019 converted to usually or always = definitely true, sometimes =	Composite score ranged from 3-9 with a higher score reflecting greater volatility

Theme	Variable Name	NSCH Items	2016-2017 Scoring	2018-2019 Scoring	Transformations	Final Scoring
		This child bullies others, picks on them, or excludes them	3-point scale from not true to definitely true	5-point scale from never to almost every day	2018-2019 converted to never or 1-2 times per year = not true, 1-2 times per month = somewhat true, 1-2 times per week or almost every day = definitely true	
	Safety & Volatility Composite					Total score of all items in child safety & volatility composite ranging from 5-17
Caregiver Mental Health	Caregiver 1 Mental Health	In general, how is your mental or emotional health?	5-point scale from excellent to poor		Individual responses were collapsed to two categories: good, very good, or excellent = good; poor or fair = not good	
	Caregiver 2 Mental Health	In general, how is Caregiver 2's mental or emotional health				

Theme	Variable Name	NSCH Items	2016-2017 Scoring	2018-2019 Scoring	Transformations	Final Scoring
	Composite Mental Health					Couples in which both caregivers rated mental health as good = good; couples in which one caregiver mental health as poor = not good
Caregiver Aggravation	Parent Aggravation	During the past month, how often have you felt:				If parent responded usually/always to one or more item in composite = parent usually/always aggravated from parenting; if no response of usually/always = parent seldom feels aggravation from parenting
		This child is much harder to care for than most children of his or her age?		5-point scale from never to always		
		This child does things that really bother you a lot?		5-point scale from never to always		
		Angry with this child?		5-point scale from never to always		
FCC	FCC	If this child has had a healthcare visit in the past 12 months, how often did the child's doctor or				If parent responded never/sometimes to one or more item in composite = did not receive

Theme	Variable Name	NSCH Items	2016-2017 Scoring	2018-2019 Scoring	Transformations	Final Scoring
		other health care providers:				FCC; if no response of never/sometimes in composite = received FCC
		Spend enough time with this child?	4-point scale from always to never			
		Listen to you carefully?	4-point scale from always to never			
		Show sensitivity to your family's values and customs?	4-point scale from always to never			
		Provide the specific information you needed concerning this child?	4-point scale from always to never			
		Help you feel like a partner in this child's care?	4-point scale from always to never			
SDM	SDM	If this child needed decisions made regarding health care, such as whether to get prescriptions, referrals, or				If parent responded never/sometimes to one or more item in composite = families never/sometimes feel that they are

Theme	Variable Name	NSCH Items	2016-2017 Scoring	2018-2019 Scoring	Transformations	Final Scoring
		procedures, how often did the child's doctors or other health care providers:				partners in decision making; if no response of never/sometimes in composite = families usually or always feel that they are partners in decision making
		Discuss with you the range of options to consider for his or her health care or treatment?	4-point scale from always to never			
		Make it easy for you to raise concerns or disagree with recommendations for this child's health care?	4-point scale from always to never			
		Work with you to decide together which health care and treatment choices would be best for this child?	4-point scale from always to never			
Sole Caregiver Status	Caregiver 2 Relationship to Child	How is Caregiver 2 related to this child?	Seven options including there is only one primary adult caregiver in			One primary caregiver = sole caregiver; all other responses = partnered caregiver

Theme	Variable Name	NSCH Items	2016-2017 Scoring	2018-2019 Scoring	Transformations	Final Scoring
			the household for this child			
School Involvement	Special Education Services	A: Has this child ever had an early intervention or special education plan?  B: Is this child currently receiving services under one of these plans	Yes or No			If no to A = Never; If yes to A and B = Current; If yes to A and no to B = Previous
	Contact for problems at school	During the past 12 months, how many times has the child's school contacted you or another adult in your household about any problems he or she is having with school?		3-point scale from none to 2 or more times		

*Note.* FCC = Family Centered Care; SDM = Shared Decision Making

### **Data Analysis**

Analysis for Phase 1 of the study followed Yin's (2018) framework. Interviews were digitally audio-recorded and transcribed.

Each interview was analyzed as a whole. Coding was conducted and discussed between investigators to identify potential themes,



revisions to ideas, and appropriate lines of inquiry for subsequent interviews. Cross-case synthesis was conducted to identify themes across cases (Yin, 2018). Discussion and review of the transcripts, codes, and themes continued until consensus was reached, with illustrative quotes identified for each theme.

For Phase 2 all analyses were performed with SPSS version 28. Demographic data were analyzed using descriptive statistics and frequency tables. Univariate logistic regression was conducted with each independent variable to determine if there was an association with medication receipt in the NSCH sample. Multivariate regression was subsequently conducted with all variables that were significant at the level of  $p < .05$  in the univariate analyses. One additional variable significance was included. FCC and SDM were excluded from multivariate regression as their Ns were significantly smaller than the analytical sample size. Demographic variables were also tested for association with medication receipt and included in multivariate analysis as a covariate if significant. A p-value of  $\leq .05$  was considered statistically significant.

## **Results**

### **Phase 1**

Seven individuals participated in six interviews for the qualitative portion of this study as one interview was conducted with a couple. There were five female participants and two male participants. Caregivers ranged in age from 30 to 63. All of the eight children discussed were male, and ranged in age from 6-17. They were all covered by a Medicaid plan. The mother and grandmother of two brothers were interviewed separately, one participant discussed both his nephew and stepson, and participants in four interviews discussed siblings with ADHD. Seven themes were identified in relation to medication receipt in children with ADHD of low income African American caregivers, including child safety and volatility, caregiver mental health,

caregiver aggravation, FCC, SDM, sole caregiver status, and school involvement. Table 4 presents these themes and illustrative quotes.

**Table 4**

*Qualitative Themes and Illustrative Quotes*

Theme	Illustrative Quotes
The Child’s Safety & Potential for Violence	<p>“No one wants to put their child on medication. But sometimes if you don't, you might raise a murderer. I don't know. So I'm just trying to keep him safe, and me too.”</p> <p>“Once he started taking the pills, all the lashing out stopped and trouble stopped, fights and all that stopped. But if you don't take it, I'm scared something going to happen.”</p> <p>“It's like something bad going to happen him if he keep going to messing with people, bullying people. Or one day, he might go out on the street, mess with somebody, calling people wrong names. They might kill him or beat him up or anything could happen to him. I mean I don't want nothing to happen to my son.”</p>
Caregiver Aggravation	<p>“He doesn't want to hear what I got to say. He don't want to hear my talks, my speeches, my lectures. He want to go play on his phone. I don't know what to do.”</p> <p>“His hygiene's is really bad, he forgets to take showers. I have to say</p> <p>A, did you take a shower? He say, I can't remember mom. And I thought he was joking at first. He's really serious. He really can't remember. He forgets to wash his clothes, so I have to make sure he puts it in the dryer. I constantly redirect him so many times on a daily basis.”</p> <p>“So I just got to keep emphasizing to him in the morning: "you can't talk on the phone, you got to eat, you got to take your meds, you got to clean your room in the morning, make your bed. Brush your teeth, wash your face, keep dressed and then get on the phone." I just got to keep constantly, every morning. Like I said.”</p>
Caregiver Mental Health	<p>“But I already knew how to deal with him with that behavior and that diagnosis because I was diagnosed with it. I already know about Adderall, Zoloft, Concerta, Metadate, and Ritalin.”</p>
Family Centered Care	<p>“No one listens. They listen, but it’s like going in one ear and out the other... I don’t think they had the patience to sit here like you’re sitting in here now to hear what I really have to say. They’re trying to get back to the next patient.”</p> <p>“First of all, they said this girl can’t read or write, she don’t know</p>

	<p>what she's talking about, she's not a professional. So I believe I was judged."</p> <p>"They should listen to when people are crying out. They should listen because people is not crying out just to be crying out. They really need your help. For the people who didn't help me, I definitely needed your help...I think if they would have helped me when I was crying out, it wouldn't be this deep."</p>
Shared Decision Making	<p>"I wish they knew that if they study ADHD children along with the medicine that they give them, and when a parent says not working for them to look more into it".</p> <p>"They want to try to change up your regimen on how you do things, or they think they know more than what you know because you're the parent and they're the nurse, so evidently they went to school for things like that. So they apparently think that you're not capable of knowing when your child's supposed to take the meds or how the meds are supposed to be given."</p> <p>"The reason why I didn't give it to him like that because like he sitting there talking, 'Oh he need pills'... 'Oh, you need pills'. How do you know you need pills if you don't do no test or try to find out? So I didn't give it to him."</p>
Sole Caregiver Status	<p>"He doesn't like it but he has no choice because I'm the sole custodial parent. What I say goes."</p> <p>"Most of the people, they know like why he on pills. They don't want me to give him the pills. Now I've got to hear that in my ear. Oh, nobody be there for me. I'm the one doing this, taking these kids by myself. Taking care of these kids by myself and no one else with the dad or nobody."</p> <p>"When anybody start helping me with the kids and see how they act 24/7, then you've got a say so, but until then I know I have them."</p>
School Involvement	<p>"The schools need to learn how to better handle these kids and not isolate them and put them in this one classroom. With actual kids that do have problems on learning...They put the kids that has the learning disabilities with the kids that have the mental health...So then that's when the behavior comes in, because they're not being challenged on that work, because they got them in there with the kids that already have a learning disability, but they don't have a learning disability."</p> <p>"The school had a problem with it. So they diagnosed... they had to do a psych eval first"</p> <p>"That school, It was like every day I was going up there for him."</p> <p>"Then he was always getting sent home. The school used to call me to pick [him] up. Always going to the Dean's. To the point like last year, he didn't get nothing done in school because he was coming home more than he was in school."</p>

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Two of the themes related to the child's behavior, included safety and volatility, and caregiver aggravation. The child's safety was frequently discussed by participants, as was the safety of others. Caregivers expressed concerns that the child's volatility and impulsivity might lead him to say or do something that would cause others to act violently against him. They were also fearful that the child could act violently against others, including the caregivers themselves or others in the home, and that the child's actions may ultimately result in involvement with the criminal justice system. The theme of caregiver aggravation related to experiences of frustration with the child's inattention, oppositional and off-task behaviors, and overall burden of caring for a child with ADHD. Participants described initiating medication as a means to keep their children and others safe, and to decrease oppositional and off task behaviors. Caregivers believed that medications were helping with impulsivity, and felt that maintaining a medication regimen was important to future safety; however, they expressed continued frustration with oppositional relationships and having to keep children on task.

Caregiver experiences with both medical and school systems shaped medication decision making for their children with ADHD. Participants felt clinicians had at times included them in decision making, while other times they had unilaterally made treatment decisions without consulting the caregiver or considering their individual needs. Some caregivers described feeling dismissed because they believed clinicians perceived them as uneducated. For these participants, being included in decision making and seen as an individual was important to agreeing to medication treatment for their children, while feeling dismissed led to feelings of indecision and mistrust. When caregivers felt their child's needs were not being met, they were persistent in seeking other resources for treatment. Caregivers also described both positive and negative experiences with schools. They expressed frustration that their days were frequently disrupted by

calls from school, and feeling that the child's behavioral needs were misinterpreted as lower intelligence. Conversely, they described appreciation to the schools for identifying the need for treatment, and for partnering in identifying when medications had been missed or administering medications during school hours.

The final themes related directly to the caregivers' life experiences and the influence of family. The theme of caregiver mental health encompassed caregivers' own mental health and history with medications for behavior health diagnoses and that of their family members. All of the caregivers interviewed were themselves on a medication for a psychiatric diagnosis, or had a spouse, sibling, or parent who was being treated. They all described favorable past experiences with psychoactive medications, and expressed that this supported their decision to use medication to treat their child's ADHD. Sole parent status comprised experiences specific to single parents and medication decision making. While participants who were single parents discussed consulting with family, they expressed that the decision to medicate rested solely with themselves. They associated feelings of being alone in dealing with the challenges of parenting a child with ADHD with a right to independence in making decisions regarding treatment.

## **Phase 2**

After limiting the NSCH database to African American children age 6-17 with a current diagnosis of ADHD who were uninsured or on public insurance and had data available for the outcome variable (currently receiving a medication for ADHD), the final sample size was 450. Overall, 69.1 % (n = 311) of the sample was currently receiving a medication for ADHD. Table 5 presents characteristics of the study sample. The only demographic variable associated with medication status was ADHD severity. Children with moderate and severe ADHD were more

likely to be receiving medication than children with mild ADHD,  $X^2(2, n = 438) = 25.46, p < .001$ .

**Table 5**

*Descriptive Statistics*

Characteristic	Phase 2 Total (n=450)  n(%)	Phase 2 Currently Taking ADHD Medication (n=311)  n(%)	Phase 2 Not Currently Taking ADHD Medication (n=139)  n(%)
Age, y			
6-9	114(25.3)	78(68.4)	36(31.6)
10-13	179(39.8)	137(76.5)	42(23.5)
14-17	157(34.9)	96(61.1)	61(38.9)
Sex			
Male	319(70.9)	225(70.5)	94(29.5)
Female	131(29.1)	86(65.6)	45(34.3)
Insurance Status			
Uninsured	44(9.8)	26(59.1)	18(40.9)
Public Insurance	406(90.2)	285(70.2)	121(29.8)
ADHD Severity			
Mild	130(29.7)	71(54.6)	59(45.4)
Moderate	200(45.7)	136(68.0)	64(32.0)
Severe	108(24.7)	92(85.2)	16(14.8)
Safety & Volatility Composite Score	8.42 ± 1.97*	8.39 ± 1.90*	8.48 ± 2.12*
Volatility Composite Score	5.29 ± 1.44*	5.37 ± 1.45*	5.12 ± 1.43*
Safety in Neighborhood			
Definitely Safe	215(48.6)	159(74.0)	56(26.0)
Somewhat Safe	172(38.9)	114(66.3)	58(33.7)
Somewhat Unsafe	33(7.5)	19(57.6)	14(42.4)
Definitely Unsafe	22(5.0)	13(59.1)	9(40.9)
Safety in School			
Definitely Safe	262(60.1)	190(72.5)	72(27.5)
Somewhat Safe	142(32.6)	88(62.0)	54(38.0)
Somewhat Unsafe	24(5.5)	15(62.5)	9(37.5)
Definitely Unsafe	8(1.8)	6(75.0)	2(25.0)

Caregiver 1 Mental Health			
Good	372(84.2)	266(71.5)	106(28.5)
Not Good	70(15.8)	46(65.7)	24(34.3)
Caregiver 2 Mental Health			
Good	340(81.0)	243(71.5)	97(28.5)
Not Good	80(19.0)	46(57.5)	34(42.5)
Parent Aggravation			
Aggravated	110(24.6)	75(68.2)	35(31.8)
Not Aggravated	338(75.4)	235(69.5)	103(30.5)
Sole Caregiver Status			
Sole Caregiver	215(50.4)	147(68.4)	68(31.6)
Partnered Caregiver	212(49.6)	147(69.3)	65(30.7)
Special Education Services			
Never	46(10.4)	26(56.5)	20(43.5)
Current	233(52.7)	155(66.5)	78(33.5)
Previous	163(36.9)	122(74.8)	41(25.2)
Contact by school in last 12 months			
None	98(22.4)	58(59.2)	40(40.8)
1	75(17.1)	50(66.7)	25(33.3)
≥2	265(60.5)	192(72.5)	73(27.5)
Family Centered Care			
Yes	297(77.1)	218(73.4)	79(26.6)
No	88(22.9)	49(55.7)	39(44.3)
Shared Decision Making			
Yes	135(79.4)	104(77.0)	31(23.0)
No	35(20.6)	20(57.1)	15(42.9)

Note. Total number of subjects varies for each variable due to the missing value. \* Mean ± standard deviation

The results of the univariate and multivariate logistic regressions are presented in Table 6. Figure 4 depicts the hypothesized and final study models. In univariate analysis, safety and volatility, parent aggravation, and sole caregiver status were not significantly related to taking a medication for ADHD. Variables with statistically significant or borderline significant associations with taking a medication on univariate analyses were included in multivariate logistic regression. These variables included safety in neighborhood, safety in school, caregiver mental health, receipt of special education services, and contact by school regarding problems with school. The regression model was statistically significant,  $X^2(12, n = 389) = 28.27, p =$

.005. The model explained 9.8% (Nagelkerke's  $R^2$ ) of the variation in ADHD medication treatment. After accounting for ADHD severity, the model was statistically significant  $X^2(14, n = 389) = 50.382, p = .001$ , and explained 16.9% (Nagelkerke's  $R^2$ ) of variation in ADHD medication treatment. In multiple regression, safety in school and neighborhood, and caregiver mental health were not associated with taking a medication. Children of caregivers who had been contacted by the school for problems in school more than once in the past year were twice as likely to be taking a medication than children whose parents had never been contacted (OR = 2.20, 95% CI [1.28-3.78]). However, this relationship was no longer significant after accounting for ADHD severity. Children who previously received special education services were more than twice as likely to be treated with a medication than those who never received services (OR = 2.61, 95% CI [1.23, 5.52], after accounting for ADHD severity (AOR = 2.86, 95% CI [1.31-6.22]).

Because FCC was only measured in individuals who had experienced a medical visit in the past year, and SDM was only measured in individuals who had made a medical decision in the past year, their sample sizes were smaller than other variables measured (FCC  $n = 374$ ; SDM  $n = 165$ ). Therefore, FCC and SDM were not included in multivariate regression analysis. In univariate analysis, children from caregivers who experienced FCC were twice as likely (OR = 2.20, 95% CI [1.34, 3.60]) to be taking a medication than those without this experience.

Similarly, children from caregivers who experienced SDM were more than twice as likely (OR = 2.52, 95% CI [1.15, 5.49]) to be taking a medication. Both relationships remained significant after accounting for ADHD severity (FCC AOR = 2.78, 95% CI [1.64, 4.73]; SDM AOR = 3.26, 95% CI [1.42, 7.50]).



**Table 6***Factors Associated with Medication Taking by Univariate and Multivariate Analysis*

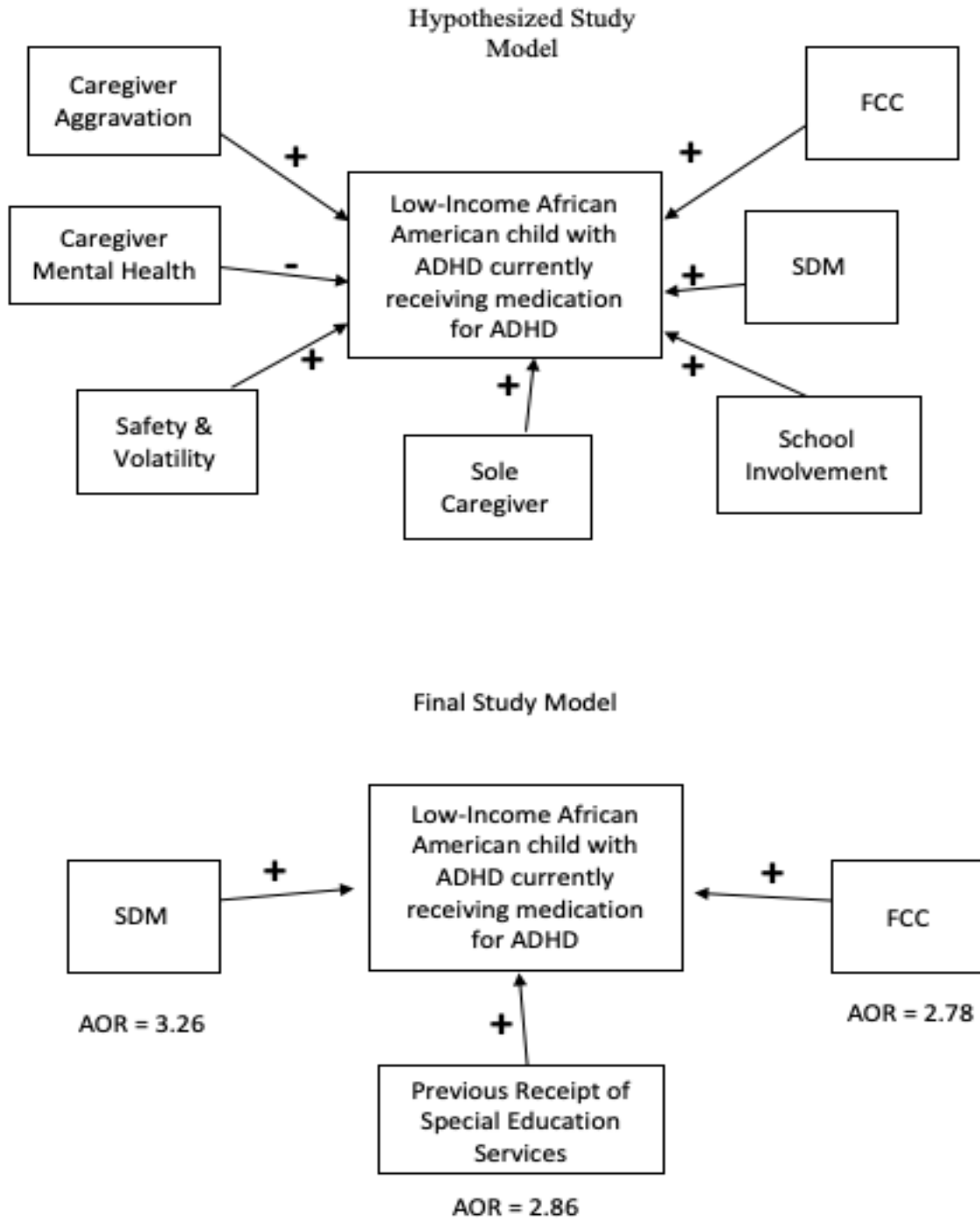
Related Theme	Variable	Univariate Analysis		Multivariate Analysis		AOR(95% CI)	P
		OR(95% CI)	P	OR(95% CI)	P		
Safety & Volatility	Safety & Volatility Composite	0.98(0.88-1.08)	.664				
	Volatility Composite	1.13(0.98-1.31)	.093				
	Safety in Neighborhood						
	Definitely Safe	Reference		Reference		Reference	
	Somewhat Safe	0.69(0.45-1.07)	.101	0.78(0.47-1.30)	.337	0.72(0.42-1.22)	.221
	Somewhat Unsafe	0.48(0.23-1.11)	.055	0.74(0.29-1.87)	.524	0.62(0.24-1.62)	.331
	Definitely Unsafe	0.51(0.21-1.26)	.142	0.76(0.25-2.30)	.630	0.78(0.24-2.52)	.682
	Safety in School						
	Definitely Safe	Reference		Reference		Reference	
	Somewhat Safe	0.62(0.40-0.95)	.030	0.66(0.39-1.10)	.112	0.71(0.42-1.21)	.210
	Somewhat Unsafe	0.63(0.27-1.51)	.300	0.87(0.31-2.46)	.795	0.87(0.30-2.52)	.797
	Definitely Unsafe	1.14(0.22-5.76)	.877	1.21(0.20-7.40)	.836	0.84(0.12-5.84)	.860
Caregiver Mental Health	Caregiver 1 Mental Health						
	Good	Reference		Reference		Reference	
	Not Good	0.53(0.32-0.90)	.018	0.63(0.17-2.27)	.479	0.48(0.13-1.78)	.272
	Caregiver Composite Mental Health						
	Good	Reference		Reference		Reference	
	Not Good	0.54(0.33-0.89)	.016	0.64(0.20-2.11)	.466	0.74(0.22-2.46)	.623
Caregiver Aggravation							
	Aggravated	Reference					
	Not Aggravated	1.07(0.67-1.69)	.791				

Sole Caregiver Status							
	Sole Caregiver	Reference					
	Partnered Caregiver	1.05(0.69-1.58)	.829				
School Involvement							
	Special Education Services						
	Never	Reference		Reference		Reference	
	Current	1.53(0.80-2.91)	.196	1.46(0.73-2.94)	.286	1.47(0.71-3.03)	.300
	Previous	2.29(1.16-4.53)	.017	2.61(1.23-5.52)	.012	2.86(1.31-6.22)	.008
	Contact by school in last 12 months						
	None	Reference		Reference		Reference	
	1	1.38(0.74-2.58)	.315	1.47(0.73-2.93)	.280	1.40(0.69-2.86)	.356
	≥2	1.81(1.12-2.95)	.016	2.20(1.28-3.78)	.004	1.48(0.83-2.64)	.183
Family Centered Care							
	No	Reference		-			
	Yes	2.20(1.34-3.60)	.002	-		2.78(1.64-4.73)	<.001
Shared Decision Making							
	No	Reference		-			
	Yes	2.52(1.15-5.49)	.020	-		3.26(1.42-7.50)	.005

Note. AOR = Odds Ratios adjusted for ADHD severity

**Figure 4**

*Hypothesized and Final Study Models*



*Note.* FCC = Family Centered Care; SDM = Shared Decision Making

## **Discussion**

The results of this study validated through qualitative and quantitative methods that experiences with healthcare providers and schools are key to medication decision making in low-income African American families of children with ADHD. Moreover, as clinicians are responsible for determining ADHD severity, the significance of ADHD severity as a covariate highlights the role of clinicians in influencing which children receive medication for ADHD. Although the quantitative results did not substantiate the relationships between taking a medication for ADHD and caregiver mental health, child safety and volatility, or sole caregiver status, these topics warrant further discussion.

Concerning experiences with healthcare providers, caregiver report of experiencing FCC and SDM were associated with medication treatment for ADHD in both phases of this study. Conversely, experiences of being dismissed or excluded from decision making were met with indecision regarding selection of medication in case study participants. While the significance of FCC in ADHD treatment outcomes have previously been noted, the findings of this study highlight the importance of these experiences in an underserved demographic (Hinojosa et al., 2012; Hogue et al., 2016). Though more than 75% of the sample in the quantitative portion of this study endorsed experiencing FCC; previous research has identified that families of poor, uninsured, and minority children with special health care needs are less likely to experience FCC and SDM, as are children with ADHD compared to those with medical diagnoses (Butler et al., 2015; Coker et al., 2010; Denboba et al., 2006). Specifically, in African American families of children with special healthcare needs, disparities in time spent with the physician and sensitivity to family values and customs have been identified (Coker et al., 2010). Clinicians must recognize that the application of their expertise in concert with FCC and SDM can ensure that the most

vulnerable children receive evidence-based treatment for ADHD. When practicing FCC and SDM, clinicians should consider the customs and values known to influence medication decision making in African American caregivers, including caregiver perspectives on norms for childhood behavior, explanatory model for ADHD, previous knowledge of ADHD, and experiences of ADHD as a form of social control (Glasofer et al., 2021). Future research should develop and test interventions to increase clinician capability, motivation, and opportunity to engage in SDM (Boland et al., 2019; Hayes et al., 2019).

The association between school systems and taking a medication for ADHD in low-income African American children was made explicit by participants of the qualitative phase of this study, and in part validated by the quantitative analysis. Receipt of special education services is evidently important to taking a medication for ADHD in low-income African American children. Interestingly, previous receipt of special services was associated with medication treatment while current services was not. The cross-sectional nature of this study makes it difficult to determine the reasons for this finding. Though the exact nature of the relationship between receiving special education services and taking a medication for ADHD cannot be determined based on these results, it is evident that special education programs can influence ADHD treatment.

Conversely, calls to home regarding school performance was not independently associated with medication taking. However, it remains an important experience for caregivers in the studied population. Over 60% of the NSCH sample had received two or more phone calls in the past year. This is in stark contrast to only 10% of families in the overall 2019 NSCH database receiving two or more calls. Qualitative participants spoke about the stress that these phone calls can cause, interrupting their workdays, and leaving caregivers feeling that they are responsible to

solve school problems. The content and frequency of these phone calls may reflect the more pervasive problem of disparities in school disciplinary outcomes, including higher rates of disciplinary referrals, corporal punishment, suspensions, and inconsistent application of sanctions for African American children (Welsh & Little, 2018). These findings suggest that school personnel can act to widen ADHD treatment disparities, or advance healthcare equity for African American children with ADHD. While schools are known to be as a major source of referral for medical treatment of ADHD (Arya et al., 2015; Sax & Kautz, 2003), the findings of this study emphasize the role of the school specific to low-income African American children with ADHD. Future research should explore the nature of communication between teachers and caregivers of African American children with ADHD. Additionally, research is needed to understand the temporal relationship between medication treatment and exit from special education services noted in this study. Interventions should focus on supporting teachers to partner with African American caregivers of children with ADHD, and developing partnerships between school districts and medical providers to ensure appropriate referrals for ADHD care and improve access to care for vulnerable populations.

Though the themes of caregiver mental health, child safety and volatility, and sole caregiver status related to medication taking in the qualitative results of this study, the relationships were not confirmed in quantitative analysis. Various reasons exist for the absence of positive findings. For caregiver mental health, the absence of significant findings likely reflect a poor fit between theme content and NSCH items. Specifically, caregivers discussed the relationship between their own experiences with medications for behavioral health diagnoses and the choice to select medication for their children with ADHD. The NSCH items most closely related to this asked about caregiver mental health, but did not ask about caregiver medications.

Given that ADHD is highly heritable (Larsson et al., 2014), with nearly half of children with ADHD having a parent with ADHD (Starck et al., 2016), the relationship between caregiver mental health and medication taking and child receipt of medication should be further investigated. Additionally, there is potential for clinicians to explore parental experiences with medication for ADHD and other behavioral health diagnoses, and incorporate this in medication decision making.

Measurement issues as well as sampling considerations may have contributed to the absence of quantitative findings for child safety and volatility. In qualitative interviews, participants made a direct connection between concerns for the child's safety and volatility and their decisions to initiate and maintain children on ADHD medications. All of the Phase 1 participants were drawn from an urban area in southern New Jersey that is historically rated as one of the most dangerous cities in the US (Schiller, 2021). In contrast only 5% of the quantitative sample rated their child as definitely unsafe in the neighborhood and less than 2% definitely unsafe at school. It is unclear if this is a true reflection of the safety of African American children living in poverty, or undersampling in families living in unsafe neighborhoods. Moreover, the rating of neighborhood and school safety may be subjective, as individuals living in different settings may have differing definitions of safety. Regardless, the low proportion of respondents perceiving unsafe conditions for their children limits conclusions that can be drawn about the relationship between child safety and being on a medication for ADHD.

Unlike child safety and volatility, the theoretical relationship between parent aggravation and ADHD medication treatment was tenuous based on Phase 1 interviews. Though aggravation was frequently expressed by participants, including frustration with hyperactive, impulsive, and

off-task behaviors, they also expressed tolerance for these behaviors. Caregivers hoped that medications would help with hyperactivity, but noted little change. Some caregivers allowed for medication vacations when the child was not in school, or remained unsure that these behaviors required treatment. Quantitative analysis confirmed that parent aggravation is not associated with medication treatment in this population. This finding is consistent with previous research exploring norms for childhood behavior in African American caregivers. Using a standardized instrument, Hillemeier et al. (2007) found that at the same level of hyperactivity, White parents were more likely to endorse hyperactive behaviors than African American parents. DosReis et al. (2007) found that African American caregivers selected treatment for their children with ADHD as a result of third party intervention rather than their own concerns for behavior. This finding again underscores the significance of outside influences, like schools and healthcare providers, in medication decision making among low-income African American caregivers of children with ADHD. It also highlights the importance of the need to explore individual customs and values as considerations when engaging in shared decision making.

The final finding of the qualitative analysis was the relationship between being a sole caregiver of a child with ADHD and medication treatment. Interview participants who were sole caregivers spoke of the burdens of being the only parent responsible to meet the demands of parenting a child with ADHD, and how this justified their choice to initiate medication treatment. However, the quantitative analysis did not confirm this relationship. It is likely that this commonality in the Phase 1 sample reflects additional influences. For example, the fact that caregivers presented to a medical setting may indicate that they were more likely to adopt a biological explanatory model for ADHD, which is associated with selection of medication treatment (Pham et al., 2010). Though not necessarily related to medication decision making,



clinicians should explore the resources and supports available to sole caregivers of children with ADHD.

Regarding limitations of our study, the nature of qualitative research and the small sample size present opportunity for bias and limit generalizability of findings. Multiple methods of triangulation were utilized to address these concerns (Patton, 2015). Data sources were triangulated through inclusion of multiple cases to incorporate varying perspectives. Investigator triangulation allowed for multiple observations, conclusions, and confirmation of findings. Finally, methodological triangulation through conduct of a sequential quantitative phase sought to confirm whether the perspectives of the qualitative sample were shared by a broader sample, and to allow for generalizability (Patton, 2015).

The quantitative phase of this study has limitations as well. The NSCH was selected as items provided the best available match to themes identified in the qualitative phase. However, survey items were not an exact representation of qualitative findings. Future instrument development may be necessary to better measure factors associated with medication decision making in diverse populations. The overall NSCH response rate ranged between 37.4-42.2% for the included years; however, the response rate in the target demographic for this study is not known. A low response rate may have led to a biased sample. Additionally, it is possible that caregiver responses were biased related to poor recall or stigma. If so, the prevalence of taking a medication for ADHD reported may not be accurate. Moreover, there is a lack of specificity regarding medication treatment. Consequently, we were unable to report on types of medications, doses, duration of therapy, or consistency in taking medications as prescribed and cannot estimate medication treatment quality. As demonstrated in the qualitative findings of this study, medication decision making is a dynamic process. While the quantitative findings offer

some insight into the factors associated with medication taking in low-income African American children with ADHD, they leave gaps in our understanding of how medication decision are made over time.

To conclude, the present study explored medication decision making in low-income African American caregivers of children with ADHD, and tested qualitative findings in a sequential quantitative analysis. Qualitative findings indicated that child volatility and safety, caregiver mental health experiences, caregiver aggravation, sole caregiver status, experiences of FCC and SDM, and experiences with school intervention would be associated with the decision to select medication treatment. In quantitative analysis, only previous receipt of special education services, as well as experiences of SDM and FCC were independently associated with current receipt of a medication after accounting for ADHD severity. Critically, these findings indicate that clinicians and school personnel can intervene to decrease disparities in the treatment of ADHD. Moreover, there are variations within minority groups that must be understood and addressed in order to improve healthcare equity. Finally, medication decision making needs to be understood as a process. Measures of treatment quality including medication type, dose, treatment duration, and consistency in taking recommended treatment regimens need to be the standard reported outcomes rather than simplistic measures of ADHD medication treatment prevalence in order to truly address ADHD treatment equity.

## **Chapter 5: Summary and Discussion**

In this chapter, a summary is provided for the study that was conducted, including findings, strengths, and limitations. The implications of the findings to healthcare education and practice are articulated. Furthermore, suggestions for future research are included.

### **Summary of the Study**

This study was comprised of three manuscripts that focused on understanding ADHD medication treatment disparities in African American children. The first manuscript was a literature review of ADHD diagnostic and medication treatment disparities in African American children. The findings established the foundation for further exploration of reasons for ADHD treatment disparities in this population. The second manuscript was a review of the literature on MDM in African American caregivers of children with ADHD. Based on the findings of this review, gaps were identified requiring further research before meaningful interventions can be implemented to narrow medication treatment disparities. The third manuscript reported results of a sequential exploratory mixed method study exploring how and why some low-income African American caregivers select medication for their children with ADHD, and testing the proposed framework. The institutional review boards (IRBs) of the University of Nevada, Las Vegas and the recruitment site (Virtua Health) granted permission to conduct the mixed method study.

### **Findings**

In the first manuscript, a review and synthesis of the literature on diagnostic and medication treatment disparities in African American children was presented. In total, 41 studies published between 1999 and 2021 were included, with 38 cross-sectional studies, and three longitudinal studies. Twenty-one of the included studies reported ADHD prevalence by race. Within this sample of studies, ADHD prevalence was significantly lower in African American

children compared to white children in 14 (66.7%) studies, while 5 studies (23.8%) reported no significant difference, and 2 studies (9.5%) reported a significantly greater prevalence of ADHD among African American children than White children. Regarding medication treatment disparities, fifteen of 23 studies (65%) found that African American children with ADHD were significantly less likely than White children with ADHD to be receiving a medication, while eight (35%) found no significant difference between the groups. Treatment disparities were also quantified in terms of medication adherence and discontinuation in three studies. Results of these studies consistently reported treatment quality to be poorer among African American children compared to White children.

Diagnostic and treatment disparity outcomes were analyzed for trends over time. Each study's reported odds for African American children either receiving a diagnosis of ADHD or receiving a medication for ADHD were plotted against the year the data was collected. The synthesis concluded that ADHD diagnostic disparities showed a trend toward reduction over time, with the earliest data points grouped around an OR of 0.50 for ADHD diagnosis in African American children, and final data points grouped around an OR of 0.90. The data points clustered near the trend line. Conversely, medication treatment disparities did not follow the same course. The treatment odds initially clustered around 0.50 and later around 0.75. The data points were spread further from the trend line, indicating there was little association between time and ADHD treatment disparities.

Very few studies assessed treatment quality, including medication selected, dosing, formulation, or medication taking behaviors such as treatment duration, or alignment between prescribed and actual dosing. Findings of the review were limited by the heterogeneity and bias of methods in included studies and lack of culturally sensitive standardized tools for the

assessment of ADHD. The review recommended that future research address the noted limitations, further explore treatment quality, and describe within group variations to identify factors contributing to MDM in African Americans.

The second manuscript provided a synthesis of the evidence on MDM in African American caregivers of children with ADHD. Fourteen publications, comprising seven observational, four qualitative, and three mixed method studies were included. The findings of this review demonstrated that SDOHs as well as experiences of structural and cultural racism and discrimination shaped the MDM beliefs and behaviors of African American caregivers of children with ADHD. Three themes were found to influence MDM including fundamental perspectives of ADHD, cultural norms for child behavior, and experiences of ADHD as a form of social control.

The theme of fundamental perspectives of ADHD and cultural norms for childhood behavior contained three subthemes: ADHD knowledge, ADHD explanatory model, and ADHD cultural perceptions. ADHD knowledge pertained to the caregivers' scientific knowledge of ADHD. In general, African American caregivers reported less formal knowledge of ADHD, and fewer contacts with individuals who had ADHD. An explanatory model refers to an individual's beliefs about an illness and its treatment, and the meaning attributed to that illness and treatment (Kleinman, 1980). This review found that African American caregivers were less likely to endorse medical or biological explanatory models for ADHD, and more likely to endorse explanatory models related to parenting or nutrition. Finally, cultural perceptions related to normal childhood behavior, especially an acceptance of hyperactivity in boys, was noted in African American caregivers. In the second theme, each of the subthemes of fundamental perspectives of ADHD and cultural norms for childhood behavior was connected to MDM.

Caregivers with less formal ADHD knowledge, a non-biological explanatory model for ADHD, or tolerance for hyperactivity were less likely to select medication treatment for ADHD. African American caregivers expressed greater uncertainty in the efficacy of ADHD medications, and greater concerns for side effects and addiction than White counterparts. Finally, African American caregivers were unique in expressing concerns regarding ADHD as a form of social control. This partially related to concerns for addiction and the historical introduction of illicit substances in African American communities (Olaniyan et al., 2007). Additionally, the social control theme encompassed experiences of the diagnosis and treatment of ADHD being used to gain control over African American children at the behest of third parties (Olaniyan et al., 2007). Recommendations for future research included further exploring how experiences of racism contribute to ADHD treatment disparities and how these experiences can be addressed, identification of barriers and facilitators to MDM, development of culturally sensitive ADHD screening and diagnostic tools, investigation of within group variations, and exploration of MDM as a process rather than an outcome.

The final manuscript presented a sequential exploratory mixed method study exploring factors and testing their associations with MDM in low-income African American families of children with ADHD. A preliminary qualitative case-study following Yin's (2018) framework was conducted in a sample of seven low-income African American caregivers of children with ADHD recruited from an outpatient clinic in an urban New Jersey neighborhood. A total of seven caregivers participated in six semi-structured interviews. Participants included mothers, a step-father, and uncle of one child who was also the step-father of another child with ADHD, and one grandmother. One step-father was interviewed concurrently with the child's mother. Interviews were analyzed as a whole, with line-by-line coding followed by second level coding

and identification of themes. cross-case synthesis was conducted to identify themes across cases, and discussion of codes and themes ensued until consensus was reached. Themes identified from analysis of semi-structured interviews included child safety and volatility, caregiver aggravation, caregiver mental health, sole caregiver status, school involvement, FCC and SDM.

In the second phase, a secondary analysis of data from the NSCH was conducted to test the relationships proposed by the preliminary framework. The NSCH is a mail- or internet-based survey conducted by the U.S. Census Bureau within the U.S. Department of Health and Human Services covering the 50 states and the District of Columbia. The survey collects information on key indicators of health and well-being for children ages 0-17. Data from the 2016-2019 surveys were utilized. Qualitative themes were mapped to NSCH items that best operationalized the theme. The investigators reviewed the themes, potential items, item scoring, and hypotheses until there was agreement on item selection and scoring. The independent variables included neighborhood safety, school safety, child volatility, an author derived safety and volatility composite score, caregiver aggravation, caregiver mental health, family centered care (FCC), shared-decision making (SDM), receipt of special education services, and contact by the school for problems at school. The outcome variable was receipt of a medication for ADHD. Additionally, demographic and descriptive variables included age, gender, insurance status (uninsured or public insurance), and ADHD severity (mild, moderate, severe).

The Phase 2 sample included 450 African American children age 6-17 with no insurance or public insurance only who were diagnosed with ADHD. Univariate and logistic regression analyses were conducted to identify relationships between independent variables and receipt of a medication for ADHD. After accounting for ADHD severity, only previous receipt of special

education services, and experiences of FCC and SDM were independently associated with medication treatment.

**Strengths.** The breadth and depth of the initial manuscript provided a comprehensive state of the science on ADHD disparities in African American children on which to base research priorities. Resulting from findings of the first manuscript, the second manuscript uncovered gaps in knowledge of how African American's make decisions regarding the medical treatment of ADHD in their children. The final manuscript had several strengths. First, it addressed gaps identified by the first two manuscripts. Specifically, the qualitative phase of the study provided an in-depth exploration of MDM in low-income African American caregivers of children with ADHD. The level of detail provided by participants allowed for insights on ADHD treatment disparities that had not previously been identified. Additionally, the second phase compared MDM factors within low-income African American families. This is unlike the majority of existing literature that compares all African American individuals to a White reference group. Within group studies, such as this one, are essential to understanding heterogeneity within race, and allow for the development of targeted interventions to address healthcare disparities (Whitfield et al., 2008). For example, the significance of FCC and SDM to low-income caregivers of children with ADHD had not previously been described. Finally, selecting a mixed method design allowed for an inductive approach to an underexplored topic with subsequent verification of findings. The Phase 2 sample was adequately powered and drawn from a national database. Thus, the findings can be generalized to a broader population than if utilizing qualitative methods alone.

**Limitations.** Constraints associated with data collection and investigator bias limit the scope and validity of the exploratory phase of this study. Recruitment was prematurely



concluded due to the coronavirus disease 2019 pandemic. Furthermore, the researcher was not African American and not previously known to participants. Her status as an outsider may have limited lines of inquiry, and restricted participant disclosure of information regarding their experiences of MDM. The researcher's bias may have influenced interpretation of data. Multiple strategies were incorporated to limit bias including inclusion of multiple cases, cross-case comparisons and confirmation with a second investigator (Yin, 2018). Despite these tactics, the potential for bias to limit findings cannot be eliminated. Ultimately, data was insufficient to generate a theory of MDM. However, there was adequate data from which to propose and test a preliminary framework.

The use of secondary data analysis further limits the validity of findings. Information on the response rate in the target population was not available. A low response rate may have biased findings. Moreover, NSCH items selected were the best approximation of themes using information available to test associations between themes and receipt of a medication for ADHD; however, they were not an exact representation of desired information. Additionally, responses relied on caregiver recall which may be inaccurate due to poor recall or stigma associated with ADHD. Finally, the instrument may not have performed similarly across participants. Some SDOH, such as neighborhood environment or social network, may have influenced participant interpretation of items and responses, thus limiting the ability to identify differences between participants.

## **Implications**

**Implications for Practice.** The three manuscripts have several implications for practice. The first manuscript indicates that despite more than twenty years of research describing inequity in the treatment of ADHD for African American children, we have not responded sufficiently to

address this disparity. The second manuscript reveals that some interventions to address disparities may be simple. For example, given the low exposure to formal sources of ADHD information or other individuals with ADHD, educational efforts in African American communities, particularly if delivered by other community members, may be effective in addressing knowledge gaps that contribute to treatment disparities. Conversely, other factors may be more difficult to address. Both the second and third manuscript reveal the significance of internalized racism to MDM. Concerns regarding addiction, social control, child safety, and being dismissed by clinicians stem from experiences of living as African Americans. The main finding of the third manuscript implies that the influence of these experiences on ADHD treatment disparities can be overcome by clinicians and educators. Incorporating FCC and SDM in clinician interactions with low-income families of children with ADHD will be essential to achieving equity in ADHD outcomes. For example, clinicians should explore ADHD explanatory models or expectations for childhood behavior with African American families, and incorporate these factors into SDM for ADHD treatment. Interventions are required to address the most common barriers to FCC and SDM amenable to clinician influence. These include lack of time, lack of high quality culturally and developmentally appropriate family education materials, and lack of clinician skill in eliminating power gradients and fostering SDM, trust, and respect in interactions with children and their families (Boland et al., 2019). Finally, clinicians must collectively and individually reflect on how we contribute to the ongoing disparities in ADHD treatment and confront our biases in order to fully engage in FCC and SDM.

In the final manuscript, schools were also revealed as an important factor in ADHD MDM. Schools can serve as a pipeline to the proper identification and treatment of ADHD in low-income African American children. Programs offering training to educators, especially those

working in special education, on recognition of ADHD symptoms and strategies to collaborate with and support families of children with ADHD, as well as confronting unconscious bias are key to promoting health equity. Likewise, developing partnerships between schools and healthcare practices in underserved communities can address access barriers. School nurses can play an invaluable role in acting as a bridge between the school and medical communities by developing ongoing and deep relationships with African American families of children with ADHD and advocating for their needs to external agencies, by screening for children who are not adequately treated, and by building partnerships with community agencies to connect children with services.

**Implications for Education.** Though concepts of SDM and FCC are not new to healthcare, they have proved difficult to operationalize. Education is a starting point for improved practice of SDM and FCC. Efforts to educate clinicians in FCC and SDM may be effective in addressing barriers to implementation (Barr et al., 2014; Durand et al., 2018; Legare et al., 2018). Concepts of FCC and SDM as well as practical application training should be incorporated in both pre-licensure and continuing education for clinicians (Barr et al., 2014; Park & Choi, 2020). Additionally, there is a need for patients to be prepared to participate in SDM (Legare et al., 2018).

### **Recommendations for Future Research**

Numerous studies are indicated based on the entirety of this dissertation. Findings from the first manuscript suggest a need for similar investigations in other marginalized populations. Many of the studies included also provided data on Hispanic children, and there have been reviews of ADHD diagnostic and treatment disparities in this population (Eiraldi & Diaz, 2010). However, information on disparities in other ethnicities, such as Asian, Native Hawaiian or other

Pacific Islander, Native American, or Alaskan Native, is absent. Also, there is a need to measure disparities in treatment quality rather than focusing on treatment prevalence. In children who have been prescribed a medication or ADHD, large surveys such as the NSCH should measure additional items including prescribed medication name, dose, frequency, formulation, and duration of treatment. Additionally, medication taking behaviors should be better described including how often the medication is taken as prescribed, how medication taking varies from the prescribed regimen, and root causes of discrepancies between medication taking and the prescribed regimen. Finally, ADHD medication treatment may require trial and error for optimization of efficacy and minimization of side effects (Wolraich. et al., 2019). Patients may expect trials with different medications as well as dosage titrations before arriving at the ideal regimen. Research is needed to explore if and how the medication initiation process contributes to disparities.

The second manuscript revealed that investigation of how experiences of racism and discrimination, or internalized racism (Williams et al., 2019) contribute to MDM in African American caregivers of children with ADHD is necessary. The third manuscript offered insights to this end; however, a single study cannot fully address this gap in the literature. There is also a need to explicate the process of MDM. This can be accomplished through qualitative research, specifically a grounded theory study aimed at delineating the process of MDM in African American caregivers of children with ADHD. The third manuscript was an initial step in this direction, but does not provide a complete understanding of African American caregiver experiences, or MDM as a process. The third manuscript also illuminates additional areas for future research. A large body of research exists evaluating interventions for increasing SDM and FCC however, the efficacy of these interventions is uncertain (Legare et al., 2018; Park et al.,

2018). Further, there is an absence of studies evaluating the impact of SDM on equity (Legare et al., 2018). The findings of the current study underscore the importance of conducting high quality studies to identify interventions promoting FCC and SDM, and evaluate their efficacy in achieving health equity for children with ADHD.

## Appendix A

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## **Appendix B**

### **Co-author Written Permission for Manuscripts 1, 2, & 3**

As second author, I grant permission for inclusion of the following manuscripts in this dissertation document. Diagnostic and medication treatment disparities in African American children with ADHD: A literature review is included as Chapter 2: Manuscript 1. Medication Decision Making in African American Caregivers of Children with ADHD: A Review of the Literature is included as Chapter 3: Manuscript 2. Medication Decision Making in African American Families of Children with ADHD: A Mixed Method Study is included as Chapter 4: Manuscript 3.

Catherine Dingley, PhD, RN FNP, FAAN

## Appendix C

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## **Appendix D**

### **Co-author Written Permission for Manuscripts 2**

As co-author, I grant permission for inclusion of the following manuscript in this dissertation document. Medication Decision Making in African American Caregivers of Children with ADHD: A Review of the Literature is included as Chapter 3: Manuscript 2.

Andrew Thomas Reyes, PhD, RN

## **Appendix E**

### **Co-author Written Permissions for Manuscript 3**

As co-author, I grant permission for inclusion of the following manuscripts in this dissertation document. Medication Decision Making in African American Families of Children with ADHD: A Mixed Method Study is included as Chapter 4: Manuscript 3.

Roseann Colosimo, PhD, RN

As co-author, I grant permission for inclusion of the following manuscripts in this dissertation document. Medication Decision Making in African American Families of Children with ADHD: A Mixed Method Study is included as Chapter 4: Manuscript 3.

Howard R. D. Gordon, EdD, MPH

As co-author, I grant permission for inclusion of the following manuscripts in this dissertation document. Medication Decision Making in African American Families of Children with ADHD: A Mixed Method Study is included as Chapter 4: Manuscript 3.

Jinyoung Kim, PhD, RN, FAAN

## Appendix F

### Proof of Submission for Manuscript 3

Manuscript 3 submission to the Journal of the American Academy of Child and Adolescent Psychiatry

JAACAP <em@editorialmanager.com>

Thu, Oct 21, 2:23 PM (8 days ago)



to me ▾

CC: "Catherine Dingley" [catherine.dingley@unlv.edu](mailto:catherine.dingley@unlv.edu), "Jinyoung Kim" [jinyoung.kim@unlv.edu](mailto:jinyoung.kim@unlv.edu), "Roseann Colosimo" [roseann.colosimo@unlv.edu](mailto:roseann.colosimo@unlv.edu), "Howard R. D. Gordon" [howard.gordon@unlv.edu](mailto:howard.gordon@unlv.edu)

Oct 21, 2021

Dear Dr. Glasofer,

The Editorial Office has received your submission, "Medication Decision Making in African American Caregivers of Children with ADHD: A Mixed Methods Study". You may monitor the progress of your paper by logging on to Editorial Manager: <https://www.editorialmanager.com/jaacap/>

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## Appendix G

### IRB Approval Letter for Study in Manuscript 1



#### UNLV Biomedical IRB - Administrative Review Exempt Notice

**DATE:** September 25, 2019

**TO:** Catherine Dingley  
**FROM:** Office of Research Integrity - Human Subjects

**PROTOCOL TITLE:** [1450723-3] Medication Decision Making among African American Caregivers of Children with Attention-Deficit/Hyperactivity Disorder

**ACTION:** DETERMINATION OF EXEMPT STATUS  
**EXEMPT DATE:** September 25, 2019  
**NEXT REPORT DUE:** September 24, 2022  
**REVIEW CATEGORY:** Exemption category # 2

Thank you for your submission of Revision materials for this protocol. This memorandum is notification that the protocol referenced above has been reviewed as indicated in Federal regulatory statutes 45CFR46.101(b) and deemed exempt.

We will retain a copy of this correspondence with our records.

**PLEASE NOTE:**

1. The following modifications were made to the Informed Consent Form:
  - a. The addition of contact information for Dr. Dingley both phone number and email address.
  - b. Deletion of the Virtua IRB since they are not main IRB of review.
  - c. Addition of pagination and the title on each page of the consent based on best practices.
2. Also, the research student confirmed that Dr. Roseann Colosimo will be removed from the study at this time until their CITI is completed. A modification request to add Dr. Colosimo with a copy of her CITI certificate will be submitted.

Upon final determination of exempt status, the research team is responsible for conducting the research as stated in the exempt application reviewed by the ORI - HS and/or the IRB which shall include using the most recently submitted Informed Consent Form.

If your project involves paying research participants, it is recommended to contact the ORI Program Coordinator at (702) 895-2794 to ensure compliance with the Policy for Incentives for Human Research Subjects.

Any changes to the application may cause this protocol to require a different level of IRB review. Should any changes need to be made, please submit a **Modification Form**. When the above-referenced protocol

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has been completed, please submit a **Continuing Review/Progress Completion report** to notify ORI - HS of its closure.

If you have questions, please contact the Office of Research Integrity - Human Subjects at [IRB@unlv.edu](mailto:IRB@unlv.edu) or call 702-895-2794. Please include your protocol title and IRBNet ID in all correspondence.

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- Wiesner, M., Kanouse, D. E., Elliott, M. N., Windle, M., & Schuster, M. A. (2015). DISC Predictive Scales (DPS): Factor structure and uniform differential item functioning across gender and three racial/ethnic groups for ADHD, Conduct Disorder, and Oppositional



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<https://dx.doi.org/10.1037%2Fa0012719>
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<https://doi.org/10.1001/jamanetworkopen.2018.1471>
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Zablotsky, B., Black, L. I., Maenner, M. J., Schieve, L. A., Danielson, M., Bitsko, R. H.,  
Blumberg, S. J., Kogan, M. D., & Boyle, C. A. (2019). Prevalence and trends of  
developmental disabilities among children in the United States: 2009-2017. *Pediatrics*,  
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Zuvekas, S. H., & Vitiello, B. (2012). Stimulant medication use in children: a 12-year  
perspective. *American Journal of Psychiatry*, *169*(2), 160-166.  
<https://doi.org/10.1176/appi.ajp.2011.11030387>

Zuvekas, S. H., Vitiello, B., & Norquist, G. S. (2006). Recent trends in stimulant medication use  
among U.S. children. *American Journal of Psychiatry*, *163*(4), 579-585.  
<https://doi.org/10.1176/appi.ajp.163.4.579>

## Curriculum Vitae

Amy Glasofer, DrNP, RN, NE-BC  
felderam@gmail.com

### Education

#### **Current**

Doctor of Philosophy in Nursing  
Post DNP

#### **University of Nevada, Las Vegas**

Las Vegas, Nevada

Expected graduation: December, 2021

Dissertation Title: Factors Associated with Medication  
Decision Making in Low-Income African American  
Caregivers of Children with ADHD: A Mixed Method  
Study

Supervising Professor: Catherine Dingley, PhD, RN,

FAAN

GPA: 4.0

#### **2014**

Doctor of Nursing Practice

Process

#### **Drexel University: DrNP**

Philadelphia, Pennsylvania

Clinical Dissertation Title: The Effect of a Business

Management Enabled Clinical Decision Support System on  
Adoption of a Protocol for Nurse-Directed Urinary  
Catheter Removal

Supervising Professor: Roberta Waite, EdD, APRN, CNS-  
BC, ANEF, FAAN

DrNP-in-London Program

April 13-28, 2007

of

Foundation for International Education

London, England with lectures from faculty of University

Surrey, St. George's University of London & Birkbeck  
College, University of London

#### **2003**

Masters of Science in Nursing

#### **University of Pennsylvania**

Adult Psychiatric and Mental Health Nursing

#### **2000**

Bachelors of Science in Nursing

#### **University of Pennsylvania**

SELF Scholar- merit based monetary scholarship

1999

Semester Abroad

Hebrew University

Completed nursing curriculum through University of  
Pennsylvania while attending liberal arts courses at Hebrew  
University in Jerusalem. Completed pediatric and obstetric  
clinical rotations at hospitals and clinics in Jerusalem and  
surrounding suburbs.

## **Professional Experience**

### **2007-present Virtua Health System**

#### **2020-present Per Diem Nurse Scientist**

- Work as needed to support nurses to conduct primary research studies. Chair of the nursing research council and system Magnet New Knowledge and Innovation component lead.

#### **2017-2020 Nurse Scientist**

- Responsible to develop infrastructure and capacity for nurses to conduct and disseminate research and translate findings to practice through innovative programming and mentoring, chair nursing research and nursing evidence-based practice councils, coordinate and participate in scientific review of all system clinical research, Magnet component advisor of New Knowledge and Innovation and Organizational Overview components for successful initial system designation with exemplar for nursing research dissemination.
- Institutional Review Board Administrator- responsible for administrative activities of the general and oncology IRBs
- Precept masters and doctoral level nursing students, serve as committee member for doctoral projects, lead system doctoral student forum.
- Member Diversity, Equity, and Inclusion Design Committee

#### **2014-2017 Director Nursing Research (Responsibilities beyond Nurse Scientist role)**

- Coordinator graduate academic affiliations- strengthen partnerships with academic affiliates, develop opportunities for placement of graduate level students throughout health system and connect to workforce development, oversee compliance process for student entry to health system, manager pre-licensure student-placement coordinator, responsible for receipt of ~ \$500,000 funding through CMS Graduate Nurse Education Demonstration Project
- System responsibility for oversight of research structure and operational approvals
- Operational responsibility for Clinical Trials Office, including industry and public funded clinical trials and clinical trial personnel, interim manager of clinical research coordinators and nurses.
- Ongoing design, delivery, and evaluation of Relationship Based Care and Shared Governance programming
- Oversight of health sciences library, manager medical librarian
- Culture of Safety Design Team Co-Chair

#### **2013-2014 Advanced Clinical Educator**

- Development of nursing research program
- Coordinator Graduate Academic Affiliations
- Institutional Review Board Administrator
- Initial design and delivery of Relationship Based Care programming

#### **2007-2013 Advanced Nurse Clinician**

Virtua Marlton

- Nursing professional development specialist responsible for clinical quality and competence on orthopedic, neuroscience, and medical-surgical units.

**2014-2017 Adjunct Faculty**  
 Rowan University Department of Nursing

  - Developed graduate certificate in evidence-based practice
  - Online and Hybrid Course Instructor Graduate Level: Nursing Research, Evidence-Based Practice in Illness/Disease Management
  
- 2005-2007 Clinical Adjunct Faculty**  
 University of Pennsylvania, School of Nursing

  - Physical Assessment, Nursing of Young and Middle Aged Adults, Nursing of Older Adults
  
- 2003-2005 Advance Practice Nurse, Clinical Research Nurse**  
 Hospital of the University of Pennsylvania, Department of Neurology, Division of Neuro-Oncology
  
- 2001-2003, 2005-2007 Clinical Nurse II**  
 Hospital of the University of Pennsylvania, Neuroscience Step-Down and Floor
  
- 2000-2001 Clinical Nurse**  
 Massachusetts General Hospital, Neuroscience Step-Down Unit

**Certification and Licensure**

Six Sigma Green Belt  
 Nurse Executive Board Certified 2015-present  
 Orthopedic Nurse Certified 2008-2013  
 Registered Nurse, Pennsylvania 2000-2018  
 Registered Nurse, New Jersey 2007-present  
 Basic Life Support 1997-present

**Scholarly Activities**

**Publications**

Barry, L., Branco, J., Kargbo, N., Venuto, C., Werfel, E., Barto, D. & **Glasofer, A.** (2016). The impact of user technique on temporal artery thermometer measurements. *Nursing Critical Care, 11(5)*, 12-14.

Fahey, D. & **Glasofer, A.** (2016). An inverse relationship: Compassion satisfaction, compassion fatigue, and critical care nurses. *Nursing Critical Care, 11(5)*, 30-35.

Fox, A. & **Glasofer, A.** (In Press). Time and effort of labor nurses working to achieve and maintain a continuous recording of the fetal heart rate via external monitoring. *Nursing for Women's Health.*

Glaser, A. (2017). Resolved: 2017 is a year for learning. *Nursing Critical Care*, 12(1), 4.

Glaser, A. (2016). Innovations in practice: A call for research, quality improvement, and evidence-based practice projects. *Nursing Critical Care*, 11(2), 7-10.

Glaser, A. (2014). Searching with critical appraisal tools. *Nursing Critical Care*, 9(2), 18-22.

Glaser, A. (2013). The role of journal clubs in bridging the research-practice gap: a review of the nursing literature. *Nursing Critical Care*, 8, 41-45.

Glaser, A., & Dingley, C. (2021). Diagnostic and medication treatment disparities in African American children with ADHD: A literature review. *Journal of Racial and Ethnic Health Disparities*. <https://doi.org/10.1007/s40615-021-01142-0>

Glaser, A., Dingley, C. & Reyes, A. T. (2021). Medication decision making among African American caregivers of children with ADHD: A review of the literature. *Journal of Attention Disorders*. <https://doi.org/10.1177%2F1087054720930783>

Glaser, A., & Lapinsky, A. B. (2019). Delineation of the nursing supervisor role: A pilot study. *The Journal of Nursing Administration*, 49, 359-365.

Glaser, A., & Laskowski-Jones, L. (2018). Mass shootings: A call for nursing awareness and action. *Nursing Critical Care*, 13(5), 14-20.

Glaser, A., & Laskowski-Jones, L. (2018). Mass shootings: A call for nursing awareness and action. *Nursing*, 48(12), 50-55.

Glaser, A., & Laskowski-Jones, L. (2019). Active shooter incidents: Awareness and action. *Nursing Management*, 50(3), 18-25.

Glaser, A., & Townsend, A. B. (2019). Determining the level of evidence: Experimental research appraisal. *Nursing Critical Care*, 14(6), 22-25.

Glaser, A., & Townsend, A. B. (2020). Determining the level of evidence: Non-experimental research appraisal. *Nursing Critical Care*, 15(1), 24-27.

Glaser, A., & Townsend, A. B. (2020). Determining the level of evidence: Non-research evidence. *Nursing Critical Care*, 15(2), 22-26.

Glaser, A., & Townsend, A. B. (2021). Determining the level of evidence: Experimental research appraisal. *Nursing*, 51(1), 60-63.

Glaser, A. & Townsend, A. B. (2021). Determining the level of evidence: Nonexperimental research designs. *Nursing*, 51(2), 62-65.

Glasofer, A. Townsend, A. B. (2021). Determining the level of evidence: Nonresearch evidence. *Nursing*, 51(3), 53-57.

Glasofer, A., Werfel, E., Dacanay, D. A. Jr. & Fazio, T. (2016). Preventing bloodstream infections: An investigation. *Nursing Critical Care*, 11(4), 6-8.

Otegbeye, M., Scriber, R., Ducoin, D. & **Glasofer, A.** (2015). Designing a data-driven decision support tool for nurse scheduling in the emergency department: a case study of a southern New Jersey emergency department. *Journal of Emergency Nursing*, 41, 30-35.

Siegmeister, D., Pilog, K., Boenisch, A., Brownmiller, E., Foran-Lee, L., Larsen, D. A., Stahre, P., Epstein, H. B., & **Glasofer, A.** (2021). Clinical case report: prone positioning for non-intubated patients with COVID-19. *Medsurg Nursing*, 30(3), 201.

Wolf, Z. R., Dillon, P. M., Townsend, A. B., & **Glasofer, A.** (2017). Caring Behaviors Inventory-24 Revised: CBI-16 validation and psychometric properties. *International Journal for Human Caring*, 21, 185-192.

### **Podium Presentations**

Glasofer, A. (2014). Best practices in bridging the research-practice gap through nursing journal clubs. Association for Nursing Professional Development Annual Convention; Orlando, Florida.

Glasofer, A. (2015). Driving patient outcomes through clinical decision support systems and nurse-directed protocols. Sigma Theta Tau International 43<sup>rd</sup> Biennial Convention; Las Vegas, Nevada.

Glasofer, A. (2015). Mind the Gap: Connecting CDSSs to Patient Outcomes. American Nursing Informatics Association Annual Conference; Philadelphia, Pennsylvania.

Glasofer, A. (2015). Pump up the volume: Speak up for patient safety. TRENDS in Critical Care Nursing Annual Conference; King of Prussia, Pennsylvania.

Glasofer, A. (2015). To IRB or not to IRB. TRENDS in Critical Care Nursing Annual Conference; King of Prussia, Pennsylvania.

Glasofer, A. (2016). To IRB or not to IRB. Association for Nursing Professional Development Annual Convention; Orlando, Florida.

Glasofer, A. (2016). Back to school: Choosing the right program for you. TRENDS in Critical Care Nursing Annual Conference; King of Prussia, Pennsylvania.

Glasofer, A. (2016). Writing for publication. APIC: Southern New Jersey Chapter Meeting; Marlton, New Jersey.

Glaser, A. (2017). Back to school: Choosing the right program for you. Options in Trauma Care Trauma Symposium; Philadelphia, Pennsylvania.

Glaser, A. (2018). A primer on evidence-based (informed) practice. APIC: Southern New Jersey Chapter Meeting; Marlton, New Jersey.

Glaser, A. & Field, L. (2014). Relationship Based Care. TRENDS in Critical Care Nursing Annual Conference; King of Prussia, Pennsylvania.

### **Poster Presentations**

Bertino-Lapinsky, A., & Glaser, A. (2017). The nursing supervisor: A role requiring further exploration. Nursing Management Congress 2017; Las Vegas, Nevada.

Glaser, A. (2013). The effect of a clinical decision support system on the adoption of a protocol for nurse-directed urinary catheter removal. Drexel University: Drexel Research Day; Philadelphia, PA.

Glaser, A. (2014). The effect of a clinical decision support system on the adoption of a protocol for nurse-directed urinary catheter removal. Drexel University: Drexel Research Day; Philadelphia, PA.

Glaser, A. (2014). The effect of a clinical decision support system on the adoption of a protocol for nurse-directed urinary catheter removal. Eastern Nursing Research Society 26<sup>th</sup> Annual Scientific Sessions; Philadelphia, PA.

Glaser, A. (2015). Pump up the volume for patient safety. Organization of Nurse Executives, New Jersey: Research Day Conference; Princeton, New Jersey.

Glaser, A., Barto, D., Fisher, S., Lynch, M. & Mansfield, K. (2012). Putting our stars in the spotlight: A strategy to celebrate and promote professional development. Professional Nursing Education and Development 39<sup>th</sup> Annual National Conference; Philadelphia, PA.

Glaser, A., & Dingley, C. (2018). Responding to errors in healthcare: A review of the literature. Western Institute of Nursing: 51<sup>st</sup> Annual Communicating Nursing Research Conference; Spokane, WA.

Glaser, A., & Dingley, C. (2019). Medication acceptance among African American caregivers of children with ADHD. The American Professional Society of ADHD and Related Disorders Annual Meeting; Washington, DC.

Glaser, A. & Dingley, C. (2021). Medication decision making among African American caregivers of children with ADHD: A review of the literature. Western Institute of Nursing: 2021 Annual Conference; Virtual



Glasofer, A., O'Malley, K., Bertino-Lapinsky, A., Epstein, H. B., Galosi, G., Mansfield, K., ... & Werfel, E. (2019). Predicting the likelihood of participation in bedside handoff. Penn Medicine 8<sup>th</sup> Annual Nursing Research Conference; Philadelphia, PA.

Konstantinides, P., & Glasofer, A. (2017). Understanding how a second victim response program supports a healthy work environment. Organization of Nurse Leaders- New Jersey; Princeton, NJ.

Mansfield, K., Buonacuore, D., Carr, D., Corcoran, A., Cucinotta, K., Fernando, B., & Glasofer, A. (2014). Improving communication through surgical services huddles. American Society of PeriAnesthesia Nurses 33<sup>rd</sup> National Conference; Las Vegas, Nevada.

Mansfield, K., Buonacuore, D., Carr, D., Corcoran, A., Cucinotta, K., Fernando, B., & Glasofer, A. (2014). Improving communication through surgical services huddles. Association of Perioperative Registered Nurses Surgical Conference and Expo; Chicago, Illinois.

Werfel, E., Dacanay, D. & Glasofer, A. (2015). Evaluating the process for prevention of blood stream infections. New Jersey State Nurses/Institute for Nursing Convention; Atlantic City, New Jersey.

Wolf, Z., Dillon, P., Townsend, A., & Glasofer, A. (2017). Paper presentation- Caring behaviors inventory revised: Validation and psychometric properties. International Association for Human Caring 38<sup>th</sup> Annual Conference; Edmonton, Alberta Canada.

## **Grants**

UNLV Tish M. Smyer Nursing Research Dissertation Award: \$1250 research grant to fund study "Medication Decision Making among African American Caregivers of Children with ADHD"

Becton, Dickinson, and Company: \$5000 research grant to fund study "Improving the Process for Prevention of Blood Stream Infections"

## **Honors & Awards**

*MEDSURG Nursing*- 2021

Mentored author awarded First-Time Author Writer's Award for the article "Clinical Case Report: Prone Positioning for Non-Intubated Patients with COVID-19"

Eastern Nursing Research Society, 2014

1<sup>st</sup> Place DNP Poster Award

Virtua Super Star Awards, 2014

Nurse Scholar

Virtua Nursing Excellence Awards, 2014  
Nurse Scholar  
Drexel Research Day, 2013  
Best Graduate Poster Presentation: Translational and Clinical Research

### **Professional Affiliations**

#### **Professional Organizations**

Sigma Theta Tau, Nu Eta Chapter 2006  
American Nurses Association  
New Jersey State Nurses Association  
American Professional Society for ADHD and Related Disorders  
•Diversity, Equity, and Inclusion Task Force

#### **Professional Activities**

**2014-2020 Editorial Advisory Board Member**  
Nursing Critical Care, Wolters Kluwer  
Coordinator Research Rounds feature, review manuscripts  
submitted to Wolters Kluwer journals relative to content expertise

**2014-2017 Clinical Associate, Academic Support Staff**  
University of Pennsylvania, School of Nursing

**2014, 2019 Eastern Nursing Research Society**  
Abstract Reviewer

**2010-2015 Academy of Medical Surgical Nurses, Delaware Valley**

#### **Chapter**

Medical Surgical Nurses Certification Review Course  
Neurological and Musculoskeletal Review

### **Community Service**

Children and Adults with Attention-Deficit/Hyperactivity Disorder- Scholarship  
Selection Committee